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# POSTIVE CONSEQUENCES OF ILLNESS

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**POSITIVE CONSEQUENCES OF ILLNESS**

By

**SAMANTHA CLAIRE SODERGREN**

A thesis submitted to the University of Plymouth  
in partial fulfilment for the degree of

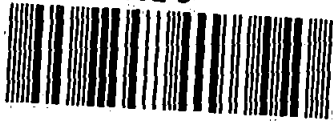
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**POSITIVE CONSEQUENCES OF ILLNESS**

This thesis identifies systematically the domains of positive consequences of illness and details the development of a measure of the positive consequences of illness – the Silver Lining Questionnaire (SLQ). Further aims of the thesis include the use of the SLQ as a predictor of health outcome and an investigation of the prevalence and correlates of positivity in illness. The first study questioned 55 people about their positive experiences of illness and uncovered 17 themes. In the second study a pilot questionnaire based on these themes was administered to the participants of the first study and an additional sample of cancer and chronic respiratory patients. Refinements to the questionnaire resulted in a 38-item measure of positivity. In study 3, the SLQ's properties of reliability and responsiveness to change were confirmed in a sample of chronic respiratory and cardiac patients in a rehabilitation setting. This study also found that positivity increased following rehabilitation. In study 4, the SLQ was used to predict the health outcome of patients with chronic fatigue syndrome. Finally, study 5, investigated the prevalence of positivity amongst respiratory patients varying in illness severity and found no significant difference between patient groups in the expression of positivity. This study identified extraversion and a sense of spirituality and religiosity as correlates of positivity. This thesis thus addresses a previously neglected field of research and presents a more comprehensive measure of positivity than existing measures. This thesis also addresses previously unanswered questions regarding the prevalence and correlates of positivity and also the potential for increasing positivity. Finally, the implications of positivity in illness for health management are highlighted.



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## AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award.

While working on this thesis, the author was employed by the University of Plymouth as a research assistant on a Medical Research Council funded project into novel approaches to the assessment of quality of life, and an internally funded project into the positive consequences of illness.

The following papers related to this thesis have been accepted or submitted for publication:

Hyland, M.E., Sodergren, S.C., & Lewith, G.T. Self-actualisation but not mood predicts better improvement in mental fatigue in chronic fatigue patients. Paper submitted to *Health Psychology* for publication.

Sodergren, S. C. & Hyland, M. E. (2000). What are the positive consequences of illness? *Psychology and Health*, **15**, 85-97.

Sodergren, S.C., Hyland, M.E., Singh, S.J., Sewell, L. (In press). The effect of rehabilitation on positive interpretations of illness. *Psychology & Health*, in press.

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A number of conferences were attended at which aspects of the thesis were presented. Work was also presented at the Exeter Cancer Help Group and to health professionals in Plymouth involved in cancer support. The following presentations were made at conferences:

Sodergren, S.C. & Hyland, M.E. (1997). Qualitative phase in the development of the Silver Lining Questionnaire. Paper presented at the 4th Annual Conference of the International Society for Quality of Life Research, 4-9 November 1997, Vienna, Austria. *Quality of Life Research*, **6**, 724.

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External Contacts:

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Partridge (Consultant) Whipps Cross Hospital, London (now at Imperial College, London).

Signed *Sanjiv S. Senger*

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## CHAPTER 1

### REVIEW OF QUALITY OF LIFE

“We should set the highest value not on living but on living well”  
(Plato)

#### 1.1 *Introduction*

This chapter addresses the following issues:

- \* The origins of the term ‘quality of life’ and its usage in different contexts;
- \* Proposed definitions of quality of life;
- \* The concepts related to, and often used interchangeably with, quality of life;
- \* Critical issues in the concept and measurement of quality of life;
- \* A positive perspective on quality of life

#### 1.2 *Etymology and Usage in Diverse Contexts*

Happiness, a term often presented as embracing the concept of quality of life (Campbell, Converse & Rodgers, 1976), has its origins rooted back to the time of the ancient Western philosopher Aristotle (McKeon, 1947) who described it as a certain kind of virtuous activity of the soul. Quality of life, as a concept, also has ancient roots. In Plato’s quotation presented above, ‘living well’ is likely to refer to quality of life. According to Zhan (1992), quality of life is embedded in the art, literature, philosophy, and traditional medicine of the ancient tradition of Chinese culture. Within the context of Chinese medicine, quality of life is achieved when Yin and Yang, opposing but complementary qualities, are in harmony. Given the history of the concept, it is perhaps surprising that the term ‘quality of life’ has only recently been introduced into the English language.

Quality of life made its first appearance in written text in 1943 in J.B. Priestley’s novel ‘Daylight on Saturday’ set in wartime Britain. The term appears in this novel as the core

ingredients of a speech delivered by the President of an aircraft factory in an attempt to boost morale. In this speech, promises are made for a 'nobler quality of life' with regards to employment, housing, education and health services.

### 1.2.1 Quality of life and politics

The quality of life catch phrase soon became popular as a political tool. In 1955, the American politician Stevenson perceived quality of life to be a concern that would touch the heart of voters and presented himself as being troubled by the quality of American life:

"He seems disturbed by the 'quality of American life' when most politicians measure it only in quantity"  
(E. Severeid, Newsmakers, cited in The Oxford English Dictionary, p. 974)

This was a particularly novel concern at the time in Western society with post-war government policies driven towards restoring material wealth. However, it was not by chance that quality of life was introduced to the vocabulary of politicians. It would seem that the restoration of wealth following the Second World War was not enough to satisfy rising expectations and that improvements to the quality of life were called for. The shift in emphasis from concerns of material wealth to those of the quality of life can be understood within the framework of Maslow's Hierarchy of Needs (1968) where the gratification of lower order needs such as hunger, thirst, and shelter, motivates individuals to concern themselves with the higher order social and psychological needs of esteem, recognition, and self-actualisation.

A concern for the quality of life rather than its quantity is echoed in the speeches of American Presidents during the 1960s. The report of President Eisenhower's Commission on National Goals published in 1960 (Report of the President's Commission, 1960) acknowledged the importance of measuring quality of life. The focus of this report was on sociological and environmental factors, such as education, concern for the individual, economic growth, health and welfare, and defence of the free world. President Kennedy's State of the Union Message 3 years later urged for the quality of American life to keep pace with the quantity of American goods:

"This country cannot afford to be rich and desperately poor"  
(Rosenberger & Tobin, 1963, p. 19228)



The quality of life catch phrase reappears in President Johnson's Inaugural address of 1965 that expressed a concern to:

“...improve the quality of life for all”  
(Rosenberger & Tobin, 1965, p. 20547)

## Conclusion

In the political context, quality of life has been used as a powerful slogan to win the support of voters. It is assumed that a better quality of life is yearned for and that by addressing this desire one is communicating an interest in the individual. The politicians quoted above did not pause for a definition of quality of life. However, their interpretation of quality of life is likely to be closely linked to the state of the physical environment and in particular economic prosperity given that materialistic quantifiers have historically been the primary measure of a nation's progress. Interpretations of promises of an 'improved quality of life for all' are unlikely to be homogeneous across individuals. For one individual such promises may mean a better education and improved employment opportunities, while another individual may interpret such promises as a cleaner environment and improved health facilities. Identification of such indicators of quality of life has been the focus of numerous social surveys.

### 1.2.2 Social surveys

Throughout the 1960s and 70s, large scale surveys on the determinants of quality of life were funded in the United States. The first major research project of this kind was pioneered by Gurin and colleagues in 1960 (Gurin, Veroff, & Feld, 1960) and was designed to identify indicators of happiness to help public policy promote a better quality of life. This project addressed psychological disturbances, physical symptoms, professional help sought and present happiness in a probability sample of the American population.

Bradburn's work in 1969 at the National Opinion Research Center emphasised the affective aspects of well being. Bradburn's focus was on the balance between two independent conditions, positive and negative affective states, rather than on the differences in type of needs.



This notion of affect balance implies that the presence of positive affect does not necessarily correspond to an absence of negative affect and vice versa.

A further pioneering study in the field, with an impressive sample composition of 13 different nations, was carried out by Cantril (1965) on *The Pattern of Human Concerns*. Cantril used an 11-point 'self-anchoring scale' with 'the best life' and 'the worst life' as extreme points and asked respondents to consider their current position on the scale. In contrast to Bradburn's approach emphasising affective states, Cantril's focus was on aspirations, needs, and satisfactions. Cantril identified health and standard of living as salient concerns.

Bauer's (1966) work on *Social Indicators* summarising the primary and secondary effects of the national space programme on American society paved the way for subsequent research on quality of life.

Further noteworthy events in the history of quality of life research are the studies carried out by Andrews and Withey (1976) and Campbell et al. (1976) whose concern with the nature of the main determinants of quality of life was identified at the 1971 Conference of the American Institute for Research as a major avenue for quality of life research. These researchers appreciated the limited focus of objective circumstances of life, such as, those monitored by Bauer (1966), and acknowledged the need to follow the tradition set by earlier researchers, such as Gurin et al. (1960), Cantril (1965) and Bradburn (1969) and study the subjective dimensions of quality of life. Campbell et al. (1976) examined reports of happiness by the American population between 1957 and 1972, a period that saw an increase in affluence. Observations were made of a gradual but consistent decline for Americans to describe themselves as very happy with 35% regarding themselves as very happy in 1957 compared with 26% and 22% of respondents in two studies conducted in 1972. These findings reflect the results of the quality of life tables constructed for British cities which show that most places of booming economic production offer a poor quality of life (Rogerson, Findlay, Paddison, & Morris, 1996). The trends uncovered by Campbell and colleagues perhaps provide an answer to the following question posed by President Nixon:

"In the next ten years we will increase our wealth by 50 percent. The profound question is: does that mean we will be 50 percent richer in any real sense, 50 percent better off, 50 percent happier?"

(cited in The Environmental Protection Agency Office of Research and Monitoring Environmental Sciences Division, 1974, p. I-13)

The trends reported by Campbell et al. (1976) challenge the approach to quality of life used by economists, which assumes that economic prosperity is a major component of an inspired quality of life for everyone. Campbell et al. (1976) argued that, as objective or 'surrogate' indicators alone provide an incomplete picture of quality of life, attention needs to be directed towards how these objective conditions are perceived and evaluated. According to Andrews and Withey (1976), "it is the individual's perception of their own well being or lack of well being that ultimately defines the quality of their lives" (p.10). Campbell et al. (1976) recognised the value of approaching individuals directly and asking them to define how life feels to them. These researchers defined the quality of life experience in terms of satisfaction of needs in 15 domains of life experience including marriage, family life, health, neighbourhood, friendships, housework, job, life in the United States, city or county, non-work, housing, usefulness of education, standard of living, amount of education, and savings.

The first major ranking of British cities to form quality of life league tables (Findlay, Rogerson, & Morris, 1988) adopted a similar methodology for studying people's opinions regarding the relative significance of a number of quality of life variables. Low crime rates, good health care provision and low pollution levels were identified as key components of a high quality of life.

## Conclusion

The social surveys that set out to identify the determinants of quality of life refer to concepts such as happiness, satisfaction and well being and imply that assessments of quality of life need to tap into the individual's personal experience of conditions of living. In this context, a good quality of life cannot be inferred by a particular level of education, housing, income and so forth. Campbell et al. appreciated that dealing with the individual's needs can be problematic as, given that they are highly personal and situational, they are not likely to be stable across the life-span and what will satisfy one individual may be totally unsatisfactory to another.

### 1.2.3 Health care provision

The World Health Organization's (1947) definition of health as: "...a state of complete physical, mental and social well being and not merely the absence of disease and infirmity" (p. 29), places an emphasis on quality of life issues. The arrival of quality of life or health-related quality of life in medical debates did not however take place until the late 1950s. Before quality of life entered the medical scene, concerns for keeping people alive - the "sanctity of life" represented the primary justification for all health care decisions. An emphasis on the quality of life offered by medical treatment programmes rather than just the quantity of life represents a more holistic approach to medicine and introduces the question of whether the chances of survival outweigh the costs of often severe side effects. According to Sartorius (1997), progress in saving life loses value if it is not accompanied by progress in improving the quality of life of the years gained. Tamburini's (1996) review of the history of quality of life in the context of health care acknowledged the field of pain research as the first to collect data on the subjective experience of the patient. Quality of life considerations soon gained significance in the field of oncology and palliative care (Richards & Ramirez, 1997) where treatments to extend survival often compromise quality of life. The first outcome measure for cancer treatment to go beyond considerations of length of survival to the quality of that survival was designed by Karnofsky and colleagues (The Karnofsky Performance Index; Karnofsky & Burchenal, 1947).

The first entry of quality of life in both the Medline, the United States National Library of Medicine, database and the PsychINFO database, which covers texts within the field of psychology and psychological aspects of related disciplines, was in 1966. Table 1.1 presents the number of citations of quality of life in titles, keywords or abstracts of research projects indexed by these databases between 1966 and 2000. The usage of quality of life continued gradually during the 1970s, especially within the medical literature, and saw a proliferation during the 1980s and 1990s. By 2000, there were 4634 citations in the Medline and 1025 in the PsyINFO database. Recognition of the importance of quality of life as a field of research led to the launch in 1992 of a journal, *Quality of Life Research*, devoted exclusively to quality of life.

Table 1.1. Citations of 'quality of life' in titles, keywords or abstracts in Medline and PsychINFO between 1966 and 2000 (recorded 12/12/01)

Year	Database	
	Medline	PsycINFO
1966	1	1
1967	1	1
1968	0	1
1969	1	1
1970	6	2
1971	7	12
1972	15	7
1973	38	13
1974	60	16
1975	170	23
1976	245	28
1977	237	28
1978	329	32
1979	362	25
1980	354	24
1981	377	40
1982	416	63
1983	476	95
1984	526	116
1985	600	137
1986	740	179
1987	862	211

1988	928	219
1989	1393	255
1990	1557	297
1991	1637	322
1992	1944	366
1993	2291	361
1994	2542	515
1995	2907	564
1996	3254	649
1997	3663	697
1998	3916	807
1999	4342	895
2000	4634	1025

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It would appear that Schalock's prediction in 1989 that the quality of life would become "THE issue in human services in the 1990s" (cited in Seed & Lloyd, 1997, p. 3) has been realised. The importance of quality of life considerations in health care is also reflected in the theme for the 1997 Annual Conference of the International Society of Quality of Life (ISOQOL): 'The improvement of quality of life: a purpose for health care'. Quality of life is likely to remain an issue of considerable importance within medicine with the Healthy People 2000 government paper (1990) advocating not only the prevention of premature mortality and morbidity but also the enhancement of quality of life.

A number of factors have contributed to the upsurge of interest in quality of life assessment in medicine. Firstly, several of the technological advances in medical interventions have promised a prolongation of life but to the expense of the quality of life. Thus the need to monitor quality of life has become paramount in order to avoid situations where a patient may be biologically 'alive' but socially 'dead'.

An increasing demand for a more 'humanised' approach to health care has also arisen in response to the shift in the burden of disease from acute to chronic conditions and also to the changes in the age structure of the population with a trend towards an ageing population (The Office of Population Censuses and Survey, 1974-1994). The World Bank (1994) estimates that between 1990 and 2030 there will be an increase from 9% to 16% in the world's population aged 60 years and above.

In an age of increasing consumer awareness, the use of quality of life as an outcome measure also represents an attempt to embrace the viewpoint of the 'consumer' and to improve patient care.

Quality of life has become increasingly relevant to health economic decision making in a climate of insufficient resources to meet increasing demands. Seed and Lloyd (1997) describe the changes in the concerns of health professionals as 'Do no harm!' (pre-1960s); 'Be complete' (1960s onwards) and 'Value for money' (the current focus). Quality of life outcomes are used to evaluate whether treatment programmes provide good value for money and are also used in policy analysis to establish priorities and allocate resources. According to Smee (1992), at least 40% of total health service expenditure can be accounted for by treatments that have little impact on prolonging life and must therefore be justified by their contribution to the quality of life. Cost utility analysis which was introduced in the 1980s is one type of economic evaluation which pays particular attention to quality adjustment and health status with net benefits expressed in terms of the common denominator of years of healthy life (Patrick & Erickson, 1993). Cost utility analysis has developed an index known as Quality Adjusted Life Years (QALYs) with years of life gained by a medical programme adjusted by utility weights. Cost utility analysis has also been used to construct league tables of health care in terms of cost per QALY.

Quality of life assessments have become an important feature of clinical trials. The study group on quality of life assessment formed by the European Organisation for Research on Treatment for Cancer (EORTC) in 1981 represented a major stimulus for the inclusion of quality of life assessments in clinical trials (Barnofsky, 1986). The pharmaceutical industry has also played an important role in promoting the use of quality of life measures in the evaluation of their



products. There are a number of reasons why pharmaceutical companies are motivated to fund trials evaluating quality of life. According to Wicklund (1998), quality of life studies are used to support a pharmaceutical company's application for approval from regulatory agencies. Quality of life data may also assist in pricing decisions, support labelling changes, provide customers with more complete information and may enhance the profiles of products. The first clinical trial to report significant results using quality of life outcome measures was carried out by Croog and colleagues in 1986 (Croog, Levine, Testa, Brown, Bulpitt, Jenkins, Klerman, & Williams, 1986). This clinical trial evaluated the effects of three major anti-hypertensive agents (Catropil, Methyldopa and Propanoldol) on quality of life by including measures of well being and satisfaction, physical state, emotional state, intellectual function, ability to perform social roles and satisfaction with these roles. All three anti-hypertensive agents were found to influence quality of life in different ways.

## Conclusion

Initially, nurses and physicians used the concept of quality of life to clarify the distinction between medical and technical aspects of care and other 'humanised' aspects of care such as social and psychological (DeHaes & vanKnippenberg, 1985). Quality of life has gained particular currency within the field of health economic decision-making and in the pharmaceutical industry where claims made of improvements to quality of life are used to the advantage of a particular resource or pharmaceutical product.

### 1.2.4 Veterinary medicine

Quality of life has also recently stepped into the field of veterinary medicine. Bateman, Catton, Pernock, and Kruth (1994) evaluated a radiation therapy for the palliation of advanced cancer in dogs using a quality of life instrument designed for veterinary use. The authors identified physical comfort as a key component of quality of life and proposed that a quality of life measure for dogs essentially needs to address pain and its interference with daily activities. The quality of life measure used in this study primarily assessed pain relief from the owner's

perspective. Within the context of veterinary medicine, as with human health care, quality of life assessments are included to provide an insight into the subjective response to treatments.

### 1.2.5 *Summary*

This section has documented the evolution of the term quality of life across different disciplines from politics to veterinary medicine. Quality of life referred to in the political context has taken the form of promises of a highly sought after state of being which goes beyond that of material wealth. In the medical domain, the same term is used to refer to considerations beyond those of survival. It is perhaps not surprising therefore why a politician's response to the question 'what is quality of life?' may differ from that of a health professional's. What may seem surprising however is the diverse meaning attached to the term when it is used within the same discipline. The next section explores various definitions proposed for quality of life.

## 1.3 *Definitions of Quality of Life*

The review of the etymology of quality of life provides some clues as to what one may expect to feature in definitions of quality of life. There may for example be reference to economic prosperity, freedom from physical discomfort and psychological disturbances, or the degree of satisfaction of needs within the context of family life and friendships. Although it is possible to conjure up many examples of what the term quality of life may mean, there is no agreed definition of quality of life and often authors do not even commit themselves to a particular definition of quality of life as Gill and Feinstein (1994) found in their review of the quality of life literature. However, systematic attempts have been made to develop a consensus concerning a definition of quality of life. The first symposium devoted to finding an agreed definition was held in 1972 and was sponsored by the United States Environmental Protection Agency (The Environmental Protection Agency Office of Research and Monitoring Environmental Sciences Division, 1974). To understand why such attempts at finding an agreed definition of quality of life have not been particularly successful, it is useful to consider the following issues which were discussed by Edlund and Tancredi (1985):



- \* Who is putting the quality into quality of life - the politician, sociologist, health care professional?
- \* What sort of quality is being specified - material wealth, a clean and safe environment, a pain-free existence?
- \* Who is the audience - potential voters, health-care purchasers?
- \* What is the user's agenda - win the support of voters, enhance the selling power of a pharmaceutical product, allocate resources?

These issues are implicit in Keyserlingk's (1990) critique of quality of life:

"It is so vague and glibly used in such quite different contexts (...) and in support of such different positions (...) that the concept seems to commit one to nothing specific and it is seldom given tangible content." (p.36)

Annas (1990) suggested that as quality of life is so misused and misunderstood, it should be banned from our lexicon.

Amongst the myriad of definitions of quality of life, however, emerge several features. Proposed definitions can be classified into those that follow the tradition of early work on social indicators and emphasise objective dimensions such as housing, income, and physical health status. In contrast, there are definitions that refer to quality of life as the subjective experience of objective conditions and mirror the approaches adopted by Andrews and Withey (1976) and Campbell et al. (1976). In addition, some authors address quality of life as a global concept while others describe quality of life as a multi-dimensional concept and identify its key components. Finally, there are several definitions that refer to cultural influences on the interpretation of quality of life.

### 1.3.1 Objective definitions

Early definitions of quality of life refer to economic indicators such as the Gross National Product (GNP) and the Consumer Price Index (The Environmental Protection Agency Office of Research and Monitoring Environmental Sciences Division, 1974). Singer (The Environmental Protection Agency Office of Research and Monitoring Environmental Sciences Division, 1974), a

participant of the aforementioned conference sponsored by the Environmental Protection Agency presented the following loose definition of quality of life:

“...having as much money as possible left over after taking care of basic necessities and having the necessary time and opportunities for spending it in a pleasant way.”

(The Environmental Protection Agency Office of Research and Monitoring Environmental Sciences Division, 1974, p. I-26)

Not all objective definitions of quality of life refer to materialistic parameters; according to Liu (1974), quality of life is the output of two aggregate input factors: physical and spiritual. Finally, using a rather complex equation, Shaw (1990) expresses quality of life (QL) as the product of the patient's natural endowment (NE) and the efforts made on his behalf by his family (H) and by society (S) ( $QL = NE * (H + S)$ ).

## Conclusion

Objective definitions of quality of life imply that quality of life indicators are easily documented and observable. In addition, they assume that a particular level of an indicator will tell us about an individual's quality of life irrespective of that individual's hopes, expectations, needs and so forth. That is to say, what will satisfy one individual will necessarily satisfy another.

### 1.3.2 Subjective definitions

The need to encompass the individual's personal experience of life in definitions of quality of life arose from the observations of researchers such as Campbell et al. (1976) that objective quantifiers alone do not tell us all there is to know about quality of life. Subjective definitions assume that quality of life is person-specific or idiographic. According to Hayry (1991):

“the quality, or value, of an individual's life is no more and no less than what she considers it to be.” (p.104)

The phenomenological approach in psychology (Rogers, 1951) acknowledges that to understand an individual's behaviour, one must work from the internal frame of reference of the individual. This perspective is embedded within the taxonomy of meanings of quality of life presented by Edlund and Tancredi (1985), in particular, quality of life as the fulfilment of personal goals and the

individualistic view where quality of life is what each individual defines it to be. Both of these meanings are implicit in Calman's hypothesis (1984):

"...The quality of life measures the difference or the gap at a particular period of time between the hopes and expectations of an individual and the individual's present experiences." (p.124)

This definition suggests that only the individual can describe quality of life and that a good quality of life is achieved when the individual's goals are matched and fulfilled by present experiences. Calman's hypothesis has been criticised by Cribb (1985) for being too subjective to be of value in making any comparative judgements. Cribb argued that objective indicators deserve attention.

## Conclusion

Subjective definitions of quality of life assume a lack of consensus across individuals as to what constitutes a good or bad quality of life. Interpretations of quality of life may be shaped by factors such as present lifestyle, past experiences and aspirations for the future (Calman, 1984). Such definitions imply that attempts to quantify quality of life and to make comparisons across individuals may be fruitless.

### 1.3.3 Global definitions

Global definitions refer to overall evaluations of quality of life and do not specify the components that contribute to this evaluation. Szalai (1980) proposed the following global definition of quality of life:

"...the more or less 'good' or 'satisfactory' character of people's life" (p.8)

Following a review of numerous objective, subjective, global and multi-dimensional definitions of quality of life, DeHaes and vanKnippenberg (1985) propose that quality of life is defined as:

"an overall evaluation of the subjective experience of life" (p. 812)

## Conclusion

Definitions that refer to quality of life as an overall summary impression of life do not provide any insight into those dimensions of life that are important to quality of life. The particular global definitions presented above suggest, in accordance with the subjective definitions, that the dimensions that contribute to an overall evaluation are likely to be highly personal.

### 1.3.4 Multi-dimensional definitions

Some authors refer to quality of life as a multi-dimensional construct and identify its core components or domains. Schipper, Clinch, and Powell (1990) argue that:

“It is apparent at a glance that the quality of life parameter measures more than a single aspect of a patient’s overall function.” (p.19)

These authors define quality of life operationally as:

“...patients’ performance in four areas: physical and occupational function, psychologic state, social interaction, and somatic sensation” (p.11)

Following a review of 15 key literature sources describing conceptual models or operationalisations of quality of life, Felce and Perry (1995) arrived at a similar list of domains and, in addition, identified material well being, personal development, and purposeful activity as relevant dimensions of quality of life. Cognitive function and spiritual well being are additional components found in Richards and Ramirez’s (1997) list. Although spirituality features in the early objective definition proposed by Liu (1974), spiritual or existential well being is often neglected in definitions of quality of life. This is also perhaps surprising given that non-physical, existential issues such as, finding purpose and meaning in life, become particularly salient for some patients especially those confronting a life-threatening illness (Cohen, Mount, Strobel, & Bui, 1995; Cohen, Mount, Tomas, & Mount, 1996; Donnelly, 1996; Ferrell, Grant, Otis, Green, & Garcia, 1997).

## Conclusion

Multi-dimensional definitions of quality of life assume that several factors of life contribute to quality of life. The list of such factors can be lengthy although reference to the individual's physical, emotional and social situation is found in many definitions. Spiritual or existential well being is increasingly recognised as a dimension of quality of life.

### 1.3.5 Culturally sensitive definitions

Some authors argue that conceptions of quality of life are largely 'culture bound' (Campos & Johnson, 1990) and that the relevance of quality of life criteria such as those presented above will vary from one culture to another. For example, in Eastern, interdependent cultures greater emphasis is placed on the family and social networks, and dependence is valued unlike in Western cultures (Saxena, 1994). By contrast, self-oriented dimensions are likely to have more relevance in Western cultures. According to Leplege and Hunt (1997), a definition of quality of life is tied up with issues of translation, meaning and conceptual equivalence in different cultures. The following definition proposed by the World Health Organization Quality of Life Group (1993) emphasises the importance of cultural influences on quality of life:

"...an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and common concerns." (cited in Seed & Lloyd, 1997, p.147)

## Conclusion

Definitions of quality of life that emphasise the culturally sensitive nature of quality of life imply that there is no particular standard of quality of life that can be applied indiscriminately to all cultures. Culturally sensitive definitions appreciate that what will satisfy one individual from one culture will not necessarily satisfy another individual from a different culture.

### 1.3.6 Towards a universal definition of quality of life: a desirable goal?

Reaching a consensus regarding a definition of quality of life may overcome problems of misuse of the term (Annas, 1990) and provide an insight into how quality of life can be quantified.

However, the advisability of finding a universally agreed definition can be questioned (Hyland, 1997). Indeed, Spilker (1990) welcomed the diversity of definitions employed by the contributors of his edited book. Given that interpretations of quality of life are likely to vary across cultures, societies, the contexts in which it is used, from one individual to another and also within individuals over time, one definition of quality of life may not necessarily be relevant to all individuals in all situations.

### 1.3.7 Summary

It has been suggested that there are as many definitions of quality of life as there are people studying the phenomenon (Baker and Intagliata, 1982). This section has provided a sample of the plethora of definitions of quality of life. Examples were presented of definitions which refer to quality of life in objective terms and which assume equivalence of a particular level of quality of life across individuals. By contrast, subjective definitions appreciate the diversity of individuals with respect to their experience of life. Subjective definitions embrace the influences of individuals' present lifestyle, past experiences and hopes for the future and thus may be described as socially and culturally sensitive. Finally, some definitions refer to quality of life as a global construct while other definitions make explicit reference to the multi-factorial nature of quality of life and identify its key dimensions.

While many authors recognise that no universal definition of quality of life exists, the question of whether it would be desirable to have such a definition is seldom considered. The quest to find an agreed definition of quality of life is not only hampered by the varying interpretations of the concept across individuals but also by the blurred distinction between quality of life and concepts such as health status, life satisfaction, well being, and happiness. These related concepts are addressed in the next section.

## 1.4 *Concepts Related to Quality of Life*

According to Richards and Ramirez (1997), there is a general agreement that quality of life is related to a subjective sense of well being or life satisfaction. Several authors refer to concepts



such as well being and life satisfaction as components of quality of life. Andrews and Witheys' (1976) definition presented earlier suggests that perceptions of well being contribute to one's evaluation of quality of life. Bowling (1991) argued that quality of life includes:

“perceptions of well being, a basic level of satisfaction, and a general sense of self-worth.” (p.9)

Life-satisfaction, well being, health, happiness, and self-esteem also feature in the list of quality of life indicators provided by Zhan (1992). Further evidence for the use of these related concepts as indicators of quality of life can be found in the clinical trial performed by Croog et al. (1986), referred to in Section 1.2.3, which used well being and satisfaction as outcome measures of quality of life.

Helburn (1982) proposed that the components that contribute to happiness also contribute to quality of life. Several other authors have also equated quality of life with such related concepts as 'well being' and 'satisfaction'. Cohen et al. (1996), for example, define quality of life as subjective well being. The early 'quality of life' studies cited in Section 1.2.2 referred to assessments of a sense of well being, satisfaction and happiness. Campbell et al. (1976), for example, in their publication *The Quality of American Life* make several references to reports of happiness. Associations have also been made between health and quality of life. According to Ware (1987), it has become fashionable to equate health, defined comprehensively, with quality of life. Leplege and Hunt (1997) recommend replacing quality of life with a more easily handled and rigorously defined notion such as 'subjective health status'.

## Conclusion

Teasing apart quality of life and related concepts such as happiness, well being, and health, would appear to be no easy task. While some authors identify these related concepts as components of quality of life, others use these concepts interchangeably with quality of life.

## 1.5 *Critical Issues in the Concept and Measurement of Quality of Life*

The absence of an agreed definition of quality of life and of an identity distinct from the related concepts addressed above suggests that quality of life is a particularly ambiguous concept. This ambiguity has particular implications for the measurement of quality of life. An essential requirement of a measuring device is that it is valid; that is to say, it must actually measure the attribute it purports to measure. In the case of quality of life, validity cannot be determined as there is no standard reference criterion or gold standard by which quality of life can be measured. Instruments have consequently been adopted, often against the recommendations of their authors, which were developed for other purposes, for example as indicators of health status (Hunt 1997). Leplege and Hunt (1997) argue that quality of life is inferred from a variety of indicators that tell us something about life but nothing about the quality of life. Comparisons across studies that have adopted different measures of quality of life are therefore questionable. Perhaps a more fundamental concern lies with the ethical implications of using 'quality of life', as determined by measures of questionable appropriateness and validity, to influence health care decisions.

### 1.5.1 Quality of life and individual value systems

The ambiguous nature of quality of life is not the only challenge facing researchers who set out to assess quality of life. Inherent in the work of Campbell et al. (1976) cited in Section 1.2.2 and the subjective definitions of quality of life discussed in Section 1.3.2 is the assumption that interpretations of quality of life are unique to individuals. According to Hyland (1998), these interpretations reflect an individual's particular value system about what is important in life. The particular value system that an individual subscribes to is likely to result from an interaction of individual, social and cultural factors. Adopting this perspective on quality of life would lead one to expect that an individual driven, for example, by pleasure would not share the same conceptions about the meaning of quality of life with an individual who, for example, has chosen to lead a contentment-oriented lifestyle.



Following on from the argument that the meaning of quality of life for a particular individual is shaped by his or her value system, is the issue of how quality of life can be meaningfully evaluated across individuals. Hyland (1998) writes:

“The same questionnaire is not an identical tool in the hands of different patients - even though it looks the same to the researcher.” (p.430)

If two patients receive the same score on an item such as: ‘I cannot work at all’, it cannot be assumed that, in terms of work, these patients are experiencing a similar level of quality of life. The implications of not being able to work are likely to be different for an achievement-oriented individual compared with an individual who is more concerned with the simple pleasures in life. Gill and Feinstein (1994) argued that quality of life can only be adequately measured by embracing the values and preferences of individual patients and that it is this requirement that distinguishes quality of life measures from other health-related measures. The issue of taking into account individual value systems when measuring quality of life will be explored in greater depth in the following section.

## Conclusion

Conceptions of what constitutes quality of life are likely to vary across individuals and it is proposed that these conceptions are driven by values about what is important in life. This implies that individuals’ value systems should not be ignored when interpreting scores from quality of life measures.

### 1.5.2 A taxonomy of measures of quality of life

The diversity of definitions of quality of life is matched by a diversity of measures purporting to address quality of life. Quality of life measures can be categorised according to whether they are generic or specific to a particular disease, population, function, condition, or indeed individual. Generic scales are nomothetic as they can be applied to all patient groups and thus allow comparisons across different conditions. Specific instruments include items that are

tailored to the area of primary interest, for example a particular illness, and therefore preclude comparisons with individuals outside the area of interest.

1.5.2.1 Generic scales. There are three main types of generic measures: Multi-dimensional, Multi-attribute utility, and Global.

Multi-dimensional scales or health profiles are single instruments that measure different aspects or domains of quality of life such as those identified in Section 1.3.4 and provide a 'picture' of the individual's quality of life. Many of the scales that fall under the umbrella of generic health profiles were originally designed as measures of health status and not quality of life (Hunt, 1997). Examples of such measures include the Nottingham Health Profile (NHP; Hunt, McEwen, & McKenna, 1986), the Sickness Impact Profile (SIP; Bergner, Bobbit, Carter, & Gilson, 1981) and the MOS 36 item Short-Form Health Survey (SF-36; Ware & Sherbourne, 1992).

Items of similar content (as defined by the authors of the particular measure) can be aggregated to produce domain scores. A total score or health index results from the summation of all items in the scale; however, profiles were not originally designed to produce a single score.

The items of several of the profiles, for example the NHP and SIP, are assigned numerical weights to account for their relative severity. The weights are derived from the ratings of judges. In the case of the items of the SIP, weights were derived from equal appearing interval-scaling procedures involving more than 100 judges. Each item was rated on an 11-point scale ranging from 'minimally dysfunctional' to severely dysfunctional'. It can be argued that these weights do not reflect the severity of limitations as perceived by the individual patient. In addition, significant inter-individual differences in weighting policies have been reported (O'Boyle, McGee, Hickey, O'Malley, & Joyce, 1992).

The above examples of multi-dimensional scales share many similar features. Firstly, they all, to some extent, require individuals to consider what they *cannot do* because they are ill and are thus negative in focus. Secondly, there is a considerable overlap between the scales with respect to their domains and individual items. As reflected in the multi-dimensional definitions of quality

of life presented in Section 1.3.4, the scales all assess some aspects of social, emotional and physical functioning. Both the NHP and the SF-36 measure energy deficits: 'I soon run out of energy' (NHP); 'Did you have a lot of energy? (SF-36)', and both the SIP and the NHP contain sleep items: 'I sleep or nap during the day' (SIP); 'I'm waking up in the early hours of the morning' (NHP). The above scales, however, neglect certain aspects of life, such as, spirituality and family functioning. With the exception of the NHP, sexual functioning is also a neglected domain.

Cost utility analysis draws upon information provided by multi-attribute utility scales and global scales, to calculate QALYs. The QALY was first formally used by Weinstein and Stason (1976) to represent a year of full life quality free from illness. QALY assessments represent improvements in the length and quality of life holistically as a single number along a ratio scale where 0 equates to death and 1 to full health. In the UK the primary measure underlying the calculation of QALYs is the Rosser Index of Disability, which was originally developed as an indicator of hospital performance (Rosser & Watts, 1972). This index places individuals in one of eight areas of disability (from no disability to unconscious) and in one of four levels of distress (from no distress to severe distress) within a matrix to provide a single figure of health status.

Multi-attribute scales, such as the Quality of Well Being Scale (QWB Scale; Kaplan & Bush, 1982), include items measuring multiple domains of quality of life deficit. As with the multi-dimensional profiles referred to earlier, responses to items on the multi-attribute utility scales can be aggregated into sub-scales, or, unlike the majority of multi-dimensional profiles, into an overall score to generate a QALY.

Global measures of quality of life also provide an overall perspective on quality of life and include exchange or preference scales and rating scales. The exchange methodology elicits individuals' preferences concerning the length and quality of life. The Standard Gamble method is based on the principles of utility theory first presented by von Neumann and Morgenstern (1953) and asks individuals to choose between their own health state and a gamble of a less desirable health state or enjoying full health for the remainder of their lives. The probability of getting the desirable or less desirable outcome is manipulated until the individual is indifferent between the

gamble and his / her own health state. The Willingness to Pay or Receive approach was first proposed by Dreze (1962) and asks individuals to consider, for example, how much they would be willing to pay to be cured of an illness. In the Time Trade-Off Technique (Torrance, Thomas, & Sackett, 1972), respondents are asked to consider how much shorter a life in good health they would prefer to a longer life with a specified level of disability. The Equivalence of Numbers method, applied by Nord (1992), asks respondents to consider the number of people in a better state of health that would have to be cured for them to think the situation barely preferable to curing a smaller number of people in a worse-off state.

Global rating scales require respondents to evaluate their quality of life on a single scale such as a visual analogue or category rating scale. Hyland and Sodergren (1996) developed a category rating scale with end point labels 'Perfect quality of life' and 'Might as well be dead' and additional quantifiers along the scale, which, according to Borg (1982), enhance a scale's ratio-like qualities. Hyland and Sodergren compared different category rating scales, visual analogue scales and category rating scales with additional quantifiers, and found the latter scales to be superior in terms of reliability.

Hyland's argument (1998) that the same quality of life scale takes on a different form from one individual to another is particularly true of global scales - the task of writing a number that 'best describes your quality of life' will depend upon the meaning of quality of life for a particular individual. In addition, individuals may encounter difficulties in referring to their quality of life in terms of numbers.

The utility approach to quality of life measurement is regarded as particularly controversial both in terms of the methodologies used and the ethics of relying on QALY values as a basis for decision-making. It is perhaps naive to assume that a QALY is of equal value whoever the beneficiary. According to Henwood (1993), the application of the QALY approach is inherently discriminatory particularly where the elderly are concerned. It can be argued that the QALY approach is merely a routine for an uncomfortable decision.

Although generic quality of life scales are valuable in terms of allowing comparisons across different patient groups, Hyland (1992) argued against the use of such quality of life scales

to compare disease states. According to Hyland, the degree of quality of life deficit experienced by a particular patient group depends on the degree of overlap between the experiences specific to that group and the balance of items included in the scale. Generic scales may ignore items that are pertinent to a particular illness and include irrelevant items that merely add noise. For example, the SF-36 may not be an appropriate measure of the quality of life deficits experienced by asthmatics as it does not measure sleep disturbance, a particularly salient problem for asthmatics, and measures pain that is not a characteristic of asthma. Using the SF-36 to compare the quality of life deficits of an asthmatic with those of an individual with arthritis is likely to paint a more positive picture of the quality of life of the asthmatic purely on the basis of the items included in the scale which are likely to be more finely tuned to the problems experienced with arthritis. The insensitivity of generic scales also results from the inclusion of items describing problems, for example, with social interactions, which are not exclusive to any one particular illness.

**1.5.2.2 Specific scales.** Specific measures of quality of life are designed to be sensitive to the aspects of quality of life that are central to a particular group of individuals, such as those with a particular illness. The field of respiratory illness would appear to have the most to offer in terms of disease-specific scales. The Living with Asthma Questionnaire (Hyland, 1991), for example, consists of 68 items covering 11 domains specific to the experience of asthma. The scale is exclusive to asthma in that it only includes items that are relevant to asthma, for example, those measuring sleep disturbance and not pain. The scale is inclusive of all quality of life deficits experienced by asthmatics and therefore distinguishes asthmatics from non-asthmatics. An example item includes:

“When invited around to a friend’s house, I worry that there may be something there which sets off an attack”

According to the psychometric properties of the scale (Hyland, Bellesis, Thompson, & Kenyon, 1996), there are four construct sub-scales - activities, distress, preoccupation and avoidance.

The McGill Quality of Life Questionnaire (Cohen et al., 1995) measures four constructs - physical symptoms, psychological symptoms, outlook on life, and meaningful existence, which are

salient to individuals experiencing a life-threatening illness. The authors argued that existing scales are inappropriate for this particular population for the following reasons: the neglect of the existential domain, the excessive emphasis on physical status, and the failure to include positive contributions to quality of life. In addition, the length of some generic scales - the SIP contains 136 items, renders them inappropriate for completion by a population such as those with an advanced illness.

The specificity of quality of life measures can be further refined to be appropriate to a specific subgroup of individuals, for example children experiencing a particular illness. There is a particular need for the development of childhood-specific measures given that children have been identified as one of five priority groups in international quality of life research (Orley & Kuyken, 1994). Adult measures of quality of life are often inappropriate for children due to their length, reference to time frames which children may find difficult to relate to, the level of literacy required, the nature of response options - children may find Likert-type scales difficult to use, and the inclusion of irrelevant items such as those referring to sexual activity. In addition, adult measures are insensitive to children's different conceptions of quality of life and to the differential impact of an illness on their quality of life depending on age and social or family context (Eiser, 1998). Adult measures can be modified to suit children, for example, the Paediatric Asthma Quality of Life Questionnaire (Juniper, Guyatt, Feeny, Ferrie, Griffith, & Townsend, 1996) represents an adaptation of the Asthma Quality of Life Questionnaire for adults (Juniper, Guyatt, Epstein, Ferrie, Jaeschke, & Hiller, 1992) with items such as gardening and vacuuming replaced by skipping and rollerblading. The Childhood Asthma Questionnaires (French & Christie, 1995) include several versions each tailored to suit the quality of life concerns experienced by children of a particular age group.

The idiographic or person-specific perspective on quality of life, presented in section 1.5.1, implies that the pre-structured measures of quality of life may be insensitive to the individual's idiosyncratic preferences regarding what is good in life. Cantril's (1965) self-anchoring scale represents an early idiographic measure. A further example of an idiographic measure is the Schedule for the Evaluation of Individual Quality of Life (SEIQoL; O'Boyle et al.,

1992), which allows individuals to nominate five areas of life (cues) that are important to them. Respondents rate their current status on each cue using a vertical visual analogue scale with end-point anchors 'best possible' and 'worst possible'. Finally, respondents weight the relative importance of each cue through a process of judgement analysis. An overall SEIQoL index is calculated by multiplying the weight and individual rating for each cue and summing the products. Research using the SEIQoL with hip replacement patients and healthy individuals (O'Boyle et al, 1992) identified social or leisure activities and family as the most frequently nominated domains by both groups. Both groups also frequently selected religion, an often-neglected domain in existing scales. Interestingly, health was nominated most frequently amongst the healthy group. An important outcome of the research using the SEIQoL is the variety of responses elicited by individuals with the same illness.

## Conclusion

When attempting to assess quality of life, the issue lies not with finding a measure of 'quality of life' - there are certainly many to choose from, but with finding an appropriate measure. Generic scales are not exclusive to any one particular illness and can be used for comparisons across patient groups. While generic multi-dimensional scales produce a 'picture' of an individual's quality of life, multi-attribute utility scales and global scales are designed to produce a single score that is often used to generate a QALY. Generic measures are not inclusive of all aspects of all types of illness and often overlook fundamental issues such as existential well being. Even though generic scales are designed to embrace all types of illness, by the very nature of their items, they may be biased towards a particular illness. Specific instruments are designed to overcome the problems of insensitivity of generic scales.

Traditional methods of quality of life assessment impose an external value system on individuals and do not embrace individuals' unique value systems. The SEIQoL represents an alternative approach that is not biased towards a particular illness, social or cultural context.

### 1.5.3 Issues of cross-cultural translation of measures

The increasing interest in cross-cultural research has arisen from a number of sources including drug companies in the application of multi-national drug trials, international organisations recommending the funding of packages of health care across developing countries and academics interested in cross-cultural comparisons (Fox-Rushby & Parker, 1994). One important consequence of this demand for quality of life measures across diverse cultures is that measures developed in one particular cultural context are used amongst populations with different cultural backgrounds. The issue of using the same quality of life instrument across diverse cultures is an issue that needs to be addressed for several reasons. Firstly, as was argued in Section 1.3.5, conceptions of quality of life are not homogeneous across cultures. For example, measures developed in Western cultures do not emphasise spirituality and family functioning, aspects of life that are particularly salient for individuals in Asian cultures (Chaturvedi, Tazaki, Fukuhara, & Ikeda, 1997). Secondly, although in Western cultures quality of life may be regarded as a highly valued state, in Asian cultures, for example, quality of life is not seen as a priority (Chaturvedi et al., 1997). An individual's experience of evaluating their quality of life may therefore differ according to their cultural background. In some cultures, for example in Indonesia, there is a poor understanding of quality of life (Chaturvedi et al., 1997) making the completion of idiographic measures of quality of life particularly difficult. In addition, levels of literacy vary across cultures and items regarded as acceptable in one culture may be considered taboo in another (Sartorius & Kuyken, 1994). Finally, items may be irrelevant to individuals from certain cultures. Jones (1998) provides the example of asking respiratory patients from Bangkok about difficulties when climbing hills. As Bangkok is a flat city, breathlessness is only likely to be experienced when climbing stairs and going over bridges and not from climbing hills. Attempts to translate quality of life measures aim to maintain as far as possible conceptual, semantic and technical equivalence between the target language and source language versions of the measures (Sartorius & Kuyken, 1994). In the context of health status measures, Sartorius and Kuyken (1994) recommend a pragmatic approach to translation that identifies those aspects of health common to both cultures as well as those features that are specific to the context in which they are being



studied. In addition, item weights, if used, should be re-assigned according to the importance of the items in the particular target culture. Hunt and Wicklund (1987) compared the weightings assigned by Swedish and English samples to the items on the NHP. Although a high level of agreement was found between the Swedish translation and the English version, some discrepancies in the weightings were identified and were attributed to differences in cultural values.

## Conclusion

Cross-cultural translation of quality of life measures is not merely a matter of maintaining linguistic equivalence. The same items may perform differently across cultures for several reasons. There is considerable cultural diversity in conceptions of what constitutes quality of life. Indeed, it cannot be assumed that members of all cultures even have a conception of what quality of life means. Also, quality of life is not equally valued across cultures.

### 1.5.4 Who should measure quality of life?

Implicit in the idiographic approach to quality of life assessment is that quality of life can only be assessed from the perspective of the individual. The argument that the individual should be the primary source of information on his or her quality of life is particularly strong in the case of children who may not share the same perspective on quality of life as adults (Eiser, 1998). There are occasions however where a proxy assessment provides the only insight into the individual's quality of life. An obvious example is provided by the case of the dogs in the clinical trial referred to in Section 1.2.4 whose quality of life was evaluated in terms of pain relief as seen from the eyes of their owners. In human health care, proxy assessments are particularly desirable in situations where individuals are not able to communicate their quality of life values or where the completion of a quality of life measure would be too burdensome for individuals given their poor state of health. It is in such settings that quality of life evaluations are particularly relevant. A need for proxy assessments is illustrated in a study carried out by Magaziner, Simonsick, Kashner, and Hebele (1988) on the health and functional status of elderly hip fracture patients. Of 858 patients identified for inclusion in this study, 517 could not be interviewed due to cognitive

impairment, physical illness, refusal or death. Enlisting the participation of proxies increased the sample size by 71%.

Research evaluating the accuracy of proxy assessments has produced mixed results. A particularly influential study performed by Slevin, Plant, Lynch, Drinkwater, and Gregory (1988) reported poor concordance between patient and caregiver ratings of three items assessing quality of life, anxiety and depression with the results obtained from health professionals rarely accounting for more than 30% of the variability in patients' scores. In addition, considerable variability, particularly for the more subjective scales, was observed in the results obtained from different health professionals. Blazeby, Williams, Alderson, and Farndon (1995) found poor to moderate agreement between ratings of oesophageal cancer patients and those of their caregivers and treating physicians and concluded that proxy assessments are not sufficiently accurate to postulate the patient's responses. A consistent trend is for the proxy to underestimate the quality of life of the patient (Browne, 1997). This may result from the emphasis by health professionals on the importance of health to the patient's quality of life. Also, the proxy may not appreciate the patient's ability to adapt to illness, an issue that will be addressed in the following section.

More optimistic data are provided by Sneeuw, Aaronson, Sprangers, Detmar, Wever, and Schornagel, (1997) who found close agreement (between 73% and 91% of cases) between the ratings of cancer patients and those of caregivers.

The degree of concordance between patient and caregiver ratings appears to be influenced by the relationship between the proxy and patient and the domains of quality of life assessed. The above studies all reported slightly higher agreement between patient and informal caregiver ratings compared with patient and physician ratings suggesting that the person who has the most contact with the patient is more in touch with the patient's quality of life. However, Abetz and Easterbrooks (1997) compared reports of quality of life made by children with maternal and teacher reports and found that, while there were few significant correlations between child and maternal reports, children's reports of depressed mood and self-esteem agreed with several of the teacher report sub-scales. Parents' own anxiety levels may provide one explanation for lower than expected correlations (Eiser, 1998). In addition, Rothman, Hedrick, Bulcroft, Hickman, and

Rubenstein (1991) found greater discrepancies between assessments in situations where the proxy had the greatest contact with the patient. One possible explanation for this finding is that if the proxy is responsible for the full-time intimate care of the patient, the burden experienced in providing this care may distort assessments and lead to an over-exaggeration of the problems experienced by the patient (Magaziner et al., 1988). Magaziner et al. (1988) suggest that an optimum proxy assessment may be provided from individuals who are not intimately involved with the patient's daily care but who maintain close contact with the patient.

Proxy ratings of concrete, observable dimensions of quality of life appear to be more accurate than ratings of internal, private dimensions, such as emotional and social function (Eiser, 1998). Blazeby et al. (1995) reasoned that physicians are more accustomed to measuring symptoms than the emotional and social aspects of illness. These findings suggest that proxy assessments are likely to be insensitive to individuals' existential concerns that, as highlighted earlier, are often brought to the forefront by illness (Cohen et al., 1995).

Although a proxy assessment may be viewed as a 'last resort', such assessments may provide a useful complementary perspective on the individual's quality of life. According to Schipper and Levitt (1986), the optimal method of measuring quality of life utilises the combined observations of those individuals whose 'universe of concern' is the patient. Such individuals may include the patients themselves, nurses, physicians, social workers, and theologians. Indeed, if quality of life is measured conventionally in terms of objective functional status, then it is possible that caregivers may provide a more accurate insight into what the individual can and cannot do (Hyland, in press).

## Conclusion

Although, in this chapter, it has been argued that quality of life is essentially a subjective evaluation that, by implication, can only be provided by the individual, there are occasions when it is considered desirable to use proxy assessments. Several studies designed to establish the interchangeability of patient and proxy assessments have produced disappointing results. However, the accuracy of proxy assessments appears to depend on the type of proxy used with informal

caregivers often producing more accurate reports, and the type of assessment made with closer agreement for objective dimensions than for internal, subjective dimensions. It was proposed that rather than merely representing a 'second best' perspective on an individual's quality of life, proxy assessments may provide additional, complementary sources of information on the individual.

### 1.5.5 Quality of life assessment and adaptation to illness

Quality of life ratings of individuals experiencing poor health have often been found to be unexpectedly high. Kagawa-Singer (1993) quotes a woman with metastatic cancer whose own perception of health contradicted her objective biomedical situation:

“I am really very healthy, I just have this problem, but I am still me.” (p.295)

As discussed in the previous section, where discrepancies are found between patient and proxy assessments, there is a tendency for proxies to underestimate the patient's quality of life.

Brickman, Coates, and Janoff-Bulman (1978) examined happiness levels amongst individuals experiencing 'bad fortune', namely victims of accidents, and found that they did not appear as unhappy as expected. There have even been reports of superior psychological well being among patients with a potentially life threatening illness (melanoma) compared with patients with less serious conditions (non-malignant dermatological illness) and healthy individuals (members of the general public) (Cassileth, Lusk, & Tenaglia, 1982).

There are several theoretical explanations for these somewhat paradoxical findings. Quality of life is considered as a dynamic construct with individuals changing their personal meaning as to what constitutes a 'good quality of life' over time (Allison, Locker, & Feine, 1997). Aristotle (circa 335-323 B.C. / 1976, cited in Patrick & Erickson, 1993) made direct reference to the dynamic nature of happiness in the *Nichomachean Ethics*:

“When it comes to saying in what happiness consists, opinions differ...often the same person actually changes his opinion. When he falls ill he says it is his health and when he is hard up he says that it is his money.” (p.20)

In addition, as noted earlier, Campbell et al. acknowledged that the determinants of an individual's quality of life are unlikely to remain stable across an individual's lifespan. The assumption that quality of life is a dynamic construct implies that not only is the same quality of life instrument a

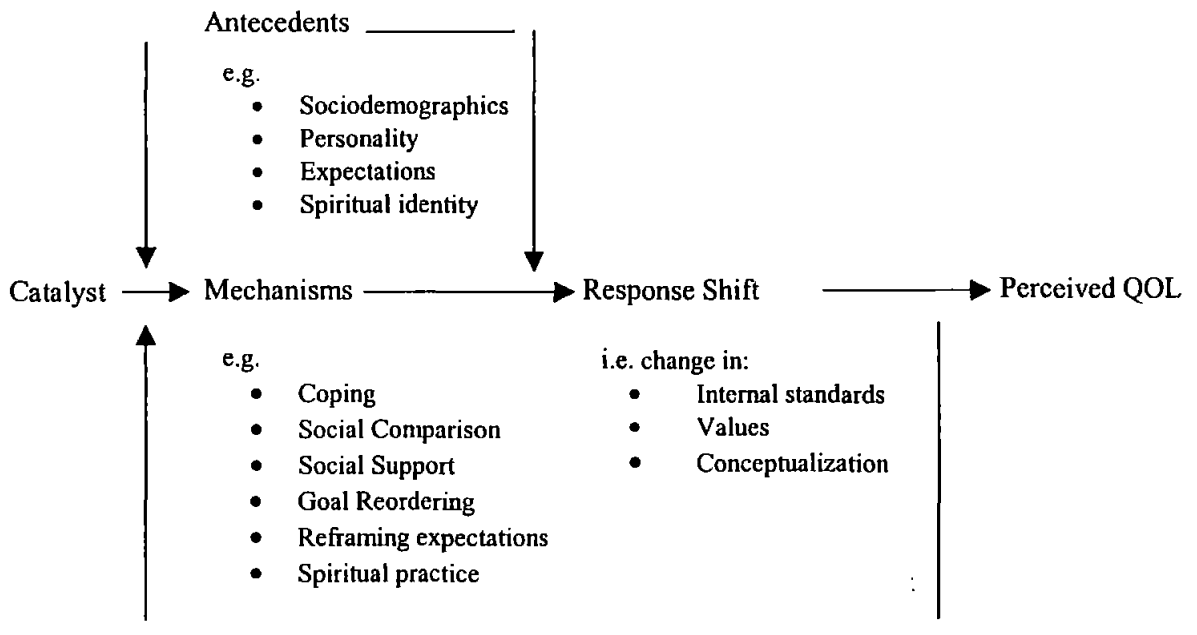
different tool in the hands of different patients (Hyland, 1998), but also a different tool in the hands of the same patient across different points of time.

The process of adaptation is one explanation offered for the instability of individuals' attitudes towards quality of life (Allison et al., 1997). Individuals may adapt to their illness by 'disengaging' from unattainable goals (Carver & Scheier, 1990). The process of disengagement is illustrated in the folk tale of the Fox and the Sour Grapes (Aesop, Handford, 1954) - when the fox found that he could not reach the grapes he pretended that they were sour. Disengagement is a psychologically healthy response to adverse conditions and protects the individual from the reminder of failure (Heidrich, Forsthooff, & Ward, 1994). However, illness is not necessarily an occasion of learning to aspire to less as individuals may develop new goals relating to the dimensions of life, often non-physical, existential, that have become more salient as a result of illness. Thus, as suggested by Cohen and Mount (1992), for example, when suffering in one domain is overridden by an enhanced personal meaning in another one sees a net increase in quality of life. Adaptation to illness may also occur as a result of selective evaluations of oneself and one's situation (Taylor, Wood, & Lichtman, 1983). Taylor et al. (1983) described the following five mechanisms which enhance one's self-evaluation in the face of a 'victimising' event such as illness: (1) downward social comparisons with inferior others; (2) selectively focusing on one's favourable attributes; (3) creating hypothetical worse worlds; (4) construing benefit from the victimising event; and (5) manufacturing normative standards of adjustment that favour oneself.

Inherent to the process of accommodating illness is the response shift phenomenon (Breetvelt & vanDam, 1991; Sprangers & Schwartz, 2000). Response shift refers to a revision of an individual's priorities, internal standards, or in the meaning of quality of life brought about by a change in health state (Breetvelt & vanDam, 1991). Sprangers and Schwartz's (2000) model of response shift (Figure 1.1) provides examples of processes (mechanisms) that lead to a response shift following a change in health state (catalyst). In this model, dispositional factors (antecedents) are acknowledged as playing a role in determining the type of mechanisms an individual will engage in to accommodate the catalyst and the magnitude and type of resulting response shift. While some of the examples of mechanisms featured in the model, namely social comparison and

goal reordering, are discussed above, a thorough treatment of the antecedents and mechanisms included in the model is provided in Chapter 2 within the context of explanations for positive consequences of illness.

Figure 1.1. A model of response shift (adapted from Sprangers & Schwartz, 2000, Figure 1.1, p.13)



The response shift bias causes serious methodological problems both for longitudinal and cross-sectional research as it implies that pre-test versus post-test measurements and patient versus control groups are not measured on the same scale. In view of this threat to the internal validity of quality of life measures, Breetvelt and vanDam (1991) recommend exercising caution when interpreting ratings of quality of life. One proposed method of accommodating the response shift bias is the 'then-test' or retrospective pre-test method that assesses changes in internal standards by asking individuals to provide a renewed judgement about previous levels of quality of life (Sprangers and Schwartz, 1997).

## Conclusion

Through the process of adaptation to illness, individuals may change their goals, self-evaluations or values about what is 'good in life'. Thus, individuals may not 'complain' about their illness despite experiencing severe limitations. This response shift phenomenon has important implications for both cross-sectional and longitudinal quality of life research. The 'then-test' assessment has been proposed as a method of detecting response shifts.

### 1.5.6 Summary

This section has considered a diverse set of factors that impinge on the conceptualisation and measurement of quality of life. The meaning of quality of life for an individual is shaped by the individual's unique value system, an issue that must be addressed when selecting an appropriate measure of quality of life. There are numerous scales which are used to assess quality of life and either fall under the umbrella of generic scales which can be applied to any patient group; although their suitability varies across patient groups, or specific scales which are tailored to the particular area of interest usually a certain disease. Person-specific or idiographic measures accommodate individuals' personal values on quality of life and therefore differ from other pre-structured measures that impose an external value system and have questionable construct validity. The issue of allowing for diverse value systems is particularly pertinent in cross-cultural research.

The argument that quality of life is idiographic implies that the individual is the only person who is qualified to provide an evaluation of his or her quality of life. There are occasions however when it is deemed desirable to seek a proxy assessment. A further critical issue addressed concerned the response shift bias resulting from the process of adaptation to illness. Conventional measures do not account for this bias and this bias is unlikely to be described in proxy assessments. This issue of individuals reporting a good quality of life despite experiencing poor health is explored in greater detail in the final section of this chapter.

### 1.6 *A Positive Perspective on Quality of Life*

Most existing quality of life measures emphasise negative life quality and represent good quality of life as the absence of health complaint. This 'absence of complaint' approach to measurement asks individuals to rate what they *cannot* do because of their illness and to evaluate their quality of life in terms of the extent to which the 'glass is half empty' (Janoff-Bulman, 1992). The underlying assumption of this approach is that illness imposes only deficits to quality of life. However, the reports presented in Section 1.5.5 of individuals experiencing a good quality of life despite their poor health challenge this assumption. If quality of life is defined in terms of the totality of subjective experiences (DeHaes & vanKnippenberg, 1985), then by only focusing on negative appraisals most existing measures may not be providing an overall picture of the illness experience for some people. In addition, such a focus on the negative aspects of illness is likely to leave patients feeling devalued (Dahl, 1992).

An alternative approach to measurement asks individuals to rate what they can do despite having an illness and therefore to consider the extent to which the 'glass is half full'. This approach was adopted by Hyland, Sodergren, Singh, and Haq (1997) who developed a positive activity checklist asking individuals to indicate activities they have carried out. The need to embrace positive contributions to quality of life is also recognised by the authors of the McGill Quality of Life Questionnaire (Cohen et al., 1995) who argued that by emphasising physical status and neglecting existential well being, traditional measures may mask the good quality of life experienced by some patients with advanced illness.



The issue of adopting a positive perspective on quality of life goes beyond that of allowing individuals to express what they can do despite their illness. A further issue involves considering individuals' positive interpretations of the illness experience, that is, what individuals may actually gain as a consequence of being ill. The positive consequences of illness will be explored in the following chapter.

## CHAPTER 2

### POSITIVE CONSEQUENCES OF ILLNESS

"I am happier than I have ever been, these are truly the best days of my life"  
(Mack, 1984, p.1642, in his personal account of living with cancer)

#### 2.1 *Introduction*

The review of quality of life presented in the previous chapter highlighted the negative focus of traditional approaches to the conceptualisation and measurement of quality of life.

Greenfield (1974) refers to quality of life as:

"...a yearning of people for something which they feel they have lost or are losing, or have been denied and which to some extent they wish to regain or acquire." (p.ii)

In the context of health care, quality of life is often defined in terms of the deficits imposed by ill health:

"...quality of life refers to illness problems, the constraints that disorder places on the patient, and his or her lifestyle or lifeworld." (Kleinman, 1986, p.43)

Measures used to assess quality of life often take the form of complaint checklists and give patients the opportunity to evaluate the extent to which their lives have deteriorated as a result of illness. The SIP (Bergner et al., 1981), for example, includes items such as:

"I am staying in bed most of the time"  
"I am going out for entertainment less"  
"I do not walk at all"

The reasoning behind this negative approach to quality of life assessment is justified - illness can cause considerable suffering and distress. An emphasis on the negative sequelae of illness, however, has meant that the possibility that illness may not only leave a patient's quality of life intact but actually produce positive consequences is often overlooked. Yet, the first reference to positivity in illness dates back to the seventeenth century:

" Priere pour demander a Dieu le bon usage des maladies" (Pascal, 1671, p.70)

translated as: a prayer to ask God for the right use of sickness. In addition, historically there are several other acknowledgements of positivity, for example:

"How sickness enlarges the dimensions of a man's self to himself" (Charles Lamb, 1822, cited in Bartlett, p.535)

"Sickness is the only way we have to obtain piece of mind" (Ishikawa Takuboku, 1885-1912, cited in Bartlett, p.985)

Although in the modern literature there are repeated reports of positivity in illness such as the one presented at the beginning of this chapter, these accounts are often anecdotal in nature and incidental to the main purpose of the research. In some cases, reports of positive outcomes of illness are even treated as untrustworthy (Hayry, 1991). Backman (1989) writes:

"When positive emotions are expressed by those who are seriously ill, others often react with surprise and interpret the unexpected positive feelings as denial and a distortion of the 'real', more appropriate feelings." (p.92)

This chapter argues that the positive consequences of illness merit attention not only for conceptual completeness but because they may have important therapeutic effects.

This chapter covers the following:

- \* Accounts in the literature of positive consequences of aversive events in general and illness in particular;
- \* Methodologies used to assess positive outcomes of aversive events including illness;
- \* Explanations for positive interpretations of illness;
- \* Implications of positive consequences of illness for the measurement of health outcome and for health management

## 2.2 *Positive Consequences of Illness: a review of the literature*

The focus of this section will be on the reports of positive consequences of illness cited in the literature. This section will however commence with a review of accounts of positivity in the context of aversive events in general.

### 2.2.1 Positive consequences of aversive events

There is a literature that suggests that stressful life events may have positive outcomes.

Indeed, Martin (1997) writes:

"relatively mild, brief and controllable stress can be stimulating and enjoyable" (p.146).

Tedeschi, Park, & Calhoun (1998) used the term Posttraumatic Growth (PTG) to describe the experiences of individuals who not only exhibit resilience in the face of trauma but who use it as a 'springboard' to further their development or growth. Positive outcomes of stressful life events are reported to be "remarkably common" (Schaefer and Moos, 1992, p.149) with more than 50% of individuals experiencing life crises reporting some gains from them (Schaefer & Moos, 1992). Ebersole and Flores (1989) asked 96 college students to rate the impact of their 'most sorrowful or painful experience or time of their life'. Positive ratings were elicited from 41.7% of the sample, a finding that led the authors to conclude that you do not have to be extraordinary to believe you can transcend or rise above a difficult life experience. Taylor, Wood, & Lichtman's (1983) analyses of reports of 'victims' of negative events such as illness suggest that perhaps there are no 'victims':

"Victims sometimes seem from their accounts not only to have overcome the victimizing aspects of their situation, but actually to have benefited from the experience." (p. 20).

A recurrent theme in the literature on traumatic life experiences is that many people come to view their experience as meaningful:

"it didn't happen for nothing" (Janoff-Bulman, 1992, p.133).

The meaning of suffering is clear in religious writings where it is described as an opportunity for bringing people closer to wisdom, truth, and God (Tedeschi et al., 1998). Frankl's autobiography of experiences in a concentration camp provides a classic account of an individual's search for meaning during suffering (Frankl, 1959). Frankl claims that this search for meaning is the primary motivation of man. The adaptive significance of viewing a crisis from a meaningful perspective is well acknowledged (for example, Silver & Wortman, 1980).

According to Caplan (1964), a fundamental assumption of crisis theory is the potential for growth in the face of negative life experiences. Maslow (1968) views aversive experiences such as grief and pain as not only an occasion for growth but also necessary for an individual's growth and

fulfilment. In this way, Maslow argues that an individual should not be shielded from these experiences.

Schaefer and Moos (1992) report three major types of positive outcomes of stress: (a) enhanced social resources such as improved relationships with others; (b) enhanced personal resources such as self-understanding; and (c) the development of new coping skills such as problem solving. These stress-related positive outcomes were identified in diverse life crises including divorce, combat and imprisonment, and caregiving and bereavement.

**2.2.1.1 Divorce.** Wallerstein (1986) reported the findings of a 10-year longitudinal study of divorcing families and located instances of psychological growth particularly within the group of females who were in their 20s or 30s at the time of divorce. For many women, divorce gave them the opportunity to enjoy success in a new career, which in turn led to enhanced self-esteem and improved social relationships. Other reported 'benefits' from the divorce include heightened sensitivity to emotions and a more realistic view of the self and the world.

**2.2.1.2 Combat and imprisonment.** As reported above, Frankl (1959) described an intensification of inner life during imprisonment in a concentration camp. Sledge, Boydstun, and Rabe (1980) also described positive changes among Vietnam prisoners of war. Some of these soldiers experienced positive changes in their character, such as becoming wiser, more confident and tolerant. Imprisonment also prompted a re-evaluation of life and of the importance of relationships with others.

**2.2.1.3 Caregiving and bereavement.** Folkman's (1997) results from a longitudinal study of how men cope with the severe and chronic stress of caring for their partners with AIDS led to a proposed revision of Lazarus and Folkman's (1984) cognitive theory of stress and coping in order to accommodate positive psychological states. Several of the men in Folkman's study commented that, by only asking them about stressful events, the research was overlooking an important aspect of their experience. Positive meaningful events were reported in 99.5% of 1794 interviews. The

three main sources of meaning cited include feeling connected and cared about, feeling a sense of achievement and self-esteem, and having an opportunity to be distracted from everyday cares.

Davis, Nolen-Hoeksema, & Larson (1998) interviewed 205 individuals prior to and 1-, 6-, 13-, and 18-months following the loss of a family member in hospice care. Respondents were asked an open-ended question regarding whether they had found something positive in their loss. Example responses to this open-ended question include:

“Yes (I found) a growth and a freedom to give fuller expression to my feelings and to assert myself to do things that I want to do”

“It has caused me to desire to be more knowledgeable and aware of AIDS. I’ve become more active in the gay community in support of healthier lifestyles and safer sex” (p.566).

At 6 months post-loss, 73% of respondents reported a benefit from their bereavement in particular that they had learned something important from it, about themselves, about others, or about the meaning of life.

## Conclusion

The experience of positive outcomes of traumatic life events such as divorce, combat and imprisonment, and caregiving and bereavement, has been documented. Positivity is often connected with a search for meaning in such events, that is, individuals often view the experience from the perspective that it happened for a positive reason. According to Schaefer and Moos’ (1992) conceptual model of stress-related growth, the ‘reason’ for encountering an aversive life experience may be for the enhancement of social resources, personal resources or for the development of new coping strategies. The following section reveals how these three major typologies of positive outcomes are also applicable to illness.

### 2.2.2 Positive consequences of illness

Illness has been referred to as a ‘turning point’ in life and the beginning of living (LeShan, 1984; 1994). In Laerum, Johnsen, Smith, and Larsen’s (1988) study of 84 men who had suffered a myocardial infarction, 33% considered their life situation to be considerably or somewhat

improved as a result of their illness. The quote presented at the beginning of this chapter also refers to an improvement in life situation as a consequence of illness.

There are a number of positive consequences of illness, as perceived by patients, reported in the literature which can be broadly categorised into those which are personal and benefit oneself and those which are beneficial to others and are altruistic in nature (Janoff-Bulman, 1992). However, there is an overlap between the themes, for example certain benefits to the self may translate into gains for others. Outcomes of illness that are beneficial to one-self are addressed first. There is no rationale for the order in which the themes are presented.

**2.2.2.1 Positive outcomes related to the self.** Twelve main themes of positive consequences of illness related to the self are reported in the literature: changes to one's character, enhanced coping strategies, creativity, an opportunity for general learning, self-knowledge, heightened spirituality and religiosity, a reappraisal and restructuring of life, reordering of priorities, the use of illness as a relief from the demands of being well, illness as an opportunity for atonement, and the use of illness to deal with problem areas of one's life.

(a) Illness has been described as a character building experience (Janoff-Bulman, 1992; Kennedy, Tellegen, Kennedy, & Havernick, 1976). One of the breast cancer survivors studied by LaFortune-Fredette (1995) claimed that illness had improved her character:

"I would never have chosen it, but it has made me a better person" (p.42).

In addition, Andreasen and Norris (1972) report that a surprising number of the severely burned adults interviewed felt that their experience had happened to make them a better person. Positive changes include greater confidence in one's abilities (Collins, Taylor & Skokan, 1990; Kerr & Stephens, 1997), increased assertiveness (LaFortune-Fredette, 1995), maturity (Langford, 1961), self-focus (O'Connor, Wicker, & Germino, 1990), and greater tolerance (Kennedy et al., 1976). In addition, cancer patients have reported being more adjusted than what they were prior to their illness (Taylor, 1983).

(b) A second positive outcome of illness included in Schaefer and Moos' (1992) analysis of the positive outcomes of stress, is the development of new coping skills. Indeed, beliefs in

benefits from adversity can themselves be used as a deliberate coping strategy that is referred to as positive reinterpretation or reappraisal (for example, Collins, Taylor & Skokan, 1990) and 'benefit-reminding' (Affleck & Tennen, 1996). In addition, by viewing illness as a challenge to overcome, individuals may be inspired to use more adaptive coping strategies (Lipowski, 1970-1971) and become more confident about dealing with future problems (Collins et al., 1990).

(c) Illness may lead to the emergence of previously untapped resources such as creative talents (Giovinco & McDougald, 1994; Kerr & Stephens, 1997). LeShan's crisis therapy (1984) helps cancer patients realise their 'special road' or 'talent' that may have been suppressed.

(d) Illness has been reported to have teaching value. Many of the cancer patients interviewed by O'Connor et al. (1990) described the time following diagnosis as a 'learning experience'.

(e) Illness provides an opportunity to learn about oneself (Janoff-Bulman, 1992). Taylor et al. (1983) liken the enhanced introspection amongst patients to "holding a mirror to one's face" (p.32). Self-examination was used by 30% of cancer patients in their search for meaning (O'Connor et al., 1990). Changes in self-perceptions were reported by 89% of cancer patients (Collins et al., 1990). Turning one's attentions inward often leads to a discovery of who one really is and who one wants to be (LeShan, 1984; 1994).

(f) *Spiritual gains*: The process of uncovering the 'real self' may bring one in touch with one's spiritual side (O'Brien, 1982). Indeed, illness and suffering have been described as spiritual encounters (Granstrom, 1985). In the following definition of spirituality, Hiatt (1986) distinguishes spirituality from religiosity:

"The spiritual dimension then is that aspect of the person concerned with meaning and the search for the absolute reality that underlies the world of the senses and the mind and, as such, is distinct from adherence to a religious system" (p.737).

To illustrate how one's spiritual side becomes more salient during suffering, O'Brien (1982) presented the following anecdote of a patient with renal failure:

"When your body fails you, you really begin to lean on your spiritual side for strength" (p.88).



According to O'Brien, illness prompts questions regarding the significance and value of life and also about one's relationship or non-relationship to a Supreme Being or creator.

*Religious gains:* Illness has also been reported to encourage stronger religious feelings (Kennedy et al., 1976; Kerr & Cowie, 1997). Zemore, Rinholm, Shepel, and Richards (1989) reported that 7/64 cancer patients had grown closer to God as a result of their illness experience. A renewed religious faith was also described by 17% of cancer patients (O'Connor et al., 1990) and was one of the benefit appraisals cited by Affleck, Tennen, Croog, and Levine (1987) in their study of myocardial infarction patients.

(g) Heightened spirituality introduces questions regarding the meaning of life, illness and death (O'Brien, 1982), the answers to which often lead to an altered perspective and appreciation of life (Taylor, 1983). LeShan quotes Gothard Booth who wrote:

"Illness is a reminder of the purpose of life" (p.109).

Mack (1984) reflected upon the irony of having to face pain, injury or even the threat of death in order to appreciate the real purpose of being and how best to follow a rewarding life.

A more positive outlook on life as a result of illness has been reported by cancer patients (Kennedy et al., 1976; Zemore & Shepel, 1989). There are several reports of a greater appreciation of the value of life as a consequence of illness (Kennedy et al., 1976; LaFortune-Fredette, 1995; Viney, 1986). One of the cancer patients interviewed by LaFortune-Fredette (1995) described this enhanced appreciation and satisfaction with life as a 'gift of cancer'. Illness can also result in a heightened sensitivity to simple pleasures:

"The simplest things in life seem lovely to you - the grass, the insects, the sky!" (Viney, 1989, p.157).

(h) An altered perspective on life may lead to a restructuring of life (Taylor, 1983). In particular, illness encourages individuals to live their life according to the philosophy 'do not put off until tomorrow what you can do today', that is living each day to its fullest and doing things now instead of waiting (Collins et al., 1990; Kennedy et al., 1976). Illness prompted 67% of cancer patients in Collins et al.'s (1990) study to modify their plans for the future. Positive lifestyle changes following a myocardial infarction have also been reported (Laerum et al., 1988).

In Laerum et al.'s (1988) study of 84 myocardial infarction patients, 60% of patients reduced or stopped smoking and 19% reduced their alcohol consumption.

(i) A reappraisal and restructuring of life may be coupled with a redefinition of priorities. There are several reports of a reordering of priorities amongst patients and, in particular, a rejection of trivial, insignificant matters (Collins et al., 1990; Kagawa-Singer, 1993; Kennedy et al., 1976; LaFortune-Fredette, 1995; Mack, 1984; Taylor, 1983). Of the 55 cancer patients questioned by Collins et al. (1990), 11% expressed a greater concern for the environment.

(j) There are accounts of the use of illness as an excuse to be relieved from the obligations of everyday life (Kerr & Stephens, 1997; Lipowski, 1970-1971; Mechanic, 1966; VandenBerg, 1972). Mechanic (1966) describes the benefits that can be accrued from an adherence to the 'sick role'. VandenBerg (1972) refers to illness as a breathing spell where the patient has an opportunity to ignore everything. A respite from the responsibilities of being well may offer a sense of freedom to engage in more 'desirable' activities and may result in the emergence of hidden talents as described earlier. This advantage of being ill is echoed in an account of illness provided by one of LeShan's patients:

"I have cancer therefore I can do what I want. I don't have to take care of these papers. I can draw again" (LeShan, 1994, p.120).

(k) Perceptions of illness as a punishment for past sins and as an opportunity for atonement (Lipowski, 1970-1971; Silver & Wortman, 1980) have been reported. Illness may therefore represent a fresh start and freedom from guilt.

(l) Finally, illness may uncover problem areas in individuals' lives, for example, awareness that one is leading an unfulfilling lifestyle, and prompt their resolution. This outcome of illness is the focus of LeShan's (1984; 1994) crisis therapy.

2.2.2.2 Benefits related to others. As noted earlier in the discussion of the positive outcomes of caregiving and bereavement, the positive consequences of illness may have a ripple effect on the family and friends of the person inflicted with the illness. Lukas (1992) discussed the positive influence that the chronically ill can have on others. In one case reported by Lukas, the father of a

sick boy felt that the boy's family and friends had gained more through the boy than they had lost through his illness.

The following five benefits of illness that are of a social nature are presented below: improved relationships with others, management of troublesome relationships, illness as an inspiration and an eye opener to others, and greater independence amongst others.

(a) A particularly well-documented positive outcome of illness is an improvement in relationships with others (Collins et al., 1990; Kerr & Cowie, 1997; Kerr & Stephens, 1997; Kennedy et al., 1976; Laerum et al., 1988; LaFortune-Fredette, 1995; Mayou, Foster & Williamson, 1978; Schaefer & Moos, 1998; Viney, 1986; Zemore et al., 1989; Zemore & Shepel, 1989). This benefit of illness may result from positive personality changes, presented earlier, such as a greater sensitivity to the feelings of others, and a greater compassion and empathy with others (Collins et al., 1990; Kerr & Cowie, 1997; Kerr & Stephens, 1997; LaFortune-Fredette, 1995; Zemore et al., 1989). A reappraisal of the important things in life may also result in improved interpersonal relationships through a greater appreciation of family and friends (Kennedy et al., 1976; LaFortune-Fredette, 1995; Viney, 1989). Viney's (1989) images of illness defined as involving family and friends include statements such as:

"This illness has made me realise what my family and friends mean to me"  
(p.195).

Illness may offer an opportunity to spend more time with others (Collins et al., 1990; Laerum et al., 1988). Relationships with others were also reported to have improved as a result of positive changes, prompted by illness, in the behaviour of others (Kerr & Cowie, 1997; Zemore & Shepel, 1989). The family members of cancer patients interviewed by Kagawa-Singer (1993) were described as more attentive, patient and present both physically and emotionally. Illness also presents an opportunity for others to express their feelings for the patient (Mack, 1984; Schaefer & Moos, 1992). In addition to strengthening existing relationships with others, illness may result in the development of a new friendship network (Kerr & Stephens, 1997; Viney, 1989):

"I've met a lot of nice people in the hospital" (a further example of an image of illness involving family and friends, Viney, 1989, p. 195).

(b) Illness may be used as a strategy to deal with troublesome relationships. Relationships with others may therefore appear to have improved as a result of the use of illness to avoid conflict (Gustafsson, Kjellman & Cederblad, 1986; Kerr & Stephens, 1997; Lipowski, 1970-1971).

Gustafsson et al. (1986) reported the use of symptoms amongst asthmatic children to manipulate dysfunctional relationships. In addition, Kerr and Stephens (1997) described the use of deafness to avoid arguments. Illness may also be used to procure the attention, support and compliance of others (Lipowski, 1970-1971).

(c) The way in which individuals adjust to their illness may provide a source of inspiration to others faced with difficult situations. Lukas (1992) argues that the suffering of the chronically ill grants them a position of trust for they can testify that life is unconditionally worth living.

(d) An individual's illness may also be an eye opener for others. According to Lukas (1992):

“the chronically ill have a greater opportunity to exercise an instructively converting influence on those in their environment” (p.96).

Other people may be encouraged to adopt preventative measures in order to avoid becoming ill themselves and adopt healthier lifestyles. Four of the cancer patients questioned by Zemore and Shepel (1989) claimed that their families had become more attentive of their own health.

(e) A further positive effect of illness on others is a greater independence amongst others as they find themselves taking on new responsibilities (LaFortune-Fredette, 1995) and this in turn may lead to greater confidence amongst others (Schaefer & Moos, 1998).

## Conclusion

This section has uncovered a vast array of themes relating to the positive consequences of illness, which have been documented in the literature. These themes are not mutually exclusive for example, a reappraisal of life may prompt changes in lifestyle and priorities.

Illness may result in self-improvement and also in a greater confidence in managing future crises. Illness often prompts individuals to take a closer look at themselves. This heightened self-awareness may open the door to one's spiritual side, which may include a religious faith. Illness is

not only a lesson about oneself but also about life and what is of intrinsic value. A reappraisal of life may prompt individuals to re-organise their life and, in particular, to lead a more fulfilled life. A restructuring of life may involve a redefinition of priorities with the non-essentials of life becoming less important. Illness may be used for self-benefit in terms of a welcome respite from the demands and responsibilities of being well. Finally, illness may offer an opportunity for atonement.

The positive outcomes of an individual's illness may be shared with other people in the individual's environment. A particularly well-cited positive consequence of illness that can be enjoyed by family and friends is an improvement in the quality of relationships. Illness may also be put to a manipulative use in order to control troublesome relationships. The individual may inspire others to cope with difficult situations and to adopt a healthier pattern of living. Finally, illness may encourage greater independence amongst others.

### 2.2.3 Summary and limitations of the research

This section has documented the positive outcomes of traumatic experiences in general and illness in particular. Positive outcomes of such experiences appear to be by no means rare. A key theme involves a search for meaning in aversive life events with the conviction that the event, whether it involves a divorce, combat and imprisonment, caregiving and bereavement, or illness, happened for a positive reason. Positive consequences of traumatic life events including illness embrace both benefits to the self, such as, personal growth, as well as benefits to others, such as improved interpersonal relationships. A total of 17 positive outcomes of illness were identified.

The number of reports of positive consequences of illness in the literature would suggest that this is a heavily researched field. However, positive consequences are often unanticipated and the reports are often incidental to the principal objective of the research. That is, with the exception of a few studies (for example, Collins et al., 1990; Kerr & Stephens, 1997; Taylor, 1983), research uncovering positive outcomes of illness was not designed specifically to address perceived benefits. Andreasen and Norris' (1972) study of adjustment problems of the burns patient following discharge from hospital uncovered several positive consequences of the

traumatic experience and were defined as adjustment mechanisms. Details regarding positive consequences are often limited. In a study of the postoperative experiences of mastectomy patients, Woods and Earp (1978) reported that the majority of the women who had felt that their mastectomy had changed their lives said that it had done so “for the better” (p.282) but no details were divulged by the authors regarding the nature of these positive changes. Where positive consequences of illness are presented in the literature, they often take the form of anecdotal reports (for example, LaFortune-Fredette, 1995; Viney, 1986). These reports do not provide an estimation of the prevalence of positive consequences of illness in general or how common they are within particular patient groups. In addition, explanations provided to account for this phenomenon are limited and do not shed light on whether there are multiple routes to positivity or whether there is some type of general factor.

### 2.3 *Methodologies used to Assess Positivity in Illness and General Adversity*

Attempts to quantify positive outcomes of illness include single open-ended questions as part of an interview or questionnaire (Affleck et al., 1987; Kerr & Stephens, 1997), items within structured or semi-structured interviews to elicit specific positive outcomes (Collins et al., 1990; Laerum et al., 1988), items within scales (the Life Evaluation Questionnaire (LEQ): Salmon, Manzi & Valori, 1996; the Missoula-VITAS ® Quality of Life Index: Byock & Merriman, 1998), adaptations of scales designed for another purpose (Hamera & Shontz, 1978) or brief questionnaires focusing exclusively on the positive effects of illness (Benefit Appraisals Scale: Tennen, Affleck, Urrows, Higgins, & Mendola, 1992; the Benefit Finding Scale: Cruess, Antoni, McGregor, Kilbourn, Boyers, Alferi, Carver, & Kumar, 2000; the Satisfaction with Illness Scale (SWIS): Hyland & Kenyon, 1992).

#### 2.3.1 Open-ended questions

General open-ended questions have been used to directly probe positive consequences of illness. In their interviews with myocardial infarction patients, Affleck et al. (1987) asked the following question:

“Despite all the problems and worries with which your illness has involved, do you see any possible benefits, gains or advantages in this experience? If so, what are they?” (p.31).

Kerr and Stephens (1997) also employed an open-ended question but in a questionnaire format to elicit positive aspects of acquired hearing loss:

“Please make a list of any POSITIVE EXPERIENCES which you have had as a result of your hearing loss. List them in order of importance starting with the biggest. Write down as many as you can think of” (pp.20-21).

The open-ended format has the merit of allowing respondents the freedom to answer within the context of their own subjective interpretation and personal experience. This methodology is also likely to generate a comprehensive picture of positive consequences (Kerr & Stephens, 1997).

### 2.3.2 Interviews

Laerum et al. (1988) used a semi-structured interview methodology to address the nature and frequency of positive (and negative) effects following a myocardial infarction. The interview protocol used in this study included questions regarding changes in lifestyle (such as smoking habits and alcohol consumption) and quality of life (such as the subjective perception of the value of life and health status). Patients were also asked to reflect on the overall impact of their illness:

“If you summarise all the negative and positive changes and consequences of the myocardial infarction as you see it today, will you then consider your total life situation to be much or somewhat worsened or improved or unchanged?” (p.68).

Using a structured interview format, Collins et al. (1990) also tapped into positive changes following illness. Cancer patients were asked to consider any changes in their priorities or daily activities, plans and goals for the future, self-perceptions, views of the world and the way they relate to others. These questions elicited both positive and negative responses.

### 2.3.3 Items within scales

In addition to measuring the negative sequelae of adversity such as illness, some scales include items assessing the positive consequences. The Changes in Outlook Questionnaire (Joseph, Williams, & Yule, 1993) was designed to assess both negative and positive responses to

disaster. Items were generated from qualitative data from an earlier study (Yule, Hodgkinson, Joseph, Parkes, & Williams, 1990) that used the following questions to uncover the impact of the Herald of Free Enterprise disaster on survivors' outlook on life:

“Has the disaster changed your outlook on life for the better, or for the worse?”  
 “In what ways has your view of life changed?”

A review of potential items by five graduate psychology students resulted in the inclusion of 15 negative response and 11 positive response items. Examples of the positive items include:

“I don't take life for granted anymore”  
 “I value my friendships much more now”  
 “I feel more experienced about life now”

The positive changes scale has good internal consistency (Cronbach's alpha of 0.83).

The LEQ (Salmon et al., 1996) was designed to assess the experiences of patients with incurable cancer. The questionnaire includes items measuring the extent to which life has been enriched as a result of cancer and comprises of five domains: clearer perception of the meaning of life, freedom versus restriction of life, resentment of the illness, contentment with past and present life, and social integration. The LEQ thus goes beyond a traditional symptom-based approach to quality of life assessment by measuring an array of experiences both positive and negative.

Examples of positive items include:

“I have a much clearer idea, now, about what is important in life”  
 “There are many people I feel closer to now than before I was ill”  
 “My illness has made me appreciate things more than I did before”

The items were selected following interviews with patients and caregivers. A draft version of the questionnaire was reviewed by a panel of judges including patients, clinicians and carers and was subsequently refined to a 61-item measure. Each item includes two opposing statements placed at each end of a 0-6 scale. Respondents are asked to circle a number which best describes their experience. The LEQ has proven reliability, validity and is highly acceptable (Salmon et al., 1996).

A further questionnaire designed to be appropriate for patients with terminal illness and which includes items describing positive experiences is the Missoula-VITAS® Quality of Life Index (MVQOLI; Byock & Merriman, 1998). One particular positive experience measured by the



MVQOLI is the potential for personal growth. The MVQOLI includes 25 items arranged within five dimensions (five items within each dimension): Symptom, function, interpersonal, well-being, and transcendent. These dimensions were generated following a review of the literature and informal interviews with hospice professionals, patients and their families. Each dimension includes three categories of subjective items: Assessment, satisfaction, and importance. Responses to items are made on a five-point scale ranging from agree to disagree. Items that can be defined as describing positive consequences of illness include two within the interpersonal dimension, for example:

“I feel closer to others now than I did before my illness”

two within the well-being dimension, for example:

“I am more satisfied with myself as a person now than I was before my illness”

and three transcendent items, for example:

“I have a greater sense of connection to all things now than I did before my illness”

Reliability and validity have been demonstrated for the MVQOLI in a population of terminally ill cancer patients in a hospice setting.

#### 2.3.4 Adaptations of scales

Scales assessing negative effects of illness have been used in a modified form for the purpose of assessing positive effects. Hamera and Shontz (1978) selected items from questionnaires (the Handicap Problem Inventory: Wright & Remmers, 1970, and the Human Services Scale: Reagles, Wright, & Butler, 1973) describing negative effects of physical disability and disease on economic, personal, family and social aspects of life. For each of the 45 items selected, an equivalent positive form was written, for example, the item: “How often do you have trouble showing your feelings to your family?” was modified to: “How often do you feel it is easy to show your feelings to your family?”

### 2.3.5 Positive outcome questionnaires

Within the context of general aversive events, Park, Cohen, and Murch (1996) developed a Stress-Related Growth Scale (SRGS). This scale includes 50 items (the short-form includes 15 items) describing positive changes in personal resources, social relationships and coping skills. This scale can be applied to but is not limited to illness. Items were generated on the basis of clinical and personal experience and were also influenced by the theoretical and empirical literature, in particular, the work of Schaefer and Moos (1992). The items reflect the positive consequences of illness themes presented earlier in Section 2.2.2. The SRGS asks respondents to refer to their most stressful event experienced in the past year and rate the applicability of each item on a three-point scale. Example items include:

“My life now has more meaning and satisfaction”  
 “I learned to be myself and not try to be what others want me to be”  
 “I learned that there are more people who care about me than I thought”

The SRGS has favourable psychometric properties including internal reliability (Cronbach’s alpha of approximately 0.95 for college students and parents of disabled children) and re-test reliability ( $r=.81$  over a 2 week period), and validity including good participant-informant concordance with a significant correlation between students’ SRGS scores and those provided by the students’ close friend or relative ( $r(72)=.21; p<.05$ ). The scale has also been shown to be immune to a social desirability / defensiveness or acquiescent response set (Park et al., 1996).

A further measure of positivity in the face of general traumatic events is the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996). The scale includes 21 items derived from a literature review of positive changes following trauma in terms of changes in self perceptions, relationships with others and philosophy of life. Responses to items are made on a six-point scale and correspond to the extent to which changes have occurred in life as a result of crisis. Example items include:

“I developed new interests”  
 “I learned a great deal about how wonderful people are”  
 “I discovered that I’m stronger than I thought I was”

The PTGI include five factors or domains labelled ‘Relating to others’, ‘Personal strength’, ‘New Possibilities’, ‘Spiritual change’, and ‘Appreciation of life’. The scale has good psychometric

properties including high internal consistency (Cronbach's alpha of 0.90) and re-test reliability ( $r=.71$ ). In addition, responses are unrelated to defensiveness (Tedeschi & Calhoun, 1996).

The SWIS (Hyland & Kenyon, 1992) was designed to measure illness-related positive outcomes. The scale comprises of six statements, for example:

"Being ill has made me value life more than I use to"  
"My illness has shown me the value of friendship"

Patients are asked to indicate their level of agreement or disagreement with each item on a seven-point scale. The scale has been used with chronic obstructive pulmonary disease patients (Hyland & Kenyon, 1992) but it can be applied to all acute and chronic physical illness types. The SWIS correlates with the Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985) and has good internal consistency (Cronbach's alpha of 0.82). The SWIS however is particularly limited in that it only samples a small number of the positive consequences of illness themes identified in Section 2.2.2. The scale does not, for example, attempt to measure changes in priorities, personality and spirituality, which, according to the anecdotal reports presented earlier, appear to be particularly common. In addition, research with the SWIS is limited (Hyland & Kenyon, 1992; Hyland, Bott, Singh, & Kenyon, 1994). While the SWIS may be regarded as a generic scale for assessing positive consequences of illness, the Benefit Appraisals Scale (Tennen et al., 1992) represents a 'condition-specific' scale that measures perceived benefits from chronic pain. The scale has been used within the context of rheumatoid arthritis and contains five items, for example:

"My pain has helped me find new faith"  
"I have learned a great deal from my pain"

A further measure of the positive contributions of a specific illness (breast cancer) is the Benefit Finding Scale (BFS; Cruess et al., 2000) (Note this scale is also referred to as the Positive Contributions Scale (PCS; Antoni, Carver, Boyers, & McGregor, 1999)). The BFS includes 17 items each with five response options. Examples of the items included in the scale are:

"Having had breast cancer has brought my family closer together"  
"Having had breast cancer has helped me become more focused on priorities, with a deeper sense of purpose in life"

The scale has good internal consistency (Cronbach's alpha of 0.95).

### 2.3.6 Summary and methodological issues

Various methodologies for measuring positive consequences of illness have been presented. The open-ended question format asks patients directly to consider any positive outcomes they may have encountered. The open-ended questions presented have little structure and do not impose on respondents any particular images of positive consequences. On the contrary, specific positive outcome items that may form part of an interview protocol or questionnaire are more prescriptive in nature. Two of the questionnaires designed specifically to assess positive consequences of illness are particularly limited in their focus with the Benefit Appraisals Scale (Tennen et al., 1992) and the SWIS (Hyland & Kenyon, 1992) including five and six items respectively. The BFS (Cruess et al., 2000) is a more comprehensive measure of positivity, however, like the Benefit Appraisals Scale, the application of this scale is limited to one particular illness type - breast cancer. Researchers interested in positive consequences have also looked to scales with a negative focus and modified the orientation of items (Hamera & Shontz, 1978).

One particular methodological problem involved in measuring positive consequences regards establishing a cause-effect relationship, that is, being able to attribute positive change exclusively to illness (Hamera & Shontz, 1978).

A particular problem of the open-ended question methodology is that it relies on the ability of respondents to articulate their experiences. Kerr and Stephens (1997) cited evidence amongst hearing impaired individuals for potential individual differences including age and memory in the incidence of reports of positive experiences.

A further methodological problem involves establishing construct validity as the interview or questionnaire items may be measuring something other than positive consequences. As reported earlier, accounts of positive outcomes are often interpreted as untrustworthy (Hayry, 1991) or distortions of reality (Andrykowski, Brady, & Hunt, 1993; Hamera & Shontz, 1978). Lehman, Davis, DeLongis, Wortman, Bluck, Mandel, and Ellard (1993) speculate that respondents may

provide fabricated reports because of the typical negative orientation of questions regarding stressful life events. In addition, individuals may be motivated to paint a positive picture of the consequences of their illness through a need to boost their self-esteem or to present a socially desirable image to others (Andrykowski et al., 1993). However, as reported earlier, responses to the SRGS (Park et al., 1996) and the PTGI (Tedeschi & Calhoun, 1996) were shown to be independent of a socially desirable response set.

Social desirability or defensiveness is just one possible explanation for reports of positive consequences of illness. Further explanations will be presented in the following section.

## 2.4 *Explanations for Positivity in Adversity*

Schaefer and Moos (1998) described the context of PTG as comprising of a complex interplay of a number of factors including the characteristics of the crisis, personal resources including personality, intrinsic religiousness, coping strategies adopted, environmental resources including social support, and how individuals perceive the crisis. These factors also feature as antecedents and mechanisms of response shift in Sprangers and Schwartz's (2000) response shift model. Thus, positivity in adversity, like other behavioural phenomena, is likely to be the result of an interaction between situational and dispositional factors (Ekehammer, 1974). The following sections (2.4.1 – 2.4.8) provide an account of the different explanations provided for positivity in the literature, much of which is embedded within the stress-related growth literature.

### 2.4.1 Event-related characteristics

Within the context of illness, initial severity of the threat and its short-term outcome have been identified as important factors in long-term adjustment (Schaefer & Moos, 1998). Schaefer and Moos (1998) suggest that patients who survive an illness with a poor prognosis are particularly motivated to find a meaning in their illness experience and may feel compelled to keep their part of the 'bargain' for a 'second chance' for example by adopting a more mature and helpful personal orientation. Collins et al. (1990) however found that, in a sample of cancer

patients, those with a poor prognosis were less likely to perceive positive changes and more likely to perceive negative ones following their diagnosis compared with patients with a good prognosis.

Calhoun and Tedeschi (1998) however emphasise that it is the personal struggle with the demands of the event and not the event per se that is viewed as the source of positive change or growth. The way in which the individual deals with this struggle is likely to be influenced by personality factors.

#### 2.4.2 Personality

Extraverts are predisposed to the use of positive thinking to cope with stressful encounters (McCrae & Costa, 1986) and are thus more likely to perceive positive consequences of illness. This is reflected in a significant correlation between the SWIS and extraversion (Hyland & Kenyon, 1992). Tedeschi and Calhoun (1996) used the PTGI and the NEO Personality Inventory (Costa & McCrae, 1985) to examine the relationship between the 'Big Five' (McCrae & Costa, 1986) personality traits of neuroticism, extraversion, openness to experience, agreeableness, and conscientiousness, and beliefs in benefits from adversity in a sample of students who reported recent major stressful life events. Extraversion displayed the highest correlation with total benefits from adversity, and in particular correlated with reports of improved relationships with others.

In contrast to extraverts, neurotic individuals are predisposed to negative affect and are more likely to make negative evaluations of their health as measured by standard quality of life instruments (Hyland et al., 1994; Jones, Baveystock, & Littlejohns, 1989). Neurotics also have a tendency to select ineffective coping resources to deal with stress (McCrae & Costa, 1986).

In their study of personality and coping amongst community dwelling adults, McCrae and Costa (1986) found that a tendency to rely on 'drawing strength from adversity' as a coping strategy was displayed by individuals high in extraversion, low in neuroticism and also by those high in openness to experience. Individuals who are open to experience have a tendency to view stressful experiences as less threatening and potentially beneficial (Tedeschi & Calhoun, 1996). In Tedeschi and Calhoun's study (1996) openness to experience correlated most strongly with reports of new possibilities arising from adversity and personal strength.

Dispositional optimism, a generalised tendency to expect positive outcomes, also influences how individuals react to stress (Scheier, Weintraub, & Carver, 1986). Scheier et al. (1986) found that optimistic individuals were more likely to focus on the positive side of a stressful situation by viewing it as an opportunity for growth or a strengthening of faith. Park et al. (1996) cite evidence to suggest that optimism promotes 'growth' within the context of arthritis and heart disease and propose that this could be a result of a relationship between optimism and adaptive coping strategies such as problem-focused coping and seeking social support. Tedeschi and Calhoun (1996) found that optimistic individuals scored higher on all the domains of the PTGI. Affleck and Tennen (1996) however, found that in chronic pain (fibromyalgia) patients dispositional hope and not optimism or pessimism was related to beliefs about benefits from adversity.

Antonovsky's salutogenic conceptualisation of stress (1987) proposes that an individual's sense of coherence or ability to manage and make sense out of stressors contributes towards adaptation to stressors and influences stress-related positive outcomes (Park et al., 1996).

#### 2.4.3 Intrinsic religiousness

Intrinsic religiousness is a further personal resource found to be associated with perceptions of stress-related growth (Park & Cohen, 1993) and is a significant correlate of the SRGS (Park et al., 1996) and PTGI (Tedeschi and Calhoun, 1996). Park et al. (1996) reason that religion may promote stress-related growth by facilitating an individual's search for meaning in a crisis.

As mentioned above, appraisal and coping processes are influenced by personality thus, an individual's personal resources may operate indirectly with their effects mediated by coping process variables (Park, 1998).

#### 2.4.4 Coping mechanisms

Lazarus and Folkman's (1984) cognitive theory of psychological stress and coping identifies two processes namely coping and appraisal, as important mediators of the impact of

stress on the individual's physical, social and emotional functioning. Coping refers to the thoughts and behaviours used to manage a given event and appraisal concerns an evaluation of the personal significance of the event (primary appraisal) and the adequacy of an individual's resources for coping (secondary appraisal) (Lazarus & Folkman, 1984). As suggested earlier, individuals who appraise a stressful life event as a challenge to overcome adopt better coping strategies and are more apt to grow from the experience (Park, 1998).

Billings and Moos (1981) present two classification schemes for coping responses. One concerns the focus of coping with problem-focused coping involving active attempts to modify or eliminate the source of stress through behaviour, and emotion-focused coping involving more passive behavioural and cognitive responses to regulate emotions. A second formulation of coping is based on the method of coping with active attempts divided into cognitive and behavioural strategies, and a separate classification for avoidance strategies.

Coping strategies vary in their ability to attenuate the impact of stress. There is a general consensus in the coping literature that, in most situations, active, problem-focused strategies lead to greater adjustment. As mentioned earlier, Park et al. (1996) named problem-focused strategies and seeking social support as adaptive coping strategies. Billings and Moos (1981) also identified active attempts as more 'effective' coping strategies. One particular active cognitive strategy – cognitive reinterpretation involves a focus on the beneficial aspects of the situation. Ell, Mantell, Hamovitch, and Nishimoto (1989) identified a correlation between cognitive restructuring and positive affectivity soon after a diagnosis of cancer. Adaptive coping strategies may soften the blow of a stressful life event such as illness, by promoting positive changes such as a redefinition of priorities and goals. In the context of illness, Collins et al. (1990) found that coping efforts facilitated change following a diagnosis of cancer and that the use of multiple and active coping strategies such as cognitive reappraisal and behavioural change was particularly conducive to positive change.

Folkman and Greer (2000) used a theoretical model based on Folkman's (1997) revised model of stress and coping, cited earlier, in order to identify factors contributing to well being in serious illness. In addition to problem-focused and emotion-focused coping, this model embraces



meaning-based coping that helps individuals abandon unattainable goals and replace them with new ones, derive meaning and appraise some benefit.

In summary, positivity has been interpreted as a coping *process* involving a positive reinterpretation or reappraisal of the situation (for example, Affleck & Tennen, 1996; Collins et al., 1990; Ell et al., 1989) as well as an *outcome* of coping (for example, Folkman & Greer, 2000; Park, 1998; Tedeschi & Calhoun, 1996). Distinguishing positivity as an outcome from positivity as cognitive reinterpretation has been described as one of the most complicated issues in PTG research (Cohen, Hettler, & Pane, 1998).

#### 2.4.5 Defence mechanisms

The experience of positivity in illness has been interpreted as signalling the use of defence mechanisms, an emotion-focused strategy that shields an individual from anxiety by distorting reality (Haan, 1977). There are a number of different defence mechanisms that have been used to interpret positivity:

(a) Individuals may report positive consequences of illness because the reality of the situation is too painful to accept. Positivity may therefore be a product of a repressive style of coping (Boden & Baumeister, 1997). Boden and Baumeister (1997) found that repressors avoided exposure to unpleasant material by accessing pleasant thoughts. Positive emotions in illness may represent a distortion of the distressed emotions, interpreted by some (for example, Haan, 1977) as the more appropriate reactions to illness. This interpretation of positive consequences of illness is also reflected in Backman's (1989) quote presented in the introductory section of this chapter. Denial was proposed by Kagawa-Singer (1993) as a possible explanation to account for cancer patients' claims of feeling healthy despite their poor physical condition. In a comparison of cancer patients and healthy individuals, Bahnson and Bahnson (1966) found that cancer patients denied and repressed conflicting impulses and emotions to a higher degree. Viney (1986), however, rejected the argument that denial is responsible for the expression of positive emotions in illness and instead proposed that positive emotions are evidence of effective coping. Tedeschi, Calhoun, & Gross (1993) also countered the view that beliefs in benefits from adversity signal denial with

their finding that students' benefit appraisals of a recent stressful event positively correlated with the event's negative and positive impact on their lives.

(b) Particular positive consequences of illness such as a reappraisal of life and a redefinition of priorities can be accommodated by the defence mechanism known as sublimation. When an individual's goals cannot be satisfied, for example as a result of illness, the individual may compensate and find comfort in 'second-best' substitutes. VandenBerg (1972) who presented this explanation argued that it represents a misunderstanding on the part of the healthy person:

"the illness of the body can represent a soundness of the mind" (p. 73).

(c) The defence mechanism known as rationalisation is illustrated in Aesop's fable of the fox and the sour grapes presented in chapter 1 (Aesop, Handford, 1954). When the fox found that he could not reach the grapes, he rejected them 'because they were sour'. Rationalisation was one of the adjustment mechanisms used by severely burned adults after discharge (Andreasen & Norris, 1972). Many of the patients addressed the question of why this happened to them and arrived at the belief that it happened for a reason, in particular to improve their character. This belief of suffering for a reason helps individuals find meaning, which, as noted earlier, can be adaptive.

#### 2.4.6 Social support

Social support is a multi-faceted construct. A distinction should be made between the number of socially supportive relationships available to an individual and the individual's appraisal or satisfaction with these relationships (Sarason, Sarason, Shearin, & Pierce, 1987). Given that individuals differ in their need for social support and in the meaning they attach to relationships, personal appraisals of supportive relationships may be more important than the actual number of such relationships (Sarason et al., 1987). Research into social support typically focuses on the number of socially supportive relationships. The stress buffering effects of social support are well documented (Cohen & Wills, 1985). Park et al. (1996) referred to seeking social support as an effective coping strategy and identified social support satisfaction as a correlate of stress-related growth. The availability of supportive relationships is associated with quicker

rehabilitation amongst accident victims (Janoff-Bulman & Wortman, 1977) and the presence of positive emotions amongst physically ill adults (Viney, 1986).

#### 2.4.7 Cognitive processes

The expression of positivity in illness may result from a perceptual bias, which, as presented earlier within the context of defence mechanisms, may take the form of denying reality, or involve a reframing or restructuring of reality. According to Taylor et al. (1983), individuals faced with victimising events selectively distort their perception of the situation in order to present it in a more positive light. In addition, the perception of positive consequences of illness may be the result of positive adjustments to self-evaluations.

2.4.7.1 Adaptation Level Theory. According to Helson's adaptation level theory (Helson, 1964), when individuals experience extreme negative stimuli, their neutral point or adaptation level changes to become more negative so that positive interpretations are made of previously negative experiences. A negative event such as illness may therefore make other experiences seem more positive.

2.4.7.2 Social Comparison Theory. An individual's judgements of the impact of illness may also be influenced by comparisons made to others. According to social comparison theory (Festinger, 1954), individuals are motivated to gain accurate appraisals of their opinions and abilities and do so by comparing them with the opinions and abilities of 'similar' others. In addition to satisfying an individual's need for self-evaluation, social comparison processes, in certain threatening situations, may serve particular motives or goals and involve comparisons with 'dissimilar' others. Comparisons with others worse off than oneself are referred to as 'downward' social comparisons and serve to boost one's self esteem. 'Upward' social comparison processes however use more fortunate others as a frame of reference and serve to inform and motivate the individual.

Illness may prompt individuals to cognitively manufacture social comparison processes for the purposes of self-enhancement. Franklin (1757) wrote:

“To be content look backwards on those who possess less than yourself, not forward on those who possess more” (cited in Janoff-Bulman, 1992, p.119).

Such downward comparisons have been found to be particularly salient amongst patients (Wood, Taylor, & Lichtman 1985). Wood et al. (1985) examined 78 breast cancer patients' references to social comparison processes and found overwhelming support for the downward social comparison perspective. Sixty percent of the respondents cited another patient who was coping less well than themselves and 80% felt that they had adjusted 'somewhat better' than others. The downward comparison processes identified by Wood et al. (1985) also included a perception amongst patients of positive consequences of illness: one respondent considered herself to be fortunate as her illness had led her to find peace and meaning which she felt many others never achieve. In addition, Heidrich and Ryff (1993) found that the effective use of social comparisons amongst elderly adults in poor physical health was associated with perceptions of personal growth and positive interpersonal relationships.

**2.4.7.3 Cognitive Adaptation Theory.** According to Taylor (1983), in the face of 'victimising' events such as illness, individuals engage in a process of cognitive adaptation in order to gain meaning, mastery, and to boost their self-esteem. Perceptual biases known as 'illusions' form the core of cognitive adaptation theory as the ability to sustain illusions is proposed to help individuals view the aversive situation from a positive perspective and thus 'de-victimise' themselves (Taylor et al., 1983). Illusions are the product of an individual's attempts to selectively evaluate themselves (for example, self-aggrandisement) and their situations in ways that favour oneself.

In an analysis of 78 breast cancer patients' accounts, Taylor et al. (1983) identified five mechanisms of selective evaluation that were presented in chapter 1. Downward social comparisons described above were found to be an important source of illusions. In addition to comparing themselves to less fortunate others, patients were found to compare their situation to a hypothetical worse world leaving them feeling lucky, as things could have been worse. A third mechanism used by 50% of the cancer patients involved an emphasis on attributes that make one appear advantaged, for example, one woman felt fortunate because rather than having the whole of

her breast removed, she had only had a lump removed. Illusions were also created through the manufacture of normative standards of adjustments that made the patients appear to be well adjusted. A final mechanism of selective evaluation makes explicit reference to positive consequences of aversive events as it involves construing benefit from harm. Fifty three percent of the cancer patients reported only positive changes in their lives following cancer.

**2.4.7.4 Control Theory.** Control theory (Carver & Scheier, 1982) postulates that the perception of discrepancies between reality and a comparison value creates discomfort and distress and that a negative feedback loop operates to correct discrepancies. Within the context of self-discrepancy theory (Higgins, 1987), reality is represented by one's actual self-state (the attributes one actually possesses), and the comparison value may take the form of one's ideal self-state (attributes that one would ideally like to possess) or ought self-state (attributes one believes one should or ought to possess).

Illness may represent an obstacle to the attainment of personal goals constituting one's ideal or ought self thus creating a potential discrepancy between the actual and ideal/ought self. However, through the process of feedback control, the individual may 'disengage' (Carver & Scheier, 1990) from unattainable goals and lower one's ideal or ought self to bring it in harmony with one's actual self. Illness may therefore not be perceived as interrupting important goals. A redefinition of the self through illness may account for the high level of adjustment amongst patients and also amongst the elderly who tend to have a poor physical health status. For example, in a comparison of young, middle-aged and elderly adults, Ryff (1991) found that the elderly individuals had achieved a closer match between their actual and ideal self-representations. In addition, Heidrich and Ward (1992) found that elderly women with cancer were comparable to elderly women with other less functional health problems in terms of levels of distress and well being, and actual-self representations. However, the women with cancer had lower ideal-self ratings suggesting that their positive adjustment was achieved through an ability to attenuate discrepancies between their actual and ideal self-representations.

## Conclusion

Cognitive explanations of positive consequences of illness embrace judgement theories, Taylor's (1983) theory of cognitive adaptation and Carver and Scheier's (1982) control theory. These theories propose that positivity results from a mechanistic process involving a positive redefinition of oneself and / or one's situation. The interpretations of positivity presented in this section overlap to some extent with the defence mechanism explanation for positivity in that positivity represents a distortion of reality.

### 2.4.8 Existential growth

An existential interpretation of positivity in illness proposes that, rather than representing a denial or redefinition of reality, positivity is associated with real changes in the nature of the individual (Sodergren & Hyland, 2000). Illness may provide opportunities for greater personal growth or self-actualisation (Maslow, 1968). Granstrom (1985) even describes illness as a potentially creative, self-actualising experience. As mentioned earlier, the capacity for growth in a traumatic event such as illness represents one of the fundamental assumptions of crisis theory (Caplan, 1964).

An existential interpretation of positivity is inherent in LeShan's (1984; 1994) conceptualisation of illness as an opportunity for individuals to discover their 'special road' and achieve a sense of personal fulfilment. According to LeShan (1984), an illness such as cancer is often an indication that there is something amiss in the life of the patient. This view of illness is also shared by the homeopathist Edward Bach (1931) who writes:

"Let it be briefly stated that disease, though apparently so cruel, is in itself beneficent and for our good, and if rightly interpreted, it will guide us to our essential faults" (p.4).

It appears that the essence of what both LeShan and Bach are saying is that patients encounter illness for a reason - to gain greater awareness of their non self-actualising lifestyle and to become a better person by regaining a more self-actualising lifestyle.

Greater self-actualisation may also be achieved through the process of disengagement, described above and in the context of meaning-based coping, whereby unattainable goals are

replaced by new goals, such as existential goals (Hyland, 1997) which, when achieved, provide a greater sense of fulfilment. In addition, by viewing illness as a challenge to overcome, individuals may experience a deeply satisfying state described by Csikzentmihalyi (1992) as 'flow'.

If greater self-actualisation is experienced, either through greater awareness of a non-fulfilling lifestyle, the development of more attainable existential goals, or through the experience of 'flow', then illness may be perceived as having positive consequences.

#### 2.4.9 Summary

Explanations for positivity in the face of adversity are largely conjecture with research in this field described by Park (1998) as "frustratingly rare" (p.274). However, evidence suggests that certain characteristics of the illness itself such as its severity may be associated with the perception of positive consequences. Some individuals may be predisposed to be positive in the face of adversity. Personality dimensions such as extraversion, optimism, dispositional hope, intrinsic religiousness and a sense of coherence have been found to favour positive consequences of illness. Individuals who have at their disposal adaptive coping resources such as active problem-focused and meaning-based strategies, and a personally valued support network are also more likely to experience positivity in illness. Positive consequences of illness have been interpreted as a defence mechanism that serves to protect individuals from the pain of reality. However, this conceptualisation is not well supported. Individuals facing adversity such as illness may engage in cognitive processes whereby they selectively evaluate their situation or themselves to create illusions in the form of positive consequences of illness. An existential interpretation of positivity, in contrast, treats illness as a catalyst for real rather than perceived changes in the nature of the individual.

### 2.5 *Why are the Positive Consequences of Illness Important?*

#### 2.5.1 Implications for the measurement of health outcome

This chapter has illustrated how, for some individuals, positivity is an important part of the illness experience. One implication of a global definition of quality of life such as the definition

offered by DeHaes and vanKnippenberg (1985), cited in chapter 1, is that any attempt to measure quality of life must embrace both the negative and positive effects of illness. However, as noted in chapter 1 and reinforced in Section 2.3 of this chapter, few attempts have been made to evaluate the positive consequences of illness, and these attempts do not accommodate the broad array of positive consequences cited in Section 2.2.

### 2.5.2 Implications for health management

Positive consequences of illness merit attention not only for conceptual completeness but also for their therapeutic properties. It is argued that positive emotions in general represent an essential ingredient for a healthy personality (Avia, 1997). As noted earlier, positive emotions in threatening events may result from biases or illusions that present one-self and the world in a favourable light and these illusions are believed to be important for normal cognitive functioning (Taylor, 1983; Taylor & Brown, 1988; 1994). Also within the context of cognitive adaptation theory, Taylor (1983) identified construing benefit from harm as one of the mechanisms for successful adaptation to 'victimising' events.

The literature presents evidence for a relationship between the experience of benefits of illness and adjustment, improved morbidity and even mortality. Croog and Levine (1982) report that patients who cited benefits from their heart attack experienced lower levels of depression and greater life satisfaction. Tennen et al. (1992) found that the rheumatoid arthritis patients who perceived benefits from their illness and then experienced severe pain reported fewer days on which their pain interfered with their activities. In an investigation into early cause and benefit appraisals among 287 heart attack patients, Affleck et al. (1987) found that patients who perceived benefits 7 weeks after their first attack were less likely to experience a reinfarction and enjoyed lower levels of morbidity 8 years later regardless of the severity of their attack. LeShan (1984; 1994) argued that positive change and growth in the face of cancer is one of the strongest weapons against the illness. LeShan's crisis therapy helps patients mobilise their immune system through inner change. This therapy has seen impressive results over the past 30 years with approximately half of LeShan's patients with poor prognoses experiencing long-term remission and nearly all



patients experiencing a marked improvement in their emotional state and quality of life (LeShan, 1994). A study by Cruess et al. (2000) was the first to formally examine whether a psychosocial intervention designed to enhance benefit finding in breast cancer could promote positive physiological changes. Women treated for stage I or II breast cancer were randomly assigned to either a 10-week cognitive-behavioural stress management (CBSM) programme or placed on a waiting list. At the end of the study patients receiving CBSM identified greater positive contributions of breast cancer as measured by the BFS and had lower cortisol levels. Control patients however experienced no changes. The physiological benefits of the intervention were found to be mediated by increases in benefit finding.

These findings suggest a therapeutic role, both physiologically and psychologically, of positivity in illness. In addition, these findings imply that, while maintaining sensitivity to the negative consequences of illness, caregivers should also look beyond these and reinforce any positive outcomes of illness that may be expressed.

### 2.5.3 Summary

Insight into the positive consequences of illness is important for two particular reasons. Firstly, they are fundamental to the concept and measurement of quality of life. Secondly, they have important implications for health management.

These implications provided the impetus for the programme of research described in this thesis. An overview of this programme of research is presented in chapter 3.

## CHAPTER 3

### OVERVIEW OF STUDIES

#### 3.1 *Study 1: Identifying the domains of positive consequences of illness*

##### 3.1.1 Aims

The first study was designed to document comprehensively the different ways positive consequences of illness are experienced by individuals who have encountered ill health. A primary concern of this study was to identify systematically the themes of positive consequences of illness.

##### 3.1.2 Design

The study involved individuals who were either currently ill or who had recovered from illness and who had construed their illness as being positive in some way. Fifty-five participants were questioned about the effects of their illness either in a semi-structured interview or questionnaire format. Questions took the form of a general open-ended question followed by eight questions probing specific consequences of illness. These items were devised on the basis of the positive consequences of illness themes presented in chapter 2.

The content of the interview and questionnaire transcripts was interpreted and organised into categories of positive consequences using a loose form of thematic analysis (Banister, Burman, Parker, Taylor, & Tindall, 1994).

##### 3.1.3 Implications

The themes identified from the participants' accounts of their positive experiences of illness provided the material for a measure of the positive consequences of illness - The Silver Lining Questionnaire (SLQ). This first study thus represents the qualitative phase in the development of the SLQ.

### 3.2 *Study 2: Development of the SLQ*

#### 3.2.1 Aims

The focus of this study was on the development of a measure of the positive consequences of illness based on the personal accounts provided by participants of study 1. The primary aim of this study was to use the measure with a wider sample, including individuals not pre-selected on the basis of reported positivity to illness, to test the properties of the items selected and to identify necessary refinements.

#### 3.2.2 Design

A first version of the questionnaire was completed by 91 individuals including 41 members of the 'illness-benefit' sample of study 1, eight patients attending a cancer support group and five a healing group, and also 37 patients with chronic lung disease enrolled in a pulmonary rehabilitation programme. The following methods of assessing the properties of items of the pilot measure were carried out: item distributions, inter-item correlations and a principal components analysis. Refinements to the questionnaire (for example, item reduction) were based on the findings of these tests and also on the comments volunteered by respondents.

#### 3.2.3 Implications

This study resulted in a 38-item questionnaire measuring the positive consequences of illness, The SLQ, which could be used to address previously unexplored issues regarding positivity in illness.

### 3.3 *Study 3: Psychometric properties of the SLQ*

#### *(I) Reliability and sensitivity to change*

#### 3.3.1 Aims

The aim of this study was to investigate the ability of the SLQ to demonstrate reliability and responsiveness to change.

### 3.3.2 Design

This study forms part of an audit of cardiac and chronic respiratory disease (COPD) patients enrolled in rehabilitation. The SLQ was completed on two occasions by three groups of patients: 35 COPD and 29 cardiac patients at the start and end of a rehabilitation programme; and a control sample of 20 COPD patients on entry to a waiting list and at the start of rehabilitation. Test-re-test reliability coefficients were calculated for the scores of the control sample. Item homogeneity was examined by applying Cronbach's alpha to the first assessment data of all three groups. Finally, changes in positivity following rehabilitation were determined.

### 3.3.3 Implications

This study represents an initial test of the psychometric properties of the SLQ in terms of re-test reliability, internal consistency, and responsiveness to change. This study also has implications for health management with respect to the potential for enhancing positivity amongst patients.

## 3.4 *Study 4: Psychometric properties of the SLQ*

### *(II) Predictive validity*

#### 3.4.1 Aims

This study used the SLQ to predict symptomatic improvement in a chronic condition.

#### 3.4.2 Design

In this study 72 patients with chronic fatigue syndrome (CFS) were recruited and followed up for 6 months. Patients completed the SLQ, the 11-item Fatigue Questionnaire (Chalder, Berelowitz, Pawlikowska, Watts, Wessely, Wright, & Wallace, 1993) and the 12-item General Health Questionnaire (GHQ-12; Goldberg & Williams, 1988). The Fatigue Questionnaire measures symptoms specific to physical and mental fatigue. A slightly modified version of the revised 11-item scale was used and five additional items were included assessing muscle pain,

duration of fatigue, percentage of time fatigued and perceived attribution for tiredness. The GHQ-12 measures perceptions of general health, with a specific focus on mood. These assessments were completed at entry to the study, at 3 months, and 6 months. The data were analysed to determine whether the SLQ total score predicted improvement in patients' perceived general health and physical and mental fatigue.

### 3.4.3 Implications

This study provided an insight into the utility of the SLQ as a predictive tool for health outcome and also has implications regarding the therapeutic properties of positivity.

## 3.5 *Study 5: Psychometric properties of the SLQ*

### *(III) Prevalence and correlates of positivity*

#### 3.5.1 Aims

This study was concerned with the correlates of positivity in illness namely, age, gender, race / ethnic group, personality (including social desirability / defensiveness), social support availability, spirituality and religiosity, and characteristics (severity and duration) of the illness itself. In addition, this study set out to determine the prevalence of positivity across different illness types including minor illness.

#### 3.5.2 Design

In this study, the SLQ, the MRC Dyspnoea Scale (Medical Research Council, 1986), and the Eysenck Personality Inventory Revised Short-Form (Eysenck, Eysenck, & Barrett, 1985) were administered to 197 patients attending a respiratory clinic. The SLQ included additional questions regarding the availability of social support, religious orientation, and sense of spirituality. The sample included 46 patients with asthma, 110 patients with chronic respiratory disease (COPD, sarcoidosis, fibrosing alveolus, cystic fibrosis, and emphysema), 16 patients with lung cancer, 21 patients with sleep apnoea, and 14 patients with tuberculosis. Prevalence across the five main illness types was compared. Positivity was also compared as a function of illness severity,

duration, co-morbidity, age, gender, race / ethnic group, personality type, social support availability, and religiosity / spirituality.

### 3.5.3 Implications

This study represents a further test of the psychometric properties of the SLQ. In addition, an insight was gained into whether some patients are predisposed to positivity, and into the prevalence of positivity in a sample of patients varying in terms of their illness characteristics who were not previously identified as having a bias towards positivity.

## 3.6 *Identifying the Factor Structure of the SLQ*

Finally, to gain an insight into the nature of positivity with respect to its dimensionality, the factor structure of the SLQ was examined by pooling the SLQ data from the current study with the baseline data from study 3 and 4 generating a total sample size of 350. Principal components analysis and maximum likelihood analysis with varimax and direct oblimin rotations were performed.

### 3.6.1 Implications

This analysis provides an insight into whether there is an overall general construct of positivity or multiple dimensions to positivity in illness.

## 3.7 *Summary*

This thesis describes a programme of research whereby the domains of positive consequences of illness are identified systematically and a psychometrically tested measure of the positive consequences of illness based on these domains is developed. This thesis sets out to gain an insight into the prevalence of positive consequences of illness and to identify potential correlates of positivity in illness. In addition, the potential for enhancing positivity through health management and the significance of positivity in terms of health outcome are examined.

## CHAPTER 4

### STUDY 1: IDENTIFYING THE DOMAINS OF POSITIVE CONSEQUENCES OF ILLNESS

“The illness was the best thing that could have happened to me”  
(33 year old recovering from CFS)

#### 4.1 *Introduction*

In chapter 2, it was argued that, for some individuals, positive interpretations of illness are an important component of the experience of being ill and that these interpretations merit attention not only for conceptual completeness but also for their therapeutic implications. A review of the literature on illness-related positive outcomes revealed that, despite being described as remarkably common (Schaefer & Moos, 1992), positive consequences of illness represent a neglected field of research.

##### 4.1.1 Aim of the study

The aim of this study is to identify systematically the diverse ways people who are or who have been ill describe their illness as a positive experience. It is not the intention of this particular study to identify how common the experience of positive consequences of illness is in general, nor is it the intention of this study to examine why some individuals feel positive about their illness and when during the illness trajectory positivity is experienced.

#### 4.2 *Method*

In order to satisfy the aim of this study, it was necessary to select individuals on the basis of reported positivity to illness and to adopt a protocol that invited these individuals to provide elaborate descriptions of their positive experiences.

#### 4.2.1 Sample recruitment

A press release describing the purpose of this research and also a separate investigation into how people derive meaning in their life was sent to various media sources including local and national newspapers and radio stations (Appendix 1). People were asked to participate in the research if they had encountered illness as positive in some way. The press release made reference to physical illness, however, no exclusion criteria were specified with regards to the particular type of illness - as will be revealed in section 4.3.1, individuals describing illnesses of a psychological nature were also included in the sample. In addition, no criteria were specified with respect to what actually constitutes an illness type.

#### 4.2.2 Settings for the study

Respondents were asked to attend for an interview at the University of Plymouth or, if they preferred, in their own home. However, given that the research was advertised nationally, some respondents were not resident in the local area. In addition, some respondents were too ill to be interviewed. These respondents were sent a letter (Appendix 2) asking them to contribute to the research by writing about their positive experiences in a questionnaire (Appendix 3). (Note, in addition to the 'Consequences of Being Ill' questionnaire, respondents were also requested to complete two further questionnaires for a separate investigation into meaning of life although the demographic information gathered from these questionnaires was drawn upon for this study).

#### 4.2.3 Interview protocol

Where possible, participants were interviewed about their experiences of illness. Within the context of images of illness, Viney (1989) presented a case for the use of personal reports and argued against views that such reports deteriorate over time and are replaced by fabricated memories (Cohen & Lazarus, 1973). Viney reasons that as illness is a highly emotive experience, it is likely to be recalled with a high level of precision and accuracy.



Prior to asking respondents to present their personal reports, information was gathered on the participant's age and sex. Details were also recorded regarding their illness, in particular, type of illness, duration of illness and whether the participant had recovered from illness.

The interview protocol (Appendix 4) reflects the recurrent themes reported in the literature (section 2.2.2) and also the interview and questionnaire items used in existing research into positive outcomes of illness (section 2.3). Participants were first asked a general open-ended question regarding the effects their illness has had on their life. As noted by Kerr and Stephens (1997), rather than directing individuals down a particular path of reflection, open-ended questions allow individuals to respond using their own interpretations and personal experiences.

The general open-ended question was followed by eight questions referring to specific effects of illness. The interview items are not necessarily positively toned, that is, as with the items used by Collins et al. (1990), they have the potential to elicit both positive and negative responses. In order to gain a comprehensive picture of the total illness experience it was necessary to invite respondents to present both the negative and positive effects of illness. It is possible that a negative aspect of illness, such as physical activity limitations, may be associated with a positive outcome, such as, an opportunity to devote more time to one's inner self or spirituality. The interview schedule ended with an open-ended question that represents a final recall attempt by asking respondents to reflect on any further positive consequences of illness that they have encountered.

Questions were delivered in a semi-structured format with the sequence of questions tailored to participants' personal experiences and to the content of their responses. Additional questions were included where necessary.

Respondents who could not be interviewed received the same questions (except the final open-ended question) in an open-ended questionnaire format (Appendix 3). Each question was presented on a single page and respondents were encouraged to continue their responses on additional pages where necessary. Respondents were given a contact number and invited to discuss any queries. A freepost return envelope was also sent to respondents for the return of their

completed questionnaire. At the end of the questionnaire, respondents were asked to indicate whether they would be interested in receiving a summary of the findings.

#### 4.2.4 Method of analysis

Interviews were audio-taped with the participant's permission and brief notes were taken during the interviews to facilitate analysis. Interviews were transcribed in an annotated form. The interview transcripts and questionnaires were analysed using a qualitative method of analysis. Qualitative analysis is of particular value in research of an exploratory nature where the concern is to uncover all the phenomena relevant to the research question. A quantitative method, by contrast, may overlook important elements (Banister et al., 1994) and this is implied in the following quote by LeShan (1984):

“...statistics are only pegs upon which to hang a fuller, more rounded picture. The rich tapestry that each human being is, many-colored and marvelously woven, can easily be lost in a table of figures.” (p.29)

Ryff (1989) acknowledged that an important challenge faced by researchers using qualitative analysis is not to stray from the words and meaning of the respondents while at the same time organising the material in a meaningful fashion.

Thematic analysis was regarded as a suitable method of analysis given that the aim of this study is to derive domains (themes) of positivity from individuals' descriptions of their illness experience. Banister et al. (1994) described thematic analysis as: “a coherent way of organizing or reading some interview material in relation to specific research questions” (p.57). The questionnaires and transcripts were read repeatedly to identify types of positive experience. Each reference to a positive consequence of illness was recorded. The interview / questionnaire items were used as initial ‘thematic headings’ for organising the data although they were not adhered to rigidly and ‘novel’ headings were sought. Categories were formed on the basis of a grouping together of different accounts based on their content. For several of the categories, sub-categories were identified.

This method of analysis allowed the frequency of themes to be determined. Comparisons were made of the total number of categories referred to across different typologies of respondent,

for example, males and females, interviewees and questionnaire respondents, recovered and currently ill individuals, and different age and illness groups.

### 4.3 *Results*

#### 4.3.1 Characteristics of the sample

Sixty-eight individuals expressed an interest in the study, 41 (60%) were interviewed (35 at the University and 6 at home). The remaining 27 individuals were sent the open-ended questionnaire. Fourteen (52%) questionnaires were returned resulting in a total sample size of 55. Two further questionnaires were received after the analyses had been performed and were thus not included in the sample.

The sample consisted of 42 females (76%) including one male-female trans-sexual, and 13 males (24%) aged between 20 and 81 years, mean (standard deviation) age 53.0 (13.5) years.

The sample had experienced a range of illnesses including those of a psychological nature, and some participants were co-morbid presenting up to four different illness types (Appendix 5). The most prevalent illness type was cancer, which was experienced by 25 (45%) participants, followed by psychological illness, including depression and addiction (16%), musculo-skeletal, including arthritis, rheumatism, and osteoporosis (13%), CFS (9%) and heart disease (7%). Twenty-eight participants (50.9%) were currently ill of whom, two were terminally ill. The remaining 27 (49.1%) participants described themselves as either fully recovered or in the process of recovery. Note that as certain illness types, such as, cancer and CFS, are characterised by periods of remission, the distinction between currently ill and recovered can be difficult to determine. The mean (standard deviation, range) duration of illness was 0.95 (1.64, 0.25-52.0) years (this information was specified by 51 participants). For respondents who had fully recovered from their illness, the mean (standard deviation, range) time since recovery was 2.43 (1.83, 0.08-7.00) years (this information was only provided by 18 respondents).

Interviewees and questionnaire respondents did not differ significantly in terms of either their demographic or illness characteristics as determined by t-tests and the Chi-square ( $X^2$ ) statistic (significance was indicated by a  $p$  value of .05 and below) (Table 4.1).

Table 4.1. Comparison of demographic and illness characteristics of interview and questionnaire respondents

	Interviewees (n=41)	Questionnaire respondents (n=14)	Test of significance
<b>Age</b>			
mean (standard deviation)	52.0 (14.4)	55.93 (10.5)	$t(53)=-0.94; p=.35$
<b>Sex</b>			
frequency (percentage)			
males	9 (22.0)	4 (28.6)	
females	32 (78.0)	10 (71.4)	$\chi^2(1)= 0.25; p=.61$
<b>Illness status</b>			
frequency (percentage)			
currently ill	20 (48.8)	8 (57.1)	
recovered	21 (51.2)	6 (42.9)	$\chi^2(1)= 0.29; p=.59$
<b>Illness duration (years)</b>			
n=39		n=12	
mean (standard deviation)	9.4 (11.6)	14.3 (15.6)	$t(49)= -1.17; p=.25$
<b>Time since recovery (years)</b>			
n=16		n=2	
mean (standard deviation)	2.5 (1.9)	2.0 (0.7)	$t(16)= 0.34; p=.74$

#### 4.3.2 Positive consequences of illness themes

Four sample transcripts (two interview and two questionnaire transcripts for participants with different illness types) along with the themes identified for these particular transcripts are presented in Appendix 6.

This section will firstly present the general accounts of positive consequences of illness and will then describe the specific themes identified.

In general, participants were very positive about taking part in the study commenting on other people's lack of interest and understanding of positivity in illness. For many participants, their involvement in this research represented a first opportunity to share their positive experiences. The average duration of interviews was 2 hours.

General comments regarding positivity in illness, such as the quote at the beginning of this chapter, refer to overall improvements in one's life situation:

"My illness has opened up a whole new world to me" (participant 8)

"My life is much better than before" (participant 11)

"Everything is better" (participant 20)

"You gain so much" (participant 47)

Some participants did not acknowledge any negative aspects of their illness:

"...this wasn't bad, this was a good experience" (participant 31)

"My breast cancer has been very positive in my life, not negative at all"  
(participant 33)

Expressions of gratitude for having encountered illness, even one which is potentially life-threatening, were made:

"I am glad I had cancer" (participant 22)

A recurrent message conveyed by participants was that they had become ill for a reason, in particular, to achieve something:

"People become ill to achieve something...I did wonder sometimes whether I had brought it on myself" (participant 36)

"The problems that brought illness to me were meant to be" (participant 54)

Finally one participant who had become disabled as a result of heart disease felt that other people would benefit from becoming disabled:

"I wish in a way, some people could, for a limited time, become disabled...it would do them a great deal of good" (participant 27)

Participants' enthusiasm to talk about their experience of positive consequences of illness is evident from the sample transcripts and is also reflected in the number of themes that emerged from the thematic analysis. Reports of positive gains from illness were classified into 17 categories. The mean (standard deviation, range) number of categories reported was 7.96 (1.89, 3-13).

The themes identified in descending frequency order are as follows: improved relationships with others, positive consequences for others, self-improvement, reappraisal of life, reorganisation of life, spiritual gains, changes in priorities, acquisition of skills and participation in new activities, self-awareness, acquisition of general knowledge, relief from responsibilities, sensitivity to emotions, resolution of past concerns, perception of illness as a challenge to overcome, practical gains, confrontation of current concerns, and greater respect for the environment. Descriptions of these themes and also their sub-themes are presented below. The percentage of participants describing the kind of positive experience in each category is shown in parentheses. Quotations from participants are used to illustrate the meaning of the categories and sub-categories (participants are identified by a number; refer to Appendix 5 for demographic and illness characteristics of each participant).

4.3.2.1 Improved interpersonal relationships (100%). All 55 participants provided at least one account of enhanced relationships with others.

(a) Several participants claimed that their illness had strengthened and deepened their relationships with others in particular, their marital relationship:

"It has made my marriage" (participant 26)

"...an already pretty solid marriage had become even more solid" (participant 53)

(b) Some participants described more harmonious relationships with others:

"I have learnt to walk in harmony with others" (participant 18)

In particular, several participants described being less judgmental of others and more accommodating of divergent opinions:

"...you have not walked in their shoes" (participant 3)

Several participants described being less likely to interfere in the lives of others and to set standards for others. One participant (participant 16) made a greater effort to get on with others and to see the best in others. Illness also encouraged participants to sort out their differences with others.

By contrast, some participants had become more aware of the faults of others and were less tolerant of these faults:

“I tend to strip these people of all their gold” (participant 24)

One participant (participant 38) felt she was less inclined now to allow others to “walk all over” her. This tendency to be less tolerant of others often resulted in a disintegration of relationships and a greater selectivity in choice of friends:

“I kept the best of my old friends” (participant 29)

“I have re-jigged my friends” (participant 53)

One participant (participant 52) was prompted to distinguish between friends who can give and those who cannot.

(c) Three participants (participants 2, 12, and 32) felt that their relationships were more positive now as they less governed by the need for approval from others.

(d) Accounts were also made of a greater honesty and openness with others with a greater tendency to communicate with others.

(e) For many participants, illness prompted a greater investment in relationships with others. As an example, participant 4 had to stop doing everything that she used to do because of her illnesses (eczema and urticaria) and was consequently able to invest more in her family and in particular her son with special needs. Reports were also made of a greater effort put into relationships to ensure their survival.

By contrast, two participants (participant 19 and participant 33) placed less emphasis on relationships with others:

“I take or leave friends now” (participant 33)

Participant 19 felt that she now “wastes” less time with others.

(f) Many participants felt that they had been put in a position whereby they are more aware of other people's pain and suffering and able to put themselves in "other people's shoes"

(participant 3). In particular, participants described a greater sensitivity and empathy for others:

"I know, I have been down that road" (participant 18)

"It has allowed me to see both sides now - as a carer and as a patient"  
(participant 21)

Further accounts of having more to offer others include being a better listener (participant 5, participant 6 and participant 47), being more approachable (participant 7 and participant 50) and more patient (participant 19).

By contrast the reports provided by two participants implied that they were less obliged to do things for others (participant 11) and were less supportive of others (participant 35).

(g) A further salient theme within the category of improved interpersonal relationships relates to a greater appreciation and respect for others:

"Everyone is more precious to me" (participant 23)

"I would not have been so conscious of these people's kindness had I not been ill" (participant 55)

and in particular friendships:

"You find out who your true friends are when the going gets tough" (participant 32)

Several reports were made of an appreciation of the emotional and practical support offered by others:

"I have come to realise just how loving and caring my family are" (participant 8)

An appreciation of the value of asking for and accepting support from others was also expressed (for example, participant 2, participant 23 and participant 28).

(h) In addition to prompting a disintegration of troublesome relationships, illness also introduced some participants to new friendship networks via illness support groups. Participant 51 described a greater willingness to meet new people. One participant (participant 55) even explained that if it had not been for her illness she would not have met her husband.



(i) Finally, for three participants (participant 15, participant 30 and participant 51), illness gave them the opportunity to make contact with old acquaintances. Participant 15 hoped that through her illness she might be a “catalyst for revived relationships”.

4.3.2.2 Positive consequences for others (93%). Fifty-one participants felt that, in addition to perceiving something positive from illness for themselves, other people around them such as family and friends also gained something. One participant explained:

“There are a lot of people whose lives are better for the fact I have had cancer (participant 22)

According to participant 36:

“It gives other people opportunities”

(a) Other people were reported to benefit from the individual’s greater ability to empathise with them. Participant 9 described how her illness encounter had encouraged others to talk to her about their experiences of illness:

“It broke down barriers with others”

This was perceived as therapeutic for others:

“I do feel better after I’ve talked to you” (participant 55 recounting a conversation she had had with a teacher)

According to participant 36, by sharing her experiences with others, she gives greater credence to what they suffer.

(b) Illness was described as an inspiration to others in 19 accounts:

“If you can keep going, so can I” (participant 36)

“I take my hat off to you” (participant 47)

Participants felt that they had instilled hope in others, and this was a particularly salient theme expressed by participants who had encountered cancer:

“You can carry on...cancer is not a death threat” (participant 10)

“It is not all doom and gloom, one can still be cheerful despite having had cancer” (participant 12)

(c) Nine participants claimed that their illness had been an eye opener for others:

“It pulled a lot of people up short and made them realise that this could be me” (participant 9)

This greater awareness amongst others of the risk of illness was reported to prompt positive lifestyle changes to avoid illness such as taking regular exercise and giving up smoking (participant 27), slowing down and avoiding “burning out” (participant 17).

(d) Many accounts were made of illness inspiring other positive changes in the life of others, for example, a tendency to live life to the full and to readjust priorities. The emergence of positive attributes in others was also noted - participant 40 reported that others had “grown” as a result of her illness. Positive attributes include greater independence, confidence, tolerance, openness, and sensitivity. Other people were also reported to be more appreciative, attentive, supportive, interested, polite, respectful, caring, friendlier and less self-centred.

(e) Changes in other peoples’ attitudes towards the participant, for example, a more realistic perception of the individual were noted:

“I am not as strong as she thought” (participant 36)

Participant 11 explained how his illness had prompted his girlfriend to clarify her feelings for him.

(f) Illness was perceived as bringing other people face to face with their own mortality:

“My wife emphasises that she has learned as a result of my illness, that our relationship is, after all, finite and that life will end sooner or later (participant 53)

Participant 36 explained how her own illness gave her mother an opportunity to discuss with her issues such as death and dying:

“It has helped her because she is not going to last forever”

Four participants provided accounts of illness encouraging others to get in touch with their spiritual side.

(g) Illness was described as a learning experience for others:

“It has been a learning curve for my husband” (participant 35)

“Everybody around me has said that they have learnt from my pain and my illness” (participant 36)

Participants found themselves in a position whereby they were able to educate and advise others, including medical professionals, about their illness. Participant 36 explained how she actively encouraged other people to question what they could learn from negative experiences such as illness:

"It is almost like I am getting people to question if something dreadful's happening, what are you getting out of it? What are you learning from it?"

(h) Two participants (participant 26 and participant 48) felt that their illness had given other people an opportunity to feel needed and to demonstrate their kind and caring nature.

4.3.2.3 Self-improvement (93%). Fifty-one participants described positive changes to their character as a consequence of illness. In some accounts the changes were perceived to be so profound that the participant felt like a completely different person:

"I cannot believe that I am the same person that I was 5 or 6 years ago, I feel totally different about myself" (participant 8)

(a) Several participants described themselves as a better person:

"It has definitely found strengths and a better side of me" (participant 36)  
"Before that, I was scum" (participant 24)

Three participants (participant 22, participant 40, and participant 44) described the positive changes to their character within the context of self-growth. Positive attributes acquired as a result of illness include maturity:

"I felt older" (participant 24)

independence, assertiveness, determination, flexibility, strength:

"Not so many people are as strong as I am mentally" (participant 19)

positivity, more responsible, more relaxed and a less tendency to worry:

"I am not so keyed up" (participant 14)  
"If there's a problem around, what does it matter?" (participant 48)

greater security, contentment:

"I just feel happy...I laugh more than ever before" (participant 12)

sympathetic, compassionate, understanding, confidence:

"I can deal with whatever life throws at me" (participant 22)

patience, honesty, less complacency, less concerned about failure and what others think, and also less conformist:

"I have become a person in my own right" (participant 29)

While six participants described themselves as more tolerant now, three participants felt that they had become less tolerant of deviations and injustices.

(b) A particularly salient theme within this category refers to greater self-acceptance and respect:

“I didn’t like myself before, now I do...This is me and I am quite happy with me” (participant 22)

“I matter as a person” (participant 23)

“I am now proud of myself” (participant 52)

Participants were now more inclined to give themselves permission to do things (participant 36) and to make mistakes (participant 39). Participant 11 felt that his illness had given him permission to say no to things and this was described as the “biggest thing” that illness had done for him - “a real tool”.

(c) While two participants (participant 8 and participant 14) felt that illness had prompted them to become less self-centred, eight participants described themselves as having become more self-focused:

“Maybe I ought to be looking after me” (participant 33)

“I am important, I am the first person who is important...I have to take some time out for myself” (participant 35)

4.3.2.4 Reappraisal of life (93%). (a) The experience of illness encouraged 51 participants to reflect on the true purpose of life:

“The illness brought me up short and made me question what life is about” (participant 11)

In particular, several participants explained how they had been forced to review their own lives:

“It was as if someone had picked all the bits and pieces that were my life and threw them in the air and said you need to look at this” (participant 2)

“My illness gave me the chance to sit still and re-stock and to think what am I doing with my life, where am I going?” (participant 4)

For participant 54, this life review process prompted her to: “make a new start” and “change things for the better”. Two participants (participant 27 and participant 31) were also prompted to contemplate their place in the pattern of life.

(b) A greater insight into the purpose of life led several participants to an altered perspective on life:

"It gives you a different perception of what life is about" (participant 32)

Five participants (participant 2, participant 4, participant 11, participant 22, and participant 54) had embraced a more positive outlook on life:

"I see the good in things" (participant 2)

Three participants (participant 9, participant 11, and participant 13) had adopted a more realistic approach to life:

"Life is hard" (participant 9)

Two participants (participant 11 and participant 54) described a reappraisal of life as an adventure or journey. Participant 29 had adopted a wider perspective on life and participant 23 described working towards achieving such a perspective. Finally, one participant (participant 16) described a more tranquil outlook to life.

(c) A recurrent theme within this category refers to a greater appreciation of life and a tendency not to take things for granted:

"Life is a complete miracle" (participant 3)

"Life is a gift" (participant 9)

"Life is so precious and can change at the click of a finger" (participant 17)

In particular, participants described a greater awareness and appreciation of: "things others don't notice" (participant 26) for example, simple pleasures such as nature:

"The illness made me take a step back from everything and see the importance of just simple things" (participant 1)

"I find myself drinking in the nature" (participant 30)

"I see the grass grow" (participant 37)

A sense of gratitude for simply being alive and doing everyday activities was also expressed.

(d) A greater appreciation of life was often coupled with a heightened awareness and acceptance of one's mortality:

"I realise how easy it is to take life away" (participant 19)

"...it can be curtailed in 2 seconds" (participant 15)

"I am very aware that I haven't got a lot of time left...there isn't always tomorrow" (participant 36)

An appreciation of the fragile nature of life is also implied in the quote by participant 17 presented above in (c).

A confrontation of one's mortality resulted in one participant (participant 22) becoming less fearful of death and left one participant (participant 12) with nothing to fear in life.

(e) Four participants (participant 4, participant 5, participant 6, and participant 10) described a greater acceptance of how things are in life:

“You should change the things you can change and accept the things you cannot change” (participant 10)

(f) Finally, while four participants (participant 20, participant 22, participant 39, and participant 47) referred to a greater emphasis on the present, two participants (participant 17 and participant 27) had become more focused on the future.

4.3.2.5 Restructuring of life (84%). As noted in the case of participant 54 presented in section 4.3.2.4 (a), a reappraisal of life often prompted changes in the way participants led their life. A total of 46 participants felt that their illness had encouraged them to restructure their life:

“I have had to totally re-shape my life” (participant 11)

Three participants (participant 22, participant 33, and participant 54) perceived their illness as an opportunity for a second chance:

“I see it as another chance to have another go and put things right” (participant 22).

For many participants, life had consequently become enriched:

“My bottle is half full not half empty” (participant 29)

“Before I was ill, I led an awful life” (participant 50)

“Life now has a capital I” (participant 53)

(a) Four participants (participant 24, participant 27, participant 45, and participant 47) described a more positive use of their time. Participant 53 had become more selective in what he does / does not do, and participant 25 had adopted a lifestyle whereby she only does the “worthwhile things”.

(b) While participant 36 described a more structured way of life following illness, the lifestyle of participant 13 was described as “less routinised”. Several participants also described a less goal-oriented lifestyle:

"Before the illness, I had clearly defined goals, now these goals are not particularly important" (participant 1)

(c) Consistent with the self-centred theme reported earlier, several participants had adopted a more self-oriented lifestyle:

"I am doing what I want" (participant 28)

Illness prompted participant 33 to choose her own preferred lifestyle.

(d) Eighteen participants described a greater tendency to "do things today for tomorrow may be too late". This concept mirrors the earlier theme that described a greater awareness of one's mortality and a belief that "there isn't always tomorrow":

"You can't put off until tomorrow what you can do today. You don't know how much longer you are going to have to live. It has made me wake up and get on with things" (participant 38)

"You just do not know what life has in store for you - there may not be a second chance" (participant 50)

Participants thus felt compelled to make the most out of life and to lead a fulfilled lifestyle:

"I try not to waste even one minute and I want each minute to count" (participant 21)

"Last year has been my most fulfilling year...I got so much out of life" (participant 30)

(e) In contrast to the philosophy that: "you must live life to its fullest" (participant 10), 19 participants described a slower pace of life with the belief that: "things can wait until tomorrow" (participant 1) and "I have got forever" (participant 31):

"It is no good working yourself into the ground for a good pension because you may not live to draw the pension" (participant 52)

It is interesting to note that two participants (participant 5 and participant 6) described both of the opposing types of lifestyle - a more fulfilled and a slower pace of life.

(f) Twelve participants described health-promoting changes to their lifestyle including pampering oneself, giving up smoking, improved diet, exercise, the use of complementary therapies, and avoidance of stress. Participant 24 described being kinder to his "fragile frame". For participant 2, this involved not beating her body into submission and clearing herself out of garbage. Finally, two participants (participant 23 and participant 49) described a more balanced lifestyle.

#### 4.3.2.6 Spiritual gains (69%). Positive changes to spirituality were described in 38

accounts, for example:

“My life has become much more enriched spiritually” (participant 2)  
“It has had a profound effect on my spiritual beliefs” (participant 48)  
“The cancer experience was to start me on the road to spiritual growth”  
(participant 54)

Participant 3 described her spiritual gains as the “most wonderful gains” brought by illness.

Spiritual gains were not always of a religious nature:

“My illness encouraged me to be more spiritual (not in a religious way) and gave me the opportunity to think about the value of life and what it is all about” (participant 1)

Participant 22 described a development of spiritual beliefs through nature.

(a) Thirty one participants provided accounts of a deeper, more intense spiritual life.

Participant 19 described a greater consideration of her inner spiritual thoughts. For several participants, illness put their faith to the test and led to a strengthening of their beliefs:

“I now know God’s presence in a very real way” (participant 9)

Participant 26 now enjoyed a closer, more personal relationship with God and had become more whole spiritually.

(b) Nine participants expressed a greater appreciation of one’s spiritual life:

“To be content and to be able to really walk with the Lord day by day brings great compensation” (participant 18)

Participant 2 felt that she was able to appreciate a spiritual life now that she had cleared herself out of garbage as reported above.

(c) Illness prompted seven participants to become more inquisitive and receptive to the doctrines of other religions, in particular, Buddhism.

(d) Five participants described greater spiritual peace. For participant 5, this had been achieved through becoming less intense about finding spiritual fulfilment.

(e) A greater perception of the support and love of God was described by three participants (participant 4, participant 9, and participant 52).



(f) Illness had encouraged two participants (participant 9 and participant 18) to become more trusting of God:

“I leave everything in God’s hands” (participant 18)

(g) Finally, two participants (participant 4 and participant 25) explained that their illness had given them more time to invest in their spiritual life.

4.3.2.7 Changes in priorities (67%). For 37 participants, a reappraisal of the important things in life and a restructuring of life were coupled with a reordering of priorities:

“It teaches you about what the real priorities are in life” (participant 13)

“I prioritise in a completely different way” (participant 20)

The analogy of a sieve was used by two participants (participant 20 and participant 27) to explain how they had kept the important things in life and discarded the irrelevant things. Greater priority was given to “things money can’t buy” (participant 9) and “things that really matter” (participant 48) in particular, family and friendships, sorting out troubled relationships, health, ‘enjoyable’ activities, small pleasures, fulfilment, achieving contentment, putting one’s affairs in order, spirituality, and oneself.

Less importance was ascribed to trivial matters and material things that, according to participant 32, “are not always worth what you pay for them”. In particular, money, achievement and work (identified by participant 11 as a priority) were deemed to be of less value now:

“Worrying about money, bills and housework is not what we are here for”  
(participant 2)

“Money is not the be all and end all” (participant 18)

“Salary, achievement - they have all gone completely out the window”  
(participant 27)

Three participants (participant 2, participant 22, and participant 39) also described the approval of others as no longer a priority.

4.3.2.8 Skills and new pursuits (49%). Illness equipped 27 participants with new skills and introduced them to new activities:

“I discovered a talent I didn’t know I had....It has led me up paths I never thought I would go” (participant 22)

"I have done an awful lot of things I wouldn't have dreamt of doing" (participant 27)

(a) Accounts were given of illness providing an opportunity to fulfil lifelong ambitions.

Participants described having more time to pursue hobbies. For seven participants, illness unleashed an artistic temperament:

"I didn't think that I would be able to produce anything but I was pleasantly surprised" (participant 6)

Participant 6 explained how becoming ill had prompted him to learn to drive. Further pursuits described by participants include writing, swimming, meditation, relaxation, yoga, charity work, counselling, gardening, singing, and playing.

(b) Illness directed three participants (participant 4, participant 29, and participant 36) down a different career path:

"I got an enormous amount of freedom from it - an excuse to change direction" (participant 36)

Illness prompted participant 29 to return to her studies:

"There was a bit more to me that needed developing"

(c) Through illness, nine participants had become better equipped to deal with the problems and trials of life:

"I am no longer afraid of what might be around the corner" (participant 2)  
"I cope better than most and find problems easy to solve" (participant 52)

4.3.2.9 Self-awareness (44%). Through illness, 24 participants learnt about themselves:

"I have discovered myself" (participant 26)

Participant 13 described a greater tendency to ask herself who she is. Greater self-understanding was reported as the biggest positive effect of illness for participant 5. For participant 40 who had recovered from CFS (M.E.), her illness compelled her to take a closer look at herself and find herself. Participant 40 explained that M.E. represents 'me' and that people who suffer from M.E. have "lost themselves" and need to get into contact with themselves before they can work towards recovery.

(a) Accounts were provided of illness encouraging altered self-perceptions:

"I have come out of it with a radically different perception of myself"  
(participant 44)

and a more realistic perception of one-self.

(b) For ten participants, illness had uncovered their strengths as well as their weaknesses:

"Being disabled has taught me to look and recognise other ways in which I have always been disabled" (participant 43)

(c) Eight participants had become more attentive to their body and more sensitive to their body's signals.

(d) An enhanced perception of one-self in relation to others was described by five participants. For two participants (participant 33 and participant 44), this perception was one of equality with others.

4.3.2.10 Acquisition of knowledge (44%). Twenty-two participants perceived their illness as an opportunity for learning:

"I feel that I have had extra learning" (participant 3)

"It is like being ill puts a break in your life and you have got to stop and either you can take stock and learn from it or you can carry on"...There's a message there and the message keeps coming and coming until you learn it" (participant 40)

As reported earlier, some participants, such as participant 40, believed that they had become ill for a reason and that this reason was to gain some wisdom. Participant 11 held onto the belief that his illness had not been a waste of time and that he was meant to be learning from it:

"It was not just suffering for suffering sake".

The perception of illness as a learning experience was a particularly salient theme for participant 36. This participant confronted her illness (and, as mentioned earlier, also urged others to adopt the same approach) with the following questions:

"What am I going to learn from this? What was the opportunity?"

Participants provided accounts of a greater insight into illness, coping, treatments, the human body and the health care system.

4.3.2.11 Relief from responsibilities (22%). Three participants (participant 8, participant 17, and participant 51) felt that their illness offered them a sense of freedom from the chores of everyday life:

“I often use my illness as an excuse not to do the things I just don’t want to do”  
(participant 51)

Ten participants used illness as an opportunity to give up their employment responsibilities:

“I am lucky, I had some reason to get out of it” (participant 33)

“We will perhaps have a better retirement” (participant 34)

For participant 28, this was perceived as a particularly positive consequence of illness as she had found her occupation unfulfilling and had been struggling to keep up:

“I was a square peg in a round hole...I don’t have to keep up”

4.3.2.12 Sensitivity to emotions (16%). Illness prompted nine participants to become more aware of their own emotions and those of others. Participant 2 explained that as her illness had confined her to her bed she had no distractions and could not avoid confronting feelings that had not been looked at before:

“Emotionally, I had to open the cupboard and start clearing it out”

Participant 47 felt that through her experience of illness she was able to sense things more easily.

(a) Three participants (participant 5, participant 6, and participant 16) described a greater ability to balance and curb their emotions. By contrast, participant 22 described a greater expression of her emotions to others. Before participant 22 went into hospital, she realised that there were so many things that she had not said to people, in particular, her children - how she felt proud of them, why she loved them and why she sometimes gets annoyed with them. She resolved this by communicating her feelings via letters addressed to her family and close friends:

“I got it all off my chest.... I now tell people and don’t put it off”

(b) In addition to a greater sensitivity to one’s own emotions, two participants (participant 19 and participant 36) had become more considerate of other people’s emotions and encouraged others to express their feelings.

4.3.2.13 Resolution of past concerns (7%). Four participants (participant 2, participant 3, participant 26, and participant 31) were encouraged to attend to conflicts embedded in their past, in particular their childhood, that had previously been “shoved away” (participant 2):

“I have dug them out and dealt with them” (participant 2).

Participant 26 explained how she had been tormented by childhood memories and how she only confronted them when she realised that she had almost died:

“I could have died and had an insecure, damaged life...Now when I die, I know I will die whole”

All four participants described a re-evaluation of the veracity of messages received from others in the past:

“...you’re okay - you are not a bad person like your mother tried to tell you” (participant 31)

Participant 31 also described a re-examination of the behaviour of her mother in the past:

“I had to get to the stage of blaming my mother - she was guilty, I did nothing as a child to deserve what happened”

4.3.2.14 Perception of illness as a challenge to overcome (7%). Four participants (participant 1, participant 3, participant 5, and participant 40) communicated a sense of achievement in rising above the challenges presented by illness:

“I didn’t want people to make exceptions as it was a real achievement to produce work without extensions or relaxed deadlines” (participant 1)

For participant 5, overcoming the challenge of illness uncovered personal strengths, a theme presented earlier:

“Having come through illness, there must be a part of me that is strong”

4.3.2.15 Practical gains (5%). Three participants (participant 28, participant 32, and participant 37) provided accounts of enjoying practical gains and certain luxuries as a consequence of illness:

“I feel that there are practical things you cannot deny and material things that have come out of it as well...practical things have been important to me”  
(participant 32)

In particular, illness provided access to financial benefits that, for participant 32, represented an opportunity to give up employment responsibilities, a theme presented earlier. Participant 28 explained how she had gained access to a ‘motability’ allowance at a time when she was struggling to keep ‘an old banger’ on the road:

“...suddenly to be provided with a new car and motability pays your road tax and insurance - I think I am a very lucky woman”

Participant 32 also described accruing aesthetic gains from her treatment for breast cancer in the form of thicker hair and breast reduction:

“I can say to people it’s good”

4.3.2.16 Confrontation of current concerns (4%). Illness brought two participants (participant 23 and participant 54) face to face with troublesome aspects of their life:

“All my unhappy problems came to a head” (participant 54)

Participant 23 perceived her husband’s death as a possible trigger to her illness. Becoming ill represented an opportunity to cope with her husband’s death:

“Coping with bereavement, definitely that was a very big plus”

4.3.2.17 Greater respect for the environment (2%). One participant (participant 2) described as a “particularly big change” a greater ability and enthusiasm to care for the environment:

“I want the best for everyone including the Planet”

This concern was described as no longer motivated by guilt or conformity.

#### 4.3.3 Summary of themes identified

A thematic analysis of the content of the interview and questionnaire transcripts yielded a vast array of themes or domains of positive consequences of illness. These themes described both

positive consequences for one-self and for others. Particularly salient themes (expressed by over half of the participants) are as follows:

- (i) improved relationships with others;
- (ii) positive consequences for others;
- (iii) improved personal characteristics including greater self-acceptance;
- (iv) a re-evaluation of life including an awareness of one's mortality;
- (v) a restructuring of life with some individuals making the most out of each day and others adopting a slower pace of life by putting things off until tomorrow;
- (vi) spiritual gains which, for most, although not all participants, included a strengthening of religious beliefs;
- (vii) a re-alignment of priorities with, for example, importance of material possessions, money and trivial aspects of life replaced by family, friendships, health, and small pleasures in life.

The remaining 10 themes identified include:

- (i) the acquisition of skills, particularly of a creative nature, and participation in new pursuits, also including the development of new coping skills;
- (ii) enhanced self-awareness;
- (iii) illness as a learning experience;
- (iv) a relief from the demands of everyday life;
- (v) sensitivity to emotions;
- (vi) resolution of troublesome aspects of one's past;
- (vii) perception of illness as a challenge to overcome;
- (viii) practical gains, including financial benefits;
- (ix) confrontation of current concerns;
- (x) a greater concern for the environment.

#### 4.3.4 Comparisons of the number of themes identified across typologies of respondent

Participants were categorised on the basis of their demographic and illness characteristics and compared in terms of the number of themes reported. Perceptions of positive consequences of

illness did not differ significantly for males and females ( $t(53)=0.59$ ;  $p=.60$ ) nor for currently ill and recovered participants ( $t(53)=-0.71$ ;  $p=.48$ ). In addition, the number of themes reported was not found to be related significantly to the age of respondents ( $r(55)=-.25$ ;  $p=.06$ ) nor to the time elapsed since recovery (for those who had recovered from illness and who answered this question) ( $r(18)=.06$ ;  $p=.81$ ).

A significant negative relationship was however identified between the duration of illness and the number of themes reported ( $r(51)=-.31$ ;  $p<.05$ ) suggesting that a longer illness episode is associated with fewer positive consequences.

Finally, one might expect differences in the data gathered from the interviews and questionnaires; the interview setting may yield a larger number of themes by allowing an opportunity for probes and including a final prompt in the form of an open-ended question (see Appendix 4). In addition, the questionnaire methodology relies on the ability of respondents to articulate their experiences on paper (Kerr & Stephens, 1997). The results of an unpaired t-test however did not confirm the existence of any significant differences between the methodologies in the total number of themes reported ( $t(53) = 0.73$ ;  $p=.47$ ).

#### 4.4 *Discussion*

##### 4.4.1 Overview of findings

A total of 17 themes describing positive consequences of illness emerged from the material divulged by 55 individuals who were either currently ill, in the process of recovery, or fully recovered from a range of illness types. The number of participants referring to each theme ranged from 1 (environmental concern) to 55 (improved interpersonal relationships). Seven of the themes were described by over half of the participants.

Some of the accounts provided appear to represent negative consequences of illness; for example, there were reports of a tendency to be less tolerant and supportive of others. These consequences of illness were however perceived by participants to be positive for them and thus were treated as positive themes in the analysis.



The majority of the themes describe personal gains from illness, for example, self-improvement, spiritual gains, and a relief from responsibilities. However, altruistic benefits from illness were also identified and account for the two most salient domains identified - improved relationships with others and positive consequences of one's illness for others.

The diversity of accounts of positivity in illness is reflected not only in the number of themes but also in the number of sub-themes identified. The themes describing improved relationships with others and positive consequences for others embrace the largest number of sub-categories - nine and eight respectively.

Several of the accounts organised under thematic headings are of a contradictory nature. Under the umbrella of improved relationships with others, one finds reference to more as well as less harmonious relationships with others, and a strengthening as well as a breakdown in relationships. The theme describing self-improvement includes eight accounts of greater self-centredness and two accounts of a tendency to be less self-focused. The sensitivity to emotions domain includes reports of both a greater expression as well as a suppression of emotions. A particular notable contradiction is found within the restructuring of life domain with 19 participants describing a slower pace of life with the belief that things can wait until tomorrow and 18 participants, by contrast, adopting the philosophy that things must be done today for tomorrow may be too late.

Participants' lifestyle prior to illness may provide some insight into the particular pattern of lifestyle changes following illness. For example, participant 19 described her life prior to illness as boring and non-fulfilling. For this participant, illness prompted her to make the most out of life. By contrast, participants, such as participant 13, who had previously led a hectic life with stresses and strains, welcomed the opportunity to slow down. Illness type may also account for particular lifestyle changes as certain illnesses, such as CFS, force individuals to conserve their energy and thus impose a slower pace of life (as noted by participant 2), while life-threatening illnesses may instil within individuals, such as, participant 30, a 'living life to its fullest' philosophy.

A number of the themes display overlapping features. As noted in the literature review in Chapter 2, some personal and altruistic gains are closely linked. In this study, several of the sub-categories within the positive consequences for others domain were found to mirror the themes describing personal gains, for example, positive changes in the attributes and lives of others, confrontation of mortality and illness as a learning experience. A reappraisal of life, restructuring of life and changes in priorities are also interrelated - a reappraisal of the purpose of life guided some participants to a different pattern of living which often involved a reordering of priorities. As a further example, for several participants, a greater priority ascribed to family and friendships translated into improved relationships with others.

An exploration of associations between participants' characteristics and the number of themes reported uncovered only one significant relationship; a longer duration of illness was related to fewer themes reported. It is possible that individuals who have encountered a lengthy illness are less positive because recovery is perceived unlikely. An alternative explanation is that this finding is a reporting effect with a greater tendency to forget positive changes with increasing duration of illness. The issue of illness duration as a potential correlate of positivity will be revisited in study 5.

#### 4.4.2 Relationship between the themes identified and the existing literature

The themes reported refer to positive benefits reported in the literature in one form or another (chapter 2), though not in the level of detail described in this chapter. Table 4.2 presents the themes identified and the corresponding citations from the literature.

Table 4.2. Relationship between the themes and sub-themes identified and reports in the literature  
(Adapted from Sodergren & Hyland, 2000)

Themes	Evidence from the literature
<i>Improved Interpersonal Relationships</i>	
(i) Strengthened relationships	Andreasen & Norris (1972); Lukas (1992); O'Connor et al. (1990); Zemore et al. (1989)
(ii) More harmonious relationships versus less tolerant of others	Kerr & Stephens (1997) No reports cited
(iii) Relationships less governed by the need for approval	No reports cited
(iv) More honest and open relationships	Mack (1984); Schaefer & Moos (1992)
(v) Greater investment in relationships versus less time wasted with relationships	Collins et al. (1990); Laerum et al. (1988) No reports cited
(vi) More to offer others (for example, sensitivity and empathy) versus less willing to offer oneself to others	Collins et al. (1990); Mayou, et al. (1978); Zemore et al. (1989) No reports cited
(vii) Greater appreciation and respect for others	Kennedy et al. (1976); Mayou et al. (1978); O'Connor et al. (1990); Viney (1989)
(viii) New friendship networks	Viney (1989)
(ix) Revived relationships	No reports cited
<i>Positive Consequences for Others</i>	
(i) Benefits from individual's ability to empathise	No reports cited
(ii) Inspiration to others	Lukas (1992); Taylor (1983)
(iii) Eye opener for others	Lukas (1992)
(iv) Positive changes in the lives and attributes of others	LaFortune Fredette (1995); Zemore & Shepel (1989)

(v) Changes in others' attitudes towards the individual	No reports cited
(vi) Confrontation of mortality	No reports cited
(vii) Learning experience	Davis et al. (1998)
(viii) Opportunity to demonstrate kindness and feel needed	Folkman (1997)

### *Self-improvement*

(i) Self-improvement (for example, better person, happier, more mature, assertive)	Andreasen & Norris (1972); Collins et al. (1990); Kennedy et al. (1976); LaFortune Fredette (1995); Zemore et al. (1989)
(ii) Self-acceptance and respect	No reports cited
(iii) More self-focused	Belcher, Dettmore, & Holzemer (1989); Giovinco & McDougald (1994); O'Connor et al. (1990); Taylor, Wood, & Lichtman (1983)
versus less self-focused	No reports cited

### *Reappraisal of Life*

(i) Greater consideration of the meaning of life	Belcher, Dettmore, & Holzemer (1989); Giovinco & McDougald (1994); Mack (1984); Northouse & Northouse (1988); O'Connor et al. (1990)
(ii) Altered perspective on life (for example, a more positive approach)	Kennedy et al. (1976); O'Connor et al. (1990); Taylor (1983); Zemore & Shepel (1989)
(iii) Greater appreciation and enjoyment of life (for example, simple pleasures)	Cella & Tross (1986); Cherry & Smith (1993); Kennedy et al. (1976); Laerum et al. (1988); LaFortune Fredette (1995); Viney (1986; 1989)
(iv) Awareness of mortality	Mack (1984); O'Brien (1982)

(v) Acceptance of one's lot in life	Affleck et al. (1987)
(vi) Present	Affleck et al. (1987)
versus future oriented	No reports cited

### *Restructuring of Life*

(i) Positive use of time	Collins et al. (1990); Kennedy et al. (1976)
(ii) More structured	No reports cited
versus less goal oriented lifestyle	No reports cited
(iii) Self-oriented lifestyle	No reports cited
(iv) More fulfilled lifestyle	Collins et al. (1990); Kennedy et al. (1976)
(v) Slower pace of life (leaving things until tomorrow)	Kennedy et al. (1976)
(vi) Positive lifestyle changes	Affleck et al. (1987); Laerum et al. (1988); LaFortune Fredette (1995)

### *Spiritual Gains*

(i) Deeper spiritual existence	Belcher et al. (1989); Kennedy et al. (1976); Kerr & Cowie (1997); O'Connor et al. (1990)
(ii) Greater appreciation of a spiritual life	Belcher, Dettmore, & Holzemer (1989); O'Brien (1982); O'Connor et al. (1990)
(iii) Interest in other religions	No reports cited
(iv) Spiritual peace	No reports cited
(v) Perception of God's love and support	No reports cited
(vi) Greater trust in God	Affleck et al. (1989); O'Connor (1990)
(vii) Greater time to invest in one's spiritual life	No reports cited

*Changes in Priorities*

Collins et al. (1990); Kagawa-Singer (1993);  
Kennedy et al. (1976); LaFortune Fredette  
(1995); Mack (1984); Taylor (1983)

*Skills and New Pursuits*

## (i) Discovery of a new talent

Giovinco & McDougald (1994); Kerr &  
Stephens (1997); LeShan (1984)

## (ii) Change career path

No reports cited

(iii) Better equipped to deal with future  
experiences

Collins et al. (1990); Lipowski (1970-1971)

*Self Awareness*

Giovinco & McDougald (1994);  
Taylor, Wood, & Lichtman (1983)

(i) Altered self-perception (for example, a  
more realistic perception)

Collins et al. (1990)

## (ii) Discovery of strengths and weaknesses

No reports cited

## (iii) More attentive to one's body

No reports cited

(iv) Heightened perception of the self in  
relation to others

No reports cited

*Acquisition of Knowledge*

Hiatt (1986); O'Connor et al. (1990); Taylor et  
al. (1983)

*Relief from Responsibilities*

Lipowski (1970-1971); Mechanic (1966);  
VandenBerg (1972)

<i>Sensitivity to Emotions</i>	Taylor (1983); Collins et al. (1990)
(i) Ability to curb/ balance emotions versus greater expression of emotions	No reports cited
(ii) Sensitivity to other people's emotions	Collins et al. (1990); Zemore et al. (1989)
<i>Resolution of Past Concerns</i>	LeShan (1984; 1994)
<i>Perception of Illness as a Challenge to Overcome</i>	Belcher et al. (1989); Giovinco & McDougald (1994); Lipowski (1970-1971)
<i>Practical Gains</i>	Mechanic (1966)
<i>Confrontation of Current Concerns</i>	LeShan (1984)
<i>Greater Respect for the Environment</i>	Collins et al. (1990)

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The prevalence of accounts of improved relationships with others, self-improvement, a reappraisal of life, a restructuring of life, and a reordering of priorities is reflected in the literature. However, the number and diversity of reports of positive consequences of illness for others cited in this chapter is perhaps surprising given the limited accounts cited in the literature (Davis et al., 1998; Folkman, 1997; Lukas, 1992; LaFortune Fredette, 1995; Taylor, 1983; Zemore & Shepel, 1989).

Reports in the literature of positive consequences of illness, in particular, of enhanced spirituality and self-discovery, often lack detail. Thus, a number of the sub-themes identified in this chapter represent novel accounts of positivity in illness. Several of the novel themes appear to be negative in their orientation, for example, less harmonious relationships and less time invested in relationships. In addition, the literature does not acknowledge the contradictory nature of some

of the positive outcomes of illness, for example, there are accounts of greater self-focus but no reports of a tendency to be less self-focused, and there are reports of a greater but not of a less tendency to offer oneself to others.

The findings of this study fail to replicate the following two benefits of illness reported in the literature (Lipowski 1970-1971): the perception of illness as a punishment for past sins, and the use of illness to manipulate relationships with others.

#### 4.4.3 Limitations of the study and further research required

Only one investigator performed the coding of the transcripts, thus inter-rater reliability could not be established. In view of the overlapping nature of the content of themes, a second rater would have been of value. However, transcripts were scrutinised repeatedly and care was taken to ensure consistency in the organisation of accounts.

Although the findings of this study are consistent with the anecdotal reports in the literature in suggesting that positivity in illness occurs, the extent to which the findings can be generalised is not known. That is, this study used a highly selected sample and did not attempt to address the prevalence of positivity in different illness groups. In addition, as noted in the introduction to this chapter, this study did not set out to identify the determinants of positivity. These unanswered questions form the rationale for further research presented in chapter 8. Theoretical explanations for the positive consequences of illness reported in this study are also beyond the scope of this chapter and these will be presented in the discussion chapter (chapter 9).

#### 4.5 *Conclusion*

The intention of this study was to explore the positive consequences of illness in a group of individuals deemed to be particularly qualified in this area, that is, those who have experienced illness as positive in some way. Consistent with the previous research presented in chapter 2, this study has found evidence of positivity in illness. A vast array of themes were uncovered some of which were inter-connected. Each theme refers to benefits of illness cited in the literature



although not necessarily in the level of detail presented in this study. Twenty-three sub-themes represent novel benefits of illness.

The findings of this study provide the material for a measure of the positive consequences of illness that can be applied to different patient groups and used to determine whether positivity can be enhanced, and also to determine the prevalence, determinants, and therapeutic properties of positivity. The following chapter describes the development and validation of this questionnaire.

## CHAPTER 5

### STUDY 2: DEVELOPMENT OF THE SLQ

“When hard times hit, strengths we never knew we had rise from unknown sources. Our discovery of these qualities is the good fortune at the core of adversity - *the silver lining*”  
(Andrews & McMeel, 1994, pp.7-8)

#### 5.1 Introduction

Existing methodologies designed to assess positive consequences of illness (reviewed in chapter 2), are particularly limited in their focus and are unlikely to capture the broad array of positive consequences of illness reported in study 1 (chapter 4). For example, one of the three illness-related positive outcome questionnaires presented in chapter 2 - the Benefits Appraisals Scale (Tennen et al., 1992) includes five items sampling only four of the 17 themes reported in study 1 namely, spiritual gains, illness as a learning experience, self-improvement, and a reappraisal of life.

The themes reported in study 1 provide the item pool for a more comprehensive measure of the positive consequences of illness - the SLQ. Study 1 thus represents the qualitative phase in the development of the SLQ.

This chapter firstly describes the items selected for the SLQ and then reports the findings of the second study of this thesis designed to identify necessary refinements to the questionnaire.

In summary, the aims of this chapter are as follows:

- \* Describe the item selection procedure for the SLQ;
- \* Pre-test and pilot the questionnaire;
- \* Refine the SLQ

#### 5.2 Scale Development

A standard procedure for scale development (for example, Devellis, 1991) was followed:

- (i) Generate an item pool;
- (ii) Determine the format for response options;
- (iii) Provide instructions for respondents;
- (iv) Submit items for an informal review by others (pre-test);
- (v) Administer the items to a development sample (pilot study);
- (vi) Evaluate items;
- (vii) Refine the questionnaire

### 5.2.1 Item generation

The content areas relating to positive consequences of illness were identified in study 1. The interview and questionnaire data provided a large pool of potential items in the form of direct quotes from participants. Themes and sub-themes referred to frequently were selected with quotes extracted from all categories of positive consequence with the exception of practical gains and greater respect for the environment. Instances of positive consequences categorised under these particular themes were not prominent in the interview and questionnaire transcripts.

A total of 70 items describing positive consequences of illness were generated initially. Given that the measure was designed specifically to assess positivity in illness, the items could not be framed negatively to control for acquiescence in responding. The number of items representing each category of positive consequence reflects approximately the frequency and diversity of such accounts provided by participants in study 1. Improved relationships with others and self-improvement, for example, account for the largest number of items (15 in each category).

The questionnaire concluded with six demographic questions included for descriptive purposes. The questionnaire asked respondents to specify their age, gender, the nature of their illness(es), whether they had recovered from their illness(es), and, if so, how long ago they recovered. The questionnaire also included a crude indicator of the availability of social support by asking respondents to indicate who, if anyone, they reside with.

### 5.2.2 Response options

Each positive consequence of illness item had three response categories - agree, not sure and disagree. Endorsement of the agree option corresponds to the experience of a positive consequence of illness while the disagree option represents a negative response. Respondents were not forced to choose between a positive or negative response as a neutral option (not sure) was provided. The method of scoring responses will be described in section 5.3.1.3.

### 5.2.3 Instructions for respondents

The front page of the questionnaire (Appendix 7) set the scene for respondents by introducing them to the purpose of the questionnaire. This introductory section provided instructions on how to complete the questionnaire and an example to complement these instructions was also included. Finally, respondents were guaranteed anonymity and confidentiality.

### 5.2.4 Item selection

Five colleagues, each of whom had a background in scale construction, reviewed the SLQ. The questionnaire items and instructions were critiqued in terms of content, ease of comprehension, and layout. Items were removed if they appeared to duplicate other items or if they were ambiguous. The final pilot questionnaire included 66 items (Appendix 7). Table 5.1 identifies the items referring to each of the 15 categories of positive consequence.

Table 5.1. SLQ item numbers describing the different categories of positive consequences of illness

Category	Item number(s)
Restructuring of life	1, 2, 3, 4, 5
Change in priorities	6
Relief from responsibilities	7
Reappraisal of life	8, 9, 10, 11, 12, 13
Spiritual gains	14, 15, 16
Self-improvement	17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31
Self-awareness	32, 33, 34
Acquisition of knowledge	35, 36
Skills and new pursuits	37, 38, 40
Perception of illness as a challenge to overcome	39
Sensitivity to emotions	41, 42

Resolution of past concerns	43
Confrontation of current concerns	44
Improved interpersonal relationships	45, 46, 47, 48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 58, 59
Positive consequences for others	60, 61, 62, 63, 64, 65, 66

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### 5.3 *Pilot Study*

The pilot study of the SLQ was designed to identify the psychometric properties of the scale's items and to refine the item pool.

#### 5.3.1 Method

The 66-item SLQ was administered to three groups of participants who had encountered ill health. Samples were selected opportunistically and included individuals not selected on the basis of reported positivity to illness.

5.3.1.1 Characteristics of the samples. Table 5.2 displays the demographic and illness characteristics of the sample as a whole (N=91) and of each individual sample. The three samples are as follows:

(i) 'Illness-benefit'. The first sample consisted of 41 individuals who had identified themselves as having experienced something positive from illness and who had participated in study 1. Fifty-four out of the original 55 participants of study 1 were contacted. The pilot SLQ was also sent to an additional two people whose responses were not included in the analyses of study 1 due to their late return. Forty-four questionnaires were returned, representing a response rate of 79%.

Questionnaires were received from 30 (68%) of the 41 interviewees, 12 of the 14 postal respondents (86%) and the two additional 'late responders'. Three of the returned questionnaires

had to be discarded as more than 10 of the items were unanswered. The final sample thus consisted of 41 respondents. Members of this sample were heterogeneous in terms of illness type.

(ii) Pulmonary rehabilitation. Forty patients enrolled in a pulmonary rehabilitation programme completed the questionnaire. All of these patients suffered from chronic lung disease and the majority had COPD. COPD is an irreversible respiratory condition characterised by chronic shortness of breath. Pulmonary rehabilitation is provided for these patients for physiological training and psychological support. Three of the questionnaires had more than 10 responses missing and were therefore not entered into the analysis resulting in a final sample of 37 patients.

(iii) Cancer support group and healing clinic. Fifty questionnaires were sent to a cancer support group and 20 to a healing clinic attended by individuals of various illness types including chronic fatigue syndrome, cancer and heart disease. As with the 'illness benefit' sample, the cancer support group and healing clinic sample were, to a certain degree, selective in terms of reported positivity to illness as the organisers of these groups administered questionnaires to individuals whom they believed would be able to relate to the questionnaire items. Only eight of the questionnaires were returned from the cancer support group (return rate of 16%) and five from the healing group (return rate of 25%), which resulted in a sample size of 13.

Table 5.2 also presents the results of significance tests of differences between the demographic characteristics of the three samples. These results suggest that the pulmonary rehabilitation sample differs significantly from the other two samples with respect to age, sex, illness type and status. Significantly more male and older participants represent this sample. In addition, while the other two samples are heterogeneous in illness type and include an approximately equal number of currently ill and recovered participants, the pulmonary rehabilitation comprises solely of chronically ill respiratory patients (although two patients described themselves as having recovered from their illness).

Given that the primary purpose of this study was to evaluate the psychometric properties of the scale's items rather than to examine patterns of responding across different typologies of illness, the three different samples were combined. The development sample thus consisted of 91 participants with a mean (standard deviation) age of 58.1 (13.6) years and who were

predominantly female (65.9%), living with a spouse or partner (54.9%) and currently ill (64.8%). The most prevalent illness types were respiratory, including COPD (44.0%), and cancer (26.4%).

Although the sample size satisfies Rust and Golombok's (1992) criteria for a development sample of one more participant than the number of items, it falls somewhat short of Devellis' (1991) recommendation of 300 participants. This recommendation, which assumes a general population, is not feasible given the scope of the present study and the highly selected nature of participants.



Table 5.2. Characteristics of the samples

Sample					
	i	ii	iii	Test of	Total sample
	'Illness	Pulmonary	Cancer	significance	(N=91)
	benefit'	rehabilitation	support and		
	(n=41)	(n=37)	general		
			healing group		
			(n=13)		
Age					
mean (standard	51.7 (14.5)	66.9 (7.2)	55.1 (11.4)	$F(2,84)=16.2$ ;	58.1 (13.6)
deviation)	3 missing		1 missing	$p<.001$	4 missing
Sex					
frequency (percentage)					
males	9.0 (22.0)	19.0 (51.4)	2.0 (15.4)	$\chi^2(2) = 10.4$ ;	30.0 (33.0)
females	32.0 (78.0)	17.0 (45.9)	11.0 (84.6)	$p<.01$	60.0 (65.9)
		1 missing			1 missing

Living arrangements

frequency

(percentage)	21.0 (51.2)	22.0 (59.5)	7.0 (53.8)	$\chi^2(12) = 16.4;$	50.0 (54.9)
spouse / partner	2.0 (4.9)	2.0 (5.4)	0 (0.0)	<i>ns</i>	4.0 (4.4)
children	1.0 (2.4)	0.0 (0.0)	0 (0.0)		1.0 (1.1)
parents	2.0 (4.9)	1.0 (2.7)	1.0 (7.7)		4.0 (4.4)
friends	6.0 (14.6)	9.0 (24.3)	4.0 (30.8)		19.0 (20.9)
alone	0.0 (0.0)	0.0 (0.0)	1.0 (7.7)		1.0 (1.1)
other	9.0 (22.0)	2 (5.4)	0 (0.0)		11.0 (12.1)
more than one		1 missing			1 missing

category

Illness type

frequency

(percentage)					
cancer	17.0 (41.5)		7.0 (53.8)	$\chi^2(8) = 81.4;$	24.0 (26.4)
respiratory	3.0 (7.3)	37.0 (100.0)	0.0 (0.0)	$p<.001$	40.0 (44.0)
psychological	6.0 (14.6)		1.0 (7.7)		7.0 (7.7)
CFS	4.0 (9.8)		2.0 (15.4)		6.0 (6.6)
other	11.0 (26.8)		3.0 (23.1)		14.0 (15.4)

Illness status

frequency

(percentage)					
currently ill	17.0 (41.5)	35.0 (94.6)	7.0 (53.8)	$\chi^2(2) = 22.8;$	59.0 (64.8)
recovered	22.0 (53.7)	2.0 (5.4)	5.0 (38.5)	$p<.001$	29.0 (31.9)
	2 missing		1 missing		3 missing

Time since recovery  
(years)

mean (standard	5.2 (10.1)	0.9 (0.9)	4.4 (4.4)	$F(2,83) = 2.6;$	54.7 (8.9)
deviation)	2 missing			<i>ns</i>	2 missing

---

5.3.1.2 Procedures. (i) ‘Illness-benefit’. This sample included participants from study 1. During the debriefing phase of the interviews for study 1, the directions for further research into the positive consequences of illness were discussed with the interviewees and their participation in further research was initially requested. It was however impressed on interviewees that they should not in any way feel obliged to participate in further research. As the SLQ is self-completed, one of the participants who was blind and who lived in isolation was not invited to take part in this pilot study. All other interviewees expressed an interest in becoming involved in subsequent research. As all interviewees and postal respondents (including the two ‘late responders’) had requested a summary of the findings of study 1, the opportunity was taken to enclose with this summary a copy of the SLQ. In addition, participants were sent a covering letter describing the nature of the study (Appendix 8) and a freepost addressed envelope for the return of their completed questionnaire. Participants were invited to share any comments they had about the questionnaire or the research.

(ii) Pulmonary rehabilitation. Patients with chronic lung disease completed the SLQ during a session in the rehabilitation clinic. Completed questionnaires were returned via the physiotherapist who organised the session.

(iii) Cancer support group and healing clinic. Following a presentation of the findings of study 1, the organisers of a cancer support group and a healing clinic volunteered their assistance in the recruitment of participants for future research. Copies of the SLQ and freepost return envelopes were sent to the organisers for distribution. Questionnaires were completed at home by members of the groups and returned individually.

5.3.1.3 Questionnaire scoring. Each item was assigned a score of 1 for an agree response, 0.5 for not sure and 0 for disagree. As noted earlier, questionnaires with 10 or more missing responses were removed from the analysis. Total scores of positivity were calculated by summing the number of agree responses with a possible range of scores between zero and sixty-six.

5.3.1.4 Item reduction techniques. The following methods of evaluating items were employed:

(i) Item distributions. Patterns of responses to individual items were examined in order to identify poor discriminators of positivity (for example, highly skewed items) and also the occurrence of missing responses. Given that the majority of the participants were selected on the basis of their reported positivity to illness, it follows that their responses will be biased towards the agree option and that there will be a large number of highly skewed items.

(ii) Inter-item correlations. Inter-item correlations were performed in order to detect redundant items, that is those, which are highly correlated (a coefficient of  $r > .80$ ) and replicate the content of other items.

(iii) Principal Components Analysis. Finally, a principal components model was used to identify items that do not belong to or correlate with the general construct (common factor) of positivity in illness. Although a sample size of 91 is considered low for a factor analysis (for example, Devellis, 1991), similar sample sizes have been employed in the development of quality of life instruments; for example, for the purposes of item refinement, the pilot version of the Breathing Problems Questionnaire including 39 items was completed by 89 patients (Hyland et al., 1994).

## 5.3.2 Results

5.3.2.1 Item distributions. Table 5.3 presents item distributions, means and variances. The distributions reveal an overwhelming agreement with items. The agree option was the most frequently endorsed response (i.e., the modal response option) for 52 of the 66 items. The number (percentage) of respondents agreeing with individual items ranged between 19 (20.9) for item 64 'My illness changed other people for the better' and 78 (85.7) for items 9 'My illness made me step back and appreciate simple pleasures' and 58 'My illness made me realise how supportive

other people can be'. Twenty-one items (2, 3, 6, 8, 9, 10, 13, 17, 20, 33, 34, 35, 36, 39, 41, 42, 48, 49, 52, 55, and 58) were endorsed positively by more than 70% of respondents and had a mean close to 1 (corresponding to agreement) and a variance of 0.1.

The not sure option was the most popular response for six items (18, 60, 63, 64, 65, 66). In particular, items describing positive consequences for others attracted this response. Fifty (54.9%) respondents opted for the not sure option for item 65 'My illness changed other people's perception of me for the better' while only 5 (5.5%) of respondents endorsed this response for item 9 'My illness made me step back and appreciate simple pleasures'.

Eight items (4, 7, 16, 19, 26, 37, 38, 57) elicited the disagree response option most frequently. Only six (6.6%) respondents disagreed with items 33 'My illness made me more aware of my body' and 58 'My illness made me realise how supportive other people can be' while 45 (49.5%) respondents disagreed with item 4 'My life is much better now than it was before my illness'.

Missing responses were not particularly frequent with 31 items completed by all respondents. The largest number (percentage) of missing responses was 4 (4.4) for items 1 'My illness gave me a new start in life' and 16 'I am more open to other religions because of my illness'.

Table 5.3. Frequency (percentage) of responses to each item and item means and variances

Item	Agree	Not sure	Disagree	Missing	Mean (variance)
1	40 (44.0)	17 (18.7)	30 (33.0)	4 (4.4)	0.6 (0.2)
2	67 (73.6)	7 (7.7)	14 (15.4)	3 (3.3)	0.8 (0.1)
3	70 (76.9)	10 (11.0)	10 (11.0)	1 (1.1)	0.8 (0.1)
4	34 (37.4)	12 (13.2)	45 (49.5)	0 (0.0)	0.4 (0.2)
5	51 (56.0)	16 (17.6)	23 (25.3)	1 (1.1)	0.7 (0.2)
6	76 (83.5)	7 (7.7)	8 (8.8)	0 (0.0)	0.9 (0.1)
7	32 (35.2)	19 (20.9)	37 (40.7)	3 (3.3)	0.5 (0.2)
8	74 (81.3)	6 (6.6)	10 (11.0)	1 (1.1)	0.9 (0.1)
9	78 (85.7)	5 (5.5)	7 (7.7)	1 (1.1)	0.9 (0.1)
10	70 (76.9)	11 (12.1)	9 (9.9)	1 (1.1)	0.8 (0.1)
11	57 (62.6)	18 (19.8)	14 (15.4)	2 (2.2)	0.7 (0.1)
12	63 (69.2)	18 (19.8)	10 (11.0)	0 (0.0)	0.8 (0.1)
13	71 (78.0)	11 (12.1)	9 (9.9)	0 (0.0)	0.8 (0.1)
14	37 (40.7)	26 (28.6)	28 (30.8)	0 (0.0)	0.5 (0.2)
15	36 (39.6)	20 (22.2)	34 (37.4)	1 (1.1)	0.5 (0.2)
16	26 (28.6)	17 (18.7)	44 (48.4)	4 (4.4)	0.4 (0.2)
17	65 (71.4)	12 (13.2)	13 (14.3)	1 (1.1)	0.8 (0.1)
18	33 (36.3)	36 (39.6)	21 (23.1)	1 (1.1)	0.6 (0.1)
19	26 (28.6)	24 (26.4)	40 (44.0)	1 (1.1)	0.4 (0.2)
20	66 (72.5)	15 (16.5)	10 (11.0)	0 (0.0)	0.8 (0.1)
21	41 (45.1)	26 (28.6)	23 (25.3)	1 (1.1)	0.6 (0.2)
22	48 (52.7)	21 (23.1)	22 (24.2)	0 (0.0)	0.6 (0.2)
23	52 (57.1)	24 (26.4)	15 (16.5)	0 (0.0)	0.7 (0.1)
24	48 (52.7)	25 (27.5)	17 (18.7)	1 (1.1)	0.7 (0.2)
25	52 (57.1)	14 (15.4)	25 (27.5)	0 (0.0)	0.6 (0.2)

26	30 (33.0)	20 (22.0)	41 (45.1)	0 (0.0)	0.4 (0.2)
27	51 (56.0)	17 (18.7)	22 (24.2)	1 (1.1)	0.7 (0.2)
28	50 (54.9)	15 (16.5)	26 (28.6)	0 (0.0)	0.6 (0.2)
29	41 (45.1)	20 (22.0)	29 (31.9)	1 (1.1)	0.6 (0.2)
30	44 (48.4)	22 (24.2)	24 (26.4)	1 (1.1)	0.6 (0.2)
31	52 (57.1)	24 (26.4)	15 (16.5)	0 (0.0)	0.7 (0.1)
32	42 (46.2)	27 (29.7)	22 (24.2)	0 (0.0)	0.6 (0.2)
33	72 (79.1)	13 (14.3)	6 (6.6)	0 (0.0)	0.9 (0.1)
34	63 (69.2)	17 (18.7)	11 (12.1)	0 (0.0)	0.8 (0.1)
35	72 (79.1)	12 (13.2)	7 (7.7)	0 (0.0)	0.9 (0.1)
36	66 (72.5)	14 (15.4)	10 (11.0)	1 (1.1)	0.8 (0.1)
37	25 (27.5)	18 (19.8)	47 (51.6)	1 (1.1)	0.4 (0.2)
38	32 (35.2)	17 (18.7)	41 (45.1)	1 (1.1)	0.5 (0.2)
39	72 (79.1)	10 (11.0)	8 (8.8)	1 (1.1)	0.9 (0.1)
40	45 (49.5)	25 (27.5)	20 (22.0)	1 (1.1)	0.6 (0.2)
41	65 (71.4)	15 (16.5)	10 (11.0)	1 (1.1)	0.8 (0.1)
42	66 (72.5)	18 (19.8)	7 (7.7)	0 (0.0)	0.8 (0.1)
43	43 (47.3)	21 (23.1)	26 (28.6)	1 (1.1)	0.6 (0.2)
44	56 (61.5)	20 (22.0)	15 (16.5)	0 (0.0)	0.7 (0.1)
45	75 (82.4)	8 (8.8)	8 (8.8)	0 (0.0)	0.9 (0.1)
46	57 (62.6)	23 (25.3)	11 (12.1)	0 (0.0)	0.8 (0.1)
47	56 (61.5)	19 (20.9)	16 (17.6)	0 (0.0)	0.7 (0.2)
48	73 (80.2)	11 (12.1)	7 (7.7)	0 (0.0)	0.9 (0.1)
49	69 (75.8)	12 (13.2)	9 (9.9)	1 (1.1)	0.8 (0.1)
50	48 (52.7)	26 (28.6)	16 (17.6)	1 (1.1)	0.7 (0.1)
51	43 (47.3)	24 (26.4)	23 (25.3)	1 (1.1)	0.6 (0.2)
52	69 (75.8)	15 (16.5)	7 (7.7)	0 (0.0)	0.8 (0.1)
53	41 (45.1)	27 (29.7)	20 (22.0)	3 (3.3)	0.6 (0.2)

54	58 (63.7)	10 (11.0)	22 (24.2)	1 (1.1)	0.7 (0.2)
55	75 (82.4)	9 (9.9)	7 (7.7)	0 (0.0)	0.9 (0.1)
56	47 (51.6)	21 (23.1)	23 (25.3)	0 (0.0)	0.6 (0.2)
57	28 (30.8)	20 (22.0)	43 (47.3)	0 (0.0)	0.4 (0.2)
58	78 (85.7)	6 (6.6)	6 (6.6)	1 (1.1)	0.9 (0.1)
59	54 (59.3)	20 (22.0)	17 (18.7)	0 (0.0)	0.7 (0.2)
60	32 (35.2)	39 (42.9)	19 (20.9)	1 (1.1)	0.6 (0.1)
61	53 (58.2)	26 (28.6)	12 (13.2)	0 (0.0)	0.7 (0.1)
62	37 (40.7)	36 (39.6)	17 (18.7)	1 (1.1)	0.6 (0.1)
63	34 (37.4)	37 (40.7)	20 (22.0)	0 (0.0)	0.6 (0.1)
64	19 (20.9)	42 (46.2)	30 (33.0)	0 (0.0)	0.4 (0.1)
65	25 (27.5)	50 (54.9)	15 (16.5)	1 (1.1)	0.6 (0.1)
66	25 (27.5)	44 (48.4)	22 (24.2)	0 (0.0)	0.5 (0.1)

5.3.2.2 Inter-item correlations. Table 5.4 presents numerous highly inter-correlated items where significance is indicated by a value of at least  $p<.05$ . High correlations suggesting a large degree of overlap of content between items are most notably found for items derived from the same category of positive consequence. For example, the correlation coefficient for two of the items describing spiritual gains - item 14 ‘My religious / spiritual beliefs deepened because of my illness’ and item 15 ‘My illness made me re-evaluate my religious / spiritual beliefs’ was .83 ( $p<.001$ ). In addition, two of the items within the acquisition of skills category - item 37 ‘Through my illness I discovered a talent I didn’t know I had’ and item 38 ‘My illness led me up paths I never dreamt possible’ yielded a coefficient of .66 ( $p<.001$ ).



Table 5.4. Inter-item correlations

(i) Items 1-10

	1	2	3	4	5	6	7	8	9	10
2	-.04									
3	.51***	.09								
4	.60***	-.28*	.34**							
5	.54***	-.08	.43***	.48***						
6	.30**	.09	.41***	.21	.48***					
7	.17	.05	.33**	.25*	.29*	.14				
8	.38***	-.06	.23	.37***	.47***	.35**	.22			
9	.29*	.08	.16	.25*	.46***	.48***	.13	.55***		
10	.28*	.05	.18	.17	.45***	.53***	.18	.46***	.63***	
11	.30**	.17	.25*	.26*	.55***	.48***	.30**	.40***	.44***	.39**
12	.31**	-.06	.15	.20	.46***	.41***	.18	.58***	.58***	.65**
13	.38***	.16	.34**	.21	.43***	.77***	.06	.33**	.54***	.63**
14	.41***	.04	.25*	.40***	.30**	.20	.12	.40***	.19	.16
15	.32**	-.07	.18	.40***	.25*	.20	.03	.34**	.09	.24*
16	.30*	.10	.14	.24*	.22	.27*	.23	.25*	.16	.27*
17	.12	.02	.09	.06	-.06	.13	-.02	.00	.23	.26*
18	.54***	-.08	.31**	.48***	.47***	.29*	.11	.42***	.41***	.23
19	.44***	-.17	.34**	.80***	.39***	.23	.20	.41***	.29*	.22
20	.08	-.04	.03	.29*	.20	.19	.09	.07	.50***	.33**
21	.48***	-.00	.40***	.35**	.39***	.41***	.22	.32**	.14	.18
22	.43***	-.04	.26*	.34**	.41***	.25*	.16	.16	.32**	.30**
23	.23*	.08	.33**	.16	.31**	.23*	.06	.15	.10	.08
24	-.05	.00	-.01	.06	.13	.15	.02	.12	.20	.35**
25	.17	.15	.17	.16	-.06	.24*	.21	.01	.11	.31**
26	.29*	-.18	.28*	.50***	.45***	.31**	.17	.37***	.22	.30**

27	.16	-.04	.24*	.27*	.31**	.35**	.16	.22	.22	.23*
28	.34**	.06	.35**	.19	.25*	.29*	.09	.23*	.17	.15
29	.37***	-.09	.37***	.35**	.39***	.28*	.18	.22	.09	.28*
30	.37***	.08	.29*	.33**	.31**	.22	.13	.29*	.19	.18
31	.30*	-.11	.30*	.23*	.26*	.38***	.07	.17	.26*	.39**
32	.36**	-.08	.20	.36**	.29*	.30**	.15	.17	.37***	.48**
33	.07	-.13	.01	-.09	-.05	.08	.15	-.11	-.01	.26*
34	.25*	-.07	.06	.24*	.14	.33**	-.03	.09	.26*	.40**
35	.43***	-.06	.31**	.21	.21	.44***	-.00	.15	.27*	.32**
36	.14	.04	.17	.06	.12	.33**	.05	.11	.20	.31**
37	.50***	.01	.31**	.39***	.41***	.28*	.13	.32**	.27*	.32**
38	.35**	-.00	.10	.27*	.34**	.29*	.09	.33**	.29*	.37**
39	.21	-.05	.15	.18	.10	.26*	-.01	.01	.13	.15
40	.37***	.02	.43***	.41***	.43***	.33**	.10	.19	.44***	.36**
41	.30**	.06	.21	.14	.23*	.39***	.07	.30*	.31**	.45**
42	.23	.01	.09	.22	.25*	.26*	.15	.19	.51***	.37**
43	.29*	.09	.12	.15	.13	.08	.13	.03	.20	.28*
44	.18	.11	.13	.17	.08	.25*	.19	.02	.34**	.36**
45	.40***	.08	.34**	.29*	.39***	.48***	.23*	.33**	.65***	.39**
46	.23*	.13	.23*	.11	.29*	.33**	.16	.19	.46***	.23*
47	.38***	.03	.22	.32**	.48***	.27*	.23*	.26*	.47***	.40**
48	.22	-.01	.24*	.11	.32**	.45***	.02	.17	.44***	.25*
49	.04	.25	.00	.18	.26*	.25*	.23	.22	.44***	.24*
50	.51***	.02	.21	.43***	.32**	.27*	.23*	.31**	.29*	.24*
51	.27*	.06	.13	.48***	.26*	.23*	.15	.31**	.37***	.23*
52	.07	.11	.05	-.02	-.06	.23*	-.01	-.02	.11	.16
53	.07	.17	.04	.17	.17	.28*	.18	.10	.42***	.37**
54	.24*	-.21	.14	.21	.29*	.31**	.02	.32**	.09	.29*

55	.22	-.01	.10	.20	.32**	.41***	.13	.13	.44***	.40**
56	.22	.03	.21	.38***	.36**	.29*	.29*	.24*	.24*	.23*
57	.21	.03	.30*	.25*	.33**	.28*	.29*	.05	.11	.10
58	-.09	-.09	-.08	-.02	.01	-.05	.14	-.17	.13	-.10
59	.25*	.04	.36**	.21	.31**	.19	.35**	.25*	.27*	.13
60	.24*	-.11	.06	.42***	.34**	.33**	.14	.29*	.35**	.31**
61	.04	-.03	-.04	.21	.23*	.22	.08	.27*	.39***	.29*
62	.31**	-.11	.09	.16	.32**	.30*	.03	.26*	.26*	.22
63	.14	.02	-.04	.33**	.18	.17	.10	.16	.32**	.17
64	.24*	-.14	.06	.21	.31**	.26*	.01	.27*	.38***	.31**
65	.23*	-.10	.13	.53***	.43***	.30*	.27*	.30*	.35**	.25*
66	.07	.03	-.10	.30**	.22	.19	.14	.15	.28*	.19

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## (ii) Items 11-20

	11	12	13	14	15	16	17	18	19	20
12	.49***									
13	.45***	.52***								
14	.29*	.35**	.24*							
15	.27*	.41***	.27*	.83***						
16	.30*	.39***	.34**	.61***	.64***					
17	.01	.37***	.38***	.25*	.27*	.36**				
18	.30**	.37***	.45***	.36**	.32**	.40***	.28*			
19	.25*	.32**	.24*	.40***	.43***	.35**	.17	.46***		
20	.19	.34**	.36**	.13	.18	.26*	.46***	.27*	.32**	
21	.28*	.17	.35**	.47***	.40***	.42***	.12	.55***	.40***	.04
22	.32**	.36**	.25*	.27*	.19	.28*	.26*	.51***	.32**	.28*
23	.17	.20	.25*	.27*	.36**	.34**	.22	.48***	.27*	.01
24	.18	.45***	.26*	.22	.21	.23*	.41***	.13	.20	.50**
25	.13	.12	.31**	.13	.08	.25*	.26*	.06	.18	.24*
26	.34**	.34**	.28*	.33**	.40***	.26*	.09	.38***	.51***	.36**
27	.20	.25*	.41***	.18	.19	.26*	.36**	.31**	.38***	.46**
28	.18	.21	.22	.18	.15	.22	.16	.55***	.26*	.04
29	.26*	.25*	.36**	.40***	.36**	.18	.20	.38***	.42***	.21
30	.26*	.24*	.34**	.35**	.31**	.22	.12	.47***	.40***	.19
31	.30**	.47***	.48***	.16	.29*	.26*	.24*	.29*	.26*	.26*
32	.29*	.51***	.46***	.28*	.31**	.40***	.52***	.41***	.45***	.43**
33	-.04	.14	-.00	-.08	-.01	-.02	-.04	-.12	-.07	-.03
34	.19	.43***	.34**	.15	.21	.21	.18	.09	.27*	.26*
35	.25*	.42***	.56***	.30**	.32**	.23*	.44***	.31**	.19	.35**
36	.25*	.28*	.31**	.03	.13	.12	.24*	.12	.04	.15
37	.29*	.39***	.39***	.35**	.26*	.38***	.20	.47***	.32**	.30**

38	.41***	.42***	.44***	.29*	.27*	.49***	.27*	.55***	.30**	.33**
39	.13	.22	.48***	.22	.28*	.25*	.41***	.35**	.17	.29*
40	.33**	.26*	.44***	.20	.25*	.20	.21	.30*	.44***	.38**
41	.30**	.37***	.57***	.35**	.34**	.34**	.37***	.29*	.17	.28*
42	.26*	.39***	.44***	.17	.12	.26*	.33**	.36**	.20	.43**
43	.20	.34**	.28*	.25*	.34**	.49***	.44***	.24*	.22	.37**
44	.28*	.39***	.39***	.18	.30**	.40***	.35**	.19	.21	.45**
45	.36**	.47***	.50***	.27*	.21	.26*	.25*	.43***	.15	.37**
46	.24*	.28*	.29*	.14	.10	.18	.10	.29*	.11	.34**
47	.29*	.34**	.34**	.07	.06	.19	.20	.45***	.42***	.31**
48	.20	.27*	.21	.11	.02	.09	.16	.26*	.14	.20
49	.35**	.19	.17	.19	.09	.09	-.04	.15	.24*	.25*
50	.32**	.32**	.27*	.37***	.29*	.48***	.21	.45***	.47***	.34**
51	.24*	.22	.21	.20	.25*	.32**	.09	.42***	.54***	.44**
52	.04	.11	.16	-.02	.07	.18	.17	.01	-.00	.25*
53	.23*	.27*	.29*	.04	.06	.24*	.22	.13	.23	.37**
54	.21	.31**	.24*	.29*	.39***	.42***	.01	.29*	.21	.20
55	.31**	.35**	.36**	-.00	-.01	.13	.16	.11	.21	.32**
56	.24*	.32**	.16	.14	.13	.24*	.12	.22	.40***	.32**
57	.25*	.16	.15	.05	.11	.20	-.02	.17	.23*	.16
58	-.06	-.07	-.10	-.27*	-.24*	-.07	.02	-.06	.03	.26*
59	.29*	.27*	.11	.19	.11	.17	.09	.33**	.25*	.20
60	.38***	.39***	.25*	.40***	.38***	.43***	.27*	.38***	.46***	.44**
61	.21	.25*	.23	.07	.06	.04	-.05	.20	.24*	.13
62	.34**	.31**	.28*	.04	.05	.05	.07	.29*	.03	.09
63	.23	.27*	.23*	.16	.19	.19	.33**	.29*	.32**	.46**
64	.33**	.35**	.34**	.08	.15	.11	.27*	.37***	.26*	.35**
65	.33**	.38***	.25*	.26*	.27*	.33**	.16	.36**	.55***	.42**

66	.30**	.31**	.13	.29*	.25*	.23*	.07	.20	.33**	.25*
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## (iii) Items 21-30

	21	22	23	24	25	26	27	28	29	30
22	.40***									
23	.47***	.53***								
24	.08	.35**	.16							
25	.05	.18	-.03	.33**						
26	.39***	.34**	.26*	.38***	.08					
27	.30*	.20	.24*	.24*	.41***	.37***				
28	.66***	.48***	.58***	.13	.04	.23*	.26*			
29	.48***	.42***	.29*	.35**	.30*	.32**	.40***	.42***		
30	.69***	.37***	.40***	.12	.13	.50***	.39***	.56***	.44***	
31	.23*	.35**	.21	.29*	.17	.46***	.41***	.28*	.36**	.22
32	.25*	.55***	.26*	.46***	.35**	.44***	.44***	.24*	.48***	.33**
33	-.11	.03	-.06	.11	.21	.02	.02	-.04	.20	-.12
34	.20	.47***	.19	.35**	.33**	.34**	.32**	.28*	.31**	.21
35	.40***	.28*	.26*	.35**	.26*	.31**	.31**	.28*	.32**	.36**
36	-.04	.23*	.24*	.36**	.34**	.17	.08	.09	.18	-.08
37	.38***	.52***	.29*	.30*	.23	.36**	.32**	.42***	.41***	.33**
38	.35**	.43***	.23*	.28*	.21	.46***	.38***	.34**	.38***	.35**
39	.29*	.35**	.41***	.28*	.22	.27*	.38***	.27*	.27*	.37**
40	.23*	.34**	.36**	.19	.07	.36**	.23	.22	.28*	.25*
41	.31**	.34**	.34**	.43***	.23	.32**	.21	.24*	.37***	.32**
42	.16	.47***	.34**	.38***	.22	.27*	.27*	.23*	.14	.22
43	-.01	.34**	.26*	.45***	.20	.20	.21	.06	.16	-.02
44	-.01	.35**	.32**	.32**	.31**	.12	.22	.19	.18	.06
45	.22	.43***	.31**	.21	.19	.15	.16	.34**	.19	.20

46	.24*	.36**	.47***	.22	.18	.12	.21	.41***	.15	.25*
47	.35**	.23	.06	.07	-.06	.27*	.29*	.22	.23*	.19
48	.15	.33**	.18	.14	.05	.02	.07	.24*	.14	.02
49	.13	.33**	.09	.16	.16	.23	.14	.10	.26*	.19
50	.36**	.55***	.29*	.34**	.27*	.41***	.31**	.30*	.32**	.21
51	.22	.33**	.19	.19	.10	.58***	.26*	.21	.10	.24*
52	-.07	-.01	-.04	.28*	.17	.27*	.28*	-.03	-.01	-.02
53	-.11	.15	-.06	.24*	.27*	.14	.30*	-.06	.11	-.05
54	.31**	.27*	.30**	.30**	.05	.44***	.21	.27*	.27*	.21
55	-.01	.21	.04	.25*	.17	.18	.08	-.03	.09	-.05
56	.05	.40***	.12	.33**	.07	.21	.23*	.13	.26*	-.08
57	.22	.41***	.34**	.21	.07	.16	.21	.33**	.27*	.09
58	-.22	-.07	-.17	.02	-.02	-.03	-.09	-.20	-.17	-.31*
59	.26*	.32**	.20	.23*	-.03	.19	.08	.28*	.29*	.08
60	.27*	.52***	.18	.53***	.26*	.54***	.23*	.26*	.40***	.24*
61	-.02	.28*	.15	.26*	.07	.23*	-.00	.08	.20	.12
62	.03	.23*	.10	.17	.08	.11	-.02	.15	.25*	-.05
63	-.11	.31**	.12	.39***	.19	.26*	.27*	.01	.17	-.01
64	.14	.27*	.08	.32**	.05	.36**	.14	.15	.33**	.15
65	.15	.45***	.15	.45***	.11	.41***	.27*	.06	.29*	.10
66	.05	.46***	.21	.49***	.22	.23	.13	.09	.23*	.12

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## (iv) Items 31-40

	31	32	33	34	35	36	37	38	39	40
32	.56***									
33	.24*	.18								
34	.63***	.62***	.27*							
35	.46***	.42***	.19	.34**						
36	.21	.22	.29*	.17	.39***					
37	.35**	.44***	.04	.39***	.27*	.21				
38	.38***	.55***	.08	.45***	.29*	.17	.66***			
39	.44***	.37***	.11	.40***	.58***	.29*	.33**	.35**		
40	.33**	.38***	-.05	.19	.32**	.11	.34**	.10	.36**	
41	.37***	.42***	.09	.37***	.52***	.46***	.38***	.36**	.65***	.42**
42	.48***	.50***	-.09	.43***	.39***	.25*	.31**	.36**	.51***	.42**
43	.33**	.46***	.08	.29*	.22	.26*	.36**	.35**	.29*	.32**
44	.43***	.42***	.12	.45***	.25*	.41***	.39***	.29*	.40***	.41**
45	.30**	.34**	-.08	.29*	.42***	.20	.32**	.23*	.32**	.47**
46	.14	.21	-.08	.20	.37***	.29*	.26*	.18	.10	.30**
47	.22	.46***	.07	.17	.20	.02	.29*	.43***	.05	.31**
48	.14	.20	-.06	.13	.23	.21	.14	.08	-.01	.20
49	.17	.38***	-.09	.27*	.07	.20	.14	.25*	.00	.08
50	.28*	.51***	.06	.45***	.36**	.34**	.48***	.58***	.17	.07
51	.32**	.38***	-.07	.31**	.12	.18	.25*	.41***	.15	.29*
52	.33**	.28*	.32**	.27*	.30*	.33**	.05	.22	.21	-.01
53	.26*	.42***	.27*	.27*	.08	.32**	.20	.33**	.11	.27*
54	.29*	.28*	.11	.32**	.37***	.38***	.28*	.37***	.25*	.08
55	.25*	.29*	.04	.24*	.35**	.54***	.08	.16	.13	.17
56	.22	.30**	.11	.20	.04	.26*	.31**	.32**	.04	.22
57	.34**	.22	-.07	.31**	.10	.25*	.39***	.27*	.13	.23*



58	-.19	-.08	-.05	-.19	-.07	.14	-.26*	-.07	-.16	-.03
59	.17	.39***	-.02	.17	.13	.03	.20	.24*	-.03	.19
60	.32**	.63***	.05	.35**	.31**	.27*	.38***	.47***	.22	.23*
61	.10	.32**	-.02	.19	.15	.17	.19	.22	.16	.20
62	.08	.18	.09	.10	.21	.26*	.27*	.32**	-.01	.12
63	.14	.40***	-.04	.16	.18	.48***	.31**	.28*	.20	.21
64	.29*	.50***	-.00	.21	.19	.31**	.38***	.40***	.16	.31**
65	.26*	.53***	-.05	.34**	.16	.19	.39***	.31**	.15	.29*
66	.11	.32**	.06	.30**	.10	.27*	.26*	.14	.12	.19

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## (v) Items 41-50

	41	42	43	44	45	46	47	48	49	50
42	.58***									
43	.41***	.36**								
44	.48***	.54***	.69***							
45	.49***	.64***	.31**	.49***						
46	.32**	.55***	.14	.35**	.71***					
47	.08	.21	.20	.02	.17	.09				
48	.26*	.31**	.18	.20	.58***	.50***	.20			
49	.14	.36**	.14	.26*	.30**	.28*	.29*	.31**		
50	.33**	.43***	.41***	.34**	.31**	.39***	.39***	.24*	.42***	
51	.22	.33**	.22	.27*	.26*	.27*	.41***	.15	.39***	.53**
52	.24*	.11	.41***	.26*	.06	.05	.14	.08	.04	.23*
53	.10	.27*	.35**	.31**	.14	.05	.35**	.09	.30*	.25*
54	.41***	.22	.28*	.19	.19	.29*	.05	.16	.08	.44**
55	.34**	.47***	.27*	.38***	.35**	.36**	.21	.40***	.35**	.35**
56	.08	.23*	.31**	.29*	.26*	.17	.27*	.31**	.26*	.39**
57	.17	.25*	.34**	.50***	.30*	.33**	.03	.20	.27*	.30*
58	-.17	.06	-.03	-.05	.06	.22	.09	.08	.09	.07
59	.13	.22	.26*	.18	.44***	.30**	.40***	.48***	.41***	.40**
60	.30**	.38***	.28*	.19	.31**	.25*	.32**	.25*	.48***	.57**
61	.29*	.49***	.15	.19	.39***	.36**	.14	.24*	.52***	.33**
62	.18	.26*	.10	.03	.33**	.30**	.21	.28*	.17	.32**
63	.32**	.34**	.43***	.50***	.23*	.21	.13	.33**	.32**	.43**
64	.30**	.32**	.31**	.29*	.23*	.17	.33**	.31**	.34**	.26*
65	.23	.31**	.32**	.30**	.36**	.26*	.31**	.33**	.32**	.52**
66	.19	.26*	.24*	.23	.22	.27*	.07	.19	.25*	.36**

## (vi) Items 51-60

	51	52	53	54	55	56	57	58	59	60
52	.33**									
53	.32**	.34**								
54	.39***	.42***	.13							
55	.32**	.31**	.29*	.39***						
56	.39***	.20	.53***	.23	.32**					
57	.28*	.14	.22	.22	.28*	.50***				
58	.20	.11	.09	-.00	.37***	.20	.02			
59	.20	.00	.00	.08	.04	.34**	.21	.01		
60	.49***	.18	.31**	.40***	.33**	.41***	.21	.13	.34**	
61	.17	.01	.21	.20	.33**	.20	.20	.11	.22	.55**
62	.11	.14	.17	.25*	.28*	.25*	.11	.23	.11	.34**
63	.40***	.34**	.47***	.17	.37***	.50***	.32**	.17	.18	.36**
64	.25*	.09	.35**	.16	.31**	.37***	.34**	.09	.34**	.53**
65	.51***	.17	.33**	.30*	.30**	.59***	.43***	.11	.42***	.57**
66	.32**	.14	.42***	.21	.23*	.40***	.28*	.09	.03	.52**

## (vii) Items 61-66

	61	62	63	64	65
62	.40***				
63	.25*	.29*			
64	.41***	.42***	.51***		
65	.42***	.16	.58***	.43***	
66	.42***	.32**	.55***	.27*	.65***

\* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$

5.3.2.3 Principal components analysis. Table 5.5 presents the findings of a principal components analysis and identifies items belonging to the common factor or underlying construct of positivity in illness. Fifty-nine items received a factor loading of .40 and above, which, as a general rule (for example, Cooper, 1998) is indicative of a high factor loading and, in this case, implies that the item is a good discriminator of positivity. The lower factor loadings of the remaining seven items (items 2, 7, 25, 33, 52, 58, and 62) suggest that these items may be tapping into different constructs.

Table 5.5. Factor loadings from a principal components analysis

Item	Factor loading
1	.56
2	-.00
3	.40
4	.55
5	.60
6	.59
7	.28
8	.48
9	.61
10	.60
11	.55
12	.66
13	.66
14	.48
15	.48
16	.54
17	.41
18	.64
19	.59
20	.55
21	.49
22	.66
23	.46
24	.51
25	.33
26	.59

27	.49
28	.46
29	.55
30	.45
31	.58
32	.74
33	.07
34	.55
35	.56
36	.42
37	.64
38	.65
39	.48
40	.54
41	.62
42	.64
43	.52
44	.56
45	.63
46	.50
47	.48
48	.42
49	.44
50	.69
51	.57
52	.28
53	.43
54	.50

55	.48
56	.51
57	.45
58	-.03
59	.43
60	.69
61	.43
62	.37
63	.53
64	.55
65	.64
66	.47

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5.3.2.4 Summary. Three techniques of evaluating items were carried out - item distributions, inter-item correlations and a principal components analysis. The patterns of responses to individual items revealed, as anticipated, a bias towards the agree response which was particularly pronounced for 21 items. Eight items received negative endorsements most frequently and only six items, in particular those referring to positive consequences for others, attracted the not sure response most frequently. Missing responses were particularly infrequent; the largest number of missing responses for any one item was four. The inter-item correlations identified a large number of high correlations. Correlations were particularly prominent for items within the same category of positive consequence. Finally, a principal components analysis resulted in the majority of items correlating with the general underlying construct of positivity with only seven items receiving low factor loadings.

The following section describes refinements to the questionnaire and refers to the above findings and the comments volunteered by respondents.

5.3.3 Questionnaire refinements

Modifications to the SLQ include the removal of items, simplification of instructions, and an alternative format for responses. The refined SLQ is presented in Appendix 9.

5.3.3.1 Items removed. The following criteria for the removal of items were employed:

- (i) Response distributions indicative of poor discriminatory power, in particular, those with a high percentage of agree responses (exceeding 70%), a mean close to 1, and a variance close to 0;
- (ii) Factor loadings falling below .40 indicating that an item does not belong to the same construct and as the other items;
- (iii) High inter-item correlations ( $r > .80$ ) implying overlap of content between items and therefore redundancy;
- (iv) Substantial overlap in content of items though not meeting criterion (iii) in which case, the items with the highest factor loading is retained.

Note. Criterion (iii) refers to an overlap of content of two ‘good’ items, while criterion (iv) refers to an overlap in content between one ‘good’ and one ‘bad’ item.

In addition, several respondents commented on the content of items, in particular that they appeared negative in their orientation.

Twenty-eight items satisfied at least one of the above criteria and were thus removed from the questionnaire. At least one item from each category of positive consequence was removed with the exception of the confrontation of current concerns category. All of the items within the following five domains were removed: change in priorities, relief from responsibilities, acquisition of knowledge, perception of illness as a challenge to overcome, and resolution of past concerns. Table 5.6 presents all of the items that were removed together with a justification for their removal.



Table 5.6. Items removed from the SLQ

Item	Reason for removal
2. My illness made me realise that things can wait until tomorrow	Poor discriminator of responses (73.6% agree), low factor loading (-.00)
3. My illness encouraged me to lead a healthier way of life	Poor discriminator (76.9% agree), factor loading of .40
6. My illness changed my priorities in life	Poor discriminator (83.5% agree)
7. My illness gave me an excuse to give up things I did not want to do	Low factor loading (.28)
9. My illness made me step back and appreciate simple pleasures	Poor discriminator (84.5% agree), substantial overlap of content with item 12 ('My illness made me think about the true purpose of life'), lower factor loading (.61) than item 12 (.66)
10. My illness made me weigh up my life	Poor discriminator (76.9% agree), substantial overlap of content with item 12 ('My illness made me think about the true purpose of life'), lower factor loading (.60) than item 12 (.66)
13. My illness changed my outlook on life	Poor discriminator (78.0% agree)

15. My illness made me re-evaluate my religious / spiritual beliefs	Overlap of content with item 14 ('My religious / spiritual beliefs deepened because of my illness') ( $r=.83$ )
17. I am not the same person I was before my illness	Poor discriminator (71.4% agree), identified by respondents as difficult to answer
20. Due to my illness I accept that I am who I am	Poor discriminator (72.5% agree)
25. My illness made me focus more on myself	Low factor loading (.33)
28. I am a more patient person because of my illness	Substantial overlap of content with item 23 ('My illness made me a more tolerant person'), identical factor loadings (.46)
30. I am a more easy going person because of my illness	Substantial overlap of content with item 21 ('I am calmer person because of my illness'), lower factor loading (.45) than item 21 (.49)
33. My illness made me more aware of my body	Poor discriminator (79.1% agree), low factor loading (.07)
35. My illness has been a real learning experience	Poor discriminator (79.1% agree), identified by respondents as not necessarily representing a positive item

36. My illness gave me a lot of practical information	Poor discriminator (72.5% agree)
38. My illness led me up paths I never dreamt possible	Substantial overlap of content with item 37 ('Through my illness I discovered a talent I didn't know I had'), similar factor loadings (.64 and .65 for items 37 and 38 respectively)
39. My illness has been a challenge	Poor discriminator (79.1% agree), substantial overlap of content with item 41 ('My illness encouraged me to reflect on how I feel about myself', lower factor loading (.48) than item 41 (.62)
42. My illness brought me face to face with how I feel for others	Poor discriminator (72.5% agree)
43. My illness made me dig up past concerns and deal with them	Substantial overlap of content with item 44 ('My illness made me face up to problem areas of my life'), lower factor loading (.52) than item 44 (.56)
45. I appreciate other people more because of my illness	Poor discriminator (82.4% agree)
48. I now have more sympathy for others because of my illness	Poor discriminator (80.2% agree)

49. Due to my illness I have more to offer other people	Poor discriminator (75.8% agree)
52. My illness made me appreciate the value of seeking help from others	Poor discriminator (75.8% agree), low factor loading (.28)
55. My illness made me aware of my true friends	Poor discriminator (82.4% agree)
58. My illness made me realise how supportive other people can be	Poor discriminator (85.7% agree), low factor loading (-.03)
61. My illness has been an eye opener for others	Substantial overlap of content with item 60 ('I have been an inspiration to others'), lower factor loading (.43) than item 60 (.69), identified by respondents as not necessarily representing a positive item
62. Other people have gained skills and knowledge from my illness	Low factor loading (.37)

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The refined questionnaire includes 38 items sampling 10 categories of positive consequence. For brevity, the questionnaire includes only two demographic items measuring sex and age.

5.3.3.2 Modifications to response options. The format for responses was modified from a three-point scale to a five-point Likert-type scale (Likert, 1932) with end-point anchors of strongly agree (5) and strongly disagree (1) and a neutral option of not sure. The three-point scale is restricted in the variability of responses it elicits as reflected in the item distributions and variances displayed in Table 5.3. In addition to encouraging greater variability in responses, it was anticipated that the

modified response format would limit missing responses. Finally, one participant expressed a preference for a five-point scale.

**5.3.3.3 Summary.** Refinements to the SLQ resulted in a 38-item scale measuring 10 of the categories of positivity in illness identified in study 1. These items displayed good inter-item correlations, favourable factor loadings, and produced distributions which were not biased heavily towards the agree response. In addition to the removal of items, the questionnaire was modified with respect to the format of response options with the three-point scale replaced by a five-point Likert-type scale.

#### **5.4      *Conclusion***

The overall objective of this chapter was to produce a measure of the positive consequences of illness that is more comprehensive compared with existing methodologies. The pilot questionnaire included 66 items generated from the accounts of positivity provided by participants of study 1. This questionnaire was completed by 91 participants including individuals not selected on the basis of a reported positive orientation towards illness. Responses to individual items were evaluated with respect to distributions, inter-item correlations and factor loadings from a principal components analysis. These evaluations led to the removal of 28 items. The resulting refined questionnaire includes 38 items.

Further tests of the psychometric properties of these items, namely reliability and validity, will be performed in studies 3 and 4 (chapters 6 and 7 respectively). Issues regarding the prevalence and determinants of positivity also fall beyond the scope of this chapter and will be the concern of chapter 8.

## CHAPTER 6

### STUDY 3: PSYCHOMETRIC PROPERTIES OF THE SLQ

#### (I) RELIABILITY AND SENSITIVITY TO CHANGE

“The illnesses were what gave me a boot in the right direction”  
(53 year old female with CFS)

##### 6.1 *Introduction*

In order for the refined version of the SLQ to be presented as a psychometrically sound measure, reliability and validity need to be established. A further important attribute of evaluative instruments is responsiveness to change (Guyatt, Walter, & Geoff, 1987).

##### 6.1.1 Aims of the study

This first study of the psychometric attributes of the SLQ focuses specifically on:

- \* Reliability in terms of the ability of the SLQ to yield consistent responses upon repeated administrations and to offer internally consistent or homogeneous items;
- \* Responsiveness in terms of the ability of the SLQ to detect minimal clinically important differences following an intervention;

##### 6.2 *Method*

In order to investigate reliability and responsiveness, the SLQ was administered on two occasions to three samples of patients: one control and two intervention samples.

##### 6.2.1 Characteristics of the samples

This study represents an audit of patients who completed the SLQ as part of normal clinical procedure. Patients were not pre-selected according to the criterion of reported positivity to illness. Patients were recruited opportunistically from two rehabilitation outpatient

programmes, pulmonary and cardiac, run by Glenfield Hospital, Leicester, UK. Recruitment took place over a 9-month period. Rehabilitation is not offered to all pulmonary patients. Patients either with insufficient disability or too great disability are not normally included, nor are patients who seem disinterested in self-help. On referral to pulmonary rehabilitation, patients are assessed for suitability with respect to anticipated benefit and those accepted for rehabilitation are placed on a waiting list for approximately 7 weeks.

Three groups of patients were included in this study:

- (i) Control. The control sample included 10 males and 10 females with a mean (standard deviation) age of 69.35 (7.25) years. The patients in this sample had been diagnosed with COPD and were on the waiting list for pulmonary rehabilitation.
- (ii) Pulmonary rehabilitation. In the pulmonary rehabilitation sample, there were 35 COPD patients, 23 males, 12 females, mean (standard deviation) age 67.03 (8.92) years. Patients in this sample were participating in a pulmonary rehabilitation programme.
- (iii) Cardiac rehabilitation. There were 23 males and 6 females in the cardiac rehabilitation sample, mean (standard deviation) age 60.25 (9.50) years. Seventeen patients had had a coronary artery bypass graft, seven a myocardial infarction and five a valve replacement. Patients in this sample were receiving cardiac rehabilitation.

### 6.2.2 Rehabilitation programmes

The rehabilitation programmes were outpatient based and included groups of up to eight patients. Rehabilitation was offered twice weekly for two hours and included one hour of exercise and one hour of education. The main component of the exercise training was aerobic walking. Patients were also provided with an individualised home exercise programme requiring periods of walking. The educational component included practical demonstrations and discussions with health professionals including a doctor, nurse, physiotherapist, occupational therapist, dietician, and a benefits advisor. The cardiac and pulmonary rehabilitation programmes differed in terms of their length: the cardiac programme lasted for 6 weeks and the pulmonary rehabilitation was of 7 weeks duration. In addition, the cardiac programme placed greater emphasis on stress

management, and in the pulmonary programme patients had the opportunity to meet a representative from a patient self-help group ('Breathe-Easy'). The drop-out rates (i.e., patients who initially agreed to take part, but did not complete the entire course) for the programmes were 13% for the pulmonary and 12% for the cardiac programme.

### 6.2.3 Procedure

All patients who agreed to undertake rehabilitation simultaneously agreed to complete the rehabilitation assessments. All patients completed the SLQ on two occasions. Members of the control sample completed the SLQ on admission to the waiting list for pulmonary rehabilitation and 7 weeks later at the start of rehabilitation. The two rehabilitation samples (cardiac and pulmonary) completed the SLQ at the start of rehabilitation and 6 or 7 weeks later at the end of rehabilitation.

### 6.2.4 Scoring the SLQ

Responses to individual SLQ items were assigned the following scores (shown in parentheses): 'Strongly agree' (5); 'Agree' (4); 'Not sure' (3); 'Disagree' (2); 'Strongly disagree' (1). Thus, a high value corresponds to a high degree of positivity. To obtain an overall score of positivity, a bi-modal scoring system was used with responses 'Strongly agree' and 'Agree' coded as '1' and all other response options as '0'. This simplified scoring procedure is designed to avoid response bias between patients in endorsing 'Strongly agree' and 'Agree' response options. The total score therefore reflects the total number of items that the patient agrees with, (i.e., the total number of positive consequences of illness experienced) and ranges between 0 (low positivity; agreement with none of the items), and 38 (high positivity; agreement at some level with all items).

### 6.2.5 Psychometric tests

Data from patients completing the SLQ on both occasions (either on entrance and exit from the waiting list or at the beginning and end of rehabilitation) were analysed. The following tests of the psychometric properties of the SLQ were performed.



(i) Test-retest reliability. Pearson product moment correlations were performed on the total SLQ scores of the control patients on admission and exit from the waiting list. The lowest acceptable values for test-retest reliability are cited as 0.75 to 0.80 (for example, Coolican, 1990).

Correlations were also carried out on the pre- and post-rehabilitation scores of the rehabilitation samples.

(ii) Internal consistency. Cronbach's alpha was calculated for each of the three samples using the responses to individual items at the first assessment (i.e., admission to the waiting list and pre-rehabilitation). A widely applied rule of thumb states that alpha should be at least .70 for reliability to be deemed satisfactory (for example, Lowenthal, 1996).

(iii) Responsiveness to change. T-tests were used to compare total SLQ values for the two administrations of the questionnaire. Significance was set at  $p < .05$ . The effect size or magnitude of change of each measure was calculated by dividing the mean change score by the standard deviation of scores at the first assessment. Cohen (1988) defined effect sizes of 0.2 and below as small, 0.5 as moderate and 0.8 and above as large.

Patterns of change in responses to individual items (i.e., increased, decreased or no change in endorsement) were also examined. Change scores were calculated by subtracting the overall SLQ score on admission to the waiting list from the pre-rehabilitation score (in the case of the control sample) and the pre-rehabilitation score from the post-rehabilitation score (in the case of the rehabilitation samples).

Finally, the degree of change was compared across patients in order to determine whether certain patients improve more than others.

## 6.3 *Results*

### 6.3.1 Test-retest reliability

The correlation between the two assessments for the control condition was  $r(20) = .90$  ( $p < .001$ ) suggesting a high re-test reliability. This coefficient exceeds the coefficients obtained for the pulmonary and cardiac rehabilitation samples with  $r(35) = .69$  ( $p < .001$ ) and  $r(29) = .71$  ( $p < .001$ ) respectively.

### 6.3.2 Internal consistency

Using the data from the first assessment, Cronbach's alpha was .93 across all three samples suggesting a high level of homogeneity among the SLQ items.

### 6.3.3 Sensitivity to change

Table 6.1 displays the mean (standard deviation) total SLQ values and effect sizes for the three samples.

In the control condition, responses to the SLQ did not differ significantly between the two assessments,  $t(19) = 0.07$ ; *ns*, and the magnitude of change was low (0.12). However, there was a significant increase in the overall SLQ scores following the pulmonary rehabilitation programme,  $t(34) = 3.40$ ;  $p < .01$ , and cardiac rehabilitation programme,  $t(28) = 3.86$ ;  $p < .001$ , and the effect sizes were moderate (-0.49 and -0.69 respectively). On average, 2.86 additional positive consequences of illness were reported following pulmonary rehabilitation and 4.07 more after the cardiac rehabilitation programme. There was no significant difference between cardiac patients who had undergone surgery (bypass and valve replacement) and myocardial infarction patients in degree of change in SLQ scores,  $t(27) = 0.19$ ; *ns*.

Table 6.1. Changes in overall SLQ scores

Sample	Assessment	Mean	Standard deviation	<i>p</i> value	Effect size
Control (n=20)	Admission to the waiting list	11.00	7.82	.95	.12
	Exit from the waiting list	10.95	7.30		
Pulmonary rehabilitation (n=35)	Pre-rehabilitation	7.51	5.83	<.01	-.49
	Post-rehabilitation	10.37	6.63		
Cardiac rehabilitation (n=29)	Pre-rehabilitation	13.21	5.88	<.001	-.69
	Post-rehabilitation	17.28	8.10		

Patterns of change in endorsement of individual items were examined in the rehabilitation samples (total sample size of 64) where responses ‘Strongly agree’ and ‘Agree’ represented endorsement. Table 6.2 presents the items displaying a positive, negative and no change post-rehabilitation compared with pre-rehabilitation. Items are presented in descending order of their percentage change pre-rehabilitation to post-rehabilitation.

Thirty-three of the 38 items were endorsed more frequently at the end of rehabilitation. These items represent all of the 10 categories of positive consequence included in the SLQ. The item that displayed the largest percentage change (increase) in endorsement following rehabilitation was: ‘My illness gave me the opportunity to meet new people’ (48% to 77%), and is consistent with the social aspect of rehabilitation. Two further items from the improved interpersonal relationships domain of the SLQ which showed a large percentage increase in

endorsement at the end of rehabilitation are: 'My illness strengthened my relationships with others' (39% to 55%) and 'My illness made me more at ease with others' (25% to 41%). Several of the self-improvement items also improved substantially following rehabilitation, for example, the item 'My illness made me a more tolerant person' improved by 15% (23% to 38%), and an increased endorsement of 11% was noted for the item 'I became a happier person because of my illness' (3% to 14%). Finally, existential gains feature amongst several of the items improving post-rehabilitation implying that rehabilitation has the potential of prompting patients to reflect on the true value of life and on who they really are as people. Examples of such existential items are 'I appreciate life more because of my illness' (58% to 72%), 'My illness made me realise that I matter as a person' (36% to 48%), and 'My religious / spiritual beliefs deepened because of my illness' (22% to 28%).

Two of the three items showing no change post-rehabilitation were also existential in nature, these items are: 'My illness made me think about the true purpose of life' (52% pre- and post-rehabilitation) and 'My illness encouraged me to reflect on how I feel about myself' (44% pre- and post-rehabilitation). The item describing changes in others ('My illness changed other people for the better') also remained unchanged following rehabilitation (20% endorsement pre- and post-rehabilitation).

Finally, two further items describing perceptions of other people ('I see others in their true colours because of my illness') and the importance of their approval ('My illness made me less concerned with the approval of others') were endorsed less frequently at the end of rehabilitation (36% to 34% and 34% to 33% respectively).

Table 6.2. Change in percentage endorsement of items pre-rehabilitation to post-rehabilitation.

Direction of change*, percentage change	Item (percentage endorsement pre-rehabilitation, post- rehabilitation)
+ve, 29%	30. My illness gave me the opportunity to meet new people (48%, 77%)
+ve, 22%	17. My illness gave me permission to do things for myself (16%, 38%)
+ve, 18%	24. My illness made me face up to problem areas of my life (34%, 52%)
+ve, 16%	25. My illness strengthened my relationships with others (39%, 55%)
+ve, 16%	28. My illness made me more at ease with others (25%, 41%)
+ve, 15%	13. My illness made me a more tolerant person (23%, 38%)
+ve, 14%	1. I appreciate life more because of my illness (58%, 72%)

\* +ve: Positive, i.e., greater endorsement post-rehabilitation compared with pre-rehabilitation  
-ve: Negative, i.e., less endorsement post-rehabilitation compared with pre-rehabilitation  
0: No change pre-rehabilitation to post-rehabilitation

+ve, 13%	27. Because of my illness I have more to offer others (14%, 27%)
+ve, 13%	31. My illness taught me how to stand up for myself (25%, 38%)
+ve, 12%	14. My illness made me realise that I matter as a person (36%, 48%)
+ve, 11%	5. Because of my illness I find it easier to accept what life has in store (52%, 63%)
+ve, 11%	10. I became a happier person because of my illness (3%, 14%)
+ve, 11%	11. I am a calmer person because of my illness (30%, 41%)
+ve, 11%	34. I have been an inspiration to others (9%, 20%)
+ve, 11%	35. People can be more open with me since my illness (25%, 36%)
+ve, 10%	2. My illness gave me a new start in life (20%, 30%)

+ve, 10%	8. I am now more open to other religions because of my illness (6%, 16%)
+ve, 9%	38. Other people appreciate me more because of my illness (22%, 31%)
+ve, 8%	9. My illness made me a better person (14%, 22%)
+ve, 8%	12. My illness made me more mature (22%, 30%)
+ve, 8%	18. My illness made me a more determined person (39%, 47%)
+ve, 8%	20. My illness made me more aware of my strengths (36%, 44%)
+ve, 8%	32. My illness made me put an end to troublesome relationships (14%, 22%)
+ve, 7%	37. My illness changed other people's perception of me for the better (13%, 20%)

+ve, 6%	3. My life is much better now than it was before my illness (17%, 23%)
+ve, 6%	4. My illness has made me live life to its fullest (33%, 39%)
+ve, 6%	7. My religious / spiritual beliefs deepened because of my illness (22%, 28%)
+ve, 6%	19. My illness helped me find myself (16%, 22%)
+ve, 6%	22. I can face whatever is around the corner because of my illness (36%, 42%)
+ve, 5%	16. I am less concerned about failure because of my illness (34%, 39%)
+ve, 5%	33. My illness made me less judgmental of others (25%, 30%)
+ve, 4%	15. My illness gave me more confidence (16%, 20%)



+ve, 4%	21. Through my illness I discovered a talent I didn't know I had (2%, 6%)
-ve, 2%	29. I see others in their true colours because of my illness (36%, 34%)
-ve, 1%	26. My illness made me less concerned with the approval of others (34%, 33%)
0, 0%	6. My illness made me think about the true purpose of life (52%, 52%)
0, 0%	23. My illness encouraged me to reflect on how I feel about myself (44%, 44%)
0, 0%	36. My illness changed other people for the better (20%, 20%)

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6.3.4 Predictors of change

To examine the effects of age, gender, disease type and initial levels of positivity on degree of change in positivity amongst rehabilitation patients, a standard simultaneous multiple regression was performed with change in positivity as the dependent variable and age, gender, disease type and SLQ score at the first assessment as independent variables. The multiple regression showed that none of these variables were associated significantly with change in positivity (Table 6.3).

Table 6.3. Predictors of change in positivity

Predictor	Beta weight	Significance
Age	.06	.69
Gender	-.06	.66
Disease type	.20	.19
SLQ score at first assessment	-.17	.24

### 6.3.5 Summary

Evidence of consistency in SLQ responses over time was obtained using the data from the control patients who completed the SLQ on two occasions and who received no rehabilitation. The findings of this study also provide support for the homogeneity of the scale's items with Cronbach's alpha reaching .93 across all three samples. Finally, while positivity did not change for the patients on the waiting list, increased positivity following rehabilitation was observed in both the pulmonary and cardiac samples for the majority of the items including those of existential content.

## 6.4 Conclusion

This first study of the psychometric properties of the SLQ provides evidence for the scale's reliability and responsiveness to change. High internal consistency was confirmed across three different samples of patients. In addition, the measure produced consistent responses over time within a sample of patients who received no intervention. These reliability data are comparable to those provided for existing positive outcome measures (for example, the BFS, Cruess et al., 2000; PTGI, Tedeschi & Calhoun, 1996; and SRGS, Park et al., 1996). The finding that positivity was enhanced following rehabilitation implies that the scale is responsive to change and also replicates the work of Cruess et al. (2000) who used a cognitive behavioural stress management programme to enhance positivity amongst early stage breast cancer patients. As no change in positivity was observed in the control sample of patients, it cannot be argued that the

increase in positivity following rehabilitation is the consequence of exposure to a questionnaire on the subject. In addition, change in positivity was not predicted by age, gender, initial levels of positivity, or whether the patients had COPD or cardiac illness.

One cannot rule out the possibility that patients were more positive following rehabilitation as a way of expressing their gratitude to the rehabilitation staff. The issue of socially desirable / defensiveness response sets will be tested in study 5 (chapter 8). Further explanations for the increase in positivity following rehabilitation will be proposed in the discussion chapter.

Finally, this study does not offer any insight into the duration of the effect of rehabilitation on reported positivity.

The following chapter presents a further psychometric study that addresses the issue of positivity as a predictor of health outcome.

## CHAPTER 7

### STUDY 4: PSYCHOMETRIC PROPERTIES OF THE SLQ

#### (II) PREDICTIVE VALIDITY

“Life is a lot richer now”  
(33 year old recovering from chronic fatigue syndrome)

##### 7.1 *Introduction*

Perceiving positive consequences of illness can have important implications for psychological well-being (for example, Croog & Levine, 1982) as well as physiology (for example, Affleck et al., 1987; Cruess et al., 2000). This is one of the reasons why, as argued in chapter 2, the positive consequences of illness deserve attention. The focus of this study centres on the use of the SLQ as a predictor of outcome in CFS. No studies examining positivity in the context of CFS have been cited. However, 9% of the participants of study 1 presented CFS as an illness that had brought them something positive.

CFS, often referred to as post viral syndrome or myalgic encephalomyelitis (ME), is characterised by disabling fatigue and a heterogeneous pattern of other symptoms, such as muscle pain, muscle weakness, anxiety, depression, difficulty concentrating and dizziness (Hyland, paper submitted for publication), which are shared with other illnesses. Left untreated, outcome in CFS is poor with only 3% of patients spontaneously recovering at 18 months follow-up (Vercoulen, Swanink, Fennis, Galama, van der Meer, & Bleijenbergh, 1996). However, cognitive behavioural therapy, which involves reducing anxiety and engendering a positive orientation towards illness, has been found to be effective (Deale, Chalder, Marks, & Wessely, 1997; Sharpe, 1997).

### 7.1.1 Aim of the study

The overall aim of this study was to determine whether positivity in illness, as measured by the SLQ, predicts improvement in patients with CFS as determined by their perceptions of general health, with a focus on mood, and symptoms of physical and mental fatigue over a 6-month period.

## 7.2 *Method*

This study employed a longitudinal design with patients completing the SLQ and a measure of general health and fatigue over a 6 month period. Ethical approval to perform this study was granted by Southampton local ethics committee.

### 7.2.1 Sample recruitment

This study included patients who had been diagnosed by a medically qualified doctor with CFS (as defined by the US definition; Fakuda, Strauss, Hickie, Sharpe, Dobbins, & Komaroff, 1994) within the last 18 months (although symptoms may have been present for longer). Patients were recruited from the database held at the Centre for the Study of Complementary Medicine at Southampton. All patients had visited the clinic for a 15-minute consultation to receive homeopathic medicine. In order to satisfy the entry criteria for the study, patients had to be aged between 18 and 60 years as it was felt that below the age of 18, patients' level of insight into how their illness has affected them, for example, existentially, might be limited. Patients beyond the age of 60 are more likely to have a concurrent illness (an exclusion criterion) that may affect completion of the SLQ, and these patients are also less likely to improve. To be included in the study, patients also had to satisfy symptomatic criteria, for example, impaired memory or concentration, sore throat, unrefreshing sleep, and muscle pain (table 7.1) with four or more of the seven symptoms present concurrently for 6 months or more (as required by the US definition of CFS). The number and percentage of patients presenting each of these symptomatic criteria are shown in table 7.1. Finally, written consent was required from all patients. Recruitment took place over a 15-month period.

Table 7.1. Symptomatic criteria for entry into the study (N=72)

Symptom	Frequency of patients presenting symptom	Percentage
Impaired memory / concentration	69	95.8
Sore throat	53	73.6
Tender nodes	45	62.5
Muscle pain	57	79.2
Multi-joint pain	48	66.7
New headaches	46	63.9
Unrefreshing sleep	67	93.1
Post-exertion malaise	62	86.1

A total of 72 patients were recruited. The sample included 52 (72.2%) females and 20 (27.8%) males. Patients were aged between 18 and 59 years and had a mean (standard deviation) age of 36.99 (11.94).

### 7.2.2 Assessments

Patients completed two questionnaires, one measuring their experience of positive consequences of illness and the other measuring fatigue as well as perceptions of general health (mood).

7.2.2.1 The SLQ. Patients completed the refined 38-item SLQ (Appendix 9). In order to calculate a total score of positivity, a bi-modal scoring system was used (see chapter 2) resulting in a maximum possible score of 38.

7.2.2.2 Health and Fatigue Questionnaire. The Health and Fatigue Questionnaire combines an assessment of physical and mental fatigue with a measure of general health (Appendix 10).

(a) The Fatigue Questionnaire (Chalder et al., 1993). Items in the Fatigue Questionnaire were generated specifically to reflect physical and mental fatigue. The measure is particularly sensitive to the problems experienced by CFS patients however, it does not include items that are associated with CFS but not related specifically to fatigue. The refined version of the Fatigue Questionnaire includes 11 items; the first seven measure physical fatigue and form a physical fatigue sub-scale and the remaining four measure mental fatigue and comprise a mental fatigue sub-scale. All items are framed negatively.

The questionnaire used in this study represents the most current version of the questionnaire (communication with the author) and differs from the original version with respect to three items: (i) the item "Are you lacking energy?" was re-worded to read: "Do you lack energy?"; (ii) the item "Do you have problems thinking clearly?" was removed in the current version; (iii) the questionnaire used in this study includes an item that was removed from the original scale in the process of refinement: "Do you find it more difficult to find the correct word?" In addition to the 11 fatigue items, the fatigue section of the Health and Fatigue Questionnaire also included two items measuring muscle pain, one item assessing the duration of fatigue and one the percentage of time the patient has felt tired. Finally, patients are asked to volunteer at least one reason why they feel tired.

Patients are asked to evaluate their symptom status within the last month and responses are made on a four-point scale. For the fatigue and muscle pain items, response options lay along a continuum of "Better" / "Less than usual" to "Much worse than usual". The response options for the duration of fatigue item are made on a scale between "Less than 1 week" and "6 months or more", and patients use a scale between "25% of the time" and "All the time" to describe the percentage of time they have felt tired. Endorsement of end options represents poorer fatigue.

A total fatigue score can be calculated by summing all of the 11 fatigue items. In addition, the first seven items can be added together to derive a physical fatigue score and the last four can be added to obtain a mental fatigue score. Finally, a muscle pain score was calculated from the summation of the two muscle pain items and the duration of tiredness and percentage of time tired treated separately. There are two options for scoring the individual items of the Fatigue

Questionnaire and the method selected can depend on the purpose to which the scale is being used. The bi-modal method was used in the original publication of the scale (Chalder et al., 1993) and has the advantage of eliminating errors due to end-users and middle-users. This method is used to identify caseness. The maximum possible total fatigue score using the bi-modal is 11, with a score of four or more indicating severe fatigue and a score of four or more for 6 months or more indicating chronic fatigue. The alternative multiple-response or Likert method involves the assignment of weights to each response option and is a more appropriate method for examining the distribution of scores and for identifying change in fatigue over time. A maximum possible total score using this method, representing the greatest degree of fatigue, is 33. Given the objective of this study to identify change in fatigue over time, the latter method of scoring was favoured.

(b) The General Health Questionnaire (GHQ-12; Goldberg & Williams, 1988). The short form 12-item version of the GHQ formed the second part of the Health and Fatigue Questionnaire. The GHQ-12 asks patients to evaluate how their mood has been in general over the past few weeks. The GHQ was designed as a psychiatric screening tool. Six of the items are framed positively and six negatively. Responses are made on a four-point scale similar to the one used in the Fatigue Questionnaire. Responses towards the end of the continuum represent poorer health. As with the fatigue section items, responses to the general health items can be treated as a Likert scale or a bi-modal response scale whereby only pathological deviations from normal represent possession. To maintain consistency with the scoring of the Fatigue Questionnaire, the Likert scoring method was favoured and resulted in a maximum possible score of 36 representing the poorest degree of general health perception.

As the study was concerned with change (improvement) in patients' fatigue and mood over time, fatigue (total, sub-scale totals, and two item scores) and health change scores were calculated for the 3 month and 6 month assessment points. Follow-up scores were subtracted from the scores upon entry to the study, a positive change score thus reflecting a positive change in fatigue and health.



### 7.2.3 Procedure

Nurses at the Centre for the Study of Complementary Medicine recruited patients to the study. Patients were given an information sheet (Appendix 11) requesting their participation in a study monitoring the progress of CFS. On agreeing to take part in the study, patients were asked to complete and sign a consent form (Appendix 12) that reminded patients that they could take their time and ask questions before deciding to take part, and that they were free to withdraw from the study at any time without penalty. On entry to the study, a clinical record form (Appendix 13) was completed by the nurse on behalf of the patients. The form recorded personal details and included a check for suitability for inclusion into the study in the form of age range, nature of fatigue, symptom status and absence of co-morbidity.

Patients completed the SLQ and Health and Fatigue Questionnaire on three occasions- upon entry to the study, at 3 months and 6 months thereafter. On the first occasion, the questionnaires were completed at the Centre giving patients the opportunity to discuss any problems they had experienced with the questionnaires. Subsequent questionnaires were sent along with a stamped addressed envelope to the patients' home address. Questionnaires were returned to the Centre. If a response was not received within 2 weeks, a repeat questionnaire was sent with a covering letter (Appendix 14). In the event that the repeat questionnaire did not elicit a response, patients were followed up with a telephone call to ascertain a reason for withdrawal.

Completed questionnaires were sent via the Centre to the University of Plymouth for data entry and statistical analysis.

### 7.2.4 Statistical analyses

Pearson product moment correlations were carried out between the SLQ total score at the first assessment and the following change scores (Upon entry to the study – 3 months follow-up and upon entry to the study – 6 months follow-up)

- (i) Total Fatigue Questionnaire
- (ii) Physical fatigue sub-scale
- (iii) Mental fatigue sub-scale

- (iv) Muscle pain sub-scale
- (v) Item measuring duration of fatigue
- (vi) Item measuring the percentage of time the patient has felt tired
- (vii) Total GHQ

These change scores were also correlated with patients' age. Finally, independent t-tests were performed to compare mean change scores of males and females.

### 7.3 Results

Despite attempts to remind patients to complete follow-up assessments, there was a small degree of patient drop-out (table 7.2) with 12.5% of the original sample no longer in the study at 6 months. Reasons for drop-out were only ascertained from two patients and these included lack of time to commit to the study due to, in one case, a return to full-time education, and, in the other, travel.

Table 7.2. Patient drop-out from the study.

Assessment	Frequency (percentage)	
	Completed questionnaires	Missing questionnaires
Upon entry to study	72 (100.0)	0 (0.0)
3 months follow-up	69 (95.8)	3 (4.2)
6 months follow-up	63 (87.5)	9 (12.5)

#### 7.3.1 Prevalence of positivity

The mean (standard deviation) total SLQ score upon entry to the study was 12.17 (7.99). The difference between mean SLQ scores across the three assessment points was not significant,  $F(2,60)=1.08;ns$ , although there was a trend for patients to become slightly less positive over time (table 7.3)

Table 7.3. Prevalence of positivity over time

	Mean (standard deviation)	Range
Upon entry to study	12.17 (7.99)	0-32
3 months	12.06 (9.49)	0-38
6 months	11.45 (8.66)	0-36

7.3.2 Fatigue scores

At the first assessment, 63 (87.5%) patients offered at least one reason for their tiredness. Seven perceived reasons for tiredness were presented, (table 7.4), the most prevalent, mentioned by 28 (38.9%) patients, was that tiredness was the result of an illness, for example, CFS. Stresses of life and not taking the opportunity to take a rest were offered as a reason by 16 (22.2%) patients.

Table 7.4. Perceived reasons for tiredness at the first assessment (N=72)

Perceived reason	Frequency (percentage)
Illness including CFS, viral infection, and glandular fever	28 (38.9)
Stresses of life / over-doing it	16 (22.2)
Lack of sleep / unrefreshing sleep	8 (11.1)
Lack of energy	6 (8.3)
Toxins including organic phosphate poisoning	3 (4.2)
Poor diet	1 (1.4)
Seasonal	1 (1.4)
Don't know	9 (12.5)

The mean (standard deviation) total fatigue scale score at entry to the study was 24.30 (6.16). Patients became less tired over time with mean total fatigue scores improving by five points over the 6 month assessment period (table 7.5). Improvements in fatigue were seen for all dimensions of the fatigue scale and with the exception of the duration of tiredness item, mean changes were significant to at least  $p < .01$  (table 7.5).

Table 7.5. Mean (standard deviation) and range fatigue scores over time

	Upon entry to the study	3 months	6 months	Significance
Total fatigue	24.30 (6.16), 6-33	20.00 (7.92), 2-33	19.10 (8.69), 0-33	$F(2,58)=10.51$ ; $p<.001$
Physical fatigue	16.09 (4.17), 4-21	13.25 (5.51), 1-21	12.62 (6.24), 0-21	$F(2,58)=9.75$ ; $p<.001$
Mental fatigue	8.30 (2.69), 2-12	6.75 (2.99), 0-12	6.51 (3.06), 0-12	$F(2,60)=9.11$ ; $p<.001$
Muscle pain	3.65 (1.58), 0-6	3.12 (1.59), 0-6	2.87 (1.70), 0-6	$F(2,61)=6.61$ ; $p<.01$
Duration of tiredness	2.56 (0.79), 0-3	2.34 (1.08), 0-3	2.26 (1.14), 0-3	$F(2,51)=1.08$ ; $ns$
Percentage of time tired	2.20 (0.83), 0-3	1.71 (1.01), 0-3	1.73 (0.98), 0-3	$F(2,57)=6.25$ ; $p<.01$

### 7.3.3 General health scores

The mean (standard deviation) GHQ score upon entry to the study was 19.69 (7.55). In accordance with the fatigue scores, mean GHQ scores improved over time (table 7.6) and to a significant degree,  $F(2,60)=4.54$ ;  $p<.05$ .

Table 7.6. GHQ scores over time

	Mean (standard deviation)	Range
Upon entry to study	19.69 (7.55)	7-36
3 months	15.96 (8.12)	2-36
6 months	16.05 (8.45)	0-35

7.3.4 Association between SLQ scores and fatigue and health scores at the different assessment points

Table 7.7 presents the Pearson correlations between total SLQ and fatigue and health scores upon entry to the study, and at the 3- and 6-month follow-up assessments. With the exception of the correlation between total SLQ and percentage of time feeling tired at 6 months, all other correlations failed to achieve significance, however, there were some trends in the patterns of correlations. At the first assessment, a higher degree of positivity was associated with poorer fatigue and better mood scores. At 3 months, the same pattern is observed for all measures with the exception of the muscle pain dimension and the percentage of time spent feeling tired item (a higher degree of positivity at 3 months is associated with better muscle pain scores and less time spent feeling tired at 3 months). At the 6 months follow-up assessment, a change in the direction of association between positivity and fatigue dimensions was observed with higher degrees of positivity associated with better fatigue scores. Consistent with the earlier assessments, the association between the total SLQ and GHQ scores, was in a negative direction suggesting a tendency for individuals who are more positive about their CFS to have a more positive mood.

Table 7.7. Pearson correlations between total SLQ and fatigue and health upon entry to the study, and at 3 months and 6 months.

	Total SLQ		
	Upon entry to the study	3 months	6 months
Total fatigue	.12 (69)	.06 (69)	-.10 (62)
Physical fatigue	.06 (69)	.03 (69)	-.12 (62)
Mental fatigue	.17 (71)	.09 (69)	-.05 (62)
Muscle pain	.06 (72)	-.02 (69)	-.22 (62)
Duration of tiredness	.07 (71)	.05 (65)	-.04 (57)
Percentage of time tired	.05 (72)	-.14 (68)	-.30 (59)*
Total GHQ	-.16 (72)	-.16 (68)	-.17 (61)

\* $p < .05$ . Note. For health and fatigue scores, a higher value relates to poorer health / fatigue, while for the SLQ, higher scores correspond to greater levels of positivity.

### 7.3.5 Positivity as a predictor of improvement in fatigue and health

Table 7.8 presents the correlations between initial positivity scores and fatigue and health change scores from the first assessment to the 3- and 6-months follow-up assessments respectively. None of the correlations reached significance although greater correlations for all dimensions except for physical fatigue are achieved for the 6 months follow-up change scores. With respect to the 3-month change scores, the coefficients for the GHQ and the total and physical fatigue dimensions are negative suggesting that higher initial levels of positivity are associated, though not significantly, to smaller improvements in these dimensions at 3 months. The pattern of correlations for the remaining fatigue dimensions is in the opposite direction. With respect to the correlations between initial levels of positivity and fatigue change scores over the 6-month period, a more consistent pattern is observed amongst the fatigue dimensions with positive coefficients for all dimensions. Thus, a greater tendency to perceive positive consequences of CFS upon entry to the study was associated, though not significantly, to improvements in fatigue symptoms, muscle pain, a shorter time feeling tired, and a smaller percentage of time spent feeling tired. The latter

two correlations were the strongest with coefficients of .22 and .21 respectively. The coefficient for the correlation between positivity and change in GHQ over the 6-month period is once again negative and non-significant.

Table 7.8. Pearson correlations between initial levels of positivity (SLQ at first assessment) and change in fatigue and health over the 3-month and 6-month period

	Improvement at 3 months	Improvement at 6 months
Total fatigue	-.02 (66)	.08 (60)
Physical fatigue	-.07 (66)	.03 (60)
Mental fatigue	.08 (68)	.11 (62)
Muscle pain	.04 (69)	.07 (63)
Duration of tiredness	.02 (64)	.22 (56)
Percentage of time tired	.07 (68)	.21 (60)
Total GHQ	-.04 (68)	-.19 (62)

Note. Positive change scores for both the SLQ and Health and Fatigue Questionnaire correspond to an improvement on these measures over time.

### 7.3.6 Age and gender as predictors of improvement in fatigue and health

There were no significant associations between patients' age and improvement in fatigue and health at 3 months and 6 months (table 7.9). With the exception of the change in percentage of time spent feeling tired and health total at 3 months, all coefficients are in a positive direction suggesting that older patients are more likely, though not significantly, to experience improvement.



Table 7.9. Pearson correlations between age and change in fatigue and health over the 3-month and 6-month period

	Improvement at 3 months	Improvement at 6 months
Total fatigue	.09 (66)	.12 (60)
Physical fatigue	.07 (66)	.13 (60)
Mental fatigue	.13 (68)	.16 (62)
Muscle pain	.06 (69)	.02 (63)
Duration of tiredness	.13 (64)	.07 (56)
Percentage of time tired	-.06 (68)	.07 (60)
Total GHQ	-.01 (68)	.01 (62)

Table 7.10 presents the mean (standard deviation) fatigue and health change scores for males and females at 3 months and 6 months. T-tests comparing the scores of males and females are also presented in table 7.10 and reveal no significant differences between males and females in degree of improvement in fatigue and health over the 6-month period.

Table 7.10. T-tests comparing mean fatigue and health change scores of males and females at 3 months and 6 months

	Improvement at 3 months		Improvement at 6 months	
	Mean	t-test	Mean	t-test
	(standard deviation)		(standard deviation)	
Total fatigue		$t(60.59)=-0.48;ns$		$t(48.67)=-0.09;ns$
Males	3.71 (4.63)		4.31 (5.80)	
Females	4.52 (9.14)		4.49 (9.00)	
Physical fatigue		$t(64)=-0.44;ns$		$t(51.64)=-0.31;ns$
Males	2.39 (3.62)		2.75 (3.87)	
Females	3.07 (6.30)		3.17 (6.49)	
Mental fatigue		$t(59.61)=-0.36;ns$		$t(60)=-0.00;ns$
Males	1.32 (1.70)		1.56 (2.48)	
Females	1.53 (3.22)		1.56 (3.54)	
Muscle pain		$t(67)=1.10;ns$		$t(61)=1.49;ns$
Males	0.85 (1.18)		1.26 (1.37)	
Females	0.43 (1.53)		0.57 (1.82)	
Duration of tiredness		$t(54.06)=-0.34;ns$		$t(54)=-0.45;ns$
Males	0.16 (0.76)		0.16 (0.76)	
Females	0.24 (1.26)		0.30 (1.24)	
Percentage of time tired		$t(66)=0.28;ns$		$t(58)=1.00;ns$
Males	0.55 (1.10)		0.58 (0.84)	
Females	0.47 (1.08)		0.33 (0.93)	
Total GHQ		$t(66)=0.02;ns$		$t(60)=-0.27;ns$
Males	3.55 (6.23)		2.28 (6.21)	
Females	3.50 (9.85)		2.91 (9.10)	

### 7.3.7 Summary

This study assessed CFS patients' perceptions of positive consequences of illness and health and fatigue symptoms over a 6-month period. While levels of positivity deteriorated slightly, though not significantly, over time, fatigue and mood improved. Initially, positivity was associated, though not significantly, with greater levels of fatigue and better mood. This relationship between positivity and health was maintained over the 6-month period while for fatigue scores the pattern of association changed at 6 months with greater positivity associated (non-significantly) with less fatigue. Only the correlation between positivity at 6 months and percentage of time tired at 6 months was found to be significant with greater positivity associated with a smaller percentage of the time feeling tired. There was no evidence of any significant correlations between initial SLQ scores and fatigue and health change scores. However, the correlations with the 6-month fatigue change scores were in a positive direction with higher levels of positivity upon entry to the study associated, though not significantly, with greater improvements in fatigue for all fatigue dimensions at 6 months. With respect to the GHQ change scores, higher initial levels of positivity were associated, once again not significantly, with a smaller degree of improvement in mood. Finally, there was no significant association between patients' age or gender and change in fatigue and health.

### 7.4 *Conclusion*

This study suggests, in line with the findings of study 3, consistency in SLQ responses over time. Although the correlations between patients' SLQ and health and fatigue scores, in general, failed to reach significance, several trends in the data were detected. The finding that positivity is weakly associated, though not significantly, with generally poorer perceptions of fatigue for the first 3 months of the study and better fatigue at 6 months implies that initially patients have to be ill enough to perceive positive consequences but, in order for positivity to be maintained, fatigue symptoms have to improve. With respect to mood scores, a more consistent pattern is found with positivity associated weakly, though not significantly, at all time points, with

better mood. This finding is consistent with findings in the literature of a positive association between positivity and positive affectivity (Park et al., 1996).

Significant improvements in patients' fatigue symptoms and health perceptions were detected which may seem surprising given the low recovery rates cited in the introductory section. However, the rates cited elsewhere are based on patients whose conditions are likely to be more serious than those of the patients of this study.

Improvements in fatigue and health scores could not be predicted significantly by patients' age, gender or levels of positivity, as indicated by the SLQ upon entry to the study, though the correlations between positivity and fatigue dimensions were, in the main, in a positive direction. This study used change scores for the fatigue and health scales, which inevitably poses an issue of reliability. Thus, it may be unrealistic to expect high correlations.

The main explanation for a lack of significant findings lies with the small sample size; for example, data from only 56 patients were included in the correlation between the SLQ at first assessment and the 6-month change in duration of tiredness. A larger sample size was not feasible due to constraints on the time of the centre staff.

Given that the strength of correlations improved over time, it is possible that the significance of the SLQ as a predictor of health outcome may only be achieved after a greater length of time. The length of this study was again dictated by time constraints.

This study focused primarily on one predictor of health outcome in isolation (though age and gender were also taken into consideration). Other factors not accounted for by this study are likely to be important in determining health outcome.

There are a number of explanations to account for the lack of evidence, in this particular study, of a significant role of positivity in determining health outcome and these explanations will be reviewed in the discussion chapter (chapter 9). Thus, one cannot rule out, on the basis of these findings with a very limited sample, the therapeutic properties of positivity as determined by responses to the SLQ.

The following chapter presents the final study of this thesis and is concerned with the prevalence and correlates of positivity. In addition, this chapter will address issues relating to the dimensionality of positivity as determined by the factor structure of SLQ responses.

## CHAPTER 8

### STUDY 5: PSYCHOMETRIC PROPERTIES OF THE SLQ

#### (III) PREVALENCE AND CORRELATES OF POSITIVITY

“It certainly improved my life for the better”  
(20 year old male treated for Hodgkin’s disease)

##### 8.1 *Introduction*

Positive consequences of illness are most notably reported in the context of life threatening illness (for example, Collins et al., 1990; Laerum et al., 1988) and this is reflected in the sample composition of study 1 with cancer representing the most prominent illness type. No study comparing positivity as a function of illness severity has been cited although, as noted in chapter 2, prognosis has been identified as a factor in determining positivity (Collins et al., 1990; Schaefer & Moos, 1998) with conflicting viewpoints concerning the direction of the effect of prognosis on positivity. There are no reports in the literature of positive consequences of minor illness. In the context of stress-related growth, Tedeschi and Calhoun (1996) examined positivity in ordinary and traumatic life events. Students who had experienced at least one major trauma of great severity in the past year reported significantly more benefits than those who experienced only ordinary life events. Individuals in poorer health may experience a larger number of positive outcomes because of a greater outpouring of support from others (Schaefer & Moos, 1998). Zemore and Shepel (1989) found that women with breast cancer received greater support from others compared with women with benign breast lumps. The present study compares the prevalence of positivity across patients varying in illness type and severity and includes patients with minor illness. Illness duration may also influence the degree of positivity. In study 1, a negative association was identified between the length of illness and the number of themes expressed by participants.

Certain patients may be more positive not only as a function of the characteristics of their illness but due to their personal resources such as demographic characteristics and personality (Schaefer & Moos, 1998). Females have been found to score higher on the SRGS in two separate studies (Park et al., 1996) and also on the PTGI (Tedeschi & Calhoun, 1996) where the greatest gender difference identified was in the domains of spiritual change ( $F(1,113)=14.09; p<.001$ ) and relating to others ( $F(1,113)=6.93; p<.01$ ). Park et al. (1996) suggest that the gender differences in stress-related growth may be a result of women being socialised to be more in tune with and expressive of their feelings and thus they may be more aware of positive changes that have occurred. Tedeschi and Calhoun (1996) propose that spirituality and support from others may be more important to women than men when faced with trauma and that improvements are more likely to be perceived in these areas as a result. Age has also been related to illness outcomes with older women reported to experience less emotional distress in the face of breast cancer compared with younger women who may have more at stake and who may have specific concerns regarding a young family (Northouse, 1994). Curbow, Legro, Wingard, and Somerfield (1993) found that the specific type of positive consequence reported amongst long-term survivors of bone marrow transplant depended on the age of survivors with younger survivors more likely to restructure their lives and older survivors finding new meaning in life, placing greater value on family relationships and devoting more time to themselves. However, in study 1 of this thesis these findings were not replicated as the total number of positive consequence themes expressed did not differ significantly between males and females and was unrelated to age.

It was reported in chapter 2 that personality affects both positive and negative evaluations of illness (Hyland et al., 1994). While neuroticism is associated with reports of negative affectivity and negative evaluations of health (Hyland et al., 1994), extraversion predisposes individuals towards positive affect and positive thinking in the face of stressful life events such as illness (McCrae & Costa, 1986). Extraversion was identified as the most significant personality correlate of the PTGI (Tedeschi & Calhoun, 1996) producing a correlation coefficient of .29 with the PTGI total score and correlated significantly (at  $p<.01$ ) with each of the five sub-scales of the PTGI.

In chapter 2 it was also suggested that expressions of positivity could represent socially desirable responding or defensiveness with individuals reporting positivity as a way of pleasing others, or, within the context of the defence mechanism of repression, in an attempt to protect the self from harm or rejection (Weinberger, Schwartz, & Davidson, 1979). In addition, in study 3 it was speculated that the improvement in positivity amongst patients following rehabilitation could have been the result of socially desirable responding. Responses to the SRGS (Park et al., 1996) and the PTGI (Tedeschi & Calhoun, 1996) however are unrelated to a tendency to appear socially desirable. An additional question addressed by this study is whether patients' responses to the SLQ reflect their true experiences of illness or a social desirability / defensiveness response set.

Two additional potential correlates of positivity that will be explored in this study are spirituality which may include religion, and the number of supportive individuals that the patient can turn to. As discussed in chapter 2 and above (in the case of social support), the use of social and religious resources has been found to be associated with 'growth' in occasions of stress (Park et al., 1996).

The issue of whether there is an underlying general factor of positivity, i.e., a general orientation towards positivity, or multiple forms of positivity will also be addressed.

This study therefore offers an insight into the prevalence of positivity across illness types, the correlates of positivity and the nature of positivity.

#### 8.1.1 Aims of the study

The study was concerned with the following questions:

- (i) How common is the experience of positive consequences of illness across different illness types?
- (ii) Does positivity vary as a function of illness severity, duration and the presence or absence of co-morbidity?
- (iii) Is positivity associated with demographic characteristics, in particular age, gender, and race / ethnic group?
- (iv) Is positivity associated with personality type?



- (v) Is positivity associated with the availability of socially supportive relationships?
- (vi) Is positivity influenced by a sense of spirituality and / or religion?
- (vii) Are reports of positive consequences biased towards defensiveness / socially desirable responses?
- (viii) Is there an underlying common factor of positivity?

## 8.2 *Method*

A cross-sectional design was adopted for this study with respiratory patients completing the SLQ and a measure of personality on one occasion. Ethical approval for this study was granted by Redbridge and Waltham Forest Health Authority.

### 8.2.1 Sample recruitment

Patients were recruited from the Chest Clinic at Whipps Cross Hospital, London. Recruitment took place over a 14-month period. Patients were recruited following a visit to the consultant. Patients were recruited at least 3 months post-diagnosis. Patients whose general condition was poor and who were unwilling or unable to give consent were not invited to participate in this study.

A total of 197 patients participated in the study. The demographic characteristics of the sample are presented in Table 8.1. The sample was comprised of 105 (53.3%) males and 92 (46.7%) females. The mean (standard deviation, range) age of patients was 56.8 (16.0, 18-85) years. The sample comprised of patients from at least nine different race / ethnic groups. The white race / ethnic group represented 76.1% of the sample.

Table 8.1. Demographic characteristics of the sample (N=197)

Demographic characteristic	Frequency	Percentage
Gender		
Male	105	53.3
Female	92	46.7
Race / ethnic group		
White	150	76.1
Indian	6	3.0
Pakistani	5	2.5
Black-Caribbean	14	7.1
Black-African	6	3.0
Black-Other	8	4.1
Chinese	1	0.0
Other	6	3.0
		1 missing

Note. The ‘Other’ race / ethnic group comprised of two patients of mixed descent, one Turkish Cypriot, one Irish/Caribbean and two patients who did not specify a race.

The following five groups of patients were recruited:

- (i) Asthma: A total of 46 (23.4%) patients with asthma were included in the study. Thirty nine of these patients presented asthma as their only respiratory illness and seven patients were co-morbid (suffering from an additional respiratory illness);
- (ii) Chronic respiratory disease: 110 (55.8%) patients presented chronic respiratory disease. This group included 59 patients with chronic obstructive pulmonary disease (COPD; nine of whom were co-morbid), 29 with sarcoidosis, 15 with fibrosing alveolus, five with cystic fibrosis, and two with emphysema;
- (iii) Lung cancer: there were 16 (8.1%) patients with lung cancer in the study and two of these patients were co-morbid;

- (iv) Sleep apnoea: 21 (10.7%) patients with sleep apnoea were included in the study. Three of these patients were co-morbid;
- (v) Tuberculosis: 14 (7.1%) patients were diagnosed with tuberculosis (one patient was co-morbid).

Finally, one (0.5%) patient had an unspecified respiratory condition.

For the purposes of analysis, co-morbid patients were categorised according to their most 'serious' illness, for example, a patient with sleep apnoea and lung cancer was placed in the lung cancer category. This method of categorisation led to the following sample sizes: (i) 40 (20.3%) patients with asthma; (ii) 109 (55.3%) patients with chronic respiratory disease; (iii) 16 (8.1%) lung cancer patients; (iv) 18 (9.1%) patients with sleep apnoea and (v) 13 (6.6%) patients with tuberculosis.

Patients were also placed in one of two groups, with chronic respiratory disease and lung cancer patients classified as 'terminal' and asthmatics, patients with sleep apnoea and patients with tuberculosis classified as 'non-terminal' (note, patients presenting a terminal and non-terminal illness were classified as terminal). One hundred and twenty five (63.5%) patients were placed in the terminal group and 71 (36.0%) in the non-terminal group (the patient with an unspecified illness type was not classified).

The mean (standard deviation, range) duration of illness was 10.0 (14.5, 0.3-81.0) years.

### 8.2.2 Assessments

Patients completed two questionnaires, one assessing their level of positivity that also included demographic, social support and spirituality / religion items and the other measured their personality type.

8.2.2.1 The SLQ. Patients completed the refined, 38-item SLQ. The SLQ used in this study was identical to the questionnaire administered in studies 3 and 4 (Appendix 9) with the exception of the front page (Appendix 15), which included additional socio-demographic items. These items asked patients to indicate their race or ethnic group (taken from the Notification and

Data Collection Form for Enhanced Tuberculosis Surveillance), to specify whether they are religious or spiritual, and also the number of people they can talk to about their illness. While scales assessing spirituality / religiousness (Intrinsic Religiousness Scale; Gorsuch & McPherson, 1989; Spiritual Assessment Guide; O'Brien, 1982) and social support (The Social Support Questionnaire; Sarason, Levine, Basham, & Sarason, 1983) exist, their inclusion in this study would have increased patient burden and may have compromised the quality of the data. Thus, single item measures developed for the purposes of this study were favoured. The bi-modal scoring system described in study 3 (chapter 6) was used for the SLQ items.

8.2.2.2 Eysenck Personality Questionnaire Revised (EPQ-R) Short Scale (Eysenck et al., 1985; Appendix 16). The EPQ-R Short Scale consists of 48 items from the 100-item EPQ-R and measures the following four personality dimensions: Neuroticism, Extraversion, Psychoticism, and Lies. Each dimension comprises 12 items. Patients are asked whether or not they agree with each statement and responses are assigned a value of 1 if they are consistent with the personality facet assessed thus, for each dimension, scores range between 0 and 12. The mean (standard deviation) norm values for each dimension for males and females aged between 16 and 70 years are as follows: Neuroticism, males = 4.95 (3.44), females = 5.90 (3.14); Extraversion, males = 6.36 (3.80), females = 7.60 (3.27); Psychoticism, males = 3.08 (2.20), females = 7.60 (3.27); Lies, males = 3.86 (2.71), females = 3.69 (2.55) (Eysenck & Eysenck, 1991). Eysenck and Eysenck (1991) define an individual high in extraversion as sociable, enjoying parties and the company of many friends, craving excitement, someone who takes chances and is generally impulsive. The introvert by contrast is quiet, introspective, prefers books to people and does not enjoy excitement. An individual high in neuroticism is typically anxious, a worrier, moody and frequently depressed (Eysenck & Eysenck, 1991). A high psychoticism scorer is described as solitary, not caring for others, often troublesome, and not fitting in anywhere (Eysenck & Eysenck, 1991). Finally, the lie scale represents a surrogate assessment of social desirability or defensiveness and measures a stable personality dimension that may be defined as social naivety or conformity (Eysenck & Eysenck, 1991).

### 8.2.3 Procedure

Patients attending the chest clinic were given a patient information and consent sheet (Appendix 17) by the nurse inviting them to participate in a study about the positive consequences of illness. Patients were informed that the study would involve the completion of two questionnaires, one asking them about themselves and the other about their experiences of being ill. Before giving their signed consent, patients were invited to ask questions. The nurse recorded each patient's identity and illness characteristics on a patient data sheet (Appendix 18). The nurse also recorded patients' MRC Dyspnoea score (Medical Research Council, 1986; Appendix 19), which assesses the magnitude of the task that provokes dyspnoea on a scale between 0 ('Not troubled by breathlessness, except on strenuous exercise') and 5 ('Breathless at rest').

The SLQ and EPQ-R Short scale were administered in a random order with 99 patients completing the SLQ first and 98 completing the EPQ-R first. Assessments were self-completed at the clinic. Nurses were present to address queries that arose. Completed questionnaires were returned via the nurses to the University of Plymouth for statistical analysis.

### 8.2.4 Statistical analyses

The following analyses were carried out

- (i) A one-way analysis of variance with five independent samples was performed to compare total SLQ scores across the different illness types. In addition, independent t-tests were used to compare total SLQ scores for the terminal and non-terminal illness groups and for the co-morbid and non-co-morbid patients;
- (ii) A one-way analysis of variance with six independent samples was carried out to compare positivity across the grades of dyspnoea;
- (iii) Pearson product moment correlations were carried out between total SLQ scores and illness duration, age, personality dimensions, and the number of social supports;

- (iv) To examine whether positivity varied as a function of gender an independent t-test was performed;
- (v) Independent t-tests were also used to compare SLQ scores as a function of religious / spiritual orientation with patients classified on one test as either spiritual but not religious or neither spiritual nor religious, and on the other test patients were classified as either spiritual / religious or neither spiritual nor religious;
- (vi) A one-way analysis of variance was used to compare mean total SLQ scores across the different spiritual / religious groups and also across the race / ethnic groups;
- (vii) A multiple regression analysis was used to identify independent predictors of positivity. Variables identified in earlier analyses as significant correlates of positivity were entered into the regression model using the enter method;
- (viii) Finally, the factor structure of the SLQ was examined by pooling the SLQ data from the current study with the baseline data from studies 3 and 4 generating a total sample size of 350. Principal components analysis and maximum likelihood analysis were performed.

### 8.3 *Results*

This section commences with a description of the patients' characteristics including further details of their illness, their spiritual / religious resources, availability of social support and their responses to the SLQ and EPQ-R. Prevalence of positivity across illness types and correlates of positivity are also examined.

#### 8.3.1 Sample characteristics

8.3.1.1 Illness characteristics. As noted in section 8.2.1, several (22, 11.2%) of the patients suffered from more than one respiratory illness. In addition to respiratory illness, patients also presented other illness types. A total of 104 (52.8%) patients were co-morbid, for example, 42

(21.3%) suffered from heart disease, 10 (5.1%), 8 (4.1%) diabetes, and 5 (2.5%) cancer (other than lung cancer). Table 8.2a. indicates that the sample were skewed towards the lower end of the MRC dyspnoea scale. The mean (standard deviation) MRC dyspnoea score for the sample as a whole was 1.66 (1.20). The chronic respiratory disease group had the highest mean grade of breathlessness, mean (standard deviation) 1.93 (1.28) (table 8.2b.) and the tuberculosis patients had the lowest mean breathlessness score, mean (standard deviation) 0.85 (0.80). Differences in dyspnoea scores across illness types were significant,  $F(4,176)=4.93;p<.001$ .

Table 8.2a. Dyspnoea scores for the sample

Grade of dyspnoea	Frequency	Percentage
0	27	13.7
1	68	34.5
2	45	22.8
3	28	14.2
4	10	5.1
5	4	2.0
		15 missing

Table 8.2b. Dyspnoea scores across illness types

Illness type	Frequency	Mean (standard deviation) MRC dyspnoea scale score
Asthma	34	1.40 (0.90)
Chronic respiratory disease	102	1.93 (1.28)
Lung cancer	16	1.69 (1.14)
Sleep apnoea	16	0.97 (0.97)
Tuberculosis	13	0.85 (0.80)

8.3.1.2 Spiritual / religious orientation. Forty-one (20.8%) patients claimed to be spiritual but not religious and 47 (23.9%) patients were neither religious nor spiritual (table 8.3). Thus, a total of 88 (44.7%) patients were not religious. One hundred and five (53.3%) patients specified a religion with Church of England the most popular religion, nominated by 71 (36.0%) patients. Eight different religions were specified. Four (2.0%) patients neither completed the spiritual item nor specified a religion.



Table 8.3. Spiritual / religious orientation of patients

	Frequency	Percentage
<b>Spirituality</b>		
Neither spiritual nor religious	47	23.9
Spiritual but not religious	41	20.8
<b>Religion</b>		
Church of England	71	36.0
Roman Catholic	14	7.1
Judaism	8	4.0
Islam	3	1.5
Methodist	4	2.0
Jehovah's Witness	2	1.0
Sikhism	2	1.0
Orthodox (Greek Church)	1	0.0

8.3.1.3 Social support. The mean (standard deviation, range) number of people whom the patient could talk to about their illness was 6.5 (6.7, 0-35). While only 77 (39.1%) patients specified a number of people they could talk to about their illness, a further 100 (50.8%) patients used alternative quantifiers, with 22 (11.2%) using quantifiers such as “few”, “not many” and “some”; 23 (11.7%) used the following descriptors “many”, “loads”, “lots”, “plenty”, “numerous”, “quite a few”, and “several”; 4 (2.0%) patients reported that they could speak to “most people” about their illness and 35 (17.8%) to “anyone”. Finally, 16 (8.1%) patients reported that they could speak to family and friends about their illness.

8.3.1.4 SLQ scores. Completed SLQs were received from 194 patients. One patient with asthma felt that it was inappropriate for her to complete the SLQ but did not offer an explanation. Two incomplete SLQs were received: one from a patient with COPD and one with asthma. The mean

(standard deviation) SLQ score for the sample as whole was 12.12 (8.44). Ten patients endorsed no positive consequences and one patient endorsed all positive consequences.

8.3.1.5 EPQ-R scores. The amount of missing data for the EPQ-R varied across dimensions with 174 patients completing items within the Psychoticism and Neuroticism dimensions, 176 the Extraversion and 179 the Lies dimension. Table 8.4 presents the mean (standard deviation) scores for the personality dimensions. While the scores for the Neuroticism and Extraversion dimensions fall between the norms for males and females, the sample scored lower on the Psychoticism and higher on the Lies dimension than the norms for both males and females.

Table 8.4. Personality characteristics of the sample

	Frequency	Mean (standard deviation)
Psychoticism	174	2.49 (1.90)
Neuroticism	174	5.83 (3.39)
Extraversion	176	6.66 (3.45)
Lies	179	5.74 (2.90)

### 8.3.2 Prevalence of positivity across illness types

Table 8.5 presents the mean (standard deviation) total SLQ scores for the eight illness classifications featured on the patient data sheet. A one-way analysis of variance revealed no significant difference between groups in the number of positive items endorsed,  $F(7,186)=1.25;ns$ . However, patients with tuberculosis were the most positive, mean (standard deviation) SLQ score of 17.23 (9.35), and sleep apnoea patients were the least positive, mean (standard deviation) of 9.11 (9.00). The other illness groups endorsed between 11 and 14 positive items.

Table 8.5. Prevalence of positivity across the eight illness types

Illness type	Frequency	Mean (standard deviation) total SLQ score
Asthma	38	10.97 (8.11)
COPD	59	12.37 (6.89)
Fibrosing alveolus	15	11.53 (10.23)
Sarcoidosis	27	12.07 (11.11)
Sleep apnoea	18	9.11 (9.00)
Tuberculosis	13	17.23 (9.35)
Lung cancer	16	13.94 (6.68)
Other	8	11.75 (4.77)

Note. The 'Other' group included five patients with cystic fibrosis, two with emphysema, and one patient with an unspecified illness.

Positivity was also compared across the five broad illness types with a chronic respiratory disease group created by combining patients with COPD, fibrosing alveolus, sarcoidosis, and seven of the patients in the 'other' category. The mean (standard deviation) score for the chronic respiratory disease group was 12.08 (8.41) (see table 8.5 for the mean and standard deviation values of the other four groups). Mean scores across these five groups did not differ significantly,  $F(4,188)=2.17;ns$ .

Finally, positivity as a function of illness type was also investigated for terminal versus non-terminal patients. No significant difference between these two groups was detected,  $t(191)=0.61;ns$ . Although, patients with a terminal condition were slightly more positive, mean (standard deviation) 12.32 (8.21), than the non-terminal patients, mean (standard deviation) 11.67 (8.91).

### 8.3.3 Correlates of positivity

No evidence of an order effect of the two questionnaires was found,  $t(192)=-1.26;ns$ .

This section considers further potential correlates of positivity including other illness characteristics, demographic characteristics of the patients, spiritual / religious orientation, availability of social support, and finally personality traits including social desirability / defensiveness.

8.3.3.1 Illness characteristics. (a) Positivity was examined as a function of illness severity as indicated by grades of dyspnoea (table 8.6). A one-way analysis of variance indicated no significant difference in positivity between groups,  $F(5,173)=0.42;ns$ .

Table 8.6. Positivity as a function of grades of breathlessness

Grade of dyspnoea	Frequency	Mean(standard deviation) total SLQ score
0	26	12.12 (9.86)
1	66	11.83 (8.49)
2	45	12.22 (8.74)
3	28	14.46 (8.38)
4	10	12.60 (5.19)
5	4	10.75 (8.30)

(b) No evidence of an association between positivity and illness duration was found,  $r(193)=.05;ns$ .

(c) Positivity was compared between patients who were co-morbid and patients who specified only one illness type. Although there was a trend for co-morbid patients to endorse, on average, more positive consequences, mean (standard deviation) of 12.95 (8.25), than non-co-morbid patients, mean (standard deviation) of 11.20 (8.59), this difference was not detected as significant,  $t(192)=-1.45;ns$ .

8.3.3.2 Demographic characteristics. (a) The total SLQ score was unrelated to age,  $r(194)=.09;ns$ .

(b) No gender difference in reported positivity was detected,  $t(192)=-1.27;ns$ , although females endorsed, on average, more positive consequences than males, with a mean (standard deviation) SLQ score of 12.94 (8.63) for females and 11.40 (8.23) for males.

(c) Positivity was compared across the eight different race / ethnic groups (table 8.7). Note, however, that with the exception of the white group, all groups were under-represented with the Chinese group including only one patient and was thus not included in this part of the analyses. Differences between ethnic groups in the number of positive consequences endorsed failed to reach significance,  $F(6,185)=1.71;ns$ . The Black-Other group, however, had the lowest mean score of 8.88 and patients of Indian origin endorsed, on average, the greatest number (19.83) of positive consequences.

Table 8.7. Positivity as a function of race / ethnic group

Race / ethnic group	Frequency	Mean(standard deviation) total SLQ score
White	147	11.66 (8.15)
Indian	6	19.83 (13.66)
Pakistani	5	9.00 (5.15)
Black-Caribbean	14	15.00 (10.08)
Black-African	6	15.50 (5.17)
Black-Other	8	8.88 (6.49)
Other	6	12.00 (7.43)

8.3.3.3 Spiritual / religious orientation. (a) Table 8.8 presents the mean (standard deviation) SLQ values of patients according to their spiritual / religious orientation. Patients who were spiritual but not religious were significantly more positive, mean (standard deviation) SLQ score of 12.93 (8.97), than patients who were neither spiritual nor religious, mean (standard deviation) 8.36 (6.20),  $t(85)=-2.79;p<.01$ . When the patients who were neither spiritual nor religious are

compared with patients who either endorsed the 'spiritual but not religious' response or specified a religion, mean (standard deviation) SLQ score of 13.50 (8.71), the significance of the difference between groups is greater,  $t(188)=-3.74; p<.001$ . A one-way analysis of variance confirmed significant differences in positivity across the three groups of patients: neither spiritual nor religious, spiritual but not religious, and religious,  $F(2,187)=7.12; p<.001$ . Post-hoc comparisons using t-tests identified significant differences between the first two of these groups (as reported above) and, in particular, between the neither spiritual nor religious group and the group of patients who specified a religion,  $t(148)=-3.83; p<.001$ . No significant differences in reported positivity were identified between the spiritual but not religious patients and the patients who specified a religion,  $t(141)=-0.49; ns$ .

(b) Table 8.8 also presents the mean (standard deviation) SLQ values for the different religious groups. A one-way analysis of variance comparing SLQ scores across the different religious groups (with the exception of Jehovah's Witness, Sikhism, and Orthodox due to low sample sizes) and the group of patients who were spiritual but not religious detected no significant differences in positivity,  $F(5,132)=1.02; ns$ . The most positive group, on average, were the Methodists, mean (standard deviation) SLQ score of 19.00 (4.24), and the least positive were Muslims, mean (standard deviation) of 8.67 (5.69).

Table 8.8. Positivity as a function of spirituality / religion.

Spiritual / religious orientation	Frequency	Mean (standard deviation) total SLQ score
Neither spiritual nor religious	47	8.36 (6.20)
Spiritual but not religious	41	12.93(8.97)
Religion specified	103	13.72 (8.65)
Church of England	70	13.43 (7.77)
Roman Catholic	13	12.69 (10.04)
Judaism	8	18.25 (15.01)
Islam	3	8.67 (5.69)
Methodist	4	19.00 (4.24)
Jehovah's Witness	2	15.00 (2.83)
Sikhism	2	9.00 (11.31)
Orthodox (Greek Church)	1	13.00 (-)

A religion / spirituality variable was created by classifying patients according to whether they were religious or spiritual or neither spiritual nor religious. This variable was then correlated with each of the SLQ items (table 8.9). Significant correlations were received for 23 (60.5%) of the 38 SLQ items. The highest correlation coefficient was achieved for the item describing a deepening of religious / spiritual beliefs ( $r(192)=.40; p<.001$ ). The religiosity / spirituality variable also correlated with greater openness to other religions ( $r(188)=.23; p<.01$ ) and also items describing existential changes, for example, reflection on the true purpose of life ( $r(189)=.21; p<.01$ ) and finding oneself ( $r(191)=.24; p<.01$ ).

Table 8.9. Spearman correlations between religiosity / spirituality and individual SLQ items

Item description	Spearman correlation coefficient (n)
(1) Greater appreciation of life	.09 (189)
(2) New start in life	.17 (186)*
(3) Life is much better now	.10 (185)
(4) Live life to its fullest	.17 (190)*
(5) Easier to accept what life has in store	.02 (190)
(6) Think about true purpose of life	.21 (189)**
(7) Deepening of religious / spiritual beliefs	.40 (192)***
(8) Greater openness to other religions	.23 (188)**
(9) Better person	.22 (192)**
(10) Happier person	.11 (192)
(11) Calmer person	.11 (191)
(12) Greater maturity	.16 (191)*
(13) More tolerant person	.19 (190)*
(14) Realise that I matter as a person	.23 (188)**
(15) Greater confidence	.21 (190)**
(16) Less concerned about failure	.20 (192)**
(17) Permission to do things for myself	.15 (189)*
(18) More determined person	.17 (191)*
(19) Helped me find myself	.24 (191)**
(20) More aware of strengths	.14 (191)
(21) Discovered a talent	.17 (188)*
(22) Ability to face whatever is around the corner	.10 (188)
(23) Reflect on how I feel about myself	.14 (189)
(24) Face up to problem areas of life	.11 (185)
(25) Strengthened relationships with others	.20 (189)**
(26) Less concerned with approval of others	.18 (188)*



(27) More to offer other people	.23 (188)**
(28) More at ease with others	.09 (186)
(29) See others in their true colours	.17 (189)*
(30) Opportunity to meet new people	.21 (188)**
(31) Taught me to stand up for myself	.18 (190)*
(32) Put an end to troublesome relationships	.12 (188)
(33) Less judgemental of others	.32 (186)***
(34) Inspiration to others	.09 (190)
(35) People can be more open with me	.10 (188)
(36) Changed other people for the better	.13 (188)
(37) Changed other's perception of me for the better	.10 (189)
(38) Others appreciate me more	.16 (190)*

\* $p<.05$ ; \*\* $p<.01$ ; \*\*\* $p<.001$

8.3.3.4 Social support. No significant association between the SLQ total score and the number of people patients can talk to about their illness was detected,  $r(76)=-.01;ns$ . In order to include in the analyses patients who did not specify a number of people but used alternative quantifiers, social support responses were categorised (see table 8.10) and the means compared across these categories. Differences between groups were not found to be significant,  $F(8, 166)=1.30;ns$ , although the most positive group of patients were those who claimed to be able to talk to ‘many people’ about their illness, mean (standard deviation) 14.91 (9.52). The least positive group included patients who could talk to ‘most people’, mean (standard deviation) 5.25 (6.55).

Table 8.10. Positivity as a function of availability of social support

Availability of social support	Frequency	Mean (standard deviation) total SLQ score
0	4	6.25 (8.66)
1-5	38	12.47 (7.24)
6-10	25	12.92 (8.24)
Above 10	10	10.20 (8.60)
<i>Other quantifiers used</i>		
Few	22	10.64 (7.50)
Many	22	14.91 (9.52)
Family and friends	16	12.00 (8.49)
Most	4	5.25 (6.55)
Anyone	34	10.56 (7.43)

8.3.3.5 Personality. Pearson product moment correlations were performed between the total SLQ score and the four personality dimensions of the EPQ-R (table 8.11). With the exception of the psychoticism dimension, the direction of association between positivity and personality types was positive. No evidence of a significant association between positivity and scores on the surrogate scale of social desirability / defensiveness was detected. Only the correlation between extraversion and the SLQ reached statistical significance,  $r(174)=.16; p<.05$ , suggesting that patients high in extraversion were more likely to perceive positive consequences of their illness.

Table 8.11. Positivity as a function of personality

Personality dimension	SLQ total score
Psychoticism	-.03
Neuroticism	.11
Extraversion	.16*
Lies	.10

\* $p < .05$ 

The extraversion dimension correlated significantly with nine (23.7%) of the SLQ items (table 8.12). The highest correlations were received for the items describing a new start in life and an inspiration to others (coefficients of .25).

Table 8.12. Pearson correlations between extraversion and individual SLQ items

Item description	Pearson correlation coefficient (n)
(1) Greater appreciation of life	.19 (172)*
(2) New start in life	.25 (172)***
(3) Life is much better now	.15 (170)
(4) Live life to its fullest	.18 (173)*
(5) Easier to accept what life has in store	.05 (173)
(6) Think about true purpose of life	.17 (172)*
(7) Deepening of religious / spiritual beliefs	.10 (175)
(8) Greater openness to other religions	.09 (171)
(9) Better person	.20 (175)**
(10) Happier person	.13 (175)
(11) Calmer person	.10 (174)
(12) Greater maturity	.04 (174)
(13) More tolerant person	.07 (173)
(14) Realise that I matter as a person	.21 (172)**
(15) Greater confidence	.18 (173)*
(16) Less concerned about failure	-.01 (175)
(17) Permission to do things for myself	.08 (172)
(18) More determined person	.15 (174)
(19) Helped me find myself	.12 (174)
(20) More aware of strengths	.09 (175)
(21) Discovered a talent	.06 (172)
(22) Ability to face whatever is around the corner	-.03 (174)
(23) Reflect on how I feel about myself	.10 (173)
(24) Face up to problem areas of life	-.01 (169)
(25) Strengthened relationships with others	.10 (174)
(26) Less concerned with approval of others	-.09 (173)

(27) More to offer other people	.21 (172)**
(28) More at ease with others	.04 (170)
(29) See others in their true colours	.04 (173)
(30) Opportunity to meet new people	.06 (172)
(31) Taught me to stand up for myself	.01 (174)
(32) Put an end to troublesome relationships	.05 (172)
(33) Less judgemental of others	.05 (171)
(34) Inspiration to others	.25 (174)***
(35) People can be more open with me	.09 (172)
(36) Changed other people for the better	.04 (172)
(37) Changed other's perception of me for the better	.06 (173)
(38) Others appreciate me more	.05 (174)

\* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$

#### 8.3.4 Predictors of positivity

A multiple linear regression of the total SLQ score was performed with the extraversion sub-scale score and religion / spirituality variable entered as potential predictors of positivity. These variables explained 8.5% of the variance in positivity and were significant independent predictors of the SLQ total score (table 8.13).

Table 8.13. Multiple regression of the total SLQ score

Variable	Beta weight	Significance
Spiritual / religion specified	.23	.00
Extraversion sub-scale score	.16	.03

#### 8.3.5 Summary

There was no evidence of a significant difference in positivity between patient groups despite different methods of illness classification. Other illness characteristics such as the presence of co-morbidity, illness duration and illness severity as indicated by degree of breathlessness were also found to be unrelated to positivity. Positivity was also investigated as a function of demographic variables, the availability of social support, spiritual / religious orientation and personality. Significant results were achieved only for the latter two variables with greater positivity expressed by patients with a sense of spirituality and by those specifying a religion compared with patients who were neither spiritual nor religious. There was also evidence of greater positivity amongst extraverted patients. These variables were entered into a multiple regression analysis and were identified as significant independent predictors of positivity.

#### 8.3.6 Factor structure of the SLQ

A principal components analysis suggested a strong first factor of positivity accounting for 33.31% of the variance amongst items. All items loaded highly onto this first factor with loadings exceeding .40 (table 8.14).

Table 8.14. Factor loadings from a principal components analysis.

Item	Factor loading
1	.52
2	.55
3	.48
4	.56
5	.60
6	.59
7	.55
8	.53
9	.62
10	.64
11	.54
12	.59
13	.61
14	.59
15	.65
16	.51
17	.65
18	.68
19	.74
20	.63
21	.55
22	.61
23	.58
24	.58
25	.62
26	.54

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27	.68
28	.67
29	.52
30	.45
31	.60
32	.41
33	.46
34	.48
35	.61
36	.53
37	.57
38	.49

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Multi-factorial solutions were investigated using a maximum likelihood factor extraction with varimax and direct oblimin rotations. However, no clear factor structure emerged and, with the oblimin rotation, the factors were found to be highly inter-correlated, for example, a two-factor extraction resulted in a correlation between factors of  $-.51$ . These findings therefore support an underlying common factor of positivity.

8.4 *Conclusions*

The finding that 184 patients out of the 194 respiratory patients who completed the SLQ could identify at least one positive consequence of illness suggests that positivity in illness is common and is experienced by patients of different illness types. On average, 12 of the 38 items of the SLQ were endorsed by the sample.

This study was also concerned with the correlates of positivity and considered a number of potential correlates including illness type. The findings suggest that positivity is determined by intrinsic rather than situational factors. That is, positivity is determined by what the individual brings to the situation, i.e., the illness, in terms of their spiritual and / or religious beliefs and a



personality disposition high in extraversion, and not the situation itself. These findings replicate Park et al.'s (1996) work on religion and stress-related growth and also the properties of the PTGI (Tedeschi & Calhoun, 1996) with respect to its correlation with extraversion and an absence of a significant correlation with neuroticism. The religiosity / spirituality variable correlated with the majority of the SLQ items. As one would expect, a sense of spirituality / religiosity was associated strongly with spiritual / religious gains as well as existential benefits of illness. Extraversion correlated with less (nine) items and the coefficients were lower in comparison with those received for the religiosity / spirituality variable. Significant item correlations with extraversion were achieved for items implying the use of illness as an occasion for trying new things and living life to the fullest, as well as those relating to existential gains and self-improvement as a consequence of illness. With the exception of the items 'Because of my illness I have more to offer other people' and 'I have been an inspiration to others', correlations with other items referring to social gains, for example, improved relationships with others which was found by Tedeschi and Calhoun (1996) to be the strongest correlate of extraversion, failed to reach significance.

Consistent with the findings of the first study of this thesis, positivity was not related to demographic factors of age and gender, nor was it related to race / ethnic group although a number of the race / ethnic groups were under-represented thus rendering statistical comparisons somewhat meaningless.

Although the degree of positivity did not differ significantly across the five main respiratory illness types studied, there was a tendency for patients with illnesses of relatively short duration, in particular tuberculosis and lung cancer to be more positive than those with chronic illness types. In addition, the low mean SLQ score of 9.11 for the sleep apnoea group and the comments received from some patients with this condition suggest that patients have to be ill enough and indeed to perceive their condition as an illness in order to perceive positive consequences. This replicates the finding reported in study 4 of a weak association between positivity and poorer fatigue symptoms at the initial assessment. In addition, support is given to Tedeschi et al.'s (1993) claim that growth is more likely for events that are more painful and

challenging. The findings of this study do not replicate those of study 1 regarding an association between positivity and illness duration.

A failure of this study to replicate findings in the existing research of an association between positivity and social resources (for example, Viney, 1986) may be explained by the crude indicator of social support used in this study. Only 39% of the sample provided a number of people whom they could talk to about their illness and a further 51% chose alternative means of expressing their answer. Thus, this item posed some patients difficulties. In addition, social support availability rather than satisfaction was measured. The value of social support satisfaction over availability is documented in the literature (Sarason et al., 1987). Satisfaction with social support rather than its availability correlated with the SRGS (Park et al., 1996).

As with the existing measures of general positivity (PTGI; SRGS), responses to the SLQ were unrelated to socially desirability / defensiveness. Finally, the results from the principal components analysis suggest that positivity is uni-dimensional. That is, although the number of themes identified in the literature and in study 1 of this thesis, and the wealth of explanations for positivity in illness (see chapter 2) would imply that positivity is multi-dimensional, there is one overall type of positivity with positivity representing a single construct. Greater attention will be devoted to this issue in the following chapter.

## CHAPTER 9

### DISCUSSION

“All in all, I have come off very well”  
(51 year old female treated for ovarian cancer)

#### 9.1 *Overview of the Thesis*

The overall objective of this thesis is to present a more comprehensive measure of the positive consequences of illness than the existing measures detailed in chapter 2 and to use this new measure to address previously unanswered questions regarding positivity in illness. The programme of research took the form of five studies.

The first study was concerned with the generation of an item pool for the measure of positivity – the SLQ. Fifty-five individuals who presented themselves as having experienced something positive from their illness were asked to share these positive experiences either in an interview or via a questionnaire. The content of the interview and questionnaire probe items was guided by the review of the literature on positive consequences of illness presented in chapter 2. These items elicited particularly rich accounts of positivity which, following a thematic analysis, were organised into the following 17 main themes (presented in descending frequency order): improved relationships with others, positive consequences for others, self-improvement, reappraisal of life, reorganisation of life, spiritual gains, changes in priorities, acquisition of skills and participation in new activities, self-awareness, acquisition of general knowledge, relief from responsibilities, sensitivity to emotions, resolution of past concerns, perception of illness as a challenge to overcome, practical gains, confrontation of current concerns, and greater respect for the environment. A number of sub-themes were also identified some of which are contradictory in nature and which appear at face value to be negative. While the main themes or domains of positivity identified in this study are cited in the literature, the diversity of sub-themes presented,

in particular those relating to spiritual gains and enhanced self-awareness, is not matched by the literature. A total of 23 novel sub-themes were identified.

Items selected for the SLQ took the form of quotes referring to prominent themes and sub-themes identified in study 1. With the exception of practical gains and greater respect for the environment, all themes were represented by the 70 items included in the first draft version of the SLQ. A pre-test of these items by five colleagues resulted in the rejection of four items.

The second study of this thesis was designed to refine the 66-item questionnaire. The SLQ was administered to 41 of the participants of study 1, 37 patients with chronic lung disease, eight members of a cancer support group and five patients attending a healing clinic. Items were considered eligible for removal if they elicited responses with poor distributions, with particular attention paid to skewed distributions, if they produced high inter-item correlations and were thus redundant, and if they did not tap into the general construct of positivity in illness as indicated by low factor loadings from a principal components analysis. Comments volunteered by participants were also taken into account. This process led to the removal of 28 items. The remaining 38 items of the refined SLQ represent 10 of the positive consequences of illness themes identified in study 1.

The refined questionnaire was subjected to psychometric testing, which firstly, in study 3, took the form of establishing properties of reliability and responsiveness to change. In this study, the SLQ was administered to the following three groups of patients on two occasions: 20 patients with COPD completed the SLQ on admission to the waiting list for pulmonary rehabilitation and 7 weeks later at the start of rehabilitation; 35 COPD patients at the start and end of a 7-week pulmonary rehabilitation programme; and 29 cardiac patients at the start and end of a 6-week cardiac rehabilitation programme. There was evidence of consistency in the responses to the SLQ of the waiting list control group with a re-test reliability coefficient of  $r(19) = .90; p < .001$ . Internal consistency was also confirmed with a Cronbach's alpha across all three samples of .93. While there was no evidence of a change in positivity amongst patients who had received no rehabilitation, pulmonary and cardiac patients receiving rehabilitation experienced a significant increase in positivity endorsing, on average, three and four additional items respectively post-

rehabilitation. Thirty-three of the items were endorsed more frequently post-rehabilitation.

Change in positivity was not predicted by age, gender, initial levels of positivity, or whether the patients had COPD or cardiac illness.

A further study concerned with the psychometric properties of the SLQ addressed predictive validity. Study 4 used the SLQ to predict health outcome in 72 patients with CFS over a 6-month period. Patients completed the SLQ, a measure of fatigue (the Fatigue Questionnaire; Chalder et al., 1993), and a measure of mood (the GHQ; Goldberg & Williams, 1988) upon entry to the study and at 3 months and 6 months thereafter. While an improvement in fatigue and mood scores was seen over the 6-month period, positivity did not change significantly, lending further support for its properties of reliability over time. Although initial levels of positivity did not correlate significantly with follow-up fatigue change scores, the pattern of correlations for the majority of the fatigue dimensions at 3 months and all fatigue dimensions at 6 months was in a positive direction implying a slight tendency for greater positivity upon entry to the study to be associated with greater improvement in fatigue. With respect to mood change scores, the pattern of correlations at 3 months and 6 months was once again non-significant and in the opposite direction suggesting a weak association between higher levels of positivity and a smaller degree of improvement in mood. This study thus provides limited evidence that the SLQ predicts health outcome. Explanations for the absence of significant findings will be addressed in section 9.4.2.4 of this chapter.

Studies 3 and 4 provide an insight into the prevalence of positivity in illness in three different illness types, however, the issue of prevalence was not addressed systematically until study 5, which examined positivity in 197 patients representing five illness types: asthma, chronic respiratory disease, lung cancer, sleep apnoea, and tuberculosis. With 184 patients identifying at least one positive consequence of illness and an average of 12 out of 38 positive consequences endorsed by the sample as a whole, positivity in illness would seem to be a relatively common phenomenon and one which is experienced by patients from different illness backgrounds. Positivity was compared across the illness types and although there were trends in the differences in positivity expressed by the patient groups, these differences were not significant,

$F(3,190)=0.53;ns$ . Patients were also classified according to whether or not they had a terminal illness, once again differences between these groups were non-significant,  $t(191)=.61;ns.$ , with both terminal and non-terminal illness groups endorsing on average 12 positive consequences. In addition to illness type, other potential correlates of illness were considered, these included the presence of co-morbidity, illness duration and illness severity as indicated by degree of breathlessness, age, gender, race / ethnicity, the availability of social support, spirituality / religion, and personality including a tendency towards social desirability / defensiveness. Only two significant correlates of positivity were identified. Patients with a sense of spirituality, including those with a religious orientation, were significantly more positive than those who were neither spiritual nor religious,  $t(188)=-3.74;p<.001$ . There was also evidence of a significant association between positivity and extraversion,  $r(174)=.16;p<.05$ . These two significant variables were identified by a multiple regression analysis as significant independent predictors of positivity accounting for 8.5% of the variance in positivity. A final concern of this thesis rested with the factor structure of the SLQ. Data on the refined SLQ gathered in studies 3, 4, and 5 were pooled generating a total sample size of 350 and were initially entered into a principal components analysis. A strong first factor of positivity accounting for 33.31% of the variance amongst items was interpreted from this analysis and also appeared as the most sensible solution from a maximum likelihood factor extraction. Thus, rather than a multi-dimensional structure to positivity, an underlying common factor of positivity was supported.

In summary, this thesis has described the development of a new measure of positivity in illness - the SLQ and has subsequently confirmed its properties of internal and re-test reliability and responsiveness to change. The use of the scale to predict health outcome hinted at a weak relationship. The scale was also used to identify the prevalence and correlates of positivity. Finally, the thesis uncovered the uni-dimensional nature of positivity in illness.

## 9.2 *Justification for the Programme of Research*

While the field of post-traumatic / stress-related growth (for example, Park et al., 1996; Tedeschi & Calhoun, 1996) has become particularly vibrant especially within the last decade,

relatively few studies have treated positivity in illness as a subject matter in its own right. As noted in the opening section of this chapter and indeed acknowledged in the literature, there are a number of unanswered questions regarding the positive consequences of illness. While there are some studies (for example, Collins et al., 1990; Laerum et al., 1988) that, on the basis of interview data, cite percentages of patients experiencing positive outcomes of illness, the prevalence of positivity in illness had not been addressed systematically prior to this thesis. In addition, no comparisons of prevalence across different illness groups, including minor illness, had been performed. Although there has been a thorough treatment of the correlates of post-traumatic / stress-related growth (Park et al., 1996; Tedeschi & Calhoun, 1996), no systematic investigation of the correlates of growth as a result of illness could be located in the literature. Finally, prior to this thesis, there had been no formal investigations of whether positivity could be enhanced amongst patients (note, Cruess et al.'s (2000) study was published after the programme of research for this thesis had commenced).

In order to address these issues, adequate tools designed specifically to measure the positive consequences of illness are required. Existing measures, for example, the Benefit Appraisals Scale (Tennen et al., 1992) and the SWIS (Hyland & Kenyon, 1992) measure only a sample of the diverse themes cited in study 1 of this thesis and are thus limited in their focus. In this thesis, the SLQ is presented as a more comprehensive measure of positivity with acceptable psychometric properties of reliability, validity and responsiveness to change. The SLQ was used to provide an insight into the previously unexplored areas of prevalence and correlates of positivity in illness. The findings of the studies of this thesis, which have put the SLQ to use, also introduce some important theoretical issues relating to the cause of positivity in illness.

### 9.3 *Theoretical and Practical Issues Arising from the Findings*

#### 9.3.1 Prevalence of positivity

The numerous accounts of positivity reported in the literature would imply a high prevalence of this phenomenon despite its general neglect in quality of life assessment. Support for this implication is provided by the findings of this thesis. Firstly, the number of people who

were involved with study 1 of this thesis gives testimony to the prevalence of positivity in illness. Secondly, it would appear that most people who have encountered illness experience positive consequences to some degree, even if it takes the form of just one positive consequence. In study 3, with the exception of six (7.1%) COPD patients (two within the control condition and four within the pulmonary rehabilitation sample), all patients endorsed at least one positive consequence of illness at the first assessment (upon entrance to the waiting list for control patients and prior to rehabilitation for the rehabilitation samples). The mean (standard deviation) number of positive consequences endorsed across the three samples at the first assessment varied between 7.51 (5.83) (pulmonary patients in the rehabilitation condition) and 13.21 (5.88) (cardiac rehabilitation patients). In study 4 only one (1.4%) out of the 72 CFS patients failed to endorse any of the positive consequences of illness at the first assessment, and the mean (standard deviation) number of SLQ items endorsed was 12.17 (7.99). Finally, only 10 (5.2%) of the 194 respiratory patients of study 5 were not able to identify with any positive consequences of illness described in the SLQ and the mean (standard deviation) number of items endorsed in this sample was 12.12 (8.44).

Thus, across the diverse samples investigated, the average number of positive consequences of illness with which patients are able to identify with at first assessment varies between eight and 13 and the percentage of patients within the samples who are able to recognise at least one positive consequence of illness described by the SLQ varies between 93% and 99%, a percentage of positivity comparable to that cited by Collins et al. (1990).

### 9.3.2 What are the factors favouring positivity? – Dispositional factors

The findings of this thesis suggest that some individuals have personal resources, namely an extraverted personality disposition and a sense of spirituality including religiousness, which favour positivity in illness. These resources are identified as antecedents in Sprangers & Schwartz's (2000) theoretical model of response shift and quality of life presented in chapter 1 of this thesis, and extensive evidence (for example, Park et al., 1996; Tedeschi & Calhoun, 1996) supporting these factors as predictors of positivity in adversity was presented in chapter 2.



Tedeschi and Calhoun (1996), for example, reported a correlation of .29 between extraversion and the PTGI, and in addition, extraversion was identified as the only personality dimension, assessed by the NEO Personality Inventory (Costa & McCrae, 1985), to correlate significantly with all five of the sub-scales of the PTGI. On the basis of these findings, Affleck and Tennen (1996) were led to the conclusion that extraversion is the most likely candidate to maintain an overall prediction of positivity in adversity.

Given the stimulus seeking nature of extraverts, in the face of an adverse event such as illness they are likely to be more adept at trying new things: extraversion correlated significantly ( $r(173) = .18; p < .05$ ) with the SLQ item 'My illness has made me live life to its fullest'. Thus it is argued (for example, Calhoun & Tedeschi, 1998) that such individuals are better positioned to benefit from adversity. Tedeschi and Calhoun (1996) present the use of social support amongst extraverts as a further explanation for the association between extraversion and PTGI scores. There is evidence in the literature that extraverts are also more likely to use coping strategies involving the use of positive reappraisals (McCrae & Costa, 1986). The mediating influences of social support and coping strategies however cannot be confirmed on the basis of the findings of this thesis as coping was not assessed and social support did not correlate significantly with the total SLQ score.

This thesis also identified spirituality, which may or may not include religious belief systems, as a significant correlate of positivity. The precise nature of spiritual / religious beliefs does not appear to be important as no differences in positivity were detected between those who were spiritual but not religious and those who were religious, nor were there differences according to specific religious organisation. This finding confirms existing research within the context of stress-related growth (for example, Park et al., 1996) although, in the literature, the focus has typically been on intrinsic religiousness, defined as: "the degree to which religion serves as an individual's framework of meaning" (Park et al., 1996, p.96) rather than on the broader concept of spirituality. On the basis of their findings with the SRGS, Park et al. (1996) proposed that individuals may draw strength from a salient, coherent belief system and this may guide them in their quest of finding meaning in adversity (Park et al., 1996). Illness may bring with it a

heightened awareness of the finite nature of life and lead individuals to seek solace in their belief in a soul or spirit that endures after death. Thus, as argued by Tedeschi and Calhoun (1996), religion (and spirituality in general) may be used as a coping mechanism and confer benefits following a trauma such as illness, in particular with respect to a strengthening of spiritual beliefs. Support for this claim is provided in this thesis with religiosity / spirituality correlating most strongly ( $r(192)=.40; p<.001$ ) with the item describing a deepening of religious / spiritual beliefs because of illness.

Religious participation may also offer individuals a social support network, which may in turn facilitate positivity. In this thesis, religiosity / spirituality correlated significantly ( $r(188)=.21; p<.01$ ) with the item describing illness as an opportunity to meet new people. However, a sense of spirituality that does not include religious participation may not necessarily present a social support network and indeed may be of a solitary nature. Once again, the influences of coping and social support on positivity cannot be verified.

Although a number of potential correlates of the positive consequences of illness were considered in this thesis, only extraversion and spirituality / religiousness emerged as significant. Thus, these findings suggest that positivity is determined more by what the individual brings to the illness in terms of personality disposition and spiritual identity rather than situational factors such as the characteristics of the illness itself and the availability of social support. However, one has to exercise a degree of caution with respect to this interpretation as a number of other unexplored factors, including those of a contextual nature, may also play an important role in determining positivity.

### 9.3.3 Situational antecedents of positivity – Can positivity be enhanced?

The finding that positivity is possibly a stable, dispositional variable implies that it may not be open to manipulation. Thus, intervention-induced positivity in illness cited in the literature (Crueess et al., 2000) and replicated in study 3 of this thesis may seem paradoxical. However, this finding suggests that this thesis has by no means exhausted all of the potential determinants of positivity – only 8.5% of the variance in positivity could be accounted for by extraversion and

spirituality / religiosity. Thus, as noted above, unexplored non-stable factors may also influence positivity. Within the field of subjective well being, the interaction of situational and dispositional factors has been acknowledged. Brief, Houston-Butcher, George, and Link (1993) recognised the value of integrating both bottom-up (situational) and top-down (dispositional) theories to explain subjective well being in the context of health. Both personality (negative affectivity) and objective health status were found to indirectly influence subjective well being through their direct effects on the interpretation of health.

There are a number of factors that could have been responsible for enhancing positivity amongst the pulmonary and cardiac rehabilitation patients in study 3 and there are also a number of factors that can be ruled out straight away. It could be argued that the mere exposure to items describing positive consequences of illness may encourage patients to think about their illness within a more positive framework and to subsequently recognise its positive consequences. This possible explanation can be ruled out on the basis of the re-test reliability data for the pulmonary patients who were on a waiting list for rehabilitation and who thus, for the duration of the study, did not receive rehabilitation. Patients may have been more positive following rehabilitation as a way of expressing their gratitude to the rehabilitation staff. Therefore, the improvement in positivity may not reflect a true increase in the number of positive consequences of illness rather a tendency towards social desirability. However, while social desirability / defensiveness was not measured in study 3, it was found to be unrelated to SLQ scores in study 5. It could also be proposed that the content of the rehabilitation programme specifically teaches patients to be more positive. However, unlike the cognitive behavioural stress management programme used by Cruess et al. (2000) to induce positive changes amongst breast cancer patients, the rehabilitation programme described in this thesis was not designed to enhance positivity with rehabilitation. Indeed, the rehabilitation staff were not only surprised by the presence of positivity at the start of rehabilitation but they were particularly taken aback by the substantial increase in positivity following rehabilitation.

Improvements to quality of life following pulmonary rehabilitation are cited in the literature (Goldstein, Gort, Stubbing, Avendano, & Guyatt, 1994; Ries, Kaplan, Limberg, &

Prewitt, 1995; Wijkstra, TenVergert, van Altna, Otten, Kraan, Postma, & Koeter, 1995), where in these cases improvement is indicated by a reduction in the degree of dissatisfaction with life. This improvement is likely to result from a combination of improved physiological function, education and psychological support, as well as the social aspects that are often present. It is possible that these factors also play a role in enhancing positivity.

The rehabilitation programme may have encouraged patients to use more adaptive coping strategies, such as problem-focused strategies. The very nature of the rehabilitation programme, for example the key component of patient education, supports the use of problem-focused strategies as opposed to emotion-focused avoidance methods. Adaptive coping strategies such as active, problem-focused strategies have been found to promote positivity in illness (Collins et al., 1990).

For many patients, the rehabilitation experience is a social one. This is reflected by the content of the item that exhibited the greatest improvement following rehabilitation: 'My illness gave me the opportunity to meet new people' (48% endorsement prior to rehabilitation and 77% following rehabilitation). In addition to the support offered by the rehabilitation staff, patients may receive support from fellow rehabilitation participants. Although the findings of study 5 did not support a relationship between social support availability and positivity, in chapter 2, evidence was cited of an association between the presence of supportive relationships and better rehabilitation outcomes amongst accident victims (Janoff-Bulman & Wortman, 1977).

Rehabilitation may offer patients the opportunity to compare themselves to other individuals in a similar situation to themselves. In particular, according to the cognitive adaptation theory (Taylor et al., 1983) presented in chapter 2, patients may be motivated to perform 'downward social comparisons' with less fortunate others for the purposes of self-enhancement. For example, a patient may feel that he or she is able to engage in a greater number of activities despite being ill compared with other patients attending rehabilitation. Such downward social comparisons may not only bolster one's self-esteem but may encourage a more positive perspective on the impact illness has had on one's life (Taylor et al., 1983).

Although on the basis of the findings of this thesis it is possible to conclude that patient management enhances positivity, reasons for this improvement are largely conjecture.

#### 9.3.4 Is reported positivity perceived or real?

Positivity in illness can be explained as a delusion or as genuine existential growth (Sodergren, Hyland, Crawford, & Partridge, paper submitted for publication). When patients report that they have experienced gains from illness, these reports may be founded on perceptual biases or 'illusions' (Taylor et al., 1983) rather than real gains. Cognitive explanations of positivity in adversity adopt this standpoint by proposing that positivity represents a distortion of the unpleasant aspects of reality and that this is achieved by either repressing / denying their presence (Kagawa-Singer, 1993) or by accepting the reality of the situation by reframing it to present it and one's self-image in a more positive light. These latter processes form the centrepiece of adaptation level theory (Helson, 1964), social comparison theory (Festinger, 1954), Taylor's (1983) cognitive adaptation theory (Taylor et al., 1983), and control theory (Carver & Scheier, 1982), presented in chapter 2. These reframing and repressive processes are essentially ego-protective.

While negative affectivity predisposes towards a negative interpretation and detection of events (Larsen, 1992), people low in negative trait affectivity are more prone to reframe their situation in a positive way (Hyland 1987; Carver & Scheier, 1990). Consequently, if reframing is the basis of positivity, then positivity should correlate negatively with neuroticism. McCrae and Costa (1986) identified a relationship between low neuroticism scores and a tendency to 'draw strength from adversity' as a coping strategy amongst community-dwelling adults.

Denial differs from reframing in that the negative situation itself is repressed. Repressors tend to summon up positive images as a way of distracting themselves from the potentially negative experience (Boden & Baumeister, 1997). Hence repressors should search out positive reasons why illness has some benefit and the negative aspects of illness should lie outside their awareness. Repressors report low trait anxiety, even though, in reality, they have higher levels of

anxiety, and therefore, as for reframing, people reporting low anxiety should have higher levels of positivity.

The results of study 5 did not confirm the prediction of both the reframing and repression explanations of positivity of a significant negative relationship between neuroticism and positivity. A lack of a significant relationship with neuroticism has been reported before both in the case of positivity in illness (Hyland & Kenyon, 1992) and post-traumatic growth (Tedeschi & Calhoun, 1996). In addition, in the present study the direction of the effect (i.e., a positive relationship between positivity and neuroticism) was opposite from that predicted by the reframing and repression theories. In view of the fact that reframing is reported in patients elsewhere (Taylor et al., 1983), it may be that reframing is used primarily to reduce negativity in illness, rather than to increase positivity. Neuroticism correlates highly with negativity in illness, as measured by quality of life scales (Hyland et al., 1994; Jones et al., 1989). Of the various types of reframing listed by Taylor et al. (1983) only one (construing benefit from harm) seems to suggest increased positivity as opposed to reduced negativity.

The low reports of anxiety amongst repressors reflect a defensive, excessively self-aggrandizing response style, i.e. they are high in defensiveness (Weinberger et al., 1979). The repression explanation of positivity therefore also predicts a positive relationship between positivity and defensiveness. A significant relationship between these two variables was not however found in this thesis, which is consistent with repression not having a major impact on positivity and also replicates the findings within the field of stress-related / post-traumatic growth (Park et al., 1996; Tedeschi & Calhoun, 1996).

Finally, the use of denial amongst participants of the first exploratory study of this thesis was not obvious with only a minority of participants not referring to any negative aspects of their illness. This is again consistent with Tedeschi and Calhoun 's (1996) finding that when benefits of trauma are expressed, the difficulties encountered are not denied.

Although one cannot assert with complete confidence that, for individuals who report positive consequences of illness, cognitive processes play no role, i.e., that perceptual changes

either in the form of reframing or repression have not taken place, the correlational data of this thesis do not favour these processes.

A third interpretation of positivity is existential growth. According to this interpretation, reports of positive consequences of illness are actual consequences that have been experienced (Sodergren & Hyland, 2000; Sodergren et al., paper submitted for publication), that is, illness leads to a fundamental change in the nature of the person, i.e., growth or self-actualisation, rather than simply a change in perceptions. Tedeschi et al. (1998) for example, as reported in chapter 2, describe the use of trauma as a 'springboard' to further individual development or growth. In study 1, the enthusiasm with which the participants shared their positive consequences of illness would suggest that these positive consequences are real. Also, 93% of the participants in this first study reported positive changes to their character as a result of illness. Three of these participants made explicit reference to self-growth, for example participant 22 said:

'My daughter says I have grown'

Implicit in the existential interpretation of positivity is that people become ill for a reason (for example, LeShan, 1984; 1994) and this was a recurrent theme amongst the participants of study 1. Further evidence in support of the existential perspective on positivity in illness can be found by once again revisiting the correlational data. One would expect extraverts, that is individuals who are able to accommodate novel situations and who respond to these situations by actively trying new things, to be more likely to use illness as an opportunity for growth (Calhoun & Tedeschi, 1998). As reported above, extraversion correlated significantly with the total SLQ score and nine of the individual items of the SLQ including the self-growth item 'My illness made me a better person' ( $r(175) = .20; p < .01$ ).

Existential growth may also take the form of spiritual gains, which, as noted earlier, are more likely amongst individuals with a spiritual identity, which may or may not include a sense of religiosity. A significant positive relationship between spirituality / religiosity and the total SLQ score and 23 of its items was identified giving further credence to the existential interpretation.

Although, on the basis of the correlates of positivity identified in this thesis, one is led to favour the existential over the cognitive interpretation of positivity, the issue of whether reported

gains from illness are real or apparent cannot be settled unambiguously on the basis of these findings. One possible method of confirming whether the positive consequences of illness reported by individuals have actually occurred for these individuals would be to question their significant others. The quote presented above by participant 22 of study 1 refers to the acknowledgement by a significant other that a positive change has occurred. Park et al. (1996) used significant others to validate responses to the SRGS and found good participant – informant concordance with a correlation between the SRGS scores of participants and informants of  $r(72)=.21; p<.05$ . However, the authors voiced some concern about the ability of informants to detect changes of a private nature, for example changes in life philosophy. In addition, the experience of positive consequences of illness may in itself be personal. For one participant of study 1 (participant 39), the interview represented her first opportunity to communicate the positive consequences of illness that she had experienced as she felt that by communicating them to her husband he would think that she had 'gone mad'.

The literature on proxy assessments of QOL (for example, Blazeby et al., 1995; Browne, 1997) presented in chapter 1 also questions their accuracy. In particular, it was noted that the proxy is likely to underestimate the quality of life of the patient (Browne, 1997) and thus, it follows that there may be an insensitivity to the positive consequences of illness experienced by the patient. In addition, positive changes in the patient that are detected may be attributed to factors other than illness, for example, giving up work.

As a final point of consideration, it is possible that both existential and cognitive processes co-exist with cognitive processes facilitating existential change. Within the context of control theory (Carver & Scheier, 1982) for example, illness may prompt individuals to redefine their goals relating to their ideal and ought-to-be self-states along existential dimensions. Thus, illness may not be experienced as an obstacle to the achievement of goals rather a catalyst for the creation of new goals which can be realised given existential change in the form of greater self-actualisation or personal growth.

In summary, although the findings of this thesis support the conclusion that existential growth is the main factor underlying positivity in illness, they do not place one in a position to



completely reject claims that positivity is, either partly or entirely, a result of cognitive processes involving illusions or perceptual biases including reframing and denial / repression.

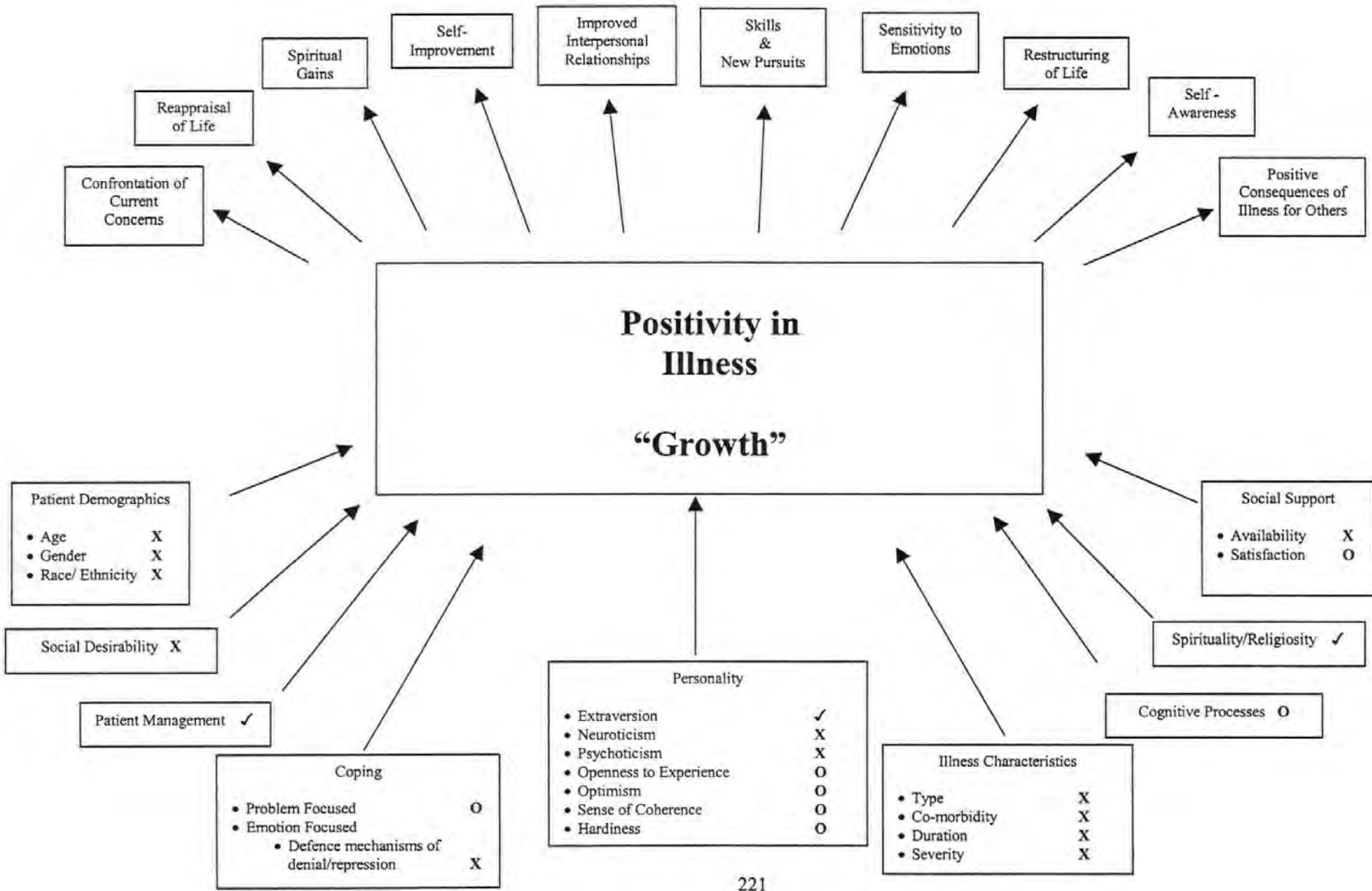
### 9.3.5 Are there different dimensions to positivity?

The findings of the factor analysis of data gathered from three of the studies of this thesis lead one to draw a conclusion regarding the nature of positivity in terms of its dimensionality. Intuitively, one would expect positivity to possess a multi-dimensional structure for the following reasons. Firstly, as suggested above, there is likely to be a number of factors responsible for positivity i.e. multiple routes into positivity. Secondly, positivity takes a number of different forms, as reflected by the number of themes identified in the literature and in study 1, and subsequently included in the SLQ. These themes can take the form of benefits to the self as well as altruistic benefits both of which embrace a number of different types of positivity.

The findings of this thesis however, suggest that despite the different types of positivity and multiple routes into positivity, positivity represents a single construct and is thus uni-dimensional. Park et al. (1996) were also led to a similar interpretation of positivity in the context of stress.

On the basis of the findings of this thesis, one is able to propose a model of positivity in illness (Figure 9.1) incorporating a number of factors (stable and unstable) that may be responsible for positivity. The model identifies these factors according to whether or not they have gained supporting evidence in this thesis. Positivity is represented as a single construct, referred to as growth, which can be experienced in a number of different ways by patients as well as other individuals in their environment.

Figure 9.1 Model of positivity in illness



Notes to accompany Figure 9.1.

- ✓ Evidence supporting factor;
- X No evidence to support factor;
- O Factor not explored in this thesis / inconclusive evidence gained;
- The factors influencing positivity (inputs) are likely to be inter-related as are the types (outputs) of positivity;
- The types of positivity represent the themes included in the revised form of the SLQ;
- These types of positivity embrace a number of sub-types not identified in the model

The reservations expressed earlier concerning the conclusions drawn from the data of this thesis, upon which this model of positivity rests, stem essentially from the limitations of this thesis and these form the focus of the next section.

#### 9.4 *Limitations of the Thesis*

As this thesis centres on the development of a measure of positivity in illness and its application to address issues regarding positivity, this section will commence with a discussion of the limitations of this measure and will then focus on the methodological issues of each study in turn.

##### 9.4.1 Limitations concerning the SLQ

It could be argued that the completion of the questionnaire items, especially those of existential content, necessitates some degree of self-insight, which some individuals may not have. In addition, during the scale development phase, several respondents commented that the items describing positive effects on others could not be completed without seeking the opinion of others and indeed, in the first exploratory study, one participant (participant 43) who completed a postal questionnaire asked his wife to complete the item regarding what others have learnt from his illness. In addition, in study 2 it was noted that items in the pilot version of the SLQ describing positive consequences of illness for others most frequently attracted the 'not sure' response option. Thus, these items may place the respondent in a position of not being able to complete the questionnaire or could lead to unintentional false responses to items. However, in the initial scale development stage described in chapter 5, items were screened for their ease of comprehension and the number of missing responses was found to be infrequent with 31 out of the 66 items of the

original pilot scale completed by all 91 participants and the largest number of missing responses for any one item was four. It must be noted however that six questionnaires were not entered into the analysis as more than 10 of the items were not responded to and the reason for their non-completion cannot be ascertained.

A further explanation for missing responses to the items of the SLQ could lie with individuals experiencing certain types of positivity described in the questionnaire prior to rather than as a consequence to illness. In such cases, an item, for example 'My illness made me live life to its fullest', elicits a written response such as 'I have always lived life to its fullest', rather than an endorsement of one of the response options. Thus, it could be inferred that, in such a case, by endorsing a disagree response option, the individual may feel that he / she is denying the presence of this type of positivity.

Although each of the questionnaire items direct respondents to consider the types of positivity that have arisen as a consequence of illness, one cannot claim with any degree of confidence that, when completing these items, respondents are exclusively using illness as their frame of reference. For example, the positive consequences endorsed may be a product of factors other than illness such as maturational changes. Within the context of response shifts, Sprangers and Schwartz (2000) recognise the potential for a response shift to occur merely with the passage of time and the authors question the extent to which a response shift is the consequence of the passage through different developmental stages in life (Erikson, 1963). In the first exploratory study of this thesis, participant 28 expressed her uncertainty regarding the extent to which the positive consequences she described could be attributed to her illnesses or to her growing older and gaining wisdom.

The absence of negatively valenced items in the SLQ, as with other positive outcome scales such as the BFS (Cruess et al., 2000), the PTGI (Tedeschi & Calhoun, 1996), and the SRGS (Park et al., 1996), does not allow for the control of acquiescence in responding. However, since the scale was concerned purely with positive changes that may occur as a result of illness, the items could not be worded in a negative direction. In addition, as reported earlier, the findings of study 5 suggest that responses to the SLQ are unrelated to defensiveness / social desirability.

A final concern regarding the SLQ rests with the bi-modal method of coding responses, which are initially made on a Likert-type response scale. It could be argued that this method results in a loss of information. This simplified scoring procedure was designed to avoid response bias between patients in endorsing 'Strongly agree' and 'Agree' response options. In addition, in this thesis the SLQ has been used to identify whether or not individuals have experienced any of the 38 types of positivity rather than the degree to which they are experienced. Given this objective, the rationale for modifying the original three-point response scale ('Agree' / 'Not sure' / 'Disagree') of the pilot questionnaire could be questioned. However, as argued in chapter 5, the five-point scale allows respondents greater freedom in their responding and could thus be a contributing factor to the low number of missing responses to the revised scale.

Although a number of limitations of the SLQ have been identified, its application in this thesis and by health professionals and academics in other research centres reflects its value as a tool for tapping into the different ways in which positivity is encountered in illness.

#### 9.4.2 Methodological issues surrounding the studies

9.4.2.1 Study 1. The open-ended question methodology used in study 1 to generate types of positivity could potentially be constrained by the ability of respondents to articulate their experiences, a point discussed in chapter 2. However, given the richness of accounts offered by both the interviewed and postal questionnaire participants, this does not appear to be an important issue in this study

The accuracy of the reports of positivity could not be determined in this study as there was no corroboration from significant others (although as reported above, one participant actually asked his wife to complete the item concerning what, if anything others have learnt from his illness). As noted in chapter 2, researchers (for example, Hayry, 1991; Lehman et al., 1993) have recognised the potential for reports of positivity to be fabricated. However, this study was more concerned with the generation of themes of positivity rather than with determining whether or not these consequences of illness were actually experienced.

A total of 17 positive themes were identified in the first exploratory study of

this thesis. However, these themes are not mutually exclusive and the justification for treating them as separate themes can be questioned. For example, the 'Redefinition of priorities' theme may fall under the umbrella of the 'Restructuring of life' theme, in addition, greater self-awareness may involve greater sensitivity to emotions, and both of these outcomes of illness were treated as separate themes.

Only one researcher carried out the thematic analysis of the interview and questionnaire transcripts with advice sought where necessary and only informal checks on reliability carried out by a second person. Given more resources, a second person could have been involved in the coding process and inter-rater reliability could have been established. This would have been of particular value given the inter-related nature of themes with the assignment of sub-types of positivity to one theme over another often an arbitrary task.

Some of the sub-types of positivity identified, for example, less tolerance of others and a breakdown of relationships with others, could be criticised for being negative in their orientation and indeed, this constituted a criterion for the removal of items in the subsequent scale development study. However, this early exploratory study welcomed participants' idiographic definitions of positivity, an approach also adopted by McMillen, Zuravin, and Rideout (1995) in their study of child sexual abuse which found them confronted with reports from women which at face value appeared negative but which were expressed as positive outcomes and thus construed by the researchers as positive.

The comparisons of the number of themes expressed across typologies of respondent in this highly selected sample were carried out tentatively. Firstly, difficulties were encountered in classifying participants; for example, the distinction between currently ill and recovered was often blurred. In addition, the number of participants who were eligible for comparison was, in some cases, low, for example, only 18 participants who had recovered from illness specified the length of time since recovery and were thus entered into the correlational analysis. The extent to which the trends observed could be generalised to other populations is thus debatable.

9.4.2.2 Study 2. Since the second study of this thesis is concerned with the development of the SLQ based on the themes identified in study 1, methodological issues relating to this study overlap with the limitations of the SLQ itself identified above. There is a further issue regarding the nature of the additional socio-demographic items included in the SLQ. Respondents were asked to make the distinction between being currently ill or recovered which, as noted above, was often difficult to make, and the indicator of social support availability, namely with whom, if anyone, the respondent lives with, could be questioned for its validity. However, these items were included for descriptive purposes only and did not serve to provide any information about the correlates of positivity.

9.4.2.3 Study 3. Methodological issues relating to study 3 concern the use of the SLQ to detect change following an intervention namely, pulmonary / cardiac rehabilitation. In this study, the long-term effects of rehabilitation on positivity were not assessed therefore the duration of the effect of rehabilitation on enhancing positivity could not be determined.

Although this study ruled out age, gender, and initial levels of positivity as predictors of improvement in positivity, the role of other factors, such as illness duration and personality, in enhancing positivity were not explored. In addition, the relationship between changes in positivity and other potential outcomes of rehabilitation such as the use of more adaptive coping strategies, lifestyle changes, and improved psychological and physical health were also unexplored in this study.

A further limitation of this study is that not all COPD were admitted to the rehabilitation programme, with the criterion for acceptance onto the programme representing anticipated benefit from rehabilitation, therefore the group of COPD patients admitted to rehabilitation might include a higher proportion of patients with positive beliefs about illness. In addition, as social desirability was not assessed until study 5, in the context of this study, one was not in a position to rule out the possibility that patients might appear more positive at the end of rehabilitation as a way of expressing their appreciation to the rehabilitation staff, a point discussed earlier.

9.4.2.4 Study 4. This study attempted to address the issue of whether patients who experience positive consequences of illness are 'better off' either psychologically or physiologically than those who do not. Although the evidence in the literature (for example, Affleck et al., 1987; Croog & Levine, 1982; Cruess et al., 2000) points to the adaptational significance of positivity, the results of study 4 did not provide any overwhelming support for the notion that positivity in illness, as determined by responses to the SLQ, fosters better health outcomes as determined by measures of fatigue and mood. However, there are a number of methodological issues associated with this study that may account for this finding.

This study examined health outcome in only one patient group – CFS patients attending a complementary medicine centre. Thus, generalisations on the basis of this highly selected sample are questionable. It is possible for example that positivity is a more salient indicator of health outcome amongst individuals with life threatening illness such as cancer (Cruess et al., 2000) and heart disease (Affleck et al., 1987; Croog & Levine, 1992).

Health outcome assessment in this study took the form of a measure of disease symptomatology and mood. In order, to address the issue more comprehensively of whether patients who report positive consequences profit physically or psychologically, other indicators need to be considered. With respect to physiological health outcome, there could, for example, be an assessment of immune system function and, in patients with life threatening illness, survival rates could be evaluated.

A major methodological issue with this study and one that is likely to be primarily accountable for the lack of significant findings is the small sample size. The number of patients included in this study falls below that of the recommended minimum size for correlational analyses. For example, Lowenthal et al. (1996) cite a minimum sample size of 85 with alpha set at 0.05, a power specification of 0.80 and where a medium effect size of 0.5 expected. Time constraints placed on the nurses involved in the recruitment for this study resulted in an initial sample size of 72 and given the longitudinal nature of this study, there was some degree of patient drop-out albeit small, with 63 patients remaining in the study at 6 months.



Health outcome was assessed using fatigue and general health questionnaire change scores, which introduces reliability issues and to some extent is likely to put a restriction on the size of the correlation coefficients.

Finally, the short time scale (6 months) of this study may account for the absence of significant findings. Patients with CFS typically show a slow rate of improvement (Wessely, Hotopf, & Sharpe, 1998) thus, the 6-month period is not likely to capture a large amount of change in patients. Given the general trend for the correlation coefficients between positivity and fatigue and health change scores to increase over time, it is possible that significant results may have been achieved if the study had been extended perhaps to 12 months. As an example, at 6 months, the coefficients for the correlations between SLQ and change in duration of tiredness and percentage of time feeling tired were .22 and .21 respectively, this compares to correlations of .02 and .07 respectively at 3 months.

On the basis of these methodological issues, one is not in a position to dismiss a therapeutic role for positivity in illness.

9.4.2.5 Study 5. The final study compared the prevalence of positivity across typologies of patient. A failure to find a significant effect of illness type, race / ethnic group, social support categorisation, and religious group could be attributed to the size of the majority of the sub-samples falling below the recommended number. For example, Lipsey (1990) recommends a sample size per experimental group of 65 given a medium effect size, power of 0.80 and alpha set at 0.05. With respect to the comparison of positivity across illness types, only one of the five main illness groups (chronic respiratory illness) entered into this analysis satisfies this recommendation with a sub-sample size of 109.

As noted in chapter 8, the majority (104) of patients in this study presented more than one illness type. One does not know to what extent, when completing the SLQ, these patients are referring to their main diagnosis identified at the beginning of the questionnaire or to their other illness / illnesses. This has an obvious implication for the comparison of positivity across illness types. In addition, several of the patients with sleep apnoea described it as a condition rather than

an illness and thus questioned the relevance of a measure of the positive consequences of illness to their 'condition'.

The crude indicators of religiousness / spirituality and social support used in this study are of unknown validity. The religious / spirituality item may have been perceived as ambiguous by some respondents. For example, several participants commented that they were both religious and spiritual – this option was not offered although by specifying a religion, participants are by implication spiritual. However, on this point of specifying a religion, it cannot be assumed that patients who do so are in fact religious as a number of patients specified a religion and indicated that they were neither spiritual nor religious (in these cases, patients were regarded as not being religious). With respect to the item measuring social support availability, not only is there an issue of whether this variable is a good predictor of positivity (Park et al., 1996) but also the item itself may not be a good indicator of social support availability. A number of patients encountered difficulties in quantifying their response to this item with only 39% of the sample specifying a number of people whom they could talk to about their illness. In addition, one patient in response to the item claimed that she does not feel any need to talk about her illness. An indicator of the significance of the relationships could have been included. The rationale for the inclusion of these single item measures rather than tried and tested scales, for example, Gorsuch and McPherson's (1989) 8-item scale of intrinsic religiousness and The Social Support Questionnaire (Sarason et al., 1983), was the concern for patient burden and the time constraints imposed on the staff at the busy respiratory clinic.

Given the constellation of personality correlates of positivity identified in the context of post-traumatic growth (for example, Tedeschi & Calhoun, 1996), it could be argued that the EPQ-R (Eysenck et al., 1985) is too restrictive and that the NEO Five-Factor Personality Inventory (Costa & McCrae, 1985) used by Tedeschi and Calhoun (1996) would have been a better choice. However, the intention to avoid patient burden once again dictated the choice of instrument – the EPQ-R is shorter and simpler to complete in comparison with the NEO Personality Inventory. Further potential correlates, personality and other, of positivity unexplored by this study include optimism, openness to experience, hardiness, locus of control, a sense of coherence, coping

mechanisms and social support satisfaction. A consideration of these additional potential correlates of positivity represents an avenue for future research.

A number of the limitations of the studies could not be overcome given the scope of this thesis and these also pave the way for future research.

### 9.5 *Future Research*

As acknowledged in the stress-related growth literature (Park, 1998), research into positivity in adversity is in its infancy and although this thesis has made an attempt to address some of the previously unexplored issues, a number of important questions remain. As discussed earlier, caution needs to be exercised with regard to the conclusions drawn from the findings of this thesis because of its limited focus. It was noted, for example, that the research of this thesis could be expanded to evaluate a larger pool of potential correlates of positivity, examine the mechanisms of positivity in different patient groups, investigate in greater detail issues relating to enhancing positivity through patient management, and to use further indicators of health outcome in order to provide a more comprehensive assessment of the predictive utility of the SLQ.

One important and unresolved aspect of positivity referred to frequently in this chapter and in the literature is the relationship between positivity and coping. Further research is needed to determine the extent to which positivity is an outcome of active cognitive reappraisal and behavioural change (Collins et al., 1990) and meaning-based coping (Folkman & Greer, 2000), a form of coping involving positive reappraisals or 'benefit-reminding' (Affleck & Tennen, 1996) or an attribute distinct from coping. In addition, in chapter 2, the development of more adaptive coping strategies is itself identified as a positive outcome of stress including illness (for example, Schaefer & Moos, 1992) and this is replicated in study 1 of this thesis.

In chapter 2, positive consequences are documented in diverse traumatic contexts including divorce, combat and imprisonment, caregiving and bereavement. The extent to which the SLQ could be used to contribute to the understanding of individuals' positive experiences in these contexts is unknown. In addition, the extent to which the domains of positivity identified in study 1 vary as a function of the type of adverse situation could be explored.

The issue of when during the illness trajectory positivity occurs for individuals fell beyond the scope of this thesis but is an important research area. For example, should the SLQ be administered weeks, months, or years after the diagnosis of illness? Within the context of post-traumatic growth, Schaefer and Moos (1998) claim that, most often, positivity is the outcome of a developmental process that follows an initial stage of emotional distress and disorganisation, and that after the event has been fully assimilated over a period of several years, both positive and negative effects may be attenuated. In the literature, the most frequent time frame for positivity assessment is several years after diagnosis, for example, Collins et al. (1990) assessed positive consequences approximately 3 years post diagnosis. In study 1 of this thesis, several of the participants made reference to the fact that they would not have welcomed questions regarding the positive consequences of their illness soon after their diagnosis. In study 5, which was concerned with the prevalence and correlates of positivity, the SLQ was administered at least 3 months post-diagnosis as it was felt that this would allow patients enough time to assimilate at least some of the effects that illness has had on their lives, and an assessment any earlier than this was deemed to be inappropriate. As noted by Cohen et al. (1998), some aspects of positivity, for example greater support from others, might appear soon after diagnosis whereas other aspects, for example, an altered philosophy on life, might not become evident until some years later. In addition, in study 3, in the context of intervention-induced positivity, items of existential content, for example, 'My illness made me think about the true purpose of life', featured amongst those items that were resistant to change following rehabilitation although it must be noted that some existential items, for example, 'My religious / spiritual beliefs deepened because of my illness' did improve in this study. Cohen et al. (1998) also speculate that the antecedents of positivity might vary as a function of time frame, for example, event severity may serve as a significant positive predictor of growth but only when it is assessed some years after the trauma. These issues represent important routes for future enquiry.

Future research could also look at the issue of whether the correlates of positivity differ for individuals according to the type of positive consequences experienced, for example, does an

individual who profits interpersonally from illness differ from an individual who profits in terms of altered self-perceptions?

Finally, a further line of future enquiry could take the form of assessing the impact of completing a scale measuring positive experiences of illness, i.e. the SLQ, versus one relying on negative appraisals, i.e., traditional measures of quality of life, on mood. As reported in chapter 1, scales emphasising negative life quality are likely to leave the patient feeling demoralised (Dahl, 1992), indeed, this accounted for one patient withdrawing from study 4, this patient wrote the following (note, the ME Questionnaire refers to the Health and Fatigue Questionnaire):

“I am returning the ME Questionnaire unanswered for the following reason. When I answer this type of questionnaire it makes me realise all of the symptoms and I am usually very unwell for days afterwards. I do try to always look forward and keep a positive frame of mind when possible, so I’m sure you will understand.”

It thus follows that the completion of positive scales such as the SLQ may result in positive mood states and even prompt individuals to think more positively about their illness (though this thesis suggests that the mere completion of the SLQ does not lead to greater reports of positive consequences of illness). Indeed, the organiser of the Cancer Help Group who was involved in the recruitment of participants for study 2 noted that several people had commented that just doing the questionnaire gave them a new outlook on their cancer. This is just one issue relating to the practical relevance of this thesis, and in particular the SLQ. Further contributions of this thesis are presented below.

## 9.6 *Practical Relevance of the Thesis*

This thesis has resulted in the development of a measure of positivity in illness – the SLQ. Research with this scale reported in this thesis and also its potential uses are likely to make a significant contribution to the conceptualisation and measurement of the consequences of illness as well as health management.

### 9.6.1 Implications for the conceptualisation and measurement of health outcome

As mentioned in chapter 1, in the context of illness an overall assessment of life quality by definition requires a consideration of the often overlooked positive experiences of illness as well as the negative impact illness has had on life. Given the limited focus of existing positivity scales, the SLQ could be a good candidate for providing health professionals with an additional and more comprehensive perspective on the illness experience. This thesis has highlighted the prevalence of positivity, which was met with some degree of surprise by the health professionals involved in the studies. For example, a counsellor involved with the Cancer Help Group used the SLQ with a client who was described as normally having a negative view of herself and was thus expected to answer 'disagree' to all the questions. Yet, she was able to identify a number of positive aspects.

This thesis affords an insight into the nature of positivity, that is, that it is likely to involve real existential changes rather than perceptual biases or illusions and implies that such reports should be treated as real rather than dismissed as a distortion of more appropriate reactions to illness (Backman, 1989).

This thesis also sheds some light onto why some patients may be more likely to achieve positivity. Religiosity / spirituality, for example, is often an overlooked aspect of illness as noted in chapter 1 by its absence from a number of quality of life measures, but was identified in this thesis as one of the significant correlates of positivity. This implies that a patient's religious or spiritual resources may represent an important consideration for those concerned with the assessment of the broader aspects of the illness experience.

### 9.6.2 Implications for health management

The finding that positivity in illness may be more common than is often anticipated by health professionals suggests that health professionals should perhaps be more receptive to and reinforce in patients the expression of positive consequences of illness, whilst not undermining the negative aspects of illness. However, if one subscribes to the existential interpretation of positivity in illness with the belief that individuals become ill in order, for example, to 'grow' or self-actualise, care must be taken not to impose on patients the belief that they are responsible for

becoming ill. In addition, although this thesis implies that positivity is a common phenomenon, it is unlikely to be universal.

The SLQ has a potential for use in counselling, and indeed, as mentioned above, feedback received on its use in this context has been favourable affording both the patient / client and counsellor a different and more extensive perspective on illness and a possible framework to work towards for the future.

This thesis not only suggested a role for personal resources, i.e., personality and religiosity / spirituality in fostering positivity but also highlighted the potential for enhancing positivity through patient management. This finding implies that the level of health care provided to patients not only can reduce the amount of complaint they have about their illness (traditional quality of life gain) but can also improve quality of life in ways not previously investigated, namely positivity.

Finally, this thesis has considered the therapeutic properties of positivity and this is recognised as an important area for future research especially with respect to determining whether positivity confers physical health benefits. With respect to psychological health outcome, the expression of positivity may itself be construed as an indicator of good adjustment (Andreasen & Norris, 1972) or adaptation (Taylor, 1983). The finding that positivity fosters better health outcomes would provide further support for the need amongst carers to be sensitive to and cultivate expressions of positivity where they occur.

### 9.7 *Final Comments*

This thesis has addressed positivity in illness as a subject matter in its own right rather than as an unusual and unexpected phenomenon as it is often presented in the literature. This thesis conveys a number of important messages. Firstly, while individuals may not be happy to have found themselves in a state of poor health (although some of the quotes presented by participants of study 1 would contradict this) and did not set out to become ill, some individuals are able to look beyond the negative aspects of illness and find something positive either for themselves or others. Thus, positivity exists and takes a number of different forms. There are

likely to be a number of different routes into positivity with person and situational variables playing an important role. One cannot afford to overlook positivity in illness not only because of its important contribution to the conceptualisation and measurement of quality of life in illness but also for its potential healing properties.



## APPENDICES

**APPENDIX 1**

**PRESS RELEASE**

**(STUDY 1)**

## Press Release

**Public Relations Department**  
University of Plymouth, Drake Circus,  
Plymouth, Devon, PL4 8AA, United Kingdom

3 December 1996

### **HAS ILLNESS BROUGHT SOMETHING POSITIVE FOR YOU?**

**University researchers continue quality and meaning of life study**

Researchers at the University of Plymouth want to hear from anyone who feels that they have gained something positive from being ill.

The researchers want to know how and why patients feel that their illness has had some benefits - and at the same time find out what gives their life meaning.

Professor Michael Hyland, Director of the University's prestigious health-related Quality of Life Research Centre said: "This research is part of our overall strategy of understanding both the quality and the meaning of life in people who are or have been physically ill".

"We have found that a small number of patients say that they have gained something positive from being ill - some even say that life improved after they became ill".

"We want to find out how and why these patients react in the way they do - we may be able to learn something from them".

A positive outcome from illness might be learning to slow down and enjoy life more.

If you have been ill and feel that something positive has come out of it, you can contact Samantha Sodergren at the University on 01752 233216.

Sam, whose family lives in Plymstock, has been researching into quality of life with Prof. Hyland for the last year, having successfully completed her degree at the University of Southampton.

**MEDIA CONTACTS: Professor Michael Hyland, Director of the Quality of Life Research Centre can be contacted on 01752 233144. Samantha Sodergren is on 01752 233216. University Public Relations Manager, Val Harrison, is on 01752 233980.**

**APPENDIX 2**

**COVERING LETTER SENT TO**

**QUESTIONNAIRE PARTICIPANTS**

**(STUDY 1)**

## Appendix 2



**Faculty of Human Sciences  
Department of Psychology**

University of Plymouth  
Drake Circus  
Plymouth  
Devon PL4 8AA  
United Kingdom

Tel: 01752 233157/233158/233188  
Fax: 01752 233176

Ian Dennis, MA, PhD  
Head of Department 1995-1999

Dear

Thank you for contacting me regarding the research I am performing into the positive consequences of illness. The aim of this research is to find out how and why some people feel that their illness has had some positive consequences and also to understand the quality and meaning of life in people who are or have been ill.

I would like to emphasise to you the confidential and anonymous nature of this research. The information that you disclose to me will be treated in complete confidence.

Please find enclosed three questionnaires. The 'Things People Do' questionnaire asks you about the activities that you have done in the past year and provides a measure of life richness. The quality of life questionnaire asks you to consider your quality of life. Finally, I have enclosed a booklet of questions asking you about your experience of illness.

I would be very grateful if you could complete the questionnaires and return them to me in the FREEPOST envelope enclosed.

If you have any questions regarding the research or the questionnaire, please do not hesitate to contact me on (01752) 233216.

Yours Thankfully

Mrs Samantha Sodergren  
(Research Assistant in Health Psychology)

## **APPENDIX 3**

### **CONSEQUENCES OF BEING ILL QUESTIONNAIRE**

#### **(STUDY 1)**

## **Consequences of Being Ill**

The following questions ask about your experience of illness.

Your responses will be completely confidential!

If you run out of space when answering any of the questions please  
continue on a separate piece of paper.

Please describe the nature of your illness (include details of when you first suffered from the illness, its duration, and whether it is an ongoing illness)

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



**What effects has your illness had on your life?**

[illegible]

**What, if anything, has your illness taught you?**

[illegible]

**In what ways, if any, has your illness altered your outlook on life?**

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

[illegible]

**Describe any changes, as a result of your illness, in the way you view yourself**

[illegible]

**What effects, if any, has your illness had on your spiritual beliefs?**

[illegible]

**In what ways, if any, has your illness affected the way you relate to others?**

[illegible]

**Describe any changes in the way others treat you as a result of your illness**

[illegible]



**What, if anything, have others learnt as a result of your illness?**

;

THANK YOU VERY MUCH FOR YOUR TIME AND FOR HELPING ME WITH THIS RESEARCH.

If you would like to receive a summary of the findings of this research, Please tick the box

☐

## APPENDIX 4

### INTERVIEW SCHEDULE

#### (STUDY 1)

## **INTERVIEW SCHEDULE**

1. What effects has your illness had on your life?
2. What, if anything, has your illness taught you?
3. In what ways, if any, has your illness altered your outlook on life?
4. Describe any changes in your priorities or daily activities as a result of your illness.
5. In what ways, if any, have you changed the way you see yourself as a result of your illness?
6. What effect, if any, has your illness had on your spiritual beliefs?
7. In what ways, if any, has your illness affected your relationships with others?
8. Describe any changes in the way others treat you as a result of your illness.
9. What, if anything, have other people gained as a result of your illness?
10. Is there anything that we have not covered?

## **APPENDIX 5**

### **DEMOGRAPHIC AND ILLNESS CHARACTERISTICS**

#### **OF INDIVIDUAL PARTICIPANTS**

##### **(STUDY 1)**

## Demographic and illness characteristics of individual participants

Participant number	Details
1	Female, 23 years old, recovered from chronic fatigue syndrome
2	Female, 33 years old, chronic fatigue syndrome
3	Female, 55 years old, depression
4	Female, 41 years old, eczema with urticaria
5	Male, 44 years old, depression and anxiety
6	Male, 65 years old, cardiovascular illness
7	Female, 32 years old, treated for breast cancer
8	Female, 48 years old, bed ridden with arthritis
9	Female, 49 years old, treated for a brain tumour
10	Female, 67 years old, treated for cancer of the colon, persistent bowel problems
11	Male, 29 years old, depression
12	Male, 66 years old, treated for cancer of the larynx

- 13 Female, 51 years old, treated for ovarian cancer
- 14 Female 68 years old, recovered from a retinal tear
- 15 Female, 51 years old, Churg-Strauss Syndrome
- 16 Female, 81 years old, treated for breast cancer
- 17 Female, 47 years old, chronic fatigue syndrome
- 18 Female, 79 years old, treated for cancer of the colon and breast cancer. Persistent eye problems, partially sighted
- 19 Female, 30 years old, haemorrhage, persistent nervous complaints
- 20 Female, 50 years old, treated for breast cancer
- 21 Male, 74 years old, terminal cancer of the spine
- 22 Female, 56 years old, treated for breast cancer
- 23 Female, 57 years old, treated for breast cancer
- 24 Male, 20 years old, treated for Hodgkin's Disease
- 25 Female, 61 years, several strokes
- 26 Female, 48 years old, brittle asthma

- 27                      Male, 68 years, cardiovascular illness
- 28                      Female, 55 years old, asthma, bronchitis, arthritis,  
cardiovascular illness
- 29                      Female, 53 years old, treated for ovarian cancer and breast  
cancer, osteoporosis
- 30                      Female, 65 years old, terminal breast cancer and cancer of the  
spine
- 31                      Female, 50 years old, stress-related heart palpitations
- 32                      Female, 49 years old, treated for breast cancer
- 33                      Female, 55 years old, treated for breast cancer
- 34                      Male, 62 years old, in remission from prostate cancer
- 35                      Female, 47 years old, non-malignant breast lumps
- 36                      Female, 49 years, back injury
- 37                      Male, 68 years old, tuberculosis, haemorrhage
- 38                      Female, 45 years old, treated for cancer of the eye and cancer  
of the face and neck, partially sighted
- 39                      Female, 56 years old, depression



- 40 Female, 53 years old, miscarriages, slipped disk, chronic fatigue syndrome
- 41 Female, 32 years old, recovered from an infection
- 42 Female, 60 years old, cardiovascular illness, emphysema, depression
- 43 Male, 58 years old, stroke
- 44 Female, 43 years old, recovered from an addiction
- 45 Male, 43 years old, nervous breakdown, accidents
- 46 Female, 73 years old, cardiovascular illness
- 47 Female, 51 years old, currently suffering from breast cancer
- 48 Female, 58 years old, back injury sustained from accident
- 49 Male, 61 years old, chronic fatigue syndrome
- 50 Female, 46 years old, arthritis
- 51 Female, 42 years old, ulcerative colitis
- 52 Female, 49 years old, in remission from Hodgkin's Disease
- 53 Male, 61 years old, treated for cancer of the colon

54. Female, 72 years old, treated for breast cancer.

55. Female, 66 years old, treated for tuberculosis and abdominal  
pains.

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## APPENDIX 6

### SAMPLE TRANSCRIPTS

#### (STUDY 1)

## Sample Transcript (1)

### PARTICIPANT NUMBER 02 (P2) (Interview)

Date: 16/12/96

*Please describe the nature of your illness*

P2 has had M.E. since 1991 and feels like she is recovering now but “not completely out of the woods”.

P2 became ill with Glandular Fever and received a lot of pressure to return to work quickly. P2 realised the importance of “taking time out” to become better.

P2 developed the flu and did not get better.

For the first three months P2 tried to carry on as if everything was okay - she continued to go out, smoke, drink, working and generally “shoving oneself along”. As a result, P2 became weaker and realised that she needed to do something different to get herself better - give herself up totally to the process of illness and do what was necessary to get better. P2 was exhausted physically, her arms and legs ached and she suffered from headaches. P2 felt as if there was “a battle going on in my body”. Fortunately, P2 was able to take “time out” and make it okay. P2 went to the doctors, negotiated a long sick note and went through a series of tests.

P2 went through a series of battles to give in and accept the label of M.E. At first, P2 did not see it as a credible illness, it was not perceived as a serious illness, such as cancer. P2 was caught up with what other people thought.

*What effects did M.E. have on your life?*

The illness represented a total breakdown of everything P2 had been doing: "It was as if someone had picked up all of the bits and pieces that were my life and through them up in the air and said you need to look at this".

In physical terms, it meant that P2 had to start taking notice of her body. Before, P2 was "trendily punitive" - weight training, running, climbing, caving - hard sports, slimming. P2 believed that you should "beat it into submission" and make the body work for you and behave itself. P2 was particularly hard on herself.

Emotionally, M.E. imposed tremendous changes. P2 got rid of her boyfriend as she realised that he really was not taking care of her. Emotionally, P2 had to "open the cupboard and start clearing it out". P2 had to start thinking about how she felt about herself and other people and had to attend to feelings that had not been looked at before. Now, these feelings were "right in front of my face". P2 spent a long period of time in bed and therefore had no distractions, she could not avoid her feelings: "it all needed doing and was very challenging".

P2 had a vague spirituality before her illness. P2 was a mild Christian and her spirituality was all about getting approval for God - a kind of Father figure rather than the self as a spiritual being.

P2 imposed major alterations to her lifestyle, P2 sorted out her diet and imposed several restrictions - this offset emotional changes and challenges. P2 cleared herself out of "garbage" and was therefore more able to appreciate a spiritual life, such as, looking at a beautiful view and cherishing it. P2 believes that: "if you take care of yourself you are more able to take care of other people and the planet". Taking this viewpoint regarding caring for others was a particularly big change as before P2 was motivated by guilt and conformity.

"The wholer you are in yourself, the more you see yourself as fitting in with everything around so that it is not always someone else's problem".

*Can you think of any further effects that your illness has had on your life?*

The effects were described as “totally profound”. P2 gave up a lot of things in order to get well.

At first, this was on a physical level - giving up sugar, yeast, etc. The last to go was smoking - once P2 gave up smoking things started to shift on other levels and then P2 began to tackle things from her past and childhood which had not been dealt with before and had been forgotten and just shoved away. P2 feels that because she has “dug them out and dealt with them” she now has a much more responsible attitude towards her family.

The main trend was going from being a victim of M.E., work and men to being able to see herself as responsible. At times, it was tough to take this responsibility. P2 felt that it was an empowering thing to feel that “I can change it, I can do something to make it happen and to stop it and prevent it from happening again”. P2 felt that it was a major thing at the beginning of her illness to reach the point of realising that “nobody else is going to do this for me”. P2 had spent her life waiting for others to do things and blaming others.

*What if anything has your illness taught you?*

The illness taught P2 patience as well as the value of slowing down and “being with what is rather than running away from what I am afraid of”. P2 appreciates that most people are afraid of slowing down.

The turning point in X’s illness was during the summer 1994 when P2 experienced a “crisis” and was very ill again. P2 had a recurrence of Glandular Fever and felt as if she was “fading away”. P2 felt as if she was not totally in her body as if she was in an hallucinatory state. P2 realised that one day if she wanted to she could die and that if she carried on like that she would die. P2 knew with absolute clarity that no one else was responsible for this and that she had the power to do it. P2 had been in a limbo state for 3 months and thought that if she was going to die she must go on and do it and if not, go on and do what it takes to get out of that state. P2 made a clear decision to stay alive and not throw things away. P2 realises that most people do not think about this - they are just here. With this realisation, P2 felt really frightened and knew that there was no point of choosing to live just because you are afraid of dying. P2 began to see why being here was a good thing. P2 felt that she really needed to sort this ambiguity out within herself. P2 sought help after

deciding to be here and underwent aromatherapy sessions twice a week, consulted a nutritionist, had an allergy test and saw a healer. P2 described the healer as amazing and creating a profound change in P2's life. P2 discussed with her healer about containing one's psychic energy- one considers what one is doing with one's energy and about one's boundaries. P2 explained that M.E. sufferers typically do not have boundaries - a sense of what constitutes their feelings and what constitutes the feelings of other people. P2 feels that a sense of boundaries was absent during her childhood as she did not grow up with the conviction that what she had was her own.

*In what ways, if any, has your illness altered your outlook on life?*

P2 feels much more a part of life now and is aware that one makes a difference. It has given P2 the ability to empathise with people and she feels a lot more "richer" for it. Due to the work that she has done to get better (particularly challenging), P2 feels that she has encountered a lot of experiences that she would no longer be afraid of confronting in the future and so meeting someone who is afraid has put P2 in a good position to say "this is what it was like for me" (this was described as a nice feeling).

P2 feels that she has slowed down a lot now and she no longer spends time "running away from herself". P2 is more thoughtful about what she is doing with her energy, what she says to people, and how she is behaving (this is a big issue). P2 can see her part in things more clearly now.

P2 appreciates being here and is much more willing to take care of the world in small ways and in ways that are easy. Before, P2 struggled with everything even with things she did well. She was always struggling to do better. Now, P2 is much more able to acknowledge herself for what she can do and to choose the easy option, for example, accepting support from others and asking others for help. Before, P2 felt that it was not right to ask for help and support.

P2 feels much more free now because she is able to evaluate old messages she got from her family and sort out what is right and what is wrong.

P2 is much more willing now to listen to her intuition (a good thing to exploit, according to P2). In the past, P2 tended to “stamp on it”.

Before, P2 feels that she was a particularly “moany” person. The conversations she has now are much more positive because she is more willing to see ways around things. P2 sees quite a big picture for herself and for others. P2 is no longer interested in gossip. The conversations she has are much more real and have meaning. P2 is no longer willing to collude with people in thinking that they are stuck and that they are victims of something that they cannot do anything about. P2 feels that what you have outside is what you have inside. If you see obstacles, it means that there is a lot to sort out inside.

Through all of the different things P2 has had to do to get well, P2 has been given a good foundation to raise her family.

P2 feels that the whole process of illness is about looking at “uncomfortable bits of oneself” (previously ignored). P2 has found out a lot about herself.

*Describe any changes in your priorities or daily activities as a result of your illness.*

Before, so much of P2 was about avoidance of feelings and living up to the expectations of others. On a day-to-day basis, P2 did not have “hold of the reins of my life”, for example, she frequently stayed on late at work and took on different projects to impress others. P2 felt very driven in the past - like being driven by conflicting “inner animals”. The need for approval was a big issue in P2’s life. Now, P2 does what she wants to do - “I am what I am, it does not matter about others’ disapproval”.

P2’s relationships with women have changed. In the past, P2 did not have many female friends. P2 realises now that what kept her separate from other women was that she was afraid of the competition with them. M.E. has taught P2 about self-acceptance - “this body is incredible, it does not matter about its shape”. P2 no longer defines herself solely by referring to her body. P2 has



had a lot of experiences of the self as something greater than just a body. As a result, P2's life has become much more enriched spiritually and has become more dynamic.

P2 now realises that worrying about money, bills and housework is not what we are really here for. Before, when P2 was in a well paid job, she always had a panic of not having enough money. P2 used to be very driven by this worry - she could not have things through fear of not having enough money. Now, P2 is a lot more comfortable with a lot less money and it does not rule her life. In terms of priorities, what P2 perceives as her needs have altered radically. P2 values herself and others more rather than other things (smoking, drinking). P2 does not feel the need to impress people like she used to and to do the high powered sport she used to do. In the past, P2 felt the need to push herself and compete with others (in sport). Now just the "doing" of a sporting activity is enough. Before, P2 did not take any notice of what her body was doing, for example during climbing, but focused on what it could not do. Now she sees sporting activities as amazing and no longer a battle.

*Describe any changes in the way you view yourself as a result of your illness.*

Before, P2 had next to no self-esteem. One year before becoming ill, someone suggested this to P2 who was aghast by this statement as she defined her self-esteem purely in academic terms.

Before, P2 could not find any positive aspects of the self that reflected a true achievement. Now, P2 sees herself as a powerful woman and she knows that she makes a difference. In the past, P2 felt almost genderless as being a woman as opposed to a person, was very dangerous to her. P2 had such a low self-esteem that being a woman was about the shape of your body and as she did not value her body, she did not feel that it was a good thing to see herself as a woman. Now, P2 feels that it is a privilege to feel like a woman and she values gender more as a result. For P2, letting herself be a mother was a big change. P2 feels that motherhood would have been terrifying before her illness.

Now when P2 gives something to someone it is much more genuine - P2 gives because she wants to rather than because she feels compelled to. As a result, P2 now has a lot more to give.

Emotionally, P2 is now a lot less ruled by fears. Through being ill, P2 has had to face up to her fears. A particularly fear for P2 was the fear of being afraid.

*Describe any changes in your spiritual beliefs as a result of your illness.*

P2 described a strengthening / deepening of her spiritual beliefs and concerns. P2 now believes that everything is connected on an energetic level and that there are two ways to live: in love and in fear. P2 feels that M.E. taught her a lot about energy. Her beliefs have allowed her to accept support, see the good in things and cherish what everybody has and to want the best for everyone including the Planet. P2 used to live in fear and felt very separate - "me against the world" feeling. The spirituality that P2 has developed as a result of her illness is a kind of physical spirituality. P2 has had to accept being in a body and realise that she is not exclusively that body. P2 feels that a lot of it is about respecting herself, other people and the Planet.

*In what ways, if any, has your illness affected the way you relate to others?*

P2 is much more genuine and less afraid of saying the wrong things. Now, P2 tends to say things without worrying. P2 is much more willing to share herself and be less secretive. Others say that they feel safe around her and that they find her calming because she has had to slow down a lot. Before, P2 was very insecure and would not let herself rest, as a result, her body took over.

Others tend to look for P2 for answers because she has: "opened up the cellar and sorted things out".

P2 no longer feels the need to take care of and control others (now that she has a sense of personal boundaries and appropriateness). Before, P2 was much more of a controller of what happened to others as this was a way of making herself feel safe.

*Can you describe any differences in the way others treat you as a result of your illness?*

People are much more respectful of P2 now and they listen more to what she says - this is a direct reflection of giving herself more respect and listening to her body. Also, P2 feels that she attracts a

different type of person in life now. Before, she attracted people who had “given up”. Now, P2 attracts people who have a sense of purpose in their lives and get on and do things. P2 feels that she is more valued by others now because she values herself.

*What, if anything, have others learnt as a result of your illness?*

They have learnt that it is safe to let somebody be ill and get well in their own time and that it is safe to slow down and let go of everything. P2 described this as a process of surrender, a total giving up. P2 feels that she is able to offer other M.E. / food allergy sufferers and their families practical information.

*Is there anything else that you would like to add?*

P2 ended the interview by claiming that the illness was: “the best thing that could have happened to me”.

## Themes Identified

### *Reappraisal of life*

Reviewing one's life - "It was as if someone had picked up all the bits and pieces that were my life and threw it up in the air and said you need to look at this"

Greater appreciation of certain life activities - sports

Realisation of the value of slowing down and "being with what is rather than running away from what you fear"

Greater appreciation of life

"Life is a lot richer now"

Greater ability to see the good in things

Greater appreciation of what one has

### *Restructuring of Life / Life-Style*

Greater acknowledgement and care of one's body -not "beating it into submission", "clearing oneself out of garbage"

### *Sensitivity to Emotions*

Greater acknowledgement of how one feels about oneself and other people

"Open the cupboard and start clearing it out"

"The whole process of illness is about looking at uncomfortable bits about yourself"

### *Spiritual Concerns / Development of Faith and Belief*

Opportunity to lead a more intense spiritual life

Greater ability to appreciate a spiritual life - through "clearing oneself out of garbage"

### *Relationships with Others*

Greater ability to care for others in a sincere way - through taking care of oneself

More to give to others

Less threatened by other females

More responsible attitude to one's family (as a result of dealing with conflicts embedded within childhood)

Greater ability to empathise with others

Appreciation of the value of asking and accepting help and support

Greater tendency to engage in positive conversations with others

Greater respect for others

Tendency to attract a different type of person

The need for approval and control of others no longer important

### *Environmental Concern*

More able and willing to care for the Planet (no longer motivated by guilt and conformity)

Greater respect for the Planet

### *Positive Influence on Others*

One is in a good position to say "this is what it was like for me"

"Others feel safe around me and find me calming because I have slowed down"

Greater awareness amongst others that it is safe just to become ill and recover in your own time

Awareness that it is safe to slow down

More valued and respected by others

Ability to offer practical information to others

### *Resolve Past Conflicts*

Greater ability to evaluate messages received from the family in the past and sort out what is right

### *Self-Change*

Alteration of definition of self - "the body is seen as something more than just a body"

Greater acknowledgement of self for what one *can* do

Greater self-acceptance, self-respect and self-esteem

Less fearful and greater security

Perception of self as a responsible being rather than a victim

Sensation of greater control over one's destiny - "it is up to me and not anybody else"

Greater patience

Greater acceptance of self as a mother

"I feel much more free now"

"I feel much more a part of life now"

Greater tendency to introspect - no longer spends time "running away from oneself"

Much more willing to listen to one's intuition

More thoughtful in terms of one's actions

### *Self-Knowledge*

Greater awareness of what one is doing with one's energy (through enhanced introspection)

Knowledge of personal boundaries (ability to distinguish self from others)

Greater awareness and appreciation of one's gender identity ("I see myself as a powerful woman")

Greater awareness of what one has to offer to the world and that one can make a difference

### *Reordering of Priorities*

Less importance attributed to work, money and approval of others - "worrying about money, bills and housework is not what we are here for"

### *Acquisition of New Skills*

Better equipped to deal with future experiences - "I am no longer afraid of what might be around the corner"

## Sample Transcript (2)

### PARTICIPANT NUMBER 05 (P5) (Interview)

Date: 19/12/96

*Please describe the nature of your illness*

P5's depressive illness started 10 years ago. P5's second bout of illness which comprised purely of anxiety attacks (without the depression) developed 3 1/2 years ago.

Prior to his illness, P5 had been living in South Africa (for 3 years) and had been very successful academically. Up until then P5 had had few worries. P5 had, however, spent a hard year working in Scotland and suddenly it was like someone had "opened a trapdoor" beneath P5 which resulted in a collapse of his nervous system. P5 did not know what was wrong and thought that it was perhaps the flu or a heart attack. P5 worried intensely about the family (more than ever before). P5 used to be a very positive and confident person. At that time, P5's illness was one of depression. P5 had been made redundant, his Gran was killed in a car accident, he had a funeral to attend and also he was going through the stresses of moving house. At that time, P5 felt that the family had been let down. P5 became extremely depressed and suicidal. P5 felt that he just could not have a nervous breakdown as he had so much going on. He had achieved a lovely house and a job but this actually made him feel worse and he ended up on anti-depressants. What P5 found frightening was that he did not know what was going on. P5 lost his self-confidence and his self-respect. P5 eventually pulled through all that and the family got on their feet for 5-6 years and then P5's wife left him. P5 appreciated that he had been very moody and that he was a deep thinker (this was difficult for his wife to cope with). P5 felt as if it was a very subtle depression. P5 came off the anti-depressants too quickly.

According to P5, the turning point was when his illness came back for a second time in the form of pure anxiety without depression. P5 went through what he described as a terrible time for a year when he had suicidal thoughts (though never actually attempted to commit suicide). P5 wanted to do things for himself and would not accept the help and support others offered him. After about 3 months, P5 found a psychologist who convinced P5 that he was “gravely ill”. P5 “ran out of steam” and admitted to the psychologist that he could not go on anymore. P5 went back on the medication. Insomnia became a big problem for X. P5 took Prozac which actually increased his anxiety. P5 then took a less aggressive form of medication. P5 “kept going” and never took a day off of work. P5 eventually coped with his divorce, leaving home, and with another redundancy. P5 came off of the tablets but is currently on them to help him cope with his new job.

P5 feels that it was going through the illness a second time that made him realise that the illness must be treated seriously.

*What effects did your illness have on your life?*

The illness stopped P5 from enjoying himself. His mind was always racing. He felt that he just was not living but just going through the motions. For a while, it destroyed P5’s faith that he had in any special philosophical meaning to life. During P5’s illness, any wisdom that he had disappeared. P5 did not understand life anymore. P5 felt that he was just hanging on from day to day. P5 became very moody and could not feel things like he used to (for example, the love for his wife and children).

By not getting rid of the illness the first time P5 felt that he had lost a lot. P5 was never violent but internally upset. His illness spoilt holidays. P5 would not take any responsibility for things through fear of tempting the anxiety feeling. P5 was afraid of being anxious. P5 lost his confidence.



P5 appreciates that the illness did bring with it some positive effects. P5 feels that the turning point was the second time of being ill. By becoming ill a second time meant that P5 had to sort things out. The first time, P5 had gained nothing because nothing had been sorted out. For P5, the biggest positive effect is that he understands that there is a part of himself that can become extremely moody and dark. P5 does not have to accept this side of himself but just say: "I don't want this" and he feels that he can catch it before it comes back. P5 now realises that there is this illness and that he does not want to suffer from it. Looking back, P5 sees that there was always this dark side to himself.

P5 is now able to sense when another human being is suffering rather than just having problems. P5 has an empathy with people who have suffered. P5 can understand the depths to which some people have sunk to. P5 feels that you should not just say to people "pull your socks up". P5 realises that depression really is an illness.

P5 feels that the illness has done him good in terms of having had to go through it by himself (without family support) and so it has made him stand on his own two feet a lot more rather than being dependent on others. The illness has made P5 more self-reliant.

P5 feels that another overwhelming feeling is that his illness has made him "live for today" - rather than it being a philosophy it is a must as he just cannot live for tomorrow. P5 plans for the future but he finds this very difficult. P5 is just happy to get through the day.

P5 used to read a lot of Buddhism and think about it intensely. Over the last year, P5 has a clearer view of things - "one is following a clear space". P5 has been given a clearer insight into religion without studying it.

P5 is more interested in helping others and has a greater tendency to approach people who are in trouble and lend them a helping hand. Before, P5 thought that it was just their problem to sort out. P5 is more charitable in that sense. P5 has become a better listener to people.

P5 appreciates sleep a lot more now and also appreciates when things in life are just okay - they do not have to be wonderful. P5 feels a bit more grateful for just being healthy.

*What, if anything, has your illness taught you?*

P5 has been taught that his abilities and confidence are due to the balance of his psychological being and that they can so easily be taken away. The illness has taught P5 the psychology of being. P5 realises that without being healthy, your abilities and confidence are nothing.

The illness has taught P5 to be patient and not to get so angry with people. P5 feels that this is practical as it avoids putting himself at risk of anxiety attacks. However, it has also taught P5 not to be afraid of getting angry. If something bothers P5 he does something about it to sort it out. P5 expresses himself more and does not turn his upset inwardly.

The illness has taught P5 a lot about relationships (maybe due to the divorce). P5 is always aware that one does not know what someone is going through and that therefore one should not judge others. P5 realises that people do stupid things under stress. It has made him a lot more understanding of others.

*In what ways, if any, has your illness altered your outlook on life?*

The illness has changed P5's priorities. P5's main priority is (a) to feel content and to have moments of peace, and (b) to enjoy oneself and have moments of pleasure. P5 will do anything to reinforce not being ill and it is for this reason that P5's priorities have changed.

P5 is not so intense about finding spiritual fulfilment. P5 feels that this is probably a good thing and that he will be able to be more spiritual by thinking less about it. P5 feels that he is more at ease and perhaps more in touch with his spiritual side. For P5 a big priority is to be at ease with things and be less deep.

*Can you describe any more changes in your spiritual beliefs as a result of your illness?*

P5 used to read the Bible a lot although he did not belong to any one particular sect. P5 used to be extremely concerned about Christianity and used to get into a lot of arguments which used to disturb him. Now, P5 takes a lot more easier approach to religion and is more at peace with it. Before, P5 used to try and solve a puzzle. Now, P5 would say: "I believe in God but I am unsure". P5's depression gave him a glimpse of Hell and of being punished. P5 felt very disappointed and that if there is a God he needed to know it straight away. There were times when P5 felt that there was nothing (this multiplied his depression). P5 has still got a dislike for the condemning side of religions.

*In what ways, if any, has your illness altered the way you view yourself?*

When P5 was ill, he felt useless and lacked confidence. P5 now realises (through the help of the psychologist) that having come through the illness there must be a part of himself that is particularly strong. P5 is a little more proud of himself because of all the things that he went through whilst being ill - "there must be something in there that wants to go on". Many of P5's friends comment on how well he has done. P5 puts this down to a very practical positive approach.

*In what ways, if any, has your illness altered the way you relate to others?*

P5 stays detached from people now as he is afraid of getting his emotions hurt and as a result he tends to hold back in personal relationships. P5 has a tendency to get too high. P5 is more cautious now. P5 describes himself as an emotional person who has had to learn to balance his emotions out.

*In what ways, if any, has your illness affected the way others treat you?*

People who know about P5's illness have been very kind and understanding and generally interested in his illness. P5's close friends are more open to P5 now and tell P5 how they see him.

P5 is much more open with regard to his feelings about himself and others. P5 does not mind sharing how he feels.

*What, if anything, have others learnt as a result of your illness?*

P5's close friends have seen him on the edge of a nervous breakdown and have seen what stress can do to you. This has made them a little more understanding. P5 is not so argumentative now and does not try to convince others to think like him - "if that's how they think, that's fine". P5 is less judgmental. There are some people who still do not understand and think that P5 should just be able to snap out of his illness by being positive.

*Can you think of any further positive effects that your illness has had on your life?*

P5 feels that he has slowed down a lot ("I can catch myself if I speed up"). P5 is a lot more sensitive to his body's signals. P5 now makes decisions more quickly. When P5 became ill, he took up water-colour painting and an artistic temperament emerged. P5 is amazed by art now and has a greater appreciation of art.

## Themes Identified

### *Reappraisal of Life*

- Opportunity to sort one's life out
- Recognition of the necessity of "living for today"
- Greater appreciation of when things are just okay
- Greater appreciation of being healthy and being able to sleep

### *Restructuring of Life / Life-style*

- "I have slowed down"

### *Sensitivity to Emotions*

- Learnt to balance emotions out
- Greater openness about feelings towards self and others
- Greater tendency to share feelings

### *Use of Previously Untapped Resources*

- Realisation of artistic temperament
- Greater appreciation of art

### *Self-change*

- More proud of oneself
- Greater self-reliance
- Greater patience
- Tendency to make decisions quicker
- More assertive - more likely to confront and sort problems out
- Greater self-expression
- More at ease with things and less deep

*Self-Knowledge*

(Described as the biggest positive effect)

Greater understanding of oneself (the dark and moody side)

Realisation that one's abilities and confidence rest on a balance of one's psychological being

Appreciation that one has strength - "having come through the illness, there must be a part of me that is strong"

Greater sensitivity to body signals

*Relationships with Others*

Greater sensitivity, empathy and understanding of others (those who suffer)

More interested in helping others

More charitable

Better listener

Less critical and judgmental of others - more acceptant of divergent opinions

More detached from others

Less argumentative and angry with others

*Illness as a Challenge*

"I have been made to stand up on my own two feet"

*Positive Influence on Others*

Perception of greater emotional support from friends

Perception of enhanced openness amongst friends

Greater understanding amongst others of what stress can do to you

*Spirituality / Development of Faith and Belief*

Greater insight into religion (without studying it)

Less intense about finding spiritual fulfilment

More at ease and in touch with one's spiritual side

*Reordering of Priorities*

Realisation of the importance of contentment and pleasure- anything that reinforces not being ill.

Importance of being at ease and less deep

### Sample Transcript (3)

#### PARTICIPANT NUMBER 47 (P47) (Questionnaire)

*Please describe the nature of your illness.*

P47 had a lump on her breast and had a biopsy operation on 18/04/83 and a total mastectomy on 19/04/83. P47 had operations on the following dates: February 1986, February 1988, March 1990, August 1990 (operation on her neck). Between September and December 1990, P47 received chemotherapy and radiotherapy. P47 commenced drugs for 6 years. P47 had another operation in March 1992.

P47 feels that it is or can be an ongoing illness. Cells can remain dormant for years and then start to multiply. P47 feels that one cannot say for certain that it is no longer there, or will not appear again in the future and, therefore, P47 feels that you somehow have to learn to live with that threat. P47, at the same time, leads a life, it is not normal but it is the way it is for her.

P47 has suffered various side effects from the above, for example, inflammation of the lungs, phlebitis, loss of hair, aches and pains and numerous others, etc.

*What effects has your illness had on your life?*

P47 has coped / not coped with her cancer for nearly 14 years, it has changed her total life and turned it upside down. P47's mother was diagnosed with cancer within 6 months of P47's diagnosis and they lived together. P47 also had to attempt to deal with that - she died after 20 months.

P47 feels she has now achieved something of a miracle, simply by continuing to wake up every morning - so life is very special and precious, and her life is terribly special now. P47 has gained



something apart from “just” living, as a matter of routine and allowing everything to happen - P47 has lived despite having a potentially terminal illness, and not least does she think she has given it a run for its money.

P47 has gone to depths that you cannot truly go without being tremendously affected and without changing. Words, P47 has discovered, are pretty inadequate for an experience like P47's. She has been through absolute total hell which lasted for years.

P47 now sees everything from a higher plane. P47 wonders “what is everyone actually doing with their lives? Do they see the wonder of life and their lives? Of nature?”

*What, if anything, has your illness taught you?*

P47 does not want or intends to wastes time but knows that it is actually okay “to be”, rather than to do, or have to prove something.

P47 can see two sides and opposites of many things. P47 appreciates having her life instead of taking it for granted, and wonders about where one comes from and why.

P47 feels that nothing, but nothing, is assumed.

P47 has learnt that she is still herself despite the cancer. P47 lost herself for years. P47 feels that you cannot really explain what it has been like to someone who has not been there or had a similar experience. The delight in being able just to walk up the stairs, or having the energy to walk a few yards up the road, after treatments, is something else.

P47 feels that whilst particular traumas are surrounding you, your entire life is put on hold, i.e., P47 just lives for the next half an hour at a time. P47 had a total mental block about tomorrow and a possible future. P47 could plan nothing. P47 appreciates the smallest things in life. P47 feels that

it is not possible to realise these things at the time, one is too busy mentally and physically trying to do one's best with it all.

P47 discovered and now has an inner strength and soon came to the conclusion that she alone was and had to be responsible for herself. P47 found and made use of every emotion there is. P47 realised that she had choices and options, she could sometimes work them out for herself. P47 feels that life is not about things but love, and people, and contentment, and understanding, and health.

*In what ways, if any, has your illness altered your outlook on life?*

P47 now knows what is important in life, and to herself, and what is not. P47 feels that it took the experience of cancer to switch her mind into different gears. P47 feels that you have to develop yourself to the full, if possible, to have even a chance of coping. P47 has made so many changes in herself, her thinking, philosophies, etc.

P47 learnt to communicate with herself, other people and listen to the messages which her body sent to her, to rely on her gut feelings, to know what was / was not okay for her.

P47 feels she has the abilities to grow, to learn, to change, to struggle, etc.

P47 feels that illness can take you to a relationship with yourself and with life which is infinitely deeper and more fulfilling than anything she has previously known. P47 learnt about so much, i.e., relaxation, self-hypnosis, visualisation, diet and nutrition, how to take care of yourself etc.

P47 feels that the greatest joy is appreciation. When you almost lose your life, you learn about appreciation (and everything). P47 gives herself permission to feel or think whatever, it's OK to cry your heart out, to be upset, to be depressed, to be angry, etc.

P47 feels that you have to support yourself in any way you can. P47 is not afraid to be human, laugh at herself and life, make mistakes, etc.

P47 realises her vulnerability, her qualities, strengths, weaknesses, limitations, which may apply to her.

*Describe any changes in your priorities or daily activities as a result of your illness.*

P47 feels that you mobilise your own resources and you should not expect doctors and hospitals to do it all for you. P47 feels that cancer changes your status in life and how you view yourself and others - it changes your importance - it can make you feel very different from others - yet special - but sometimes very insignificant.

P47 trusted herself to do the best to help herself (and others), even if the result was not a success. P47 feels that she views herself with some respect, and shifts the focus into the present and nurtures oneself. P47 feels that she has sorted out her priorities. P47 has developed a deeper understanding absolutely everything. P47 found that she can get to complete depths of despair and depression. P47 feels that cancer may strengthen and weaken every part of you, it deepens every thought and perception and gives you a new and altered awareness.

P47 feels that she has a grasp on her life that it was not necessary to have before - a strange sense of control and responsibility. P47 tends to know now when things are / are not a good idea.

P47's imagination and thoughts have expended - she can think better and differently and can normally come up with ideas and alternatives. P47 does not understand the words "boring", "can't", "won't", "always", "never", etc. Cancer has enabled P47 to make her life more complete, more of everything.

*Describe any changes, as a result of your illness, in the way you view yourself.*

P47 has to view herself differently, as a result of her operations, the body image has changed, treatments, drugs, side effects, etc. P47 feels that cancer moves you forward mentally and physically, and backwards. P47 learnt about homeopathy. P47 does not rely on false hope but reality. P47 feels that one sometimes expects other people to provide a solution for cancer and for replies to questions which do not have answers - which you somehow have to accept - having cancer can be a terribly lonely place to be and you do have to do it all yourself.

P47 found that you do get to know avidly what you like / do not like, accept / would not, what is fair / unfair, what upsets you / what doesn't, etc.

P47 feels that cancer changes life. For those who live, their bodies and minds are altered, there is no going back. It changes every aspect of life profoundly and dramatically, not through choice, and you can see yourself and your life so differently.

P47 can now "see" things, feel things rather than doing or thinking. P47 learnt what life meant to her. P47 learnt about herself, about others, to value, about trivia, considering others, understanding, giving, believing. P47 accepts that she does not have to be helpless. P47 feels that you learn be the living, the experiencing what it is like, what it feels like. P47 learnt that she had rights. P47 took stock of everything and assessed her life. She found that you become stronger and weaker and that your attitudes shift.

*What effects, if any, has your illness had on your spiritual beliefs?*

P47 found that you lose as a result of your cancer but can gain so much. You learn not to be complacent - you may not be here shortly. P47 feels that you learn about determination, challenge, courage. You learn to be flexible, to compromise, to change your mind, to explore things to their absolute ultimate. P47 found that you write things down because you find that it sometimes helps your feelings, thoughts, etc. You understand that there may not be a right / wrong way of doing things, your way is acceptable. You adopt new strategies. P47 found that you go with the flow

(i.e. the cancer - to a reasonable extent), or how you are feeling, it is sometimes easier. P47 feels that cancer damages you mentally and physically - your own little world and your way of life is terribly and totally shattered - you lose or use all your strengths and normal ways of dealing and thinking about everything. Life shifts to "how do I survive, let alone live?" P47 feels that you gain skills and much knowledge. You sort out what you really think, feel, etc. You do not quite know what to think or believe on a spiritual level, you sort of think there is a power outside man and something greater than yourself. P47 realises that it is not always necessary to give reasons for anything.

P47 feels that you should always make your mind up for yourself and make your own decisions, and not necessarily believe what you are told, read, advised, etc. P47 feels that you learn to actually listen to others and hear what they are saying. (We have two ears, but one mouth).

*In what ways, if any, has your illness affected the way you relate to others?*

P47 feels that you care very much, almost too much, and sense things more easily. You feel more alive and vital because of the cancer, only you know the struggle you had to get to this position. You step into a different world after diagnosis. You are alive. Your life will have infinitely more meaning, and you become stronger because of the cancer. P47 feels that true friends are vital, one needs a support system, whatever it is. According to P47, people support without realising. P47 feels that you do not have to be particularly strong for other people, you just have to be there and show that you care. P47 feels that it would be great if people would ask you if they can help in any way, if they do not know what to say or do - anything is a help - but leave it up to the person who is dealing / not dealing with the cancer to know what is best. P47 finds that one tends to dodge people who may mean well, but actually hinder rather than help.

P47 does not quite know what others have learnt as a result of her illness. P47's doctor has told her that she is an "inspiration". P47 has a friend who will say "I take my hat off to you". There have been numerous comments, just to have someone merely acknowledge the struggle, the heartache,

and illness, in some way, helps no end. Others, P47 finds, have difficulty in treating her normally because of the cancer. P47 accepts this, whether it is because of their own fear, or whatever.

*Describe any changes in the way others treat you as a result of your illness.*

P47 finds that a lot of people are not able to talk to her about the subject, including close family members and friends - P47 knows that when they ask "how are you?" - they would probably run a mile if she was to reply properly because they do not want to know and are unable to deal with it. P47 could perhaps assure them that it is a thousand times worse to have cancer yourself, and her problems seem much greater than their feelings about themselves.

P47 finds that doctors and the medical profession treat one very differently when one has cancer. P47 thinks they sometimes could learn by asking how one actually feels because she gets the impression that one is purely a body to be poked and prodded at, instead of a human being with a brain and someone who would like to be treated with respect.

P47 read and researched much that she probably would not have done had the diagnosis not arrived. P47 made her life different in every aspect and is actually very proud of her achievements. P47 is delighted still to be here, nearly 14 years after the diagnosis, and likes to feel that her efforts have made a difference to the present outcome. P47 feels that it has certainly improved the quality of her life. That was P47's aim and to concentrating on getting as fit as possible, given the circumstances.

*What, if anything, have others learnt as a result of your illness?*

P47 feels that before cancer you know you are going to die of something some day but you know this vaguely. After cancer you know where the door is. Living with cancer means being scared to a lesser or greater extent at least some of the time. It means that every time P47 gets a sore throat she thinks "maybe it's in my throat". Then she tells herself "that's silly - everyone gets a sore

throat". Until the next ailment. P47 feels that it is a matter of trust - the sudden lack of it. P47 feels that one's body has normally been one's friend, but now one can never feel the same way

about it again. P47 feels that that is what cancer is. The pain of losing a part of one's body is multidimensional and extremely complex. Even the kindest person cannot banish the loss or band-aid the mental and physical pain. P47 feels that the grieving is never over.

P47 finds that one has cycles of emotions, anger, acceptance, etc., including times of remorse, sadness, fears, etc. Cancer threatens life and, in P47's case, it has altered her feminine image and how she feels about her body. P47 feels that cancer permanently alters every aspect of life and there is no going back. P47 sees herself and her life so differently. The way one relates to people and vice versa change. P47 feels that these changes are so traumatic, so personal, and so painful and so hard to understand. P47 feels that cancer builds walls between people. It is isolating and hurts. P47 feels that she is on one side of the world, the sick side, and she does not want to be there. Everyone else in her world is on the other side, the normal side.

P47 feels that cancer, cancer treatments, and the way people around one react to cancer all depletes one physically as well as emotionally. Sometimes, P47 thinks and does cope okay. Then she gets knocked sideways that just highlights the differences, the complete changes in herself and her life. P47 cannot shake the fear of pain and death, even though she is surviving. The fear is complex, of status, deformity, recurrence, helplessness, pain, quality of life, etc. P47 finds that she has periods of depression, loneliness, pain, etc. P47 feels that you can be glad to be alive and sad at the same time. P47 has periods of shock, denial, frustration, of being cheated, to name but a few.

P47 feels that people never pause long enough to make up their minds about basic issues of life and death. P47 feels that it is quite possible to go through your entire life, making the mechanical motions of living, adopting on your own set of ideas you have picked up some place or other and

die - never having come to any conclusion for yourself as to what life is all about. According to P47, men go abroad to wonder at the height of mountains, at the huge waves of the sea, at the

circular motion of the stars, etc.; and they pass by themselves without wondering. P47 feels that you do not have to be anything, you just have to be. P47 feels that life is precious - all of life, you and me, every bird, squirrel, etc. P47 feels that we pay so much attention to where we live, so little

to when. P47 feels that if you do not look after your body, where do you live? P47 feels that life is for living. Every day is for living.



## Themes Identified

### *Restructuring / Reappraisal of Life*

Greater appreciation of life and "being here" - "life is for living" (described as the greatest joy)

Perception of life as very special and precious

"I now see everything from a higher plane, I wonder what is everyone actually doing with their lives?"

Less tendency to waste time

Acceptance of just "being" rather than doing or proving something

Consideration of the intrinsic value of life - "Life has more meaning". "...wonder about where you come from and why"

Review of one's life - "you take stock of everything and assess your life"

Greater appreciation of simple things in life - "...just walking up the stairs"

Greater consideration of what is important in life - Greater value of love and people in life

Greater consideration of one's mortality

"It took the experience of cancer to switch my mind to different gears"

Deeper, more fulfilling relationship with life

Greater focus on the present

New altered awareness

More complete life - more of everything

### *Self-Knowledge*

"I learnt about myself"

"You do get to know avidly what you like / do not like, accept / would not, what is fair / unfair, what upsets you / what doesn't

"I have rights"

"I discovered and now have an inner strength"

“I have choices and options”

Greater ability to listen to one’s body

Greater knowledge of what is okay for oneself

“I realise my vulnerability, qualities, strengths, weaknesses, limitations”

Change and deepening of one’s perception of oneself in relationship to others

### *Self-Change*

Expansion of thoughts and imagination - ability to think better and come up with alternatives

Greater ability to communicate with oneself

Stronger

Less tendency to be complacent

Feel more alive and vital

More able to grow, learn, change and struggle

Deeper, more fulfilling relationship with oneself

Tendency to allow oneself to feel and think about what one wants

Deeper understanding of everything

Grasp on one’s life - Greater control and responsibility

“I can “see” things rather than doing or thinking

### *Relationships with Others*

Greater ability to communicate with others

Change in perception of others

Realisation of the value of true friends

Perception of support from others

Change in perception of others

Consideration and understanding of others

Ability to listen to others and hear what they are saying - “we have two ears but one mouth”

*Acquisition of Skills*

“You gain skills and much knowledge”

*Reordering of Priorities*

“you sort out (your priorities)”

*Sensitivity to Emotions*

Sense things more easily

*Teaching Value*

Awareness of Homeopathy

Learn about determination, challenge and courage

“You learn to be flexible, to compromise, to change your mind, to explore things to their absolute ultimate”

*Positive Influence on Others*

Inspiration to others (doctor)

“I take my hat off to you”

## Sample Transcript (4)

### PARTICIPANT NUMBER 50 (P50) (Questionnaire)

*Please describe that nature of your illness.*

P50 has rheumatoid arthritis. It was first diagnosed in 1971 and P50 had fairly mild symptoms up until 1978 when the illness went into total remission for 15 years during which time P50 was very fit and active.

P50 began to get symptoms again around Christmas 1993. The illness has been much more severe this second time. P50 gets some degree of pain in most of her joints at different times. P50's hands and feet are most severely affected, her neck, shoulders and knees slightly less, and other joints are only slightly affected. Since rheumatoid arthritis is a debilitating illness, P50 also gets very tired very easily.

The illness is ongoing although it fluctuates in severity. P50 has occasional flare-ups and occasional partial remissions. Because it is a completely unpredictable illness, P50 cherishes the faint hope of another total remission, but also has to face the possibility that it may get worse.

*What effects has your illness had on your life?*

The illness has placed a number of constraints on P50's way of life. P50 has some restrictions on her mobility, although she has a long way from needing a wheelchair. However, P50 has difficulty with stairs (although she manages okay in her house) and she walks quite slowly. P50 used to be a fitness fanatic and can no longer do things like aerobics, or go to the gym, or go off on 10 mile walks on Dartmoor. Also, P50 cannot sit down in the bath, or get down onto the floor - let alone get up again. P50 also gets exhausted very easily.

Basically, P50 is no longer able to do anything very strenuous at all. P50 is still able to work full-time, but she no longer attempts to look after her garden and she pays someone to do this for her.

P50 is considering getting help with the housework as she finds it very hard to keep up with this.

P50 also had to change her car to an automatic with power-steering as she could no longer cope with the car she had.

P50 is also affected in that she eats a lot of convenience food because she cannot cope with a lot of shopping. P50 also wears very casual clothes (e.g. leggings with baggy jumpers or T-shirts and very sensible shoes) because it takes too long to cope with the fastenings on "smart" clothes.

P50 also had to give up knitting, but has been able to do some embroidery instead.

*What, if anything, has your illness taught you?*

P7 has been taught the following things:

To live in the here and now rather than continually projecting into the future, either by worrying about things that may never happen or by imagining some wonderful future life that was always being postponed for a few months or a few years until some real or imagined obstacle was out of the way.

To listen to her body, e.g. to rest when she was tired or eat when she was hungry, rather than ignoring these signs.

That life is much more enjoyable taken at a slightly slower pace.

To take time for herself, to relax or just to do the things she enjoys doing.

That, although “count your blessings” is a dreadful cliché, she still leads a very privileged existence compared to others in the world, even though she has arthritis.

To take notice of her surroundings and to enjoy the flowers and the birds in the garden, or a beautiful sunset.

*In what ways, if any, has your illness altered your outlook on life?*

P50 used to be a deeply angry and resentful person, always thinking “why has this happened to me? Why have I got such a lousy job / marriage / life?”

Although P50 was initially very depressed when the arthritis came back again, after about a year she had more or less come to terms with it.

P50 is now basically quite happy and contented with her life. She has more time to do the things she wants to do. P50 also gets much joy from life’s small pleasures.

P50 used to be a workaholic. These days she does her basic hours, takes all the leave she is owed, etc. P50 feels that work no longer dominates her life; in particular, she does not think about work much when she is at home.

P50 used to be very “driven” and she can see that she must have been very difficult to get on with. P50 also now believes that it is important to do something while you have the opportunity and not continually put things off, because you just do not know what life has in store for you - there may not be a second chance.

P50 used to be very ambitious in career terms, but she is no longer looking for promotion. She does not want the increased responsibility, stress and hassle, no matter how much more she was paid.

*Describe any changes in your priorities or daily activities as a result of your illness.*

Getting a good night's sleep is now one of P50's top priorities. Prior to being ill, P50 was quite prepared to run herself into the ground and get by on very little sleep. P50 also used to work-out most days (P50 feels she was somewhat obsessive about this). P50 feels that, now of course, she is unable to do this sort of thing.

P50 tries to make sure that she has at least half an hour, preferably an hour, just to relax and watch television or read.

P50 feels that she does not have high standards these days where housework is concerned. If she is too tired to do something then it just gets left. In the past, P50 would have forced herself to do some chore, no matter how exhausted she felt.

*Describe any changes, as a result of your illness, in the way you view yourself.*

P50 thinks she is now a much nicer person than she used to be. She feels that she is more patient, tolerant and easy-going than before. She recognises that she used to be very impatient and irritable and most of the people she worked with were, she is told, a bit scared of her.

However, in terms of physical attractiveness, P50 now rates herself as considerably less attractive to men than before and she has much less confidence in this area than she used to have. P50 feels this is rather a shame as she thinks she has a great deal more to offer these days.

*What effects, if any, has your illness had on your spiritual beliefs?*

Prior to becoming ill P50 had no spiritual beliefs at all. However, suffering from a stress-related illness led her to find out about stress-management techniques. Practising meditation led P50 in turn to Buddhism and she now attends regular meetings. So being ill, P50 feels, has had an enormous impact on her spiritual beliefs, even though this may only have been indirect. However,

P50 suspects her previous frame of mind was such that, prior to being ill, she would have rejected Buddhism if she had been exposed to it at that time.

*In what ways, if any, has your illness affected the way you relate to others?*

P50 finds it much easier to get along with other people. She is much more even-tempered than she used to be and now rarely loses her temper. However, she lives on her own, as was the case before she became ill so she does not have any particularly close relationships to be affected.

*Describe any changes in the way others treat you as a result of your illness.*

P50 thinks other people are more relaxed with her. P50 feels that work colleagues are less scared to approach her with problems. P50 also feels that friends and neighbours have been very kind, helpful and supportive. P50 has always found it hard to accept help, but she thinks it is beginning to get a little easier.

*What, if anything, have others learnt as a result of your illness?*

P50 is single and has no really close relationships so she finds this question difficult to answer. At work, she thinks people have learned that disabled people can still make a contribution.

## Themes Identified

### *Reappraisal of Life*

Review of one's life - "Becoming ill forced me to look at what I was doing with my life"

Tendency to "count one's blessings"

Enjoyment of small pleasures in life

Greater contentment with one's life

### *Restructuring of Life / Life-style*



Tendency to do things today - importance of doing things when the opportunity arises - "you just do not know what life has in store for you - there may not be a second chance"

Ability to switch off from work

Doing things one wants to do

Greater time for oneself

Tendency to live in the here and now - less consideration for the future

Slower pace of life

More enjoyable life - "Before I was ill, I led an awful life"

### *Self-change*

Happier person

Nicer person

Less driven, angry and resentful

Less ambitious

More even-tempered

"I am more patient, tolerant and easy-going"

### *Self-knowledge*

Greater ability to listen to one's body

### *Reordering of Priorities*

"Work no longer dominates my life"

Housework has become less important

Greater importance of getting sufficient sleep and relaxing

### *Relationships with Others*

Perception of oneself as more approachable and more easy to get on with

Perception of support from others (friends and neighbours)

Greater ability to accept help from others

*Spiritual Concerns / Development of Faith and Belief*

More intense spiritual life (Buddhism)

*Positive Influence on Others*

“..others are more relaxed with me”

Greater ability amongst others to share their problems

Teaching value - “disabled people can still make a contribution”

**APPENDIX 7**

**THE SILVER LINING QUESTIONNAIRE –**

**PILOT VERSION**

**(STUDY 2)**

## The Silver Lining Questionnaire

### What is this questionnaire all about?

This anonymous and confidential questionnaire asks you about your experience of illness. Although illness can be a distressing experience, some people who have or have had an illness talk about its positive aspects. This questionnaire asks you to think about this positive side of illness.

### How do I complete this questionnaire?

This questionnaire consists of a series of statements which may or may not be true of your experience of illness. For each statement, please indicate whether you agree, disagree or are uncertain. If, after thinking about it, you want to change any of your replies, feel free to do so. There is no right or wrong way of responding to any of the statements, your own personal views are important.

An example to help you:

My illness has made me value other people more	Agree	Not sure	Disagree
	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you feel that you value other people more now as a result of your illness, you would respond by placing a tick in the "agree" box as above.

*Please tick one response for each statement*

	Agree	Not sure	Disagree
1. My illness gave me a new start in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My illness made me realise that things can wait until tomorrow	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My illness encouraged me to lead a healthier way of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. My life is much better now than it was before my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. My illness has made me live life to its fullest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My illness changed my priorities in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My illness gave me an excuse to give up things I did not want to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I appreciate life more because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. My illness made me step back and appreciate simple pleasures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. My illness made me weigh up my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Because of my illness I find it easier to accept what life has in store	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. My illness made me think about the true purpose of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. My illness changed my outlook on life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. My religious / spiritual beliefs deepened because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. My illness made me re-evaluate my religious / spiritual beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I am now more open to other religions because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I am not the same person I was before my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. My illness made me a better person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I became a happier person because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Due to my illness I accept that I am who I am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I am a calmer person because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Agree	Not sure	Appendix 7 Disagree
22. My illness made me more mature	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. My illness made me a more tolerant person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. My illness made me realise that I matter as a person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. My illness made me focus more on myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. My illness gave me more confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I am less concerned about failure because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I am a more patient person because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. My illness gave me permission to do things for myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. I am a more easy going person because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. My illness made me a more determined person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. My illness helped me find myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. My illness made me more aware of my body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. My illness made me more aware of my strengths	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. My illness has been a real learning experience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. My illness has given me a lot of practical information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Through my illness I discovered a talent I didn't know I had	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. My illness led me up paths I never dreamt possible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. My illness has been a challenge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. I can face whatever is around the corner because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. My illness encouraged me to reflect on how I feel about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. My illness brought me face to face with how I feel for others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. My illness made me dig up past concerns and deal with them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. My illness made me face up to problem areas of my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. I appreciate other people more because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Agree	Not sure	Appendix 7 Disagree
46. My illness strengthened my relationships with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. My illness made me less concerned with the approval of others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. I now have more sympathy for others because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Due to my illness I am able to put myself in other people's shoes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. Because of my illness I have more to offer other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. My illness made me more at ease with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. My illness made me appreciate the value of seeking help from others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. I see others in their true colours because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
54. My illness gave me the opportunity to meet new people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55. My illness made me aware of my true friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56. My illness taught me how to stand up for myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
57. My illness made me put an end to troublesome relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. My illness made me realise how supportive other people can be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
59. My illness made me less judgmental of others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60. I have been an inspiration to others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
61. My illness has been an eye opener for others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. Other people have gained skills and knowledge from my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. People can be more open with me since my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. My illness changed other people for the better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. My illness changed other people's perception of me for the better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. Other people appreciate me more because of my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**AND FINALLY.....**

It would be very useful if you could fill in the following information about yourself.

Age .....

Gender (*tick*)    Male    ☐  
                          Female    ☐

Who do you live with? (*tick any that apply*)

spouse /	children	parents	friend(s)	alone	other
partner					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please describe your illness(es)

.....

.....

.....

.....

Have you recovered from your illness? (*tick*)    Yes    No  
    ☐    ☐

If yes, how long ago did you recover from your illness? .....

Thank you for your time in completing this questionnaire



## **APPENDIX 8**

**COVERING LETTER SENT TO THE**

**'ILLNESS-BENEFIT' SAMPLE**

**(STUDY 2)**

**Appendix 8**

**Faculty of Human Sciences  
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United Kingdom

Tel: 01752 233157/233158/233188  
Fax: 01752 233176

14 May 1997

Ian Dennis, MA, PhD  
Head of Department 1995-1999

Dear

I would like to take this opportunity to thank you for taking part in my research on the positive side of illness. I was particularly encouraged by the large number of people who volunteered to take part in this research. Between December 1996 and March of this year, I managed to interview 41 people and I received 14 questionnaires from people who were unable to be interviewed. I found both the interviews and questionnaires very interesting. As you will see from the summary of the results that I have enclosed, the interviews and questionnaires provided a rich source of information.

The information collected from both the interviews and the questionnaires has been used to develop the "Silver Lining Questionnaire" which measures positive aspects of illness and is the first of its kind. I have enclosed a copy of this questionnaire and would be very grateful if you could fill it in. Do not feel obliged to complete the questionnaire but if you do, please return it in the FREEPOST envelope enclosed. Also, I would welcome any comments you might have about the questionnaire or indeed the research itself.

I hope you find the summary of the results interesting.

Thank you once again for your valuable contribution to this research.

Yours sincerely

Samantha Sodergren

**APPENDIX 9**  
**REFINED VERSION OF THE**  
**SILVER LINING QUESTIONNAIRE**  
**(STUDY 2)**

## The Silver Lining Questionnaire

### What is this questionnaire all about?

Although illness can be a distressing experience, some people who have or have had an illness talk about its positive aspects. This questionnaire asks you to think about this positive side of illness.

### How do I complete this questionnaire?

On the next two pages, there are 38 statements about the experience of being ill. Please indicate the extent to which you agree or disagree with each statement by circling a number between 5 "strongly agree" and 1 "strongly disagree". There are no right or wrong answers, your own personal views are important.

An example to help you:

I appreciate other people  
more because of my illness

strongly  
agree

agree

not  
sure

disagree

strongly  
disagree

5

4

3

2

1

If you strongly feel that you appreciate other people more now as a result of your illness, you would circle the number five.

Please complete:

Age .....

Sex (*tick*)

Male

☐

Female

☐

Please circle *one* number for *each* statement

	<b>strongly agree</b>	<b>agree</b>	<b>not sure</b>	<b>disagree</b>	<b>strongly disagree</b>
1. I appreciate life more because of my illness	5	4	3	2	1
2. My illness gave me a new start in life	5	4	3	2	1
3. My life is much better now than it was before my illness	5	4	3	2	1
4. My illness has made me live life to its fullest	5	4	3	2	1
5. Because of my illness I find it easier to accept what life has in store	5	4	3	2	1
6. My illness made me think about the true purpose of life	5	4	3	2	1
7. My religious / spiritual beliefs deepened because of my illness	5	4	3	2	1
8. I am now more open to other religions because of my illness	5	4	3	2	1
9. My illness made me a better person	5	4	3	2	1
10. I became a happier person because of my illness	5	4	3	2	1
11. I am a calmer person because of my illness	5	4	3	2	1
12. My illness made me more mature	5	4	3	2	1
13. My illness made me a more tolerant person	5	4	3	2	1
14. My illness made me realise that I matter as a person	5	4	3	2	1
15. My illness gave me more confidence	5	4	3	2	1
16. I am less concerned about failure because of my illness	5	4	3	2	1
17. My illness gave me permission to do things for myself	5	4	3	2	1
18. My illness made me a more determined person	5	4	3	2	1
19. My illness helped me find myself	5	4	3	2	1

*Please turn over*

Please circle *one* number for *each* statement

	<b>strongly agree</b>	<b>agree</b>	<b>not sure</b>	<b>disagree</b>	<b>strongly disagree</b>
0. My illness made me more aware of my strengths	5	4	3	2	1
1. Through my illness I discovered a talent I didn't know I had	5	4	3	2	1
2. I can face whatever is around the corner because of my illness	5	4	3	2	1
3. My illness encouraged me to reflect on how I feel about myself	5	4	3	2	1
4. My illness made me face up to problem areas of my life	5	4	3	2	1
5. My illness strengthened my relationships with others	5	4	3	2	1
6. My illness made me less concerned with the approval of others	5	4	3	2	1
7. Because of my illness I have more to offer other people	5	4	3	2	1
8. My illness made me more at ease with others	5	4	3	2	1
9. I see others in their true colours because of my illness	5	4	3	2	1
0. My illness gave me the opportunity to meet new people	5	4	3	2	1
1. My illness taught me how to stand up for myself	5	4	3	2	1
2. My illness made me put an end to troublesome relationships	5	4	3	2	1
3. My illness made me less judgmental of others	5	4	3	2	1
4. I have been an inspiration to others	5	4	3	2	1
5. People can be more open with me since my illness	5	4	3	2	1
6. My illness changed other people for the better	5	4	3	2	1
7. My illness changed other people's perception of me for better	5	4	3	2	1
8. Other people appreciate me more because of my illness	5	4	3	2	1

Thank you for completing this questionnaire

## APPENDIX 10

### HEALTH AND FATIGUE QUESTIONNAIRE

#### (STUDY 4)

**HEALTH AND FATIGUE QUESTIONNAIRE:**

would like to know whether or not you have been having any problems with feeling tired, weak or in energy in the last month. Please answer ALL the questions simply by underlining or the answer which you think most nearly applies to you. We would like you to answer the questions whether or not you have these symptoms. We also would like to know how you feel either at present or recently, rather than a long time ago. If you have been feeling tired for a long time, we would like you to compare yourself to how you felt when last well.

Do you have problems with tiredness?	Less than usual	No more than usual	More than usual	Much more than usual
Do you need more sleep?	Less than usual	No more than usual	More than usual	Much more than usual
Do you feel tired or drowsy?	Less than usual	No more than usual	More than usual	Much more than usual
Do you have problems doing things?	Less than usual	No more than usual	More than usual	Much more than usual
Do you lack energy?	Better than usual	No more than usual	More than usual	Much more than usual
Do you have less strength in your muscles?	Better than usual	No more than usual	More than usual	Much more than usual
Do you feel weak?	Less than usual	Same as usual	More than usual	Much more than usual
Do you have difficulty concentrating?	Less than usual	Same as usual	Worse than usual	Much worse than usual

Please turn over.



Do you make slips of the tongue when speaking?	Less than usual	No more than usual	Worse than usual	Much worse than usual
--	-----------------	--------------------	------------------	-----------------------

Do you find it more difficult to find the correct word?	Less than usual	No more than usual	Worse than usual	Much worse than usual
---	-----------------	--------------------	------------------	-----------------------

How is your memory?	Better than usual	No worse than usual	Worse than usual	Much worse than usual
---------------------	-------------------	---------------------	------------------	-----------------------

The next questions ask about muscle pain.

Do your muscles hurt at rest?	Less than usual	No more than usual	Worse than usual	Much worse than usual
-------------------------------	-----------------	--------------------	------------------	-----------------------

Do your muscles hurt during exercise?	Less than usual	No more than usual	Worse than usual	Much worse than usual
---------------------------------------	-----------------	--------------------	------------------	-----------------------

If you are tired at the moment please indicate approximately how long this has lasted. (Please circle the answer which applies to you.)

Less than 1 week	Less than 3 months	Between 3 and 6 months	6 months or more
------------------	--------------------	------------------------	------------------

Overall what percentage of the time do you feel tired? (Please circle the answer which applies to you.)

25% of the time	50% of the time	75% of the time	All the time
-----------------	-----------------	-----------------	--------------

Why do you think you are feeling tired? Please try to give one reason.

We should like you to complete the very short health questionnaire on the next page.

should like to know if you have had any medical complaints and how your health has been in general the past few weeks. Please answer ALL the questions on the following page simply by underlining answer you think most nearly applies to you. Remember that we want to know about present and not complaints, not those that you had in the past. It is important that you answer ALL the questions.

# VE YOU RECENTLY:-

able to concentrate whatever you're doing	Better than usual	Same as usual	Less than usual	Much less than usual
much sleep over ry?	Not at all	No more than usual	Rather more than usual	Much more than usual
that you are playing useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
capable of making sions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
constantly under in?	Not at all	No more than usual	Rather more than usual	Much more than usual
you couldn't over- e your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
able to enjoy your mal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
able to face up our problems?	More so than usual	Same as usual	Less able than usual	Much less able
a feeling unhappy depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
losing confidence yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
thinking of yourself worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
feeling reasonably ry, all things idered?	More so than usual	About same as usual	Less so than usual	Much less than usual

## **APPENDIX 11**

### **INFORMATION SHEET**

#### **(STUDY 4)**



**University of  
Southampton**

**School of Medicine  
Respiratory, Cell &  
Molecular Biology  
Research Division**

**Dr G T Lewth MA DM  
FRCP MRCGP**

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United Kingdom**

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Fax (+44) 023 80 798444  
Email GL3@soton.ac.uk**

## **Questionnaires to Monitor the Progress of Chronic Fatigue Syndrome**

You have been diagnosed as having chronic fatigue syndrome (CFS). This is a diagnosis based on the pattern of symptoms with which you present, and the history of your illness. We are involved in a number of research projects that have looked, and are continuing to look, at CFS. We are particularly interested in how people's symptoms progress over a long period of time. What we would like to ask you to do is fill in the enclosed questionnaires, it should take you about 10 minutes. We would then like to send you these questionnaires every 3 months for a year (that will be 10 questionnaires in total, including the two you will complete at your visit to the centre). We would ask you to complete both of them and return them to us in a stamped addressed envelope. The information you provide us with will be entirely confidential and will be used solely for the purposes of our research project; the data will be stored on a study-specific database. The information will allow us to monitor the various different aspects of your CFS over a year.

Participation in this study is entirely voluntary and you are free to withdraw from the study at any time, should you wish to do so. If you are willing to participate in this study you will be asked to sign the attached consent form just to show you have been fully informed regarding the study.

**APPENDIX 12**  
**CONSENT FORM**  
**(STUDY 4)**



**University of  
Southampton**

**School of Medicine  
Respiratory, Cell &  
Molecular Biology  
Research Division**

**Dr G T Lewth MA DM  
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**Telephone (+44) 023 80 794594  
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Email GL3@soton.ac.uk**

## CHRONIC FATIGUE SYNDROME SURVEY

### CONSENT FORM

*Please tick*

	YES	NO
Have you read the patient information sheet ?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss the study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you received satisfactory answers to all your questions?	<input type="checkbox"/>	<input type="checkbox"/>
Have you received enough information about the study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had enough time to decide about taking part?	<input type="checkbox"/>	<input type="checkbox"/>
Who have you spoken to? -----		
Do you understand that you are free to withdraw from the study:		
At any time	<input type="checkbox"/>	<input type="checkbox"/>
Without having to give a reason for withdrawal?	<input type="checkbox"/>	<input type="checkbox"/>
And without affecting your medical care?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to take part in this study?	<input type="checkbox"/>	<input type="checkbox"/>

Signed ----- Date -----

[ name in block letters ] -----

Signed [ investigator ] ----- Date -----

**APPENDIX 13**

**CLINICAL RECORD FORM**

**(STUDY 4)**

PATIENT NUMBER

DATE

PATIENT NAME

ADDRESS

DATE OF BIRTH

AGE

SEX MALE 1  FEMALE 2

GP NAME AND ADDRESS

CENTRE DR NAME:



PATIENT NUMBER DATE INCLUSION CRITERIA

BOTH QUESTIONS MUST BE ANSWERED YES

YES 1      NO 2

PATIENT BETWEEN AGE 18 -60? ☐ ☐

UNEXPLAINED PERSISTENT OR RELAPSING FATIGUE OF NEW OR DEFINATE ONSET  
 THAT IS NOT DUE TO ONGOING EXERTION, IS NOT RELIEVED BY REST, AND RESULTS  
 IN SUBSTANTIAL REDUCTION IN PREVIOUS LEVELS OF ACTIVITY

YES 1      NO 2

☐ ☐

FOUR OR MORE OF THE FOLLOWING SYMPTOMS ARE CONCURRENTLY PRESENT FOR  
 SIX MONTHS OR LONGER.

NO 2

YES 1

1. IMPAIRED MEMORY OR CONCENTRATION.  
 [ Severe enough to reduce levels of occupational, social and personal activities ]

☐ ☐

2. SORE THROAT.

☐ ☐

3. TENDER CERVICAL OR AXILLARY LYMPH NODES.

☐ ☐

4. MUSCLE PAIN.

☐ ☐

5. MULTI-JOINT PAIN.  
 [ Without joint swelling or redness ]

☐ ☐

6. NEW HEADACHES.

☐ ☐

7. UNREFRESHING SLEEP.

☐ ☐

8. POST-EXERTION MALAISE.  
 [ Lasting more than 24 hours ]

☐ ☐

PATIENT NUMBER DATE EXCLUSION CRITERIA

YES 1

NO 2

/

Concurrent illness which may affect the  
completion of the silver lining questionnaire  
and the health fatigue questionnaire

☐☐

YES 1

NO 2

PATIENT FULFILLS CRITERIA TO TAKE PART IN THE STUDY ? ☐☐

CONSENT GIVEN ?

☐☐

**APPENDIX 14**

**COVERING LETTER FOR  
REPEAT QUESTIONNAIRES  
(STUDY 4)**



**The Centre for the Study of  
Complementary Medicine**

51 Bedford Place  
Southampton SO15 2DT

Tel. 023 8033 4752

Fax 023 8023 1835

E-mail: [cscm.compmed@btinternet.com](mailto:cscm.compmed@btinternet.com)

Website: [www.complemed.co.uk](http://www.complemed.co.uk)

Dear

Please find enclosed a further questionnaire for the Silver Lining Study. I would be most grateful if you could complete it and return to me in the enclosed envelope. If we do not receive this by two weeks time, I shall post a further questionnaire to you in case it has been mislaid or failed to reach you.

Thank you very much for your very valuable help with this study.

Yours sincerely

Margaret McGuirk (RGN)

Silver lining letter/jgl/orig/nurses/7.2.01

Dr Nick Avery

MB, BS, LRCP, MRCS, MFHom

Dr Michael Clark

B.Sc, MBChB, DRCOG, MFHom

Dr George Lewith

MA, DM, FRCP, MRCGP

Dr David Marshall

MRCS, MRCGP, DRCOG, MFHom

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## **APPENDIX 15**

### **ADDITIONAL DEMOGRAPHIC, RELIGIOUS / SPIRITUAL ORIENTATION AND SOCIAL SUPPORT ITEMS (STUDY 5)**

# The Silver Lining Questionnaire

## What is this questionnaire all about?

Although illness can be a distressing experience, some people who have or have had an illness talk about its positive aspects. This questionnaire asks you to think about this positive side of illness.

## How do I complete this questionnaire?

On the next two pages, there are 38 statements about the experience of being ill. Please indicate the extent to which you agree or disagree with each statement by circling a number between 5 "strongly agree" and 1 "strongly disagree". There are no right or wrong answers, your own personal views are important.

An example to help you:

I appreciate other people more because of my illness

strongly agree	agree	not sure	disagree	strongly disagree
----------------	-------	----------	----------	-------------------

5

4

3

2

1

If you strongly feel that you appreciate other people more now as a result of your illness, you would circle the number five.

*Please complete:*

Age .....

Sex (please tick)

Male	<input type="checkbox"/>
Female	<input type="checkbox"/>

## Race or ethnic group/descent

White	<input type="checkbox"/>	Indian	<input type="checkbox"/>	Pakistani	<input type="checkbox"/>
Bangladeshi	<input type="checkbox"/>	Black-Caribbean	<input type="checkbox"/>	Black-African	<input type="checkbox"/>
Black-Other	<input type="checkbox"/>	Chinese	<input type="checkbox"/>		

Other race, or group, or of mixed descent ☐ Please specify .....

Your religion ..... or, (please tick)

Are you spiritual but not religious? ☐

Neither spiritual nor religious? ☐

How many people do you think you can talk to about your illness? .....

**APPENDIX 16**

**THE EYSENCK PERSONALITY QUESTIONNAIRE**

**REVISED (EPQ-R) SHORT SCALE**

**(STUDY 5)**

**INSTRUCTIONS:** Please answer each question by putting a circle around the 'YES' or 'NO' following the question. There are no right or wrong answers, and no trick questions. Work quickly and do not think too long about the exact meaning of the questions.

**PLEASE REMEMBER TO ANSWER EACH QUESTION**

**PAGE 1**

1	Does your mood often go up and down?	YES	NO
2	Do you take much notice of what people think?	YES	NO
3	Are you a talkative person?	YES	NO
4	If you say you will do something, do you always keep your promise no matter how inconvenient it might be?	YES	NO
5	Do you ever feel 'just miserable' for no reason?	YES	NO
6	Would being in debt worry you?	YES	NO
7	Are you rather lively?	YES	NO
8	Were you ever greedy by helping yourself to more than your fair share of anything?	YES	NO
9	Are you an irritable person?	YES	NO
10	Would you take drugs which may have strange or dangerous effects?	YES	NO
11	Do you enjoy meeting new people?	YES	NO
12	Have you ever blamed someone for doing something you knew was really your fault?	YES	NO
13	Are your feelings easily hurt?	YES	NO
14	Do you prefer to go your own way rather than act by the rules?	YES	NO
15	Can you usually let yourself go and enjoy yourself at a lively party?	YES	NO
16	Are <i>all</i> your habits good and desirable ones?	YES	NO
17	Do you often feel 'fed-up'?	YES	NO
18	Do good manners and cleanliness matter much to you?	YES	NO
19	Do you usually take the initiative in making new friends?	YES	NO
20	Have you ever taken anything (even a pin or button) that belonged to someone else?	YES	NO
21	Would you call yourself a nervous person?	YES	NO
22	Do you think marriage is old-fashioned and should be done away with?	YES	NO
23	Can you easily get some life into a rather dull party?	YES	NO
24	Have you ever broken or lost something belonging to someone else?	YES	NO
25	Are you a worrier?	YES	NO



**APPENDIX 17**

**PATIENT INFORMATION AND CONSENT FORM**

**(STUDY 5)**

## **Patient Information and Consent**

Project Title: Positive Consequences of Illness

### **What is this study all about?**

Although illness can be a distressing experience, some people report that something good has come out of their illness. The purpose of this study is to find out about the different effects of illness on people's lives and to discover whether particular illness types are associated with greater positivity.

### **What will happen if I decide to take part?**

You will be asked to complete two short questionnaires asking you about yourself and your experiences of being ill. The information you provide will be completely confidential and anonymous.

### **Does taking part in this study affect my care?**

No. Whether or not you decide to take part in this study will have no impact on your care.

### **Does this study help in any way?**

The study will not provide you with any direct benefit, but taking part will help us understand more about the ways people react to different illnesses.

### **Can I discuss this before deciding to take part?**

Yes. You are very welcome to ask any questions before deciding to participate. The researcher, Samantha Sodergren, can be contacted at the following address:

Freepost, Department of Psychology, University of Plymouth, Drake Circus, Plymouth, Devon, PL4 8AA.  
Or alternatively by telephoning 01752 233216.

Thank you for your interest.

### **Patient's name:**

I understand what I am being asked and I am happy to be involved in this research.

**APPENDIX 18**

**PATIENT DATA SHEET**

**(STUDY 5)**

PATIENT DATA SHEET

HOSPITAL NO. ....  
SURNAME .....  
FIRST NAMES .....

TYPE OF ILLNESS (*Tick which applies*)

- Asthma ☐
- COPD ☐
- Fibrosing alveolus ☐
- Lung cancer ☐
- Sarcoidosis ☐
- Sleep apnoea ☐
- Tuberculosis ☐
- Other (*Please state*) .....

CO-MORBIDITY

Please list other significant diagnoses (e.g., heart disease)  
.....  
.....  
.....

DURATION OF ILLNESS

(*Please state*) .....

## **APPENDIX 19**

### **MRC DYSPNOEA SCALE**

#### **(STUDY 5)**

## **MRC Dyspnoea Scale**

**Patient Name:**

<b>Grade</b>	<b>Degree of breathlessness related to activities</b>
<b>0</b>	<b>Not troubled by breathlessness except on strenuous exercise.</b>
<b>1</b>	<b>Short of breath when hurrying, or walking up a slight hill.</b>
<b>2</b>	<b>Walks slower than contemporaries on the level because of breathlessness, or has to stop for breath when walking at own pace.</b>
<b>3</b>	<b>Stops for breath after walking about 100m, or after a few minutes on the level.</b>
<b>4</b>	<b>Too breathless to leave the house, or breathless when dressing or undressing.</b>
<b>5</b>	<b>Breathless at rest.</b>

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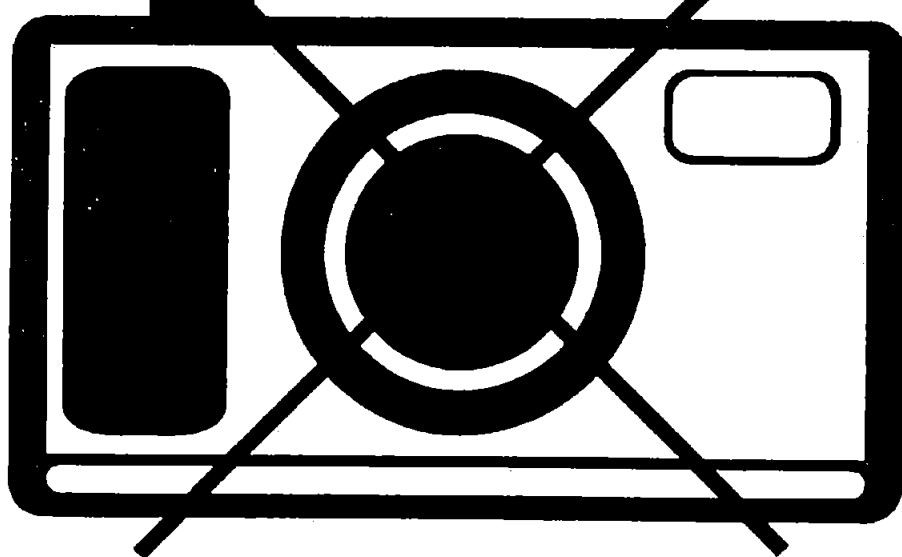
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## PUBLICATIONS

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## **CHRONIC FATIGUE SYNDROME**

### **Self-actualisation but not Mood Predicts Better Improvement in Mental Fatigue in Chronic Fatigue Patients**

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**Running Head: Chronic Fatigue Syndrome**

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Abstract

We used a prospective, uncontrolled outcome study to test two predictions: that chronic fatigue syndrome (CFS) patients who (a) interpret their illness as a positive, life changing experience or (b) have greater well-being, recover faster. Seventy-five CFS patients were recruited from a complementary medical centre of whom 53 were followed up over 12 months. Fatigue (mental, physical and total scores of a fatigue scale), well-being (General Health Questionnaire, GHQ), and illness self-actualisation (Silver Lining Questionnaire, SLQ) were assessed every three months. At 6 and 9 months, the SLQ predicted ( $p < .001$ ) mental fatigue (but not physical fatigue) at 12 months independently of current mental fatigue, initial mental fatigue, duration since diagnosis, and time between start of treatment and entry to the study. The GHQ did not predict fatigue at any time point. The results suggest that mental and physical fatigue have different causal determinants in recovery, and that a positive interpretation of illness contributes to recovery as one of several inputs to a complex multi-factorial system.



Although Chronic Fatigue Syndrome (CFS) remains a controversial disease where several different mechanisms have been suggested (e.g., immunological, psychological, and hypothalamic-pituitary-adrenal axis), there is an increasing consensus that the underlying mechanism results from an interaction of several mechanisms (Clark, Bachwald, MacIntyre, Sharpe, & Wessely, 2002; Jason et al., 1999). This perspective is supported by data showing that the cause of CFS is multi-factorial, often involving an interaction between physiological and psychological factors (see, for example, review in Wessely, Hotopf, & Sharpe, 1998), and that lifestyle prior to the disease, in particular, an overburdened, driven lifestyle (Abbey, 1996; Van-Houdenhove, Neerincx, Onghena, Lysens, & Vertommen, 2001), create conditions that combined with other factors lead to CFS.

Although there is some consensus on the interactional antecedents of CFS, there is less consensus about what exactly that interactional mechanism is. One recently suggested mechanism is based on the assumption that the whole body, and not just the brain, functions, in part, as a complex, network system, and that this 'extended' or psychoneuroimmunoendocrine network, which has both neurological and humoral causal links, exhibits properties labelled 'intelligent' (Hyland, 2001a). The extended network sets the parameters of lower level (physiological and psychological) control systems, but it does so in an 'intelligent' way that responds to internal feedback. In responding to internal feedback, the extended network self-organises (or 'learns'), and sets the lower level control system parameters so as to achieve self-regulatory patterns that are genetically specified, and it does so by compensating for disturbances to that pattern. This is called the compensation rule. Under most circumstances, the compensation rule is adaptive leading to more effective regulation, but under particular circumstances, it creates dysregulation in the lower level control loops (Hyland, 2001a, 2001b, 2002).

According to the network theory of CFS (Hyland, 2001a), the repeated combination of immune challenge or trauma (i.e., cytokine inducing events) with lifestyle challenge (i.e., septo-hypocampal activating events), leads to the network compensating for the constant behavioural disregard of fatigue inducing signals (i.e., cytokines). This compensation leads to up-regulation of the fatigue response to cytokines, but also a dysregulated hyper-immune response, as well as hypothalamic abnormalities. This theory is consistent with data showing that pharmacological treatment provides limited symptom control, whereas lifestyle changes that promote general health and well being (e.g., graded exercise, psychological well being) is associated with better long-term outcome (Deale, Chalder, Marks, & Wessely, 1997; Fulcher & White, 1997; Sharpe, 1997; Wearden et al., 1998; Whiting, Bagnall, Sowden, Cornell, Mulrow, & Ramirez, 2001). Lifestyle appears to be an important aspect of both onset and recovery from CFS.

The compensation rule has been applied to CFS in the context of lifestyle plus immune challenge – where there is an assumption that the body is designed for lifestyle challenge (e.g., to fight mammoths) and physiological challenge (e.g., to manage infection and trauma), but not to do both simultaneously (Hyland, 2002). A higher level interpretation of the compensation rule suggests that failure to follow a genetically determined life pattern (i.e., lack of self-actualisation) may also lead to dysregulation as the body tries to compensate for differences between the actual lifestyle and this genetically specified, overall pattern of living. The idea that lack of self-actualisation (or some equivalent concept) is the cause of disease has been suggested by several authors, both inside and outside the field of psychology, so this idea is not unique to the network theory of CFS, though is implicit in it (Antonovsky, 1987; Bach, 1931; LeShan, 1984; 1994).

Despite the negative consequences of disease, many patients, including some who have CFS, report being happier overall during or after their illness (Sodergren & Hyland, 2000). This phenomenon of positivity appears to be an example of a more general response to life-changing stress (Park, Cohen, & Murch, 1996; Schaefer & Moos, 1992; Tedeschi & Calhoun, 1996), which occurs for some people where stress facilitates self-actualisation or some form of existential growth. Measures of positivity correlate positively with extraversion, openness to new experiences and spiritual/religious beliefs, negatively with neuroticism but do not correlate with repression (Park et al., 1996; Sodergren, Hyland, Crawford, & Partridge, 2002; Tedeschi & Calhoun, 1996). The finding that positivity is associated with novel experiences is consistent with the common view that stress-related growth reflects some form of self-actualisation (Granstrom, 1985; LeShan 1984; 1994). That is, illness provides some patients with an opportunity to take stock and become more like the 'person they are supposed to be' – which often is expressed by patients as becoming a 'better person' (LaFortune-Fredette, 1995; Sodergren & Hyland, 2000).

This paper tested the hypothesis that self-actualisation after developing CFS is a predictor of recovery. That is, if patients are able to 'grow' as people because of their illness, and thereby adopt a lifestyle (including mental perspective) more suited to that individual, they should be more likely to recover. Positivity in illness has shown to affect outcome in heart disease (Affleck, Tennen, Croog, & Levine, 1987; Croog & Levine, 1982) so there is related data as well as a theoretical prediction (i.e., the network theory of CFS, Hyland, 2001a) to suggest that self-actualisation, which is measured by scales of positivity in illness, predicts recovery in CFS. We compared this hypothesis with an alternative hypothesis, that positive mood is the important predictor of recovery. The assumption that mood or well being is important to CFS recovery is based on evidence that immune dysregulation is observed in CFS (Tirelli, Marotta, Improtta, & Pinto, 1994; Vollmerconna, Lloyd, Hickie, & Wakefield, 1998), that mood is a determinant of immune function, and that positive mood

tends to improve immune function (Hucklebridge, Lambert, Clow, Warburton, Evans, & Sherwood, 2000). Moreover, one of the aims of cognitive behavioural therapy (CBT) for CFS is to improve mood or well being in CFS patients by focusing attention away from negative cognitions. CBT has been shown to enhance recovery from CFS (Deale et al., 1997; Sharpe, 1997), as have self-help booklets (Chalder, Wallace & Wessely, 1997). Thus, this paper tests whether self-actualisation or mood (or both) predict recovery from CFS.

## **Method**

### *Design*

This is a prospective cohort study in which patients with CFS were assessed over a 12-month period.

### *Recruitment and setting*

Patients were recruited if they had been diagnosed by a medically qualified doctor as having CFS as defined by Fakuda et al. (Fakuda, Strauss, Hickie, Sharpe, Dobbins, & Komaroff, 1994). Patients were recruited from a complementary medical clinic (The Centre for the Study of Complementary Medicine, Southampton, UK) where they are treated with individualised homeopathy, acupuncture and nutritional medicine but with no psychological intervention. Patients were recruited while they attended the clinic for treatment, and all patients meeting the entry requirements were asked until 75 sequential patients had been recruited.

### *Assessments*

Because fatigue is the primary symptom of CFS, we assessed outcome by an 11-item fatigue questionnaire (Chalder et al., 1993). This scale is a common outcome measure in CFS studies; psychometric analysis suggests the independence of physical fatigue (seven items) and mental fatigue (four items), and the scale is scored to produce physical and mental fatigue sub-scales, and an overall score (based on all 11 items). We measured mood and well-being using the General Health Questionnaire (GHQ) short form 12-item version (Goldberg & Williams, 1988). This scale measures patients' general well-being over the last few weeks and is highly correlated with neuroticism.

The 38-item Silver Lining Questionnaire (SLQ; Sodergren & Hyland, 2000) was selected as the most comprehensive of the three published illness-specific positivity scales (Hyland & Kenyon, 1992; Tennen, Affleck, Urrows, Higgins, & Mendola, 1992; Cruess et al., 2000). The SLQ measures 10 facets of positivity with illness: Restructuring of life; reappraisal of life; spiritual gains; self-improvement; self-awareness; skills and new pursuits; sensitivity to emotions; confrontation of current concerns; improved interpersonal relationships; and positive consequences for others. Patients respond on a five-point scale of agreement / disagreement, and an overall score is produced by adding the number of items to

which patients either agree or strongly agree. The scale has good retest reliability ( $r = .90$ ) and internal consistency (alpha coefficient  $= .93$ ) (Sodergren, Hyland, Singh, & Sewell, in press). In a group of 197 respiratory patients, this scale was found to correlate with extraversion ( $r(174) = .16, p < .05$ ) but there was a non-significant positive correlation with neuroticism ( $r(172) = .11, ns$ ), not a negative correlation which would be expected if the SLQ simply reflects positive mood. The GHQ and the SLQ therefore appear to measure different constructs.

### *Procedure*

Ethical approval was obtained from the local ethics committee (No. 169/99). Patients were recruited during a visit for treatment, and after giving written consent take part, they were given all three questionnaires to complete in the clinic (baseline). We recorded the duration of the disease, the duration between first treatment at the clinic and entry to the study, the patient's age and gender. At 3, 6, 9, and 12 months the three questionnaires were sent by post to the patient's home, with a request to complete and return them using the stamped addressed envelope provided. If a questionnaire was not completed within two weeks, a repeat questionnaire was sent, and if there was still no response no further questionnaires were sent and a telephone call was made to ascertain the reason for withdrawal.

### **Results**

Eighty-nine patients were asked to take part in the study of whom 75 agreed to take part. Three patients were excluded because they failed to meet the study criteria, leaving 72 patients (52 females, 20 males, age range = 18 – 59 years, age mean = 37 years) who completed the first assessment. Completed questionnaires were received from 69 patients at 3 months, 63 patients at 6 months, 55 patients at 9 months and 53 patients at 12 months. Compared to other patients at baseline, those 19 patients who did not complete the study were not significantly different on physical fatigue ( $t(30.47) = -0.38, ns$ ), mental fatigue ( $t(30.84) = 0.12, ns$ ), or overall fatigue ( $t(30.95) = -0.29, ns$ ), nor were they different in the duration of CFS ( $t(34.14) = -1.45, ns$ ), nor time since treatment at the Centre ( $t(70) = 0.65, ns$ ). Two patients discontinued due to time commitments; the remainder gave no reason.

Table 1 shows the correlations amongst questionnaire measures of those 72 patients who started the study. The SLQ was unrelated to any of the questionnaire measures but it was significantly lower ( $r(72) = -.25, p < .05$ ) in patients who had CFS for longer. The GHQ showed improved health ( $r(72) = .32, p < .01$ ) for those who had the disease longer and for those with less physical fatigue ( $r(69) = .30, p < .05$ ). Time since start of treatment did not correlate significantly with any of the questionnaire measures. As one would expect, the fatigue sub-scales were significantly inter-correlated.

All of the following analyses were carried out on those 53 patients who completed the study. There were 16 males and 37 females, mean age was 38.62 years, the median time since diagnosis with CFS was 6 years, and the median time between treatment at the clinic and entry into the study was 2 months. Twenty-three (43.4%) patients were entered into the study on their first visit to the clinic, and 38 (71.7%) patients were entered within 6 months of their first visit. Thus, for the majority of patients, the start of the study coincided with or was shortly preceded by the start of a new treatment. Table 2 shows baseline and 12-month scores on all questionnaire measures. There was a significant reduction in total fatigue ( $t(50)=5.36, p<.001$ ), physical fatigue ( $t(50)=4.97, p<.001$ ), and mental fatigue ( $t(51)=5.20, p<.001$ ), and improvement on the GHQ ( $t(51)=4.03, p<.001$ ), but no change for the SLQ over the course of study ( $t(51)=0.05, ns$ ).

The statistical procedure to test whether positivity (either mood or self-actualisation) predicted outcome was based on the following assumptions. First, we assumed that the outcome measures (i.e., physical, mental and total fatigue) as well as the GHQ and SLQ could change during the course of the study. Second, we assumed that if there is an effect of the GHQ or SLQ on outcome, it could occur at varying points over the course of the study. Third, we assumed that change in outcome earlier in the study may predict positivity (i.e., patients become more positive about their illness if they improve), so it is necessary to control for the effect of change in outcome when determining the contribution made by the GHQ or SLQ at any point over the study on outcome at 12 months.

We tested each outcome variable using four regression models where variables were entered simultaneously. In these regression models the dependent variable was always outcome at 12 months (i.e., either the physical, mental or total fatigue score at 12 months), and independent variables included the corresponding outcome at baseline, time since diagnosis, and time between first treatment at the clinic and entry to the study. We tested the additional contribution of the GHQ and SLQ at 3, 6 and 9 months to outcome at 12 months by adding as independent variables the GHQ, SLQ and corresponding outcome at 3, 6 and 9 months respectively. For example, in assessing the contribution of the GHQ and SLQ at 3 months on outcome at 12 months, we entered as independent variables: (a) outcome at baseline, (b) time since diagnosis, (c) time since treatment started, (d) outcome at 3 months, (e) SLQ at 3 months, and (f) GHQ at 3 months. This method therefore tests whether either the GHQ or SLQ explains additional variance in the outcome at 12 months than can be explained by the earlier outcome measures and other factors, such as time.

Table 3 shows the results of the multiple regression models. The results show that, at 6 months and 9 months, the SLQ predicts mental fatigue at 12 months. The SLQ does not predict physical fatigue (significant effects on total fatigue at 6 months can be attributed to the effect on mental fatigue). The GHQ did not predict any outcome variable. As expected,

earlier outcome predicted final outcome. Mental fatigue at either 3, 6 or 9 months also predicted final mental fatigue independently of initial fatigue: those who had less fatigue at 3, 6 or 9 months had less final fatigue, independently of initial levels of fatigue. In sum, mental fatigue at 12 months is predicted independently at 6 and 9 months by the current SLQ, current mental fatigue and baseline fatigue.

The finding that the SLQ predicts final mental fatigue at 6 and 9 months but not at baseline or 3 months suggests that the SLQ is not stable, despite the fact that there is no overall mean change over the 12 months. Because the potential for improving scores on the SLQ has been demonstrated in a rehabilitation setting (Sodergren et al., in press), we carried out a follow up analysis. We examined the effect of SLQ change on outcome by classifying patients as increasing, decreasing, or remaining the same on the SLQ in comparison with their baseline assessment. Table 4 shows the mean final mental and physical fatigue values for the increasers, decreasers, and those who remained the same with respect to their SLQ values as defined at 3 months, 6 months, and 9 months. We tested the significance between the values of the increasers and decreasers (the number of those remaining the same was small). Patients who had improved SLQ scores at 3 months had lower levels of final physical fatigue ( $t(47)=2.02, p<.05$ ), but not mental fatigue ( $t(47)=1.53, ns$ ). Those who had increased their SLQ values at 6 months had lower levels of final physical fatigue ( $t(45)=2.50, p<.05$ ), but not mental fatigue ( $t(45)=1.54, ns$ ). Those who had increased their SLQ values at 9 months had both lower levels of physical fatigue ( $t(43)=2.66, p<.05$ ) and mental fatigue ( $t(43)=2.62, p<.05$ ). Thus, the reason that the SLQ predicts mental fatigue at 6 and 9 months in the multiple regression, but not at baseline appears to be because the SLQ changes over the course of the study.

### Discussion

The aim of this study was to examine whether illness initiated self-actualisation, as measured by the SLQ, predicted outcome in CFS. We compared this hypothesis with the alternative hypothesis that positive mood or well-being, as measured by the GHQ, predicted outcome. We found that the SLQ but not the GHQ predicted mental but not physical fatigue. This finding suggests that the psychological contribution to the interactional disease that is CFS is one that works primarily at a higher rather than lower psychological level. This finding is consistent with informal reports that patients with CFS often experience an 'event' when they start to improve (Collinge, 1993) and that this 'event' often involves a reappraisal of themselves and their illness. Self-actualisation therefore seems to be one aspect of recovery from CFS, suggesting that psychological therapy should include an existential focus.

Our finding that illness-generated self-actualisation predicts better outcome in CFS can be considered in relation to earlier data showing that believing CFS is caused by a virus

predicts worse outcome (Sharpe, Hawton, Seagroatt, & Pasvol, 1992; Wilson, Hickie, Lloyd, & Wakefield, 1994). The belief that CFS is caused by a virus may have a deleterious effect on outcome for several reasons, including a reluctance to engage in exercise. However, belief that CFS is caused by a virus is an attribution that would make patients less likely to believe that the pre-disease lifestyle was sub-optimal in some way and therefore responsible for disease onset. Thus, it may be that belief in a viral cause of CFS is associated with a non-self-actualising response to the disease.

One unexpected finding of our study was that the SLQ affected only mental fatigue and not physical fatigue. This finding suggests that physical and mental fatigue may have different causal determinants, at least with regard to recovery. The reason for this is unknown, but the findings are consistent with the view that a multi-disciplinary approach to therapy is most helpful for patients. It is also consistent with the view that a purely psychological approach may miss out on other factors that contribute to recovery.

This interactional perspective is supported by our finding that the SLQ predicted final mental fatigue at 6 and 9 months but it did not predict final mental fatigue at baseline nor at 3 months. The ability of the SLQ to predict mental fatigue at 6 or 9 months was independent of mental fatigue at 6 or 9 months, so it seems unlikely that that values of the SLQ are simply a response to improvement – i.e., patients become more actualising when they improve. Another reason why this finding cannot be attributed to patients becoming more self-actualising when they improve was that there was no baseline correlation between the SLQ and fatigue, though the SLQ was lower in patients who had the disease longer. There may be some people who become less self-actualising about their illness as time proceeds. This is consistent with our follow up analysis that showed that the value of the SLQ increased for some patients and decreased for others over the course of the study, and that the increasers had better outcomes than the decreasers.

There are two other reasons why the SLQ predicts mental fatigue at 6 and 9 months but not at baseline or 3 months. One is that SLQ changes naturally over the course of the disease, and that our findings are the consequence this natural change. However, the median time since first diagnosed with CFS was 6 years, and because of this time scale it seems unlikely that we are detecting natural change. A second explanation is that the treatment at the clinic induced changes in the SLQ, and these changes started to appear at about 6 months or more after the beginning of treatment. Because the SLQ at 6 and 9 months predicted mental fatigue independently of mental fatigue at 6 or 9 months, it seems possible that the clinic was responsible for those psychological changes reflected in a change in SLQ score. The clinic did not provide psychological therapy, but it did provide a warm, supportive environment for patients. Positivity to illness can be increased by psychological intervention (Cruess et al., 2000) as well as by therapies that are not intentionally psychological

(Sodergren et al, in press). Thus, the clinical context may have been a factor in inducing some patients to self-actualise in response to their illness. In addition, the homeopathic treatments in the clinic included 'constitutional remedies' which are designed to work on the person as a whole rather than on symptoms, and the purported action of these remedies would be consistent with greater self-actualisation (Boyd, 1989). Whether it is the context or treatments that increased positivity on the SLQ in some patients is unknown, but it is possible that the therapy may have been responsible either directly or indirectly for changes on the SLQ.

Thus, the most likely explanation of our findings is that treatment at the clinic induces changes that provide the opportunity for self-actualisation, and then if this self-actualisation occurs, it potentiates the recovery process. This interpretation supports a multi-disciplinary, multi-therapeutic approach to CFS where different inputs to a dysregulated network gradually nudge it back into health, and one of these inputs is a high level, psychological pattern of the way a person lives his or her life.

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Table 1. Correlations between measures at baseline. N=72.

	Time since diagnosis	Time since treatment	SLQ	Total Fatigue	Physical Fatigue	Mental Fatigue
Time since treatment	-.03					
SLQ	-.25*	.13				
Total Fatigue	-.15	.04	.12			
Physical Fatigue	-.19	-.01	.06	.94***		
Mental Fatigue	-.06	.14	.17	.84***	.60***	
GHQ	-.32**	-.11	-.16	.31	.30*	.22

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

Table 2. Mean (standard deviation) SLQ, fatigue, and GHQ scores at baseline and 12 months.  
N=53.

	Baseline	12 months
SLQ	13.23 (8.11)	13.19 (8.94)
Total Fatigue	24.43 (6.26)	18.10 (9.04)
Physical Fatigue	16.21 (4.22)	11.98 (6.37)
Mental Fatigue	8.28 (2.67)	6.04 (3.12)
GHQ	18.94 (7.92)	13.46 (6.99)

Table 3. Multiple regression of three outcome variables, total fatigue, physical fatigue, and mental fatigue measured at 12 months as a function of time since diagnosis, time between start of treatment and entry to the study, outcome at baseline and outcome, SLQ, and GHQ scores at either baseline, 3, 6, or 9 months. N = 53.

	Total Fatigue		Physical Fatigue		Mental Fatigue	
	Beta	p	Beta	p	Beta	p
Time since diagnosis	.12	.40	.16	.29	.01	.94
Time since treatment	.17	.22	.18	.20	-.03	.81
Outcome at baseline	.45	.00	.41	.01	.49	.00
SLQ at baseline	-.11	.43	-.02	.88	-.24	.09
GHQ at baseline	-.10	.50	-.10	.50	-.01	.95
	R <sup>2</sup> =.17		R <sup>2</sup> =.14		R <sup>2</sup> =.17	
Time since diagnosis	.13	.25	.14	.23	.07	.55
Time since treatment	.12	.29	.16	.17	-.10	.39
Outcome at baseline	.19	.12	.17	.17	.26	.09
Outcome at 3 months	.57	.00	.58	.00	.40	.02
SLQ at 3 months	-.12	.31	-.06	.62	-.18	.16
GHQ at 3 months	-.00	.99	-.02	.91	.16	.25
	R <sup>2</sup> =.45		R <sup>2</sup> =.43		R <sup>2</sup> =.35	
Time since diagnosis	.18	.15	.17	.18	.12	.29
Time since treatment	.08	.54	.11	.40	-.17	.14
Outcome at baseline	.32	.01	.27	.04	.35	.01
Outcome at 6 months	.47	.00	.49	.00	.43	.01
SLQ at 6 months	-.27	.03	-.19	.13	-.34	.01
GHQ at 6 months	-.20	.18	-.21	.17	-.04	.77
	R <sup>2</sup> =.44		R <sup>2</sup> =.39		R <sup>2</sup> =.45	
Time since diagnosis	.12	.22	.13	.26	.09	.33
Time since treatment	.01	.93	.05	.64	-.11	.23
Outcome at baseline	.29	.01	.22	.07	.39	.00
Outcome at 9 months	.56	.00	.55	.00	.55	.00
SLQ at 9 months	-.09	.35	-.01	.93	-.25	.01
GHQ at 9 months	.07	.52	.11	.39	.04	.68
	R <sup>2</sup> =.61		R <sup>2</sup> =.53		R <sup>2</sup> =.66	

Table 4. Mean (standard deviation) physical and mental fatigue scores at 12 months as a function of an increase, decrease, or no change on the SLQ. N=53.

	n	Physical Fatigue	Mental Fatigue
<i>3 months</i>			
Increase	20	10.05 (6.46)	5.10 (3.04)
Decrease	29	13.62 (5.80)	6.48 (3.15)
No change	4	10.00 (6.58)	7.00 (2.58)
<i>6 months</i>			
Increase	17	9.41 (6.42)	5.12 (3.04)
Decrease	30	13.77 (5.32)	6.53 (3.01)
No change	5	12.40 (7.44)	7.00 (2.55)
<i>9 months</i>			
Increase	22	10.50 (6.38)	5.27 (3.03)
Decrease	23	14.87 (14.51)	7.43 (2.50)
No change	4	9.25 (7.97)	3.75 (1.89)

## WHAT ARE THE POSITIVE CONSEQUENCES OF ILLNESS?

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Fifty five people, either currently sick or having recovered from their illness, were recruited if they reported positive consequences of illness. They were questioned about their experiences of illness, 41 by semi-structured interview and 14 by open-ended questionnaire and responses were classified into 17 categories. The categories were similar but slightly more extensive than previous accounts of positive consequences reported in the literature. The content of the interviews and questionnaires was used to construct a 66 item questionnaire about positive consequences of illness which was then completed by 97 patients. A principal components analysis indicated a large first factor accounting for 27% of the variance. Endorsement of items varied between 87% and zero for chronic lung disease patients attending pulmonary rehabilitation. However, all patients endorsed at least one item and the median number of items endorsed was 31. Positive consequences of illness are highly varied and more common than often realised, and this has implications for the concept and measurement of quality of life.

**KEY WORDS:** Quality of life, illness, meaning, happiness, chronic lung disease.

### INTRODUCTION

The purpose of medicine is to treat or cure illness. A commonly accepted assumption is that illness imposes deficits on a patient's quality of life. For example Kleinman (1986) defines quality of life as:

"...the constraints that disorder places on the patient, and his or her lifestyle and lifeworld." (p. 43)

Consistent with this definition, health-related quality of life is measured by questionnaires which often take the form of complaint checklists. The possibility that illness, though undesirable, produces some positive consequences is seldom considered, though implicit in the definition of quality of life provided by DeHaes and vanKnippenberg (1985):

"...an overall evaluation of the subjective experience of life." (p. 872)

Despite the negative bias in quality of life research, there is a literature, often anecdotal in nature, which indicates that illness can have positive consequences (Table 1). In addition, positive effects of stress have been noted (Schaefer and Moos, 1992) and Park,

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**Table 1** Relationship between the themes identified and the literature

<i>Themes</i>	<i>Evidence from the previous literature</i>
<i>Improved Interpersonal Relationships</i>	
–Greater investment in relationships	Taylor (1983)
–More to offer others	Collins <i>et al.</i> (1990); Mayou <i>et al.</i> (1978); Zemore <i>et al.</i> (1989)
–Greater appreciation of others	Kennedy <i>et al.</i> (1976); Mayou <i>et al.</i> (1978); O'Connor <i>et al.</i> (1990)
<i>Positive Influence on Others</i>	
–Inspiration to others	Lukas (1992); Taylor (1983)
–Positive changes in the behaviour of others	LaFortune Fredette (1995)
<i>Positive Personality Changes</i>	
–Self-improvement (for example, better person, happier, more mature, assertive)	Collins <i>et al.</i> (1990); Kennedy <i>et al.</i> (1976); LaFortune Fredette (1995); Zemore <i>et al.</i> (1989)
–Self-focused	Belcher <i>et al.</i> (1989); Giovinco and McDougald (1994); O'Connor <i>et al.</i> (1990); Taylor <i>et al.</i> (1983)
–Greater concern for others	Collins <i>et al.</i> (1990)
–More tolerant	Kennedy <i>et al.</i> (1976)
<i>Reappraisal of Life</i>	
–Greater consideration of the meaning of life	Belcher <i>et al.</i> (1989); Giovinco and McDougald (1994); Northouse and Northouse (1988); O'Connor <i>et al.</i> (1990)
–Altered perspective on life (for example, a more positive approach)	Kennedy <i>et al.</i> (1976); O'Connor <i>et al.</i> (1990); Zemore <i>et al.</i> (1989)
–Greater appreciation and enjoyment of life (for example, simple pleasures)	Cella and Tross (1986); Cherry and Smith (1993); Laerum <i>et al.</i> (1988); LaFortune Fredette (1995)
<i>Restructuring of Life or Lifestyle</i>	
–Improved or healthier way of life	Affleck <i>et al.</i> (1987); Laerum <i>et al.</i> (1988); LaFortune Fredette (1995)
–More fulfilled lifestyle	Collins <i>et al.</i> (1990); Kennedy <i>et al.</i> (1976)
<i>Spiritual Changes</i>	
–Richer spiritual life	Belcher <i>et al.</i> (1989)
–Greater spiritual insight	Oreopoulos (1985)
–Confirmation of beliefs	O'Connor <i>et al.</i> (1990)
–Re-evaluation of spirituality	Affleck <i>et al.</i> (1987); Belcher <i>et al.</i> (1989)
<i>Changes in Priorities</i>	Collins <i>et al.</i> (1990); LaFortune Fredette (1995); Taylor (1983)
<i>Skills and New Pursuits</i>	
–Discovery of a new talent	Giovinco and McDougald (1994); LeShan (1984)
–Equipped to deal with future experiences	Collins <i>et al.</i> (1990); Lipowski (1970–1971)
<i>Self-knowledge</i>	
–Self-discovery	Giovinco and McDougald (1994)
<i>General Knowledge</i>	Hiatt (1986); O'Connor <i>et al.</i> (1990); Taylor <i>et al.</i> (1983)
<i>Ability to Give Up Certain Demanding Activities</i>	Lipowski (1970–1971); Mechanic (1966); VandenBerg (1972)
<i>Improved Awareness of Own Emotions</i>	Taylor (1983); Collins <i>et al.</i> (1990)
<i>Resolution of Past Concerns</i>	LeShan (1984)
<i>Seeing Illness as a Challenge to Overcome</i>	Belcher <i>et al.</i> (1989); Giovinco and McDougald (1994); Lipowski (1970–1971)
<i>Resolution of Current Concerns</i>	LeShan (1984)
<i>Practical Gains</i>	Lipowski (1970–1971); Mechanic (1966); VandenBerg (1972)
<i>Greater Respect for the Environment</i>	Collins <i>et al.</i> (1990)

Cohen and Murch (1996) have developed a Stress-related Growth Scale which can be used in the context of various life crises including illness. There is one measure which specifically addresses the positive consequences of illness; the Satisfaction with Illness Scale (Hyland and Kenyon, 1992) and contains six items, for example, "My illness has shown me the value of friendship". In addition, five items describing positive effects of illness are included in the Life Evaluation Questionnaire (Salmon, Manzi and Valori, 1996).

There are several theoretical explanations for why patients may interpret their illness positively. (a) Illness may encourage individuals to confront problem areas of their life and deal with them. Illness may act as a stimulus to achieve outcomes which were previously put off and bring patients closer to a cherished goal (Cassell, 1982). (b) Patients may "disengage" (Carver and Scheier, 1990) from unattainable goals, so that the illness is no longer perceived as interrupting important goals. Disengagement is a healthy reaction to unattainable goals: an inability to disengage is associated with increased risk of depression (Carver and Scheier, 1982; Hyland, 1987). Following disengagement, patients may develop new goals, such as existential goals (Hyland, 1997), which, when achieved, provide greater satisfaction than before. This re-organisation of goals brought about by changes in internal standards has also been referred to as a "response shift" (Breetvelt and vanDam, 1991). (c) According to Helson's Adaptation Level Theory (1964), when individuals experience extreme negative stimuli their neutral point or adaptation level changes to become more negative so that positive interpretations are made of previously negative experiences. Consequently, illness may make other experiences seem more positive. (d) Taylor, Wood and Lichtman (1983) describe a process of selective distortion of victimising events whereby "victims" of serious events such as illness selectively evaluate themselves and their situations in ways that are self-enhancing. The authors' analysis of patient protocols revealed the following five mechanisms of selective-evaluation: (1) making downward social comparisons with inferior others; (2) selectively focusing on one's favourable attributes; (3) creating hypothetical worse worlds; (4) construing benefit from the victimising event; and (5) manufacturing normative standards of adjustment that favour oneself.

The diversity of theoretical reasons for positive consequences of illness is reflected in the heterogeneity of empirical reports. As documented in Table 1, observed positive consequences include illness as a learning experience, illness as a challenge, reappraisal of life including a greater appreciation of life, restructuring of life or life-style, changes in priorities, relief from the demands of everyday life, personality changes, spiritual development, an opportunity for atonement, acquisition of new skills, improved relationships, and positive influences on others. While these reports of positive consequences are often incidental to the main purpose of the research, Kerr and Stephens (1997) took the approach of directly asking patients to describe their positive experiences of acquired hearing loss and identified twelve themes.

The purpose of this paper is to provide a systematic description of the several different ways people who are or have been ill describe their illness as a positive experience. We recruited people who reported that illness had had positive consequences, and questioned them to determine the nature of these positive consequences. We then generated questionnaire items and used them to examine the factor structure of positivity in illness and also to explore the frequency of positivity in a group of patients taking part in a rehabilitation program for respiratory disease.

## STUDY I

### *Method*

*Recruitment.* The purpose of the research was advertised through newspapers and on the radio: People were invited to take part if they had experienced illness as positive in some way. Sixty eight people responded of whom 41 people (60%) attended for an interview or were interviewed at home. The remaining 27 people (40%) were inaccessible for interview, either for health reasons or because they were not resident in the local area, and were asked to complete a questionnaire containing the same open-ended interview items. Fourteen (52%) questionnaires were returned resulting in a total sample size of 55.

*Characteristics of the sample.* The final sample consisted of 42 females (76%), including one male-female trans-sexual, and 13 males (24%), aged between 20 and 81 years, mean (standard deviation) age 53.0 (13.5) years. Twenty five people had been diagnosed with cancer and the remainder of the sample had experienced a range of illnesses including depression, heart disease, chronic fatigue syndrome, and arthritis; some participants were co-morbid. Of the total sample, 28 participants (50.9%) described themselves as currently ill while 27 (49.1%) were in a state of recovery.

*Interview setting and procedure.* The items of the Stress-related Growth Scale (Park, Cohen and Murch, 1996) and reports of positive consequences of illness referred to in the literature (Table 1) were considered when writing the interview protocol. After background questions about age and illness history, the interview schedule consisted of the following open-ended questions:

1. What effects has your illness had on your life?
2. What, if anything, has your illness taught you?
3. In what ways, if any, has your illness altered your outlook on life?
4. Describe any changes in your priorities or daily activities as a result of your illness.
5. In what ways, if any, have you changed the way you see yourself as a result of your illness?
6. What effect, if any, has your illness had on your spiritual beliefs?
7. In what ways, if any, has your illness affected your relationships with others?
8. Describe any changes in the way others treat you as a result of your illness.
9. What, if anything, have other people gained as a result of your illness?

Participants who were not interviewed received the same questions in an open-ended questionnaire format with a freepost return envelope. Each question was presented on a single page and participants were encouraged to continue their responses on additional sheets of paper where necessary.

*Method of analysis.* Interviews were audio-taped with the participant's permission and transcribed in an annotated form. Interview and questionnaire transcripts were analysed by the first author using a loose form of thematic analysis (Banister, Burman, Parker, Taylor and Tindall, 1994) in which transcripts were repeatedly read to identify types of positive experience. Each reference to positive consequences of illness was recorded. Categories

were formed on the basis of grouping together different accounts based on their content according to the first author and the interview items.

### *Results*

Many participants were very positive about taking part in the study, commenting on other people's lack of interest and understanding about the positive side of illness. Several participants saw their involvement in this research as their first opportunity to share their positive experiences. Interviews lasted, on average, for two hours.

#### *Positive Consequences of Illness Themes*

A thematic analysis of reports of positive gains of illness described above resulted in 17 categories of positive experience. The mean (standard deviation) number of categories reported was 7.96 (1.89). One might expect differences between the data gathered from the interviews and questionnaires, for example, the interview setting allows an opportunity for probes and thus may yield more varied themes. The results of an unpaired t-test, however, suggest no significant differences between the methodologies in the total number of themes reported:  $t(53) = 0.73, p = 0.47$ .

The themes reported are presented below in order of their frequency of occurrence. The percentage of participants describing the kind of positive experience in each category is shown in brackets. Quotations are used to illustrate the meaning of the categories.

*Improved interpersonal relationships* (100%). Every participant made at least one reference to improved relationships with others. Participants referred to a greater investment in relationships and felt that they had more to offer others, in particular, a genuine empathy for others. Twenty six participants described a greater appreciation of others. For many participants, being ill presented them with the opportunity to establish new friendship networks. One participant explained that if she had not become ill she would not have met her husband. For three participants, the illness encounter had encouraged a renewal of contact with friends. This category also included reports of more harmonious or, as one participant described, "healthier" relationships with others:

"... if anything, my marriage is better than it was" (participant 17, chronic fatigue syndrome)

Thirteen participants felt that they had become less argumentative and more tolerant of others. However, not all accounts of improved relationships with others took this form of greater harmony and tolerance. One woman who had been treated for cancer felt that her relationships with others had been enhanced because she no longer allows others to "walk all over her" (participant 38), another participant who had been treated for Hodgkin's Disease explained how being ill made him "strip people of their gold" (participant 24). Being ill also brought an awareness of true friends often resulting in a greater selectivity in terms of choice of friends and a disintegration of troublesome relationships.

*Positive influence on others* (93%). Fifty one participants believed that the benefits brought by their illness were also experienced by other people around them such as family and friends. These gains were often attributed to the fact that illness provided the opportunity

to invest more time in relationships with others as reported above. One participant explained:

"There are a lot of people whose lives are better for the fact I have had cancer" (participant 22)

Nineteen reports in this category refer to illness as an inspiration to others:

"... if you can keep going, so can I" (participant 36, recovered from a back injury)

The illness was described in nine accounts as an eye opener for others, prompting positive alterations in their life-style:

"It pulled a lot of people up short and made them realise that this could be me" (participant 9, treated for a brain tumour)

Other positive changes in the behaviour of others include greater sensitivity, tolerance, confidence and maturity. Changes in other people's attitudes towards the participant, for example, a more realistic perception of the person, were also noted.

The illness was also seen as an opportunity for others to gain practical information and advice, and to become more aware of their own mortality.

*Positive personality changes (93%).* Fifty one participants felt that their illness had altered their personality in a positive way. One participant explained:

"I can't believe that I am the same person I was..." (participant 8, arthritis)

Many participants discussed changes in their personality within the context of self-growth. Changes reported include becoming a better, happier, calmer, deeper and more mature person. Twenty participants felt that their illness had encouraged them to become more assertive and self-reliant. The illness experience enhanced their sense of competence and encouraged greater self-acceptance:

"... I am what I am" (participant 2, chronic fatigue syndrome)

Eight participants described themselves as having become more self-focused. Two participants however talked about being less concerned about themselves and more focused on others.

*Reappraisal of life (91%).* The experience of illness encouraged 50 participants to look at their life from a different perspective and become more thoughtful about the true purpose of life and about their mortality. One participant explained:

"...there was more to the world than I had previously realised" (participant 1, chronic fatigue syndrome)

Seven participants felt that their illness had encouraged them to adopt a more positive outlook on life. One participant described her life review process as follows:

"... it was as if someone had picked up all of the bits and pieces that were my life and threw them up in the air and said you need to look at this" (participant 2, chronic fatigue syndrome)

Thirty seven of the positive experiences classified as involving a reappraisal of life refer to a greater enjoyment and appreciation of life:

"Life is a gift" (participant 9, treated for a brain tumour)

In particular, participants referred to a greater appreciation of simple pleasures such as nature:

"The illness made me take a step back from everything and see the importance of just simple things" (participant 1, chronic fatigue syndrome)

*Restructuring of life* (84%). Forty six participants felt that their illness had encouraged them to re-shape their life and that consequently life had become enriched by their experience of illness:

"Before I was ill, I led an awful life" (participant 50, arthritis)

Illness prompted 12 participants to lead a healthier lifestyle and to be kinder to their "fragile frame" (participant 24, treated for Hodgkin's Disease). For 23 participants, this involved taking greater care of themselves and avoiding stressful situations with the philosophy that things can wait until tomorrow. Eighteen participants however believed that each day should be lived to its fullest and that tomorrow may be too late.

*Spiritual changes* (69%). A deeper, more intense spiritual life was described in 31 accounts. Illness provided five participants with a greater spiritual insight and a confirmation of their beliefs. Many participants explained that their illness had given them more time to invest in God and in prayer and that they had become more appreciative of God and religion. Illness prompted three participants to re-evaluate their spirituality, in particular their religious orientation, and to become more open to other religions.

*Changes in priorities* (67%). For 37 participants, a restructuring of lifestyle and a reappraisal of the important things in life were coupled with a reordering of priorities. One participant (participant 20, treated for cancer) used the analogy of a garden sieve to explain how she had retained the important things in life and "weeded out" the insignificant things. Important things in life were identified as "things money can't buy" (participant 9, treated for a brain tumour) such as health, family and friends, simple pleasures, spirituality and oneself. Participants reported attaching less importance to aspects of life such as material things, money, work, career, achievement, and aesthetics.

*Skills and new pursuits* (49%). Illness provided 27 participants with new skills and introduced them to new activities:

"I discovered a talent I didn't know I had... It has led me up paths I never thought I would go" (participant 22, treated for cancer)

Examples of new pursuits include art, writing, singing, yoga, relaxation, meditation, counselling, and charity work. Illness gave two participants the impetus to change the direction of their career path. Nine participants felt better equipped to cope with future experiences. One participant explained:

"My illness gave me a framework to move forward in life" (participant 31, heart palpitations)

*Self-knowledge* (44%). Illness was described by eight participants as a process of self-discovery:

"I have literally found myself" (participant 49, chronic fatigue syndrome)

Reports were made of illness encouraging an altered, more realistic perception of oneself, and a greater awareness of one's strengths as well as limitations.

*General knowledge* (40%). Twenty two participants described their illness as a learning experience. Some participants felt that they had become ill for a reason, in particular, to gain some wisdom. Reports were made of gaining a greater insight into illness, the human body, and the health care system.

*Ability to give up certain demanding activities* (22%). Illness was viewed by three participants as a release from the chores of everyday life:

"I often use my illness as an excuse not to do things that I just don't want to do" (participant 51, ulcerative colitis)

Illness gave 10 participants the opportunity to give up work:

"I am lucky, I had some reason to get out of it" (participant 33, treated for cancer)

"I got an enormous amount of freedom from it... an excuse to change direction" (participant 36, recovered from a back injury)

*Improved awareness of one's emotions* (16%). One participant explained how her illness had forced her to:

"...open up the cupboard and start clearing it out" (participant 2, chronic fatigue syndrome)

This participant, as with others, was prompted by illness to consider how she felt about herself and other people. For some participants, this process involved attending to feelings that had previously been "locked away" (participant 2, chronic fatigue syndrome).

*Resolution of past concerns* (7%). For four participants, illness encouraged a confrontation of aspects of the past including a re-evaluation of the behaviour of other people in the past. One participant explained:

"...I have dug them up and dealt with them" (participant 2, chronic fatigue syndrome)

*Seeing illness as a challenge to overcome (7%).* Four participants communicated a sense of achievement in rising above the restrictions imposed by illness. Illness was visualised by one participant as a brick wall:

"...in life you meet brick walls which you have to walk through" (participant 3, depression)

*Resolution of current concerns (4%).* Illness was seen by two participants as an occasion to confront and deal with troublesome aspects of life such as financial worries and relationship problems:

"All my unhappy problems now came to a head" (participant 54, treated for cancer)

*Practical gains (4%).* Two participants reported that illness provided access to certain luxuries and disability allowances.

*Greater respect for the environment (2%).* One participant felt that through her experience of illness she had become more willing and able to care for the environment.

### *Discussion*

We questioned 55 people who reported positive benefits from illness, and these positive experiences of illness were classified into 17 different categories. The themes refer to both personal (for example positive personality changes) and altruistic (for example improved interpersonal relationships) gains. Each category refers to positive benefits reported in the literature in one form or another, though not necessarily in the level of detail provided here. Table 1 shows the relationship between each of the categories and other publications describing similar content. Themes identified which, to our knowledge, had not been referred to in the previous literature include the development of new friendship networks, renewal of contact with old acquaintances, more harmonious relationships, less tolerance of others, an eye opener for others, practical advice and information for others, awareness of mortality among others, greater self-acceptance, a more relaxed lifestyle, change of career, and a more realistic perception of oneself.

Consistent with previous research, our data show that patients find positivity in many different ways. For example, some patients said that improved interpersonal relationships arose from increased tolerance of others whereas others felt that their illness had encouraged them to be less accepting of other people's "deviances". Some participants said they had adopted a more relaxed lifestyle whereas others said their illness had encouraged them to engage in new activities.

## STUDY 2

### *Method*

We constructed a 66 item questionnaire based on the themes identified in Study 1. We used this questionnaire for two purposes (a) to examine the factor structure of positive experiences associated with illness and (b) to examine the degree of positivity in a group of patients who were not selected on the basis of reported positivity to illness.



There were two samples of participants. In the first sample, participants were 40 patients (21 males, 18 females, mean age of 67.4 years) attending a pulmonary rehabilitation course. All patients had chronic lung disease and the majority had chronic obstructive pulmonary disease (COPD). COPD is a chronic disease of airways obstruction in which poor lung function leads to increasing breathlessness and eventually death. Pulmonary rehabilitation is provided both for physiological training and for psychological support when patients' lung function is interfering with everyday activities. Patients completed the questionnaire during a session in the rehabilitation clinic. The second sample consisted of 44 people who had taken part in study 1 and a further eight cancer patients attending a cancer self-help group, and five patients attending a healing group. These participants completed the questionnaire by post.

### Results

A principal components analysis was conducted for the group as a whole (i.e., samples 1 and 2) and revealed a single first factor accounting for 27% of the variance. There was no clear evidence of any further factors. Sixty two items received a factor loading above 0.30.

The frequency of endorsement of questionnaire items was examined using data from only the COPD sample (i.e., a non-selected sample). An inspection of individual questionnaire items revealed that positive experiences of illness, far from being an abnormal experience, are common. The most frequently endorsed items include "My illness made me realise how supportive other people can be" (87.5%); "My illness made me realise that things can wait until tomorrow" (85.0%); and "My illness made me take a step back and enjoy simple pleasures" (80.0%). Only one item had no endorsement: "My life is much better now than it was before my illness". Some items had low levels of endorsement, for example, "My illness gave me a new start in life" (2.5%); "I became a happier person because of my illness" (5.0%); and "Through my illness I discovered a talent I didn't know I had" (7.5%). Although some patients reported more benefits than others, all patients reported at least one positive consequence of illness and the median number of items endorsed was 31.

### GENERAL DISCUSSION

We found that positive consequences of illness are commonly reported by individuals who have encountered illness. We developed a 66 item questionnaire covering 17 (possibly inter-related) categories of positivity which appears to be unidimensional. All 40 COPD patients attending a pulmonary rehabilitation course endorsed at least one item of the questionnaire and the median number of items endorsed was 31. We conclude that positivity in illness is a missing aspect of most quality of life instruments. With few exceptions (for example the Life Evaluation Questionnaire, Salmon *et al.*, 1996), quality of life scales do not refer to positive consequences, though they may phrase negative consequences in a positive way to avoid response bias (for example, the Living with Asthma Questionnaire; Hyland, Finnis and Irvine, 1991). Thus, our data suggest that if quality of life is defined in terms of the totality of subjective experiences of people with illness, then most current scales measure only a component of that totality of experience.

Although we feel confident that positivity occurs, consistent with the anecdotal reports in the literature, the extent to which it occurs in different groups is not known. For example,

it is possible that positivity only occurs in serious illness. The determinants of positivity also remain unexplored.

The importance of understanding the positive consequences of illness is more than just a matter of conceptual completeness: positive consequences of illness have implications for outcome. Affleck, Tennen, Croog and Levine (1987) investigated whether early cause and benefit appraisals among 287 men who had experienced a heart attack were predictive of long-term health outcomes. Failure to perceive benefits 7 weeks following the heart attack was identified as one of the factors associated with reinfarction. Affleck *et al.* suggested that construing benefit from harm could bolster a sense of well-being and that such benefit appraisals could aid recovery either directly through their self comforting quality or indirectly through their effects on one's social support network. LeShan's crisis therapy (1984) focuses on positive change and growth in the face of cancer and helps patients to mobilise their immune system against cancer. This therapy has achieved impressive results with approximately half of the patients with a poor prognosis experiencing long-term remission (LeShan, 1994). Positive consequences of illness merit further attention given their implications for health outcome.

Several theoretical explanations for positivity were described in the introduction all of which suggest that illness is not really good but that patients make the best out of adverse circumstances. An alternative perspective is provided, not in psychology, but in homeopathic medicine. Edward Bach (1931) writes: "let it be briefly stated that disease, though apparently so cruel, is in itself beneficent and for our good and, if rightly interpreted, it will guide us to our essential faults" (p. 4). In terms of modern psychology, it is possible to interpret Bach's theory of personality-soul divergence as saying that illness makes the patient aware of a non self-actualising lifestyle, and thereby enables the patient to regain a more self-actualising lifestyle. From Bach's perspective, the positivity associated with illness is the consequence of greater self-actualisation, rather than perceptual change, because the patient realises that change is needed to become a better person. A similar approach is taken by LeShan (1984; 1994) who suggests that illness enables patients to find a different journey through life<sup>1</sup>.

Of course, this is not to say that perceptual change may not take place. Positivity associated with illness probably arises for a number of reasons. However, we believe that the theory of existential growth plays an important and often neglected role in the experience of positivity in illness. The theory of existential growth (Maslow, 1968) states simply that illness can provide people with an opportunity for greater self-actualisation. If people self-actualise as a consequence of illness, then they perceive that illness has been a positive benefit. It is a real benefit not just a perceived benefit.

Further research is needed to understand the different types of antecedents and consequences of positive interpretations of illness, a phenomenon which appears to be a non-trivial aspect of the experience of illness.

### *Acknowledgement*

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<sup>1</sup>The second author (MH) developed Chronic Fatigue Syndrome about 6 months before the first submission of this article to *Psychology and Health*. At the time of re-submission (after a further 4 months), he had experienced the positive effects of illness for himself. From the perspective of his personal experience, the existential explanation provides an accurate explanation of changes taking place. That is, the experience of illness leads to a fundamental change in the nature of the person rather than simply a change in perceptions.

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**The Effect of Rehabilitation on Positive Interpretations of Illness**

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**Running Head: Positive Interpretations of Illness**

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**Note: The Silver Lining Questionnaire shown in Appendix 1 can be used without charge, and permission is not needed.**

## ABSTRACT

This study investigated changes in positive perceptions of illness following rehabilitation. Patients completed the 38 positive-item Silver Lining Questionnaire (SLQ) on two occasions: 20 chronic obstructive pulmonary disease (COPD) patients on entry to a waiting list and at the start of rehabilitation; 35 COPD and 29 cardiac patients at the start and end of a rehabilitation programme. At first assessment, on average, between seven and 13 items were endorsed depending on group. Positivity increased after rehabilitation for COPD patients ( $p < .01$ ), and cardiac patients ( $p < .001$ ): On average three and four additional items were endorsed respectively. There was no change in positivity for patients on the waiting list. The data suggest that rehabilitation leads to an increase in perceived positive consequences of illness.

Keywords: COPD, cardiac disease, rehabilitation, quality of life

General definitions of health-related quality of life (HRQOL) emphasise the breadth of the concept so as to include both positive and negative consequences of illness (DeHaes & vanKnippenberg, 1985). By contrast, most specific definitions focus only on only the negative consequences of illness (Bijttebier, Vercuysse, Vertommen, Van Gool, Uyttebroeck, & Brock, 2001; Kleinman, 1986), and this emphasis on the negative rather than the positive is reflected in a frequent belief that positivity is rare. Additionally, where positivity is expressed, it is often treated as untrustworthy (Backman, 1989). Despite the negative orientation of quality of life research, there are repeated reports of patients perceiving some benefits of illness, such as improved interpersonal relationships, a reappraisal of life including priorities, and self-improvement (for example, Collins, Taylor, & Skokan, 1990; Kagawa-Singer, 1993; Kennedy, Tellegen, Kennedy, & Havernick, 1976; LaFortune-Fredette, 1995).

Several studies have assessed positivity in patient populations. Laerum, Johnsen, Smith, and Larsen (1988) used a semi-structured interview with 84 males to elicit positive as well as negative changes in lifestyle and life quality following a myocardial infarction and found that 33% of males considered their life situation to be considerably or somewhat improved as a result of illness. Collins et al. (1990) used a structured interview with 55 cancer patients to investigate positive and negative changes following illness with respect to self-views, views of the world, future plans, relationships, and activities/priorities. Patients in this study reported significantly more positive than negative changes in each domain, and positive changes were most pronounced within the activities/priorities and relationships domains with 62 % patients reporting positive changes in these domains. In a more detailed study of the

positive consequences of illness, Sodergren and Hyland (2000) identified 17 categories of positivity as perceived by a sample pre-selected on the basis of reported positivity towards illness. This study provided greater details on the different themes, such as restructuring of life, reappraisal of life, spiritual gains, self-improvement, improved relationships with others and positive consequences for others and also identified novel sub-themes such as a renewal of contact with old acquaintances and less tolerance of others.

There are two broad types of interpretation of the phenomenon of positivity in illness: First, that it is in some sense a delusion, involving either a reframing or a repression of a negative situation (for example, Taylor, 1983); second, that it is a phenomenon of real existential growth (LeShan, 1984; 1994). Each of these explanations suggests that positivity is susceptible to change. Rehabilitation programmes are successful in improving quality of life (Goldstein, Gort, Stubbing, Avendano, & Guyatt, 1994; Ries, Kaplan, Limberg, & Prewitt, 1995; Wijkstra et al., 1995), but in these studies improvement in quality of life has been assessed from the more specific perspective of degree of dissatisfaction with life. The improvement demonstrated in these rehabilitation studies is likely to result from a combination of improved physiological function, education and psychological support, as well as the social aspects that are often present, and it is possible that these improvements also affect positivity. Cruess et al. (2000) demonstrated an increase in positivity after using a cognitive-behavioural stress management programme in breast cancer patients, and so there is evidence that positivity is susceptible to change. The aim of the present study is to investigate whether the less psychologically focused care provided by health professionals in a rehabilitation setting increases patients' perceived positivity of illness.



## METHOD

### *Patients*

Two groups of patients were studied as part of continuing audit in a hospital (Glenfield Hospital, Leicester, UK) rehabilitation programme – i.e., this is an opportunistic sample. Clinical judgement (no specified rules) is used to assess whether patients are likely to benefit from rehabilitation (patients either with insufficient disability or too great disability are not normally included, nor are patients who seem disinterested in self-help). Recruitment of patients took place over a 9-month period. All patients who agreed to undertake rehabilitation simultaneously agreed to complete the rehabilitation assessments. Cardiac patients included those who had undergone surgery (e.g., coronary bypass, valve replacement) and those with a cardiac event (myocardial infarction). Outcome is generally good for these patients given appropriate changes to lifestyle. Pulmonary patients had chronic obstructive pulmonary disease (COPD), a disease of progressive, non-reversible, airways limitation, which leads to gradually increasing breathlessness and death. In both groups rehabilitation is helpful, but there is no treatment that prevents deterioration of lung function in COPD. Patients accepted for rehabilitation are placed on a waiting list for approximately 7 weeks.

The cardiac and pulmonary patients were divided into three groups for the purposes of analysis:

(i) Control. This sample included 10 males and 10 females, mean age 69.35 years.

The patients in this group had all been diagnosed with COPD and were on the waiting list for pulmonary rehabilitation;

(ii) Pulmonary rehabilitation. This group of 23 male and 12 female COPD patients, mean age 67.03 years, had completed a pulmonary rehabilitation programme;

(iii) Cardiac rehabilitation. This sample comprised of 23 male and 6 female cardiac patients, mean age 60.52 years, who had received cardiac rehabilitation. Of these patients, 17 had received a coronary bypass graft, 7 a myocardial infarction, and 5 a valve replacement.

### *Rehabilitation programmes*

The rehabilitation programmes were out-patient based and included groups of up to eight patients attending twice weekly for 2 hours (one hour exercise, one hour education) over a period of 7 weeks in the case of pulmonary rehabilitation and 6 weeks for the cardiac programme. Patients were provided with an individualised home exercise programme and the educational component consisted of demonstrations and discussions with health professionals (e.g., dietary information, information that breathlessness was not harmful, information about social security benefits). In the case of pulmonary rehabilitation these included a doctor, physiotherapist, nurse, occupational therapist, benefits adviser and a representative from a patient self-help group ('Breathe-Easy'). In the case of cardiac rehabilitation the same contact was given with the exception of the patient self-help group, and more time was spent on stress management. Drop out rates (i.e., patients who initially agreed to take part, but did not complete the entire course) were 13% for the pulmonary and 12% for the cardiac programme.

### *Measure*

Questionnaires used to assess positive consequences of illness include the Benefit Appraisals Scale (Tennen, Affleck, Urrows, Higgins, & Mendola, 1992), the Satisfaction with Illness Scale (Hyland & Kenyon, 1992), the Benefit Finding Scale (Crueess et al., 2000), and the Silver Lining Questionnaire (SLQ; Sodergren & Hyland, 2000, Appendix 1). The 38-item SLQ was selected for use as it has the broadest coverage of positivity and, unlike the Benefit Appraisals Scale and Benefit Finding Scale, is a generic scale of positivity. Responses to individual SLQ items are assigned the following scores (shown in parentheses): 'Strongly agree' (5); 'Agree' (4); 'Not sure' (3); 'Disagree' (2); 'Strongly disagree' (1). Thus, a high value corresponds to a high degree of positivity. To obtain an overall score of positivity, a bi-modal scoring system is used with responses 'Strongly agree' and 'Agree' coded as '1' and all other response options as '0'. This simplified scoring procedure is designed to avoid response bias between patients in endorsing 'Strongly agree' and 'Agree' response options. The total score therefore reflects the total number of items that the patient agrees with, (i.e., the total number of positive consequences of illness experienced) and ranges between 0 (low positivity; agreement with no items), and 38 (high positivity; agreement at some level with all items).

### *Procedure*

All patients completed the SLQ on two occasions. Members of the control sample completed the SLQ on admission to the waiting list for pulmonary rehabilitation and 7 weeks later at the start of rehabilitation. The two rehabilitation samples (cardiac and pulmonary) completed the SLQ at the start of rehabilitation and 6 or 7 weeks later at the end of rehabilitation.

## RESULTS

*Prevalence of positivity in the three groups*

With the exception of six COPD patients (two within the control condition and four within the pulmonary rehabilitation sample), all patients endorsed at least one positive consequence of illness at the first assessment (upon entrance to the waiting list for control patients and prior to rehabilitation for the rehabilitation samples). The mean (standard deviation) number of positive consequences endorsed across all three samples at the first assessment was 10.31 (6.78). The most frequently endorsed items (endorsed by over half of the overall sample) include: 'I appreciate life more because of my illness' (60%); 'My illness made me think about the true purpose of life' (55%); and 'Because of my illness I find it easier to accept what life has in store' (51%).

Within the cardiac sample, patients who had undergone surgery (i.e., valve replacement and bypass patients) did not differ significantly from myocardial infarction patients in positivity either at pre-rehabilitation,  $t(27) = 1.08$ ; *ns* (mean = 12.55 and 15.29 respectively) nor at post-rehabilitation,  $t(27) = 0.91$ ; *ns* (mean = 16.50 and 19.71 respectively) and so we have treated all cardiac patients as a single sample. In addition, there was no significant relationship between age and positivity,  $r(83) = -.07$ ; *ns*, and between males and females with respect to positivity,  $t(82) = 1.19$ ; *ns*.

*Reliability of the SLQ*

Using the data from the first assessment, Cronbach's alpha was .93 across all three samples suggesting a high level of homogeneity among the SLQ items. The Pearson product moment correlation between the two assessments for the control condition was  $r(20) = .90$ ;  $p < .001$  showing good retest reliability.

*Change in SLQ scores and the nature of positive change*

The interaction term of a 3 (group: control, COPD, MI)  $\times$  2 (assessment time: first versus second) repeated measures analysis of variance was significant,  $F(2,81) = 4.24; p < .05$ , showing that there was a significant difference between pre and post assessment scores different between the three groups. As a follow up analysis we compared first and second assessments for each of the groups. Responses to the SLQ did not differ significantly between the two assessments in the control condition,  $t(19) = 0.07; p = .95$ , (means are shown in Table 1). However, there was a significant increase in the overall SLQ scores following the pulmonary rehabilitation programme,  $t(34) = 3.40; p < .01$ , and cardiac rehabilitation programme,  $t(28) = 3.86; p < .001$ .

Taking only those patients undergoing rehabilitation, twelve were less positive at the second assessment, six patients showed no change in positivity, and the remaining 46 patients became more positive at the second assessment. Change in total SLQ scores varied between -8 and 18. On average, 2.86 additional positive consequences of illness were reported following pulmonary rehabilitation and 4.07 after cardiac rehabilitation. We examined individual items to determine whether particular items created the increase in positivity. Thirty-three of the 38 items were endorsed more frequently (not necessarily significant) post-rehabilitation compared with pre-rehabilitation; there was no change for three items (items 6, 23, 36); and there was a small negative change for two items (items 26,29). The three items where endorsements increased most after rehabilitation were: 'My illness gave me the opportunity to meet new people' (48% to 77%); 'My illness gave me permission to do things for myself' (16% to 38%) and 'My illness made me face up to problem areas of my life' (34% to 52%). There was no evidence that a shift in items was domain

specific, and high shifting items included social ones, such as, 'My illness strengthened my relationship with others' (39% to 55%) and existential ones, such as 'I appreciate life more because of my illness' ((58% to 72%).

### *Predictors of change*

To examine the effects of age, gender, disease type and initial levels of positivity on degree of change in positivity amongst rehabilitation patients, we carried out a hierarchical multiple regression where the post-rehabilitation score for the rehabilitation groups was entered as the dependent variable, the pre-rehabilitation score was entered as the independent variable in the first block, and age, gender, and disease type entered in the second block (i.e., the control group was not entered into the regression). Only pre-rehabilitation score predicted post-rehabilitation score (Table 2).

## DISCUSSION

The possibility that patients may experience something positive from illness is often overlooked. We found that rehabilitation significantly enhanced positivity, and that the increase was substantial (approximately three or four additional items were endorsed after rehabilitation). The increase in positivity cannot be attributed to patients being prompted to think more about positivity after they had completed a questionnaire on this subject, as there was no difference for patients who completed the questionnaire while on a waiting list. In addition, after patients had experienced rehabilitation, their final level of positivity was not predicted by age, gender, or whether the patients had COPD or cardiac illness though it was by initial levels of positivity.

There are several limitations to our study. We did not measure the long-term effects of rehabilitation on positivity. Our study did not provide insight into whether other factors such as personality lead to greater positivity. We assumed that it was rehabilitation and no other factor, such as time, that increased positivity over the 6 week rehabilitation period – though the fact that there is no change in the COPD waiting group and that both subgroups of cardiac patients (MI and valve replacement) show similar degrees of improvement to the COPD patients makes this unlikely. A further limitation of our study is that not all COPD or cardiac patients were admitted to the rehabilitation programme, and that those patients who were perceived as likely to benefit (the criterion for acceptance onto the programme) might include a higher proportion of patients with positive beliefs about illness. In addition, such patients might appear more positive at the end of rehabilitation as a way of expressing their gratitude to the rehabilitation staff.

Our finding that rehabilitation enhances positivity has an important implication for clinical practice, as rehabilitation is not always available to patients despite clinical need. The level of health care provided to patients not only can reduce the amount of complaint they have about their illness (traditional quality of life gain) but can also improve quality of life in ways not previously investigated, namely positivity including, in some cases, the way patients think about themselves as people. That is, management can have a fundamental existential effect on patients' self-concept: it does not just affect the way they think about their illness. Rehabilitation programmes sometimes include a psychologist as part of the rehabilitation team, but the presence of a psychologist does not seem to be a necessary condition for increased positivity, in contrast to previous research showing that psychological interventions increase positivity (Cruess, et al., 2000).

Although our patient samples were small, we found evidence that positivity in illness is common. Most of the patients in our sample expressed some degree of positivity, with the mean number of items endorsed across the two assessments varying between 7 and 17 items of a 38-item questionnaire, depending on the group. However, given the selected nature of our sample and the small sample size, we cannot draw any conclusions regarding the prevalence of positivity amongst patients in general.

Some types of positivity were expressed more frequently than others. For example, three items describing a reappraisal of life: 'I appreciate life more because of my illness'; 'Because of my illness I find it easier to accept what life has in store'; and 'My illness made me think about the true purpose of life' were initially endorsed by more than half of the patients in the total sample. This finding is consistent with the large number of reports in the literature of a greater appreciation of life and its meaning following illness (Kennedy et al., 1976; Laerum et al., 1988; LaFortune-Fredette, 1995). By contrast, only one patient endorsed the item 'Through my illness I discovered a talent I didn't know I had' and this is reflected in the limited accounts of such a gain in the literature (Giovinco & McDougald, 1994; LeShan, 1984). We found that many of the types of positivity endorsed were consistent with the theoretical explanations of why positivity occurs. For example, endorsement of the items 'My illness made me more aware of my strengths' and 'Other people appreciate me more because of my illness' indicates a change in perceptions following illness. Other items, for example, 'My illness gave me a new start in life' and 'My illness made me live life to its fullest', are indicative of existential change. Our methodology does not, however, allow us to distinguish whether a benefit is a cognitive



rationalisation (i.e., making the best of a bad job) (Taylor, 1983) or whether it is the true existential growth suggested by LeShan (1984; 1994).

Our results have implications for the way quality of life is conceptualised and measured. If HRQOL is defined in its more general sense to include any subjective consequence of illness, then scales that measure only the negative consequences of illness provide a limited view of HRQOL so defined. Of course, it is possible to define HRQOL in a more limited and restricted way (i.e., just negativity), but if the more general type of definition is used then positivity should be measured to obtain a complete picture of HRQOL. Positivity is a neglected aspect of health experience.

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Table 1. Change in total SLQ scores

Sample	Assessment	Mean	Standard deviation
Control (n=20)	Admission to the waiting list	11.00	7.82
	Exit from the waiting list	10.95	7.30
Pulmonary rehabilitation (n=35)	Pre-rehabilitation	7.51	5.83
	Post-rehabilitation	10.37	6.63
Cardiac rehabilitation (n=29)	Pre-rehabilitation	13.21	5.88
	Post-rehabilitation	17.28	8.10

Table 2. Predictors of change in positivity

Predictor	Beta weight
SLQ score at first assessment	.75*
Age	.00
Gender	-.05
Disease type	.12

For the model,  $F(1,63) = 82.4$ ;  $p < .001$ , adjusted  $R^2 = .56$ .

\*  $p < .001$

Appendix 1. The Silver Lining Questionnaire (SLQ)

Please circle <i>one</i> number for <i>each</i> statement					
	strongly agree	agree	not sure	disagree	strongly disagree
1. I appreciate life more because of my illness	5	4	3	2	1
2. My illness gave me a new start in life	5	4	3	2	1
3. My life is much better now than it was before my illness	5	4	3	2	1
4. My illness has made me live life to its fullest	5	4	3	2	1
5. Because of my illness I find it easier to accept what life has in store	5	4	3	2	1
6. My illness made me think about the true purpose of life	5	4	3	2	1
7. My religious / spiritual beliefs deepened because of my illness	5	4	3	2	1
8. I am now more open to other religions because of my illness	5	4	3	2	1
9. My illness made me a better person	5	4	3	2	1
10. I became a happier person because of my illness	5	4	3	2	1
11. I am a calmer person because of my illness	5	4	3	2	1
12. My illness made me more mature	5	4	3	2	1
13. My illness made me a more tolerant person	5	4	3	2	1
14. My illness made me realise that I matter as a person	5	4	3	2	1
15. My illness gave me more confidence	5	4	3	2	1
16. I am less concerned about failure because of my illness	5	4	3	2	1
17. My illness gave me permission to do things for myself	5	4	3	2	1
18. My illness made me a more determined person	5	4	3	2	1
19. My illness helped me find myself	5	4	3	2	1
20. My illness made me more aware of my strengths	5	4	3	2	1

	Positive Interpretations of Illness				
21. Through my illness I discovered a talent I didn't know I had	5	4	3	2	1
22. I can face whatever is around the corner because of my illness	5	4	3	2	1
23. My illness encouraged me to reflect on how I feel about myself	5	4	3	2	1
24. My illness made me face up to problem areas of my life	5	4	3	2	1
25. My illness strengthened my relationships with others	5	4	3	2	1
26. My illness made me less concerned with the approval of others	5	4	3	2	1
27. Because of my illness I have more to offer other people	5	4	3	2	1
28. My illness made me more at ease with others	5	4	3	2	1
29. I see others in their true colours because of my illness	5	4	3	2	1
30. My illness gave me the opportunity to meet new people	5	4	3	2	1
31. My illness taught me how to stand up for myself	5	4	3	2	1
32. My illness made me put an end to troublesome relationships	5	4	3	2	1
33. My illness made me less judgmental of others	5	4	3	2	1
34. I have been an inspiration to others	5	4	3	2	1
35. People can be more open with me since my illness	5	4	3	2	1
36. My illness changed other people for the better	5	4	3	2	1
37. My illness changed other people's perception of me for the better	5	4	3	2	1
38. Other people appreciate me more because of my illness	5	4	3	2	1



**Positivity in illness: self-delusion or existential growth?**

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## Abstract

*Objectives:* This study investigated the relationship between a measure of positivity in illness, the Silver Lining Questionnaire (SLQ), and measures of personality and spirituality/religious beliefs as a way of determining whether positivity in illness is a delusion or existential growth.

*Method.* This is cross-sectional study comparing response to the SLQ, to the Eysenck Personality Questionnaire (EPQ-R), breathlessness, illness type, and spiritual and religious beliefs in a sample of one hundred and ninety four respiratory outpatients patients.

*Results.* The SLQ was positively associated with extraversion ( $r(174) = .16, p < .05$ ), unrelated to neuroticism ( $r(172) = .11, ns$ ) and repression ( $r(179) = .10, ns$ ) and was positively associated with spiritual and religious beliefs,  $F(2,187) = 7.12, p < .001$ , as predicted by the existential growth but not the delusion interpretation. There was no relationship between positivity and age,  $r(194) = .09, ns$ , or between positivity and gender  $t(192) = -1.27, ns$ , and nor were there relationships with type of illness  $F(4,188) = 2.17, ns$  or breathlessness  $F(5,173) = 0.42, ns$ .

*Conclusions.* The results suggest that positivity in illness reflects existential growth. The non-significant correlation between the SLQ and neuroticism is in the opposite direction to the delusion explanation but the non-significant relationship between the SLQ and repression is in the predicted direction. We cannot rule out the possibility that some positivity is delusional.

It seems self-evident that illness is bad and health is good. Despite this fact, there are many cases, both anecdotal and supported by questionnaire, where patients report benefits from illness (for example, Collins, Taylor & Skokan, 1990; Giovenco & McDougald, 1994; Laerum, Johnsen, Smith, & Larsen, 1988; LaFortune-Fredette, 1995; O'Connor, Wicker, & Germino, 1990; Taylor, 1983). In some cases these benefits go some way to mitigating the negative consequences of illness, but there are also instances where patients report an overall benefit from being ill. For example, in a study (Laerum et al., 1988) of 84 men who had suffered a myocardial infarction, 33% considered their life situation to be considerably or somewhat improved as a result of their illness. Positivity in adversity has also been cited in the context of other stressful life events such as combat and imprisonment, divorce, caregiving and bereavement (Schaefer & Moos, 1992). Stress-related growth in adversity is reported to be "remarkably common" (Schaefer & Moos, 1992, p.149), and positivity in illness may be one aspect of such growth.

There are two broad types of interpretation of the phenomenon of positivity in illness: First, that it is in some sense a delusion, involving either a distortion or denial of reality; second, that it is a phenomenon of real existential growth. A common perspective is that such positivity must be a delusion. Backman (1989) writes:

"When positive emotions are expressed by those who are seriously ill, others often react with surprise and interpret the unexpected positive feelings as denial and a distortion of the 'real', more appropriate feelings." (p. 92)

Denial and distortion may, however, represent a healthy response to illness. Taylor (1983) suggests that such a cognitive reinterpretation of illness serves the function of bolstering self-esteem when people are 'victims' of circumstance. Similar

self-enhancing but incorrect attributional biases protect against depression (Alloy & Abramson, 1987). Thus, irrationality is not necessarily bad.

The terms *denial* and *distortion* refer to different kinds of psychological processes. Distortion is also known as reframing and is consistent with adaptation level theory (Helson, 1964), response shift (Breetvelt & vanDam, 1991; Sprangers & Schwartz, 1997) and disengagement and modification of goals in control theory (Carver & Scheier, 1982). In each of these cases the frame of reference by which people make assessments about themselves and their situation is changed as part of the process of adaptation to illness. By reframing the negative situation in a more positive way, not only do people protect themselves from negative emotions such as depression (Carver & Scheier, 1990; Hyland 1987), but they may also generate positive emotions, for example, by perceiving themselves as lucky or fortunate (Taylor, Wood, & Lichtman, 1983). In a study of 78 breast cancer patients Taylor et al. (1983) identified the following ways by which patients reframed their situation: (a) comparisons with less fortunate others ('downward social comparisons'), (b) comparisons to a hypothetical worse world, (c) an emphasis on attributes that make one appear advantaged, (d) the manufacture of normative standards of adjustments that make one appear to be well adjusted, and (e) construing benefit from harm.

While negative affectivity predisposes towards a negative interpretation and detection of events (Larsen, 1992), people low in negative trait affectivity are more prone to reframe their situation in a positive way (Hyland 1987; Carver & Scheier, 1990). Consequently, if reframing is the basis of positivity, then positivity should correlate negatively with neuroticism. In a study of personality and coping strategies amongst community dwelling adults, McCrae and Costa (1986) found a negative

relationship between neuroticism and a tendency to 'draw strength from adversity' in the face of a range of stressors.

Denial differs from reframing in that the negative situation itself is repressed in some way as the basis for ego-protection. Repressors tend to summon up positive images as a way of distracting themselves from the potentially negative experience (Boden & Baumeister, 1997). Hence repressors should search out positive reasons why illness has some benefit and the negative aspects of illness should lie outside their awareness, and therefore repression should correlate positively with positivity. Repressors report low trait anxiety, even though, in reality, they have higher levels of anxiety, and therefore, as for reframing, people reporting low anxiety should have higher levels of positivity. The low reports of anxiety of repressors reflect a defensive, excessively self-aggrandising response style, i.e. they are high in defensiveness (Weinberger, Schwartz, & Davidson, 1979). However, research on stress-related growth has failed to find an association between defensiveness and positivity (Park, Cohen, & Murch, 1996; Tedeschi & Calhoun, 1996). Tedeschi and Calhoun (1996) rule out repression as a mechanism underlying positivity following general traumatic events because people cite both negative and positive aspects of their situation, rather than only the positives, which would be expected if the underlying mechanism was repression.

In addition to reframing and repression, a third explanation for positivity in illness is existential growth. The link between adversity and growth has always featured in the existential literature. For example, a fundamental assumption of crisis theory (Caplan, 1964) is the potential for growth in the face of negative life experiences. Maslow (1968) views adverse experiences such as grief and pain as not only an occasion for growth but also sometimes necessary for an individual's growth

and fulfilment. Schaefer and Moos (1998) suggest that patients who survive an illness with a poor prognosis are particularly motivated to find a meaning in the illness, and may feel compelled to keep their part of the 'bargain', for example, by adopting a more mature and helpful personal orientation. LeShan (1984) suggests that illness can provide an opportunity for people to find their 'special road' and thereby provides an opportunity for change and personal development. Not every ill person will grasp this opportunity should it be present, but positivity is more likely in those who respond positively to novel situations, and in particular extraverts or those open to new experiences (McCrae & Costa, 1986). Thus, if there is genuine existential growth in illness, positivity should correlate with extraversion, because extraverts are more likely to respond positively to the novel interpretation of events that is likely to be a characteristic of existential growth in illness. Extraversion (but not neuroticism) has been found to correlate with post-traumatic growth (Tedeschi & Calhoun, 1996) and also positivity in illness (Hyland & Kenyon, 1992).

Existential growth in illness may take the form of spiritual gains (O'Brien, 1982; Granstrom, 1985), where people self-actualise their spiritual development. Illness, particularly if it emphasises the finite nature of human existence, can be a stimulus for growth in those areas that are perceived as infinite. People who believe in a soul or spirit that endures after death, either for religious or other reasons, are therefore more likely to experience positivity from illness, if such positivity is the result of genuine growth. This prediction is confirmed by the finding that religiousness is a positive correlate of stress-related growth scales (the Stress-Related Growth Scale; Park et al., 1996; the Post-Traumatic Growth Scale, Tedeschi & Calhoun, 1996).

The three explanations for positivity (reframing, repression and existential growth) therefore make different predictions about personality correlates of positivity. Reframing predicts that positivity should be negatively correlated with neuroticism. Repression predicts that positivity should be negatively correlated with neuroticism and positively with defensiveness. The existential growth interpretation predicts that positivity should be positively correlated with extraversion and religiousness.

The aim of the present study is to test whether neuroticism, extraversion, defensiveness, or religious/ spiritual experience are associated with positivity in five groups of patients, some of whom had life threatening disease. In addition, we examined to what extent positivity was determined by situational factors, such as illness type.

## METHOD

### *Participants*

One hundred and ninety seven patients were recruited from the Chest Clinic at a London Hospital. The mean (standard deviation, range) age of patients was 56.8 (16, 18-85) years. Gender and ethnic group are shown in Table 1. Patients were from several different ethnic groups with the white ethnic group representing 76.1% of the sample.

Patients were classified according to five categories of disease diagnosis, such that co-morbid patients were categorised according to their most 'serious' illness (e.g., a patient with sleep apnoea syndrome and lung cancer was placed in the lung cancer category). The numbers of patients in each group were: (a) 40 (20.3%) patients with asthma; (b) 109 (55.3) patients with chronic respiratory disease (comprising in decreasing order of frequency, chronic obstructive pulmonary disease, sarcoidosis,

fibrosing alveolus, and cystic fibrosis); (c) 16 (8.1%) lung cancer patients; (d) 18 (9.1%) patients with sleep apnoea syndrome and (e) 13 (6.6%) patients with tuberculosis. One (0.5%) patient had an unspecified respiratory condition.

In addition to disease type, patients were classified as either life-threatening or non-life-threatening. Patients with chronic respiratory disease and lung cancer patients were classified as 'life-threatening' and those with asthma, sleep apnoea syndrome and tuberculosis classified as 'non-life-threatening' (note, patients presenting a life-threatening and non-life-threatening illness were classified as life-threatening). One hundred and twenty five (63.5%) patients were placed in the life-threatening group and 71 (36.0%) in the non-life-threatening group (the patient with an unspecified illness type was not classified). Patients were recruited at least 3 months post-diagnosis. The mean (standard deviation, range) duration of illness was 10.0 (14.5, 0.3-81.0) years.

### *Measures*

*The Silver Lining Questionnaire* (SLQ; Sodergren & Hyland, 2000; Sodergren, Hyland, Singh, & Sewell, in press) is a 38-item questionnaire measuring 10 aspects of positivity in illness. Examples of items include: 'My illness helped me find myself'; 'Through my illness I discovered a talent I didn't know I had'; and 'My illness strengthened my relationships with others'. Patients respond using five categories, strongly agree, agree, not sure, disagree, and strongly disagree. An overall score is obtained by scoring each item as 1 for responses 'strongly agree' and 'agree', and 0 for all the other response options. The total score therefore reflects the total number of items that the patient agrees with, i.e., the number of positive of consequences of illness experienced, and varies between 0 (low positivity, i.e., the



patient agrees with no items) and 38 (high positivity, i.e., the patient agrees with all items). Cronbach's alpha is .93 and retest reliability is  $r = .90$  (Sodergren & Hyland, in press)

We selected the SLQ in favour of three other possible questionnaires because it has the broadest coverage of positivity. The Benefit Appraisals Scale (Tennen, Affleck, Urrows, Higgins, & Mendola, 1992) and the Satisfaction with Illness Scale (Hyland & Kenyon, 1992) consist of five and six items respectively. The 17-item Benefit Finding Scale (Cruess et al., 2000) is a more comprehensive measure of positivity, but was designed to measure positivity only in breast cancer.

*Demographic characteristics and religion/spirituality* were assessed by questionnaire. Patients were asked to specify their age, gender, and race / ethnic group. In addition, as an indicator of their religious beliefs / spirituality, patients were asked to specify whether they were spiritual but not religious, neither spiritual nor religious, or, if they were religious, to specify their religion. In the literature on posttraumatic / stress-related growth (Park et al., 1996; Tedeschi & Calhoun, 1996), the focus has been solely on intrinsic religiousness / religious participation. Our pilot work with the SLQ showed that some patients wished to indicate that they were spiritual but not religious rather than just spiritual (they wished to explicitly deny being involved in religion), and so we included a single item to that effect. The need to reduce the study burden in seriously ill patients meant that we were unable to use a more detailed measurement of spirituality / religiousness, such as the Intrinsic Religiousness Scale (Gorsuch & McPherson, 1989) or the Spiritual Assessment Guide (O'Brien, 1982).

*Eysenck Personality Questionnaire Revised (EPQ-R) Short Scale* (Eysenck, Eysenck, & Barrett, 1985) consists of 48 items from the 100-item EPQ-R and

measures the following four personality dimensions: Neuroticism, Extraversion, Psychoticism, and Lies. Each dimension comprises 12 items. Patients are asked whether or not they agree with each statement and responses are assigned a value of 1 if they are consistent with the personality facet assessed thus, for each dimension, scores range between 0 (low in personality trait) and 12 (high in personality trait). The lie scale measures a tendency on the part of some respondents to 'fake good' and has also been shown to measure a stable personality trait that may be defined as social naivety or defensiveness (Eysenck & Eysenck, 1991). The lie scale was therefore used in this study as an indicator of defensiveness.

*The MRC Dyspnoea Scale* (Medical Research Council, 1986) is a measure of breathlessness on a scale between 0 ('Not troubled by breathlessness, except on strenuous exercise') and 5 ('Breathless at rest').

### *Procedure*

Outpatients attending the chest clinic were given a patient information and consent sheet by the nurse inviting them to participate in a study about the positive consequences of illness. The nurse recorded each patient's identity, disease type, and duration since diagnosis.

The SLQ and EPQ-R were administered in a random order with 99 patients completing the SLQ first and 98 completing the EPQ-R first. Assessments were self-completed at the clinic. Nurses were present to address queries that arose. Completed questionnaires were returned via the nurses to the University of Plymouth for statistical analysis.

## RESULTS

*Prevalence of positivity in the total sample*

Completed SLQs were received from 194 patients. One patient with asthma felt that it was inappropriate for her to complete the SLQ but did not offer an explanation. Two incomplete SLQs were received: one from a patient with COPD and one with asthma. The mean (standard deviation) SLQ score for the sample as whole was 12.12 (8.44). Ten patients endorsed no positive consequences and one patient endorsed all positive consequences.

*Positivity as a function of gender, age, and race / ethnic group*

There was no significant difference in positivity between males and females,  $t(192)=-1.27$ , *ns*, with a mean (standard deviation) SLQ score of 12.94 (8.63) for females and 11.40 (8.23) for males. Positivity was also found to be unrelated to age,  $r(194)=.09$ , *ns*.

Positivity was compared across race / ethnic groups (table 2) using a one way ANOVA. There was no significant difference between the seven groups,  $F(6,185)=1.71$ , *ns* (the Chinese group was excluded from this analysis as there was only one patient). This failure to find significance may be because of the low number of people in categories other than the white group, and so should be treated with caution.

All subsequent analyses were carried out without regard to gender, age or race / ethnic group.

*Positivity as a function of illness characteristics*

Table 3 shows the mean (standard deviation) SLQ total scores of patients classified firstly according to the five disease groups, secondly, according to whether their illness was life-threatening or non-life-threatening, and finally according to the six levels of breathlessness. Positivity was unrelated to disease type using a one way

ANOVA,  $F(4,188)=2.17$ , *ns.*, and there was no significant difference in positivity between those classified as life-threatening and non-life-threatening  $t(191)=0.61$ , *ns.* Positivity was not significantly related to disease severity as measured by the MRC breathlessness scale, using a one way ANOVA  $F(5,173)=0.42$ , *ns.*, nor was it related to duration since diagnosis using a Pearson correlation,  $r(193)=.05$ , *ns.*

#### *Positivity as a function of religion / spiritual beliefs*

Table 4 shows the mean (standard deviation) SLQ values of patients according to their spiritual / religious orientation. For the purpose of analysis, patients were divided into three categories, 'neither religious nor spiritual,' 'spiritual but not religious,' and 'religious.' A one way ANOVA showed a significant effect of positivity across these three groups of patients,  $F(2,187)=7.12$ ,  $p<.001$ . Post-hoc comparisons using t-tests showed significant differences in positivity between the 'neither spiritual nor religious' and the 'spiritual but not religious groups,'  $t(67.71)=-2.71$ ,  $p<.01$ , and between the 'neither spiritual nor religious' and 'religious groups,'  $t(148)=-3.83$ ,  $p<.001$ . The 'spiritual but not religious' and 'religious' groups did not differ significantly in reported positivity,  $t(141)=-0.49$ , *ns.*

Table 4 also shows the mean (standard deviation) SLQ values for the different religious groups. Although there are some intriguing possibilities that different religions may foster different levels of positivity, the numbers are too low for meaningful statistical comparison.

#### *Positivity as a function of personality*

Pearson product moment correlations were calculated between the total SLQ score and the four personality dimensions of the EPQ-R (table 5). The only significant correlation was for extraversion such that patients high in extraversion were more likely to perceive positive consequences of their illness.

*Multiple predictors of positivity*

A multiple linear regression was carried out with the total SLQ score as the dependent variable and the extraversion score and religious / spiritual versus neither religious nor spiritual entered as independent variables. Extraversion and religious / spiritual belief independently predicted positivity, with 8.5% of the variance in positivity explained by these two variables (table 6).

## DISCUSSION

There are three explanations for positivity in illness: reframing, repression, and existential growth. We found considerable evidence to support the existential growth explanation. As predicted by the existential growth hypothesis, we found a positive correlation between positivity and extraversion – confirming previous findings in the case of positivity with illness (Hyland & Kenyon, 1992) and post-traumatic growth (Tedeschi & Calhoun, 1996). We also found an association between religious / spiritual beliefs and positivity, which is consistent with the hypothesis that religious or spiritual gain is an important aspect of positivity. Our findings are consistent with Park et al. (1996) who reason that religion may promote stress-related growth by facilitating an individual's search for meaning in a crisis. We found no difference in degree of positivity between those who described themselves as religious and those who described themselves as spiritual but not religious. Consequently, this relationship with positivity seems unlikely to be due to the practice of religious observance but rather due to the holding of spiritual beliefs – spiritual beliefs are usually common to those who are religious as well as those who are spiritual but not religious. We found trends in positivity between different religious groups, but the numbers were too small to conclude one way or the other.

Consequently we cannot say whether particular types of spiritual belief predispose towards positivity. This line of inquiry could be followed up in the future. People who hold the spiritual belief that suffering is part of spiritual development (e.g., turning the other cheek, accepting what God gives you, loving your enemy) may be more prone to positivity in adversity.

Both the reframing and repression explanations of positivity predict a negative relationship between positivity and neuroticism. We did not find a significant relationship between positivity and neuroticism, a lack of a significant relationship has been reported before both in the case of positivity in illness (Hyland & Kenyon, 1992) and stress related growth (Tedeschi & Calhoun, 1996). However, in the present study the direction of the effect (i.e., a positive relationship between positivity and neuroticism) was opposite from that predicted by these two theories. That is, the more neurotic the person was, the higher they were (non-significantly) in positivity. In view of the fact that reframing is reported in patients elsewhere (Taylor et al., 1983), it may be that reframing is used primarily to reduce negativity in illness, rather than to increase positivity. Neuroticism correlates highly with negativity in illness, as measured by quality of life scales (Hyland, Bott, Singh, & Kenyon, 1994; Jones, Baveystock, & Littlejohns, 1989) though there are several explanations for this finding. Of the various types of reframing listed by Taylor et al. (1983) only one (construing benefit from harm) seems to suggest increased positivity as opposed to reduced negativity. Furthermore, it seems unlikely that positivity reflects a self-serving memory bias because, although a correlation with extraversion might be expected, there should be a negative, not a positive correlation between positivity and neuroticism.

The repression explanation of positivity predicts a positive relationship between positivity and defensiveness. We did not find a significant relationship between these two variables, but the size of the correlation was not significantly different from the correlation between positivity and extraversion. Thus, whereas the correlation with neuroticism is insignificant but in the wrong direction, the correlation with repression is insignificant but in the right direction for the repression explanation. We therefore cannot rule out the effect of repression as a factor determining positivity.

Our study also allowed us to examine the relationship between positivity and patient demographic and illness characteristics. Our findings did not replicate those in the stress-related growth literature of greater positivity amongst females (Park et al., 1996; Tedeschi & Calhoun, 1996) nor did we find any relationship between positivity and age. In addition, we found no differences in positivity as a function of race / ethnic group though numbers in some groups were small. More importantly, however, we found no difference in positivity as a function of illness type, disease severity as measured by breathlessness, and whether the illness was life-threatening or not. However, all the patients in our sample presented a disease that was sufficiently serious for a specialist attention. It may be that a minimum level of disease severity is needed for positivity to be perceived, and once over this criterion, then other factors relating to personality determine the level of positivity experienced.

Our findings suggest that positivity is an effect that is determined by psychological characteristics of the patient rather than the specifics of their medical condition. A cognitive-behavioural stress management program has been shown to increase positivity in breast cancer patients (Cruess et al., 2000) and this enhanced

positivity produced physiological gains, a finding that emphasises the importance of psychological factors for this aspect of patient experience.

Because illness is commonly viewed as a purely negative experience, it is easy to suppose that patients who report positive consequences are deluded, and that their reports are the consequence of cognitive adjustments such as reframing or repression. Our data suggest that patients' reports of positivity should be taken at face value, and they really do experience gains as a result of illness. Through illness, many patients develop as people, seeing themselves and their situation in a new light. Of course, not all patients perceive benefit and the degree of benefit varies. However, when patients report benefit, that benefit should be treated as real rather than as a delusion.



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Table 1. *Demographic characteristics of the sample*

Demographic characteristic		Frequency	Percentage
Gender			
	Male	105	53.3
	Female	92	46.7
Ethnic group			
	White	150	76.1
	Indian	6	3.0
	Pakistani	5	2.5
	Black-Caribbean	14	7.1
	Black-African	6	3.0
	Black-Other	8	4.1
	Chinese	1	0.0
	Other	7	3.2

Table 2. *Positivity as a function of race / ethnic group*

<b>Race / ethnic group</b>	<b>Mean(standard deviation) total SLQ score</b>
White	11.66 (8.15)
Indian	19.83 (13.66)
Pakistani	9.00 (5.15)
Black-Caribbean	15.00 (10.08)
Black-African	15.50 (5.17)
Black-Other	8.88 (6.49)
Other	12.00 (7.43)

Table 3. *Prevalence of positivity as a function of illness characteristics*

Illness characteristic	Frequency	Mean (standard deviation) total SLQ score
Asthma	38	10.97 (8.11)
Chronic respiratory disease	108	12.08 (8.41)
Lung cancer	16	13.94 (6.68)
Sleep apnoea syndrome	18	9.11 (9.00)
Tuberculosis	13	17.23 (9.35)
Life-threatening	125	12.32 (8.21)
Non-life-threatening	71	11.67 (8.91).
Grade of dyspnoea		
0	26	12.12 (9.86)
1	66	11.83 (8.49)
2	45	12.22 (8.74)
3	28	14.46 (8.38)
4	10	12.60 (5.19)
5	4	10.75 (8.30)



Table 4. *Positivity as a function of spirituality / religion*

<b>Spiritual / religious orientation</b>	<b>Frequency</b>	<b>Mean (standard deviation) total SLQ score</b>
Neither spiritual nor religious	47	8.36 (6.20)
Spiritual but not religious	41	12.93(8.97)
Religion specified	103	13.73 (8.65)
Church of England	70	13.43 (7.77)
Roman Catholic	13	12.69 (10.04)
Judaism	8	18.25 (15.01)
Islam	3	8.67 (5.69)
Methodist	4	19.00 (4.24)
Jehovah's Witness	2	15.00 (2.83)
Sikhism	2	9.00 (11.31)
Orthodox (Greek Church)	1	13.00 (-)

Table 5. *Positivity as a function of personality*

Personality dimension	SLQ total score
Psychoticism	-.03
Neuroticism	.11
Extraversion	.16*
Lies	.10

\* $p < .05$

Table 6. Multiple regression of the total SLQ score

Variable	Beta weight	Significance
Spiritual / religion specified	.23	.00
Extraversion sub-scale score	.16	.03