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Meeting the psychological needs of community-living stroke patients and carers: a study of third sector provision

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ABSTRACT

Purpose: To elucidate how community stroke staff in a major third sector organisation experienced their role and understood and responded to clients' psychological needs.

Method: In stage 1 three focus groups of 28 staff in total were recorded, transcribed and analysed using inductive thematic analysis. Themes were authenticated by new staff groups. In stage 2 these themes informed the construction of a questionnaire delivered through the organisation's intranet by 'Survey Monkey'.

Results: Five themes emerged from the focus groups: background and context; perceptions of clients' psychological issues; approaches to meeting psychological needs; the experience of working with psychological needs and sources of support; aspirations for future development. Four themes were used in constructing the questionnaire. Responses from 144 staff with diverse qualifications and experience were received; over half encountered 16 (of 35) psychological issues at least once per week. Stroke survivors' needs predominated over carers' needs. Skills used to address psychological problems were identified, also training and support needs and future aspirations. Support needs included information, training and access to specialist consultants.

Conclusions: Psychological issues were central in the work of third sector community stroke staff; psychological skills were routinely used. Attention to means of supporting and developing these skills is required.

Key Words: Stroke, Psychological Care, Stroke Association, Third Sector,

Community.

INTRODUCTION

Social and psychological issues are common after stroke [1,2] occurring in about 40% of survivors at any given time and encompassing depression, anxiety, cognitive impairment, sexual problems, attitudes to recovery, identity change and isolation [3]. Self-reported psychological problems (which may be mild and subclinical) are very prevalent; nearly 60% of survivors feel depressed and 67% anxious. Forty-eight percent of carers feel stressed, 79% anxious, 60% sleep-deprived and 56% depressed [4]. Stroke carers also have difficulty coping with fluctuating mood and uncooperative behaviour in the survivor and lack of social engagement [5-7]. Over half of carers and nearly half of survivors experience difficulty in their personal relationships [4]. Cross-sectional surveys show that at any one time depression is present in about 33% of survivors [8] and anxiety in about 20% [9]. However, longitudinal studies show that around 55% of survivors experience depression at some stage after stroke [10].

Psychological problems, especially depression, have a major impact on outcomes [11] and psychological problems over the first 26 weeks after stroke predict poorer functional outcome at 52 weeks [12]. Psychological problems in the carer also affect the quality of care they provide and the outcome for the survivor [13,14]. Finally, co-morbid mental health issues such as depression and anxiety increase the cost of managing stroke patients [15].

Effective psychological care in the community is necessary to reduce service usage and the cost of healthcare [16]. But a Healthcare Commission survey in 2006 [17] found that a year after hospital discharge only 22% of patients reported 'excellent' or 'good' care (27% fewer than in the hospital phase), and lack of psychological care was the most frequent shortfall, reported by 49%. More recently the National Audit Office (2010) [18] found psychological care was rated the least satisfactory aspect of community care, with over half of the respondents rating it as poor or very poor, and only 24% of respondents rating it as good or very good. Surveys [3,4] have consistently shown that psychological and emotional problems were not routinely addressed, and between 40 and 80 percent (depending on the problem) reported unmet psychological needs. This contrasted with interventions for physical health problems, for which most respondents received help. Despite the fact that psychological aspects of care were the most prominent concerns of carers during the community phase [6], separate surveys have demonstrated that stroke carers also experienced service shortfalls. For example, about two thirds did not receive any support with feelings of anxiety or depression following discharge [4] and 61% were dissatisfied with community services (while only 33% were dissatisfied with hospital care) [19].

In the UK inadequate psychological care in the community may, in part, be a function of the poor organisation of community stroke services. Community stroke services face more practical challenges than hospital services [20], they are frequently very diverse and fragmented [21] and are often impeded by poor co-ordination and tension between different service providers [22]. Moreover, they have

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few staff with specialist psychological expertise [18,23]. Surveys in England found that 60% to 70% of localities had no access to psychological therapy or neuropsychology, no peer support arrangements for carers or survivors, and no integrated mental health provision. And information and signposting of services after discharge were absent in over 50% of the areas surveyed [24,25].

Despite its importance in terms of patient and carer welfare and economic impact, there are few studies of community stroke services with a psychological focus. Two studies have considered staff factors in community stroke services: the first demonstrated that staff were aware of some, but not all, of the service limitations and shortfalls [26] and the second found that staff perceived their overarching aim as supporting the survivor's sense of continuity [27]. However, the implications of these findings for service improvement were not elucidated. The present study was conducted within a third sector organisation, The Stroke Association, since non-NHS providers currently deliver a significant amount of community care, [28,29] and new policy and legislation dictate that their role will increase [30,31]. Statutory funding for health and social care by the third sector grew from £8.4 billion to £13.9 billion between 2000/1 and 2009/10 [32,33]. The Stroke Association is now a major provider of community stroke services with over 600 employees and 4,750 volunteers in 400 Services [34]. Moreover, in some areas, The Stroke Association is the only stroke service capable of delivering psychological care to many community-living survivors and carers [18,23,24].

This study explored how community stroke staff understand and respond to the psychological needs of stroke patients and carers and how they experience their role. An initial exploratory focus group study informed the development of a questionnaire that was used for a UK-wide survey.

METHOD

Ethical approval for the project was granted by the XXXXX University School of Psychology Ethics Committee.

DESIGN

The study was conducted in two stages. The first stage employed focus groups of staff within two geographical regions to elucidate the nature, scope and support received for their involvement in psychological care after stroke. This stage was primarily designed to formulate questions to be asked in a questionnaire survey. A secondary aim was that the content of the focus group material could potentially triangulate conclusions drawn from the subsequent questionnaire survey. The second stage was an organisation-wide intranet-delivered questionnaire survey for all staff in the UK.

FOCUS GROUPS

Three focus groups explored psychological and emotional support. Focus groups can elicit unexpected experiences and perspectives, and permit flexible, interactive exploration to reveal the reasoning behind conclusions. They can also identify areas of consensus and divergence, in an interactive manner [35,36].

Recruitment

Focus group members were recruited from The Stroke Association's service delivery and management staff by circulating a brief description of the nature and purpose of the groups by email to all service-based staff in Wales and south west England. To encourage frank and open discussion staff were reassured that all responses were to be anonymous, and no data that would permit individual identification were to be reported. Individuals in groups were not required to give their name when they spoke, and quotations were not to be ascribed. Three focus group of 28 salaried staff in total were convened in different locations.

Procedure

The groups were facilitated by a clinical psychologist and lasted for 1.5 to 2 hours. The groups' agendas followed a semi-structured schedule based on published guidelines, policy and research documents and staff consultations. Initial drafts were critiqued by key staff [36]. The schedule included case vignettes highlighting psychological care to provide material for discussions. The final schedule encompassed: the understanding of, and engagement in, 'psychological support'; organisational support for the delivery of psychological support; and aspirations for improving psychological care.

Data Analysis

The focus groups were recorded and transcribed and the transcripts analysed to identify themes and instances of themes using inductive thematic analysis [37]. The results from each group were initially analysed separately to produce themes, and

the themes for each group were then examined to identify unique and overlapping themes. Overlapping themes were amalgamated if they indexed similar material, or differentiated and re-labelled if distinct. The findings were reported back for participant verification to two separate groups of 15 staff and one group of 35 staff. These groups worked in smaller groups of 5 to 7 to consider subsets of the themes. The results of each subgroup were recorded in writing and discussed in a plenary session, which was also noted, to identify salient points and to achieve a consensus. The themes were then modified in response to the feedback received.

THE QUESTIONNAIRE SURVEY

Recruitment

The target population was all service-based staff in the UK, approximately 625 in total. The aim was to collect information about psychological issues and care across services. Stroke Association services include Communication Support Services that are primarily concerned with the needs of survivors with aphasia and their carers. A principal activity of these workers is the co-ordination of communication support groups. Information and Support Services and Life after Stroke Services have a similar focus (a recent reorganisation had resulted in a change of title) and provide direct support to clients and carers through individual contact and organising groups. A key feature of this support is the provision of information, networking with peers and signposting to services. The great majority of staff have generic roles. Staff were advised about the questionnaire by organisation-wide email and briefings, and it was

available for completion on the organisational intranet between March and May, 2012.

Materials

The questionnaire items were based upon statements related to four of the focus group themes: perceptions of clients' psychological needs; strategies and activities for meeting psychological needs; sources of support and the experience of working with psychological needs; and aspirations and plans for future development.

At the end of each section there was a free-form box for comments, and at the end of the questionnaire respondents were invited to make free comments.

Within the constraints of length, items were designed to be as concrete and specific as possible [38]. The draft questionnaire was initially critiqued by a group of psychologists and subsequently piloted with a group of three Stroke Association co-ordinators and two volunteers.

Procedure

The final version was adapted for UK-wide delivery to staff on The Stroke Association's Intranet using 'Survey Monkey'.

Analysis

Quantitative data were summarised in tables using simple percentages based on the number of valid responses to each question. Free form responses to the open-ended questions were collated and organised into themes using content analysis. The comments were inspected and, if necessary, divided into elements dealing with a particular topic. These elements were then sorted into categories according to content by a research assistant. The categories were then inspected by the

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researcher for overlap, consistency and to determine if they were hierarchically related. Each category was examined to identify the theme it represented and a label was chosen to represent each theme based on the items in the category.

RESULTS

FOCUS GROUPS

The Groups

Group 1 comprised 9 members: 3 male, 6 female; average age 40.0 years; average length of service 8.2 years. Group 2 comprised 13 members: 2 male, 11 female; average age 46.8 years; average length of service 3.2 years. Group 3 comprised 6 members: 6 female; average age 45.7 years; average length of service 8.4 years. Four of the staff were in management roles, the remainder had roles described as 'stroke co-ordinators', 'peer support co-ordinators', 'communications support co-ordinators'. Seven members of the groups had current membership of professional bodies (e.g. The Nursing and Midwifery Council, the Health and Care Professions Council). Fourteen had qualifications in health and social care ranging from professional nursing and social work qualifications to certificates in specific therapies. Three held management qualifications.

Themes

The outcomes for the three focus groups were broadly similar in structure with five main themes emerging.

Service shortfalls and importance of The Stroke Association.

The staff perceived NHS and statutory community services to be very sparse indeed and that stroke survivors and carers had needs that would not be met if it were not for The Stroke Association provision.

"And then by the time [they] have been discharged from hospital and [they] are back home all the OTs have disappeared and the support network has disappeared and [they] are suddenly left there on [their] own and this is what the rest of [their] life is going to be like…"

Staff member: "She turned round and said that she felt abandoned and there was nobody else left."

Group members: "Yes, yes"

Staff member: "There was only us left."

The Stroke Association was perceived as having a unique and vital role.

"…. that is because we are proactive, when people go home we phone them ….. there is nobody else who actually does that, ….. can jump in there and offer all of these services. But otherwise there is nobody else,…..."

Perceptions of clients' psychological needs.

This theme encompassed the ubiquitous nature of psychological problems and needs following stroke, and the immense range of problems and issues encountered.

Stroke was perceived as a life-changing event that requires major psychological adjustment.

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"I mean for me to put it in a nutshell, I suppose where we are working on a daily basis with people who are coping with a huge life change that they didn't want and they don't have any control over."

A range of psychological reactions were perceived as frequent and important.

"…fear of actually moving forward with their lives to accepting that the stroke has happened and that maybe their communication skills are not going to come back…"

"I think they are anxious as well, there is anxiety in there as well it's not just depression 'cos they are very anxious to get back to the normal…"

"There is a lot of grief ….especially in carers, …. they have lost sometimes the person that they know or they love …..a grief there for that kind of either life style or relationship they had before,…."

Strategies and activities for meeting psychological needs.

A key aspect of the focus group conversations were descriptions of the ways in which staff sought to meet the psychological needs they found in their work.

Many staff highlighted the importance of being there to listen.

"…. but just having a friendly ear to listen to them can be a massive boon …. sometimes they do just need someone to talk to."

Holistic working was seen as important.

"…there's nobody looking at the whole picture all together and I think that's what we get a lot of, …. listen to people's problems but also the system as well."

There were also specific strategies.

"I think peer support as well; I think sometimes if you can introduce a carer to another carer they will often get a lot of support off one another."

"I think signposting is what we call it. We do so much signposting to other voluntary agencies to whomever that we feel would be of financial or emotional [benefit]."

"…. we are putting a label on it that we have done some counselling or we have done some goal setting which you just do it normally….."

The experience of working with psychological needs and sources of support.

Another key area of concern was the impact on staff of working with people with high levels of distress and unmet needs. This aspect also encompassed thoughts about where staff could turn for support and the value and effectiveness of what was available.

Working with this client groups was experienced as demanding and stressful at times.

"…. we are enabling them out in the community they can get kind of really, not addicted to the success, but really, sort of, fond of moving on. And if they feel that

you are the facilitator of that success, well, they want more and more out of you in a way. Which can be kind of draining in a sense…."

"…and [the client] did actually take their own life and the impact of that on the communication support coordinator at the time was huge because although she had … tried to give her everything she could, she felt very bad that she hadn't been able to step in and stop and this happening."

Many sources of support were identified including supervision and management. Peer support from colleagues was a key element, but there was recognition that support was limited in relation to demands experienced by staff.

"We do have discipline meetings so we can keep in touch ….we do have an opportunity if they want to have peer support then as well."

"… the staff deal with the stroke survivors and carers on a daily basis .....and there isn't really …. a formal way of offloading that for staff so they get burden[ed] with everybody offloading to them but how do they release it?"

Aspirations and plans for future development.

Staff were keen to enhance support for their psychological work and had developed ideas about how these might be achieved. For example, though external supervision/review of cases, organised peer support, expert consultation, access to relevant materials and training.

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"I think assessing skills and some form of assessing training ….because all staff do assessing in their day to day role but none of them have ever been given formal training on it."

"…. to have somebody external qualified and accredited to deliver that training in a more structured way……And somebody that could give related examples as well,…..rather than talking hypothetically."

Professional supervision and consultation, independent of management, was also a perceived support need.

"… I mean the people we are supposed to go to for supervision are the people who make decisions about whether or not we get a pay increment. So if I'm going to go in and say certain things and it is going to flavour, colour their view of me and my service. So you don't do it."

QUESTIONNAIRE STUDY

Characteristics of Respondents

Of the 144 staff completing the demographic information, nine did not go on to complete the whole questionnaire. The 135 completed responses comprised 22% of the total workforce and covered most regions of the UK. Scotland and Northern Ireland were under-represented reflecting less development of services in these areas. The sample was predominantly aged 36 to 55, overwhelmingly female, and

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the majority had over 2 years of experience with the organisation. Most were part-time workers and the sample included those working in the three principal Stroke Association Services.

[Insert Table 1 about here]

Frequency of Issues Encountered in Clients

The percentages for staff encountering particular issues in stroke survivors and carers are shown in Table 2. There was a question allowing respondents to rate the importance of each problem area ('not important' or 'important'), but nearly all areas were rated 'important', so these data were not analysed.

A very high percentage of staff reported frequent experience with the majority of the listed issues, further discussion of these findings is provided in the Discussion section below.

[Insert Table 2 about here]

Skills Used in Providing Psychological Care

Table 3 depicts the percentage of staff using each skill in day to day practice and their perceived need for training in each skill. The table is ordered according to the percentage of staff expressing need for training in the use of skills. It is evident that the need for training in the skills was not always congruent with the use of skills; some commonly used skills were not perceived as requiring training (e.g. team-working, linking and networking, and signposting) while in contrast some less used

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skills were perceived by most as requiring training (e.g. risk assessment and risk management, and resolving arguments).

[Inset Table 3 about here]

Sources of Development and Support

[Insert Table 4 about here]

Ratings for sources of support are shown, in rank order, in Table 4. Since not all staff would have had experience of particular methods, but might well know about them, the wording allowed them to rate sources of support that they thought would be helpful. Most staff rated most of the methods helpful, but some said they were unsure about key support methods and some methods, such as buddies and supervision, were ranked low. These points are taken up in the Discussion.

Responses to Open Ended Questions

Fifty-eight of 144 staff responded to the final open ended question. Three staff also added to the problems list in question 12 (suicidal thinking in carers, loss of self in carers and apathy). Six staff commented after the question on the use of particular helping methods and the need for training; one endorsed counselling as an additional method, one referred to dealing with sexuality after stroke and four referred to the need for regular refresher training. Five staff also made relevant comments after the question about sources of development and support. Three

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made comments indicating that any support or training to enhance psychological care would be useful, one referred to lack of supervision and went on to describe a need or more support for staff self-care, one referred to lack of time for any kind of support. Six themes emerged and all respondents whose quotes are listed below were female and White British, other individual details are given after the quotations.

The perceived importance of psychological care highlighted the centrality of this area of work.

"This [psychological care] is probably the most important area of our work and the one where there is the greatest need..." (Age 56-65; worked 2 to 4 years in Information and Support Service 4 days per week; professional degree in non-health area).
"A very great part of what I do is offering emotional support to clients." (Age 46-55; worked 2 to 4 years in Information and Support Service 4 days per week; non-degree level professional health qualification).

Neglect of psychological care was a central concern and demonstrated an awareness of unmet need and service shortfalls.

"There is a huge gap in emotional and mental health care for both stroke survivors and carers." (Age 36-45; worked over 10 years in Life after Stroke Service 5 days per week; non-degree level qualifications).

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"A lot of services are available after stroke to support people practically and physically but few seem to be able to support emotionally." (Age 26-35; worked 0 to 2 years in Communication Support Service 5 days per week; professional health degree).

Focus on survivors rather than carers was a theme that echoed the findings of the focus groups and the results of the questionnaire.

"I feel that although I support stroke survivors at the support groups, the carers quite often feel the need to talk and get some reassurance." (Age 36-45; worked 2 to 4 years in Information and Communication Support Service 4 days per week; non-degree level qualification).

Sources of support and skill development emerged as a major aspect of staff's thinking and there was acknowledgement of multiple ways in which this could be accomplished.

"Colleagues in the office are supportive of each other and we talk through difficult cases and the emotional impact." (Age 46-55; worked 2 to 4 years in undisclosed Service 4 days per week; professional health degree).
"… most of my knowledge and skills in this area have been built up through experience in employment…. where there has been an immediate need to develop

skills in dealing with emotional care." (Age 26-35; worked 0 to 2 years in Communication Support Service 5 days per week; professional health degree).

"I feel my clinical background and previous training and experiences have equipped me to deal with emotional issues relating to clients and carers affected by stroke." (Age 56-65; worked 2 to 4 years in Information and Support Service 4 days per week; professional health degree).

Aspirations for enhanced support and greater fidelity between the service's aims and its activities were themes that appeared to demonstrate an interest in service improvement.

"I would, though, very much appreciate more education relating to assessing psychological problems and memory and cognitive issues relating to stroke." (Age 56-65; worked 2 to 4 years in Information and Support Service 4 days per week; professional health degree).

"….when we come across difficult or emotionally challenging cases we would benefit from supervision for these as we are currently not offered this." (Age 26-35; worked 2 to 4 years in Information and Support Service 5 days per week; non-degree level qualifications).

"We would also be helped by …… making it much clearer what exactly they expect us to do as part of our roles and where they expect us to draw a line. This would protect both us and our service users." (Age 26-35; worked 2 to 4 years in Information and Support Service 5 days per week; non-degree level qualifications).

DISCUSSION

The questionnaire completion rates was 22% of the total workforce (the total potential sample). Allowing for underestimate of actual completion rate due to those who did not receive the questionnaire for one reason or another, and considering the many comments to the optional open-ended questions, suggests that there was interest in psychological care and reflection upon practice amongst these community-based stroke service staff [26, 27]. The spontaneous written comments reinforced the quantitative results and echoed the results of the focus groups in pointing up the perceived centrality of psychological care. But this perspective co-existed with the view that psychological care is fragmented, inadequate and is not prioritised.

 A median average of 85.9% of staff reported encountering each of the 35 psychological problems at least once a month. The problem domains were selected on the basis of the focus groups outcomes, so this finding triangulates those results. The frequency with which staff encountered particular psychological issues generally mirrored the results of surveys discussed in the Introduction; fatigue, cognitive problems, depression, anxiety and changed roles or relationships were frequently encountered. The enormous range of problems encountered may reflect milder, subclinical psychological issues that are less visible than clinical problems, but are nevertheless more prevalent in the general population and have implications for

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prognosis [39]. Such subclinical problems may lead to increased service utilisation [40] and are amenable to intervention [41,42]. Training and support to enable staff to address these issues could prevent more serious problems, reduce service utilisation and costs, and could reasonably be encompassed within Level 1 of a stepped care service configuration [43]. The finding that survivor problems were more frequently encountered than problems in carers could reflect an absence of need, or, more probably, a service focus upon survivors that diverts attention from carers [18]. Risky or dangerous behaviours and suicidal behaviour were only infrequently encountered. However, frequency is not the only criterion for evaluation of impact, and these issues merit consideration by virtue of their potentially severe consequences, and the complex demands they place upon staff in balancing the duty of care with the principle of autonomy [44]. Staff also endorsed the need for training in this area (Table 3), despite only occasionally encountering these problems and utilising related skills. It is noteworthy that information and support and life after stroke personnel encountered nearly half the issues more frequently than communications support staff. This may reflect the different nature of the services and the more generic roles of the former staff group. Carers and survivors who experienced positive benefits of stroke were encountered more often than once per month by over half of staff, and at least once a week by over a quarter of staff. This provides further evidence of benefit finding and growth in stroke survivors and their carers [45,46]. It may be beneficial to consider how to harness positive facets of recovery from stroke and the factors that promote its development within therapeutic approaches [47].

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The skills and helping methods reported as used during routine practice corroborate the view that psychological care is not limited to psychology practitioners [43] and encompass skills for dealing with a diverse range of psychological needs. All the listed skills were endorsed by over 75% of the staff. The frequency of skill use and the need for training in them were not always congruent, and the low perceived need for training in some vital and commonly used skills such as active listening, signposting and networking, linking, team-working, boosting confidence or acting as a point of contact suggests that they were perceived as well-developed and not requiring further training. On the other hand, 73% of staff requested risk assessment and management training despite only 3% of staff using this skill once a week or more. Several other psychological skills were identified as requiring additional training, and of these the assessment and management of mood and cognition have been considered as central to stroke service improvement [43]. The current results suggest that training should be extended to include skills in risk assessment and management, basic counselling and conflict resolution.

Responses to the questions about sources of development or support revealed the majority of staff valued most of the listed methods; only two methods were rated extremely helpful by less than 49% of respondents. Consistent with responses to the questions about specific psychological skills, over 80% of staff reported need for training in psychological skills (assessment and intervention) relevant to anxiety, depression and cognition, and over 70% felt a need for training in listening and counselling skills. General information about psychological care was also seen as necessary, as was having better information about referrals and access to feedback

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from clients. Access to specialist consultation was endorsed by over 85% of respondents. In view of the results of the focus groups, it was unexpected that the majority of staff did not rate as 'extremely helpful' externally facilitated case supervision or review, structured peer support with case review, and a mentor or buddy system. In each case over 40% endorsed the 'unsure if it would be helpful' option, and therefore a lack of appreciation of what these sources of support offer may explain the low endorsement rates. Clinical supervision, in particular, is included in practice guidelines and is an aspect of clinical governance for those working with psychological problems, [48] and it is required by professional bodies [49,50]. The finding that only 55.5% of staff felt a need for help in dealing with their reaction to casework was also unexpected on the basis of the focus group results. Once again, uncertainty about the value of potential sources of support may have contributed to this finding. Staff identified a range of support measures, in addition to training, as important for improving the delivery of psychological care. These included explicit organisational policy, consultation and informational resources. This resonates with research findings demonstrating that practice change requires attention to broad organisational context, [51,52] and evidence from stroke services suggests that training alone has limited benefits [53-55] except when the skills involved are specific and technical [56,57].

The outcomes contain some important messages for psychological care following stroke. Presently the principal approach is the stepped care model in which all stroke care staff become engaged in psychological care with support from specialists

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[43,58,59]. Service specifications for achieving one aspect of stepped care (mood screening) in community services have been advanced, [60] but to date there is an absence of evidence for its effectiveness [58]. The current study demonstrates that front-line, non-specialist community stroke staff are routinely engaging with a range of psychological problems using a range of broadly psychological approaches. However, a large proportion of staff in this sample reported the need for further training in a number of important areas, some felt unsupported in the delivery of psychological care, and over 40% had a limited appreciation of the value of several key methods of support. These findings highlight the challenge in meeting the recommendation that all those working with stroke should provide help with psychological issues within a stepped care approach [43].

A very high proportion of staff in the current study, over 90%, reported that they make referrals to mental health services. But written comments, and the focus group results, indicated that services providing specialist psychological and mental health care were often unavailable, and this echoed the findings of surveys of community stroke services [24,25] and of unmet psychological needs [3,6,18]. Whilst the delivery of psychological care by a range of staff is a key feature of the stepped care model, specialist psychologist input is also required [58]. The Stroke Improvement Programme estimated that 26% of stroke patients will be seen by non-psychologists (11% at level 1 and 15.3% at level 2), but that 23% will need to see a psychologist [16]. In addition, there will be some relatives and carers who require specialist psychology support. For such cases, the lack of access to community mental health

services will be an impediment since few psychologists are available in stroke services [18,23].

The service gaps identified in the focus group results and the comments in the questionnaire are salient. Unmet psychological needs have implications for outcomes; depression, for example, impacts upon recovery [11, pp. 284). Depression in the general population has been shown to increase the use of services [61] and this is also true of depression after stroke [62]. Further adverse outcomes include entry into care and increase medication and service use [16]. Increased service use by stroke patients with untreated psychological problems has been estimated to cost a total of £108,000 over two years for a catchment of 250,000. Using these cost parameters, it has been estimated that an investment in such a psychology service could save health and social care services £40,000 and realise a benefit in quality adjusted life years (QALYs) worth and estimated £463,000 [16].

Psychologists have well developed skills in organisational development and in supporting non-specialist staff through supervision and training [63]. However, the challenge of improving psychological care in community stroke services will be to support a cadre of front line staff that is much more heterogeneous (Table 1) than in NHS services. Delivery methods will also require adapting to work with larger and more heterogeneous catchment areas than in the NHS. Further challenges are the absence of additional resources for the implementation of psychological care and the impact of staff turnover. It may be necessary to consider supplementing, or even

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replacing, aspects of the stepped care approach with affordable specialist-led alternative approaches to psychological support such as self-help [64] or group psycho-education [65]. Such developments may be informed by the outcome of the current pathfinder site evaluations of a stepped care model based on the Increasing Access to Psychological Therapies approach which is being applied to long term conditions (including stroke) and medically unexplained symptoms [66].

This study has a number of limitations. Although just under a quarter of all staff responded to the questionnaire, 78% did not, and this volunteer sample may not have been representative of non-responders and there may have been other sources of bias that led to some staff not receiving the questionnaire. It would be useful to collect information about the number of clients exhibiting particular psychological issues, and data to distinguish new issues from repeated issues in the same clients. This information could be obtained by a weekly log of contacts. Such a log would also alleviate any memory biases associate with a retrospective questionnaire such as this. A substantial proportion of the questionnaire respondents were unsure about some of the support methods listed in the questionnaire and this impacted on responses. Future web-based questionnaires could educate staff about what particular methods have to offer using information tabs. The use of focus groups and participant consultation to frame questions ensured that lack of familiarity with particular technical terms and techniques was not an impediment, and that the language used was appropriate for the population. However this did entail the avoidance of some common terms and reference to specific intervention

and assessment procedures. The use of tabs offering further information or a glossary of terms could also assist with this aspect.

This study has demonstrated the centrality of psychological problems in the work of community stroke staff in a third sector organisation. It also highlighted the types of psychological issues that staff encountered most frequently. Although there were some areas of inconsistency (in relation to support needs), the results of the qualitative study were generally corroborated by those of the questionnaire study. The workforce were very diverse in terms of qualifications and experience. The participants were able to identify the skills that they drew upon and a number of training and support needs. The outcome has implications for the configuration and delivery of community stroke services.

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Declaration of Interest

The author has no conflicting interests to report.

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