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Dementia

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Dementia and its relationship with suicidality: A Critical Interpretive Synthesis.

Gary Hodge RNMH, BSc (Hon), MSc.

# **Abstract**

# **Objectives**

This objective of this literature review and synthesis of data was to consider the presence, drivers, and protectors of suicidality in people diagnosed with dementia. The review also aimed to consider if any protective exist, and what constitutes an increased risk of suicidality. Finally, it reflected on the morality and ethics of choice when discussing dying in dementia.

### Method

This article used a Critical Interpretive Synthesis model which interpreted data associated with the subject of suicidality in dementia. A sample frame was used to determine the quality, and relevance of extracted data, and finally conduct a critical interpretive synthesis. Data was extracted from eight key papers.

### Results

The review and synthesis concluded with eight synthetic constructs, and two concluding synthesised arguments. Argument one was the substantial increased risk of suicidality in people diagnosed with dementia and clinical depression. The second argument was that end of life discussions are common place in people with a dementia diagnosis and their families.

### Conclusion

Death remains a difficult subject for some to discuss, especially when talking about suicidality. Nevertheless, having these conversations is possible, even when there are added complexities that a dementia diagnosis can bring. These conversations do however need to be individualized and measured. And, whilst respecting the person's pre morbid wishes, advance decisions, and ethics of choice, we also need to consider the ongoing arguments of the 'right to life' versus the 'right to die'. However, before these conversations can take place additional suicidality risk factors such as a new and early dementia diagnosis, and mental health comorbidities such depression need to be acknowledged and addressed.

# **Key Words**

Dementia, Cognition, Suicide, Suicidality, Memory.

### Introduction

Suicide rates in the UK are changing and indicate an overall decrease; except for the figures for middle aged and older men, where there is an increase of 25.1 and 14.5 per 100,000 respectively since 2012 (Davies, 2015; Office for National Statistics, 2015). The older adult rise in completed suicides peaks in those aged 80-90 and above (Samaritans, 2015). Dennis (2009) suggests that any suicidal ideation, self-harm, or attempts of suicide need to be taken extremely seriously in older adults, as suicide completion is statistically indicated within the near future, if precipitating issues are not addressed. The explanations for a suicide risk rise in those aged 80 and above has not yet been established, although certain risk factors associated with ageing have been indicated. One factor, not exclusive to older adults, but more evident in ageing is cognitive impairment and dementia.

Dementia has become a much-debated subject within the arena of health and social care. The reasons for this are multi factorial, and arguably instigated by the financial and resource pressures this diagnosis brings to providers. Worldwide there are an estimated 46.8 million people diagnosed with dementia (Alzheimer's Disease International, 2015). Research conducted by the Alzheimer's Society in 2014 suggests that care provided currently cost the UK £26 billion a year for the 850,000 diagnosed with dementia in the UK alone (Alzheimer's Society, 2014). This figure however includes the cost of £11.6 billion of unpaid care, often provided by elderly spouses and relatives (Alzheimer's Society, 2014; Metcalfe & Curtice, 2010).

In an Age UK report, Royal Voluntary Service chief executive David McCullough expressed that it is a "wonderful thing that people are living longer, but the challenges that this brings with it has led to older people being seen as a burden" (Age UK, 2013 p1). Services for older people, especially mental health services, have been neglected financially and in terms of policy for a long time, and dementia is one of those areas of neglect (Bernard & Phillips, 2000). It is the hidden "Cinderella service of the NHS" (McCartney, 2013, p.1). This is by no means a justification for considering if suicidality is a problem in dementia, but arguably an acknowledgment of the need to explore if it as a factor. Shah and Baht (2007) found no connection between policy, spending, service provision, and suicide rates in respect to older adults. They did however note that their cross-national study did not correlate with findings from other single nation research projects, including the UK (Shah & Bhat, 2007) where suicide rates decreased when mental health provision spending improved. They note however that this may have been partly influenced by policy makers introducing national suicide reduction targets alongside the additional expenditure (Shah & Bhat, 2007; Shah, Bhat, MacKenzie, & Koen, 2008).

Little research has taken place into dementia as a proven indicator of being a suicide risk within its own right. Haw, Harwood, and Hawton (2009) report very few studies associated with dementia and the risk of suicide, and found bias, and flaws, in many of those completed. One of the areas of concern raised was the use of words such as 'not worth living' which are often passive thoughts, rather than suicidal ideation, and in fact related more to mood disorders than dementia (Haw et al., 2009). Erlangsen, Zarit, and Conwell (2008) did however find a subset of people diagnosed in a hospital setting with dementia were at a higher risk of suicide; noting this was particularly the case for those over 70 years old.

Seyfried, Kales, Ignacioa, Conwell, and Valenstein (2011) explored the risks factors of suicide in dementia further and found that of a cohort of 241 people diagnosed with dementia who had completed suicide, 75% were newly diagnosed. They also noted that 24.5% of those completing suicide had a diagnosis of depression, in contrast with 9% of the non-suicide group (Seyfried, Kales, Ignacioa, Conwell, and Valenstein, 2011). Two recent narrative reviews also support this finding noting an increased prevalence of suicide completion in people with a co-morbid depression diagnosis (Conejero, et al., 2018; Diehl-Schmid, et al., 2017).

# Methodology & Review Design

This literature review will employ a Critical Interpretive Synthesis (CIS) (Dixon-Woods et al., 2006) as a process to consider the presence, drivers, and protectors of suicidality in people diagnosed with dementia. The term suicidality was chosen as opposed to suicide as it allowed the topic to be opened up to suicidal ideation, behaviours, and triggers, rather than just considering and discussing the completed act of suicide (Meyer et al., 2010). The review question was formed by searching literature about suicide and dementia and will use the

exploratory review statement of 'Dementia and its relationship with suicidality', rather than a strictly formed question. The title and statement were chosen as they are simple and open ended. This allows the opportunity of interpretation and transformation as part of the CIS process. A CIS question is often used as a "compass to guide the review journey", rather than an anchor to hold on to steadfastly. (Eakin & Mykhalovskiy, 2003, p.454).

The process of CIS will be achieved by establishing a sample frame for the selected literature, determining its quality, extracting data and finally conducting an interpretive synthesis (Dixon-Woods et al., 2006). The review and synthesis will include all ages, genders, dementia diagnosis types, and subtypes. The CIS approach allows new theories and concepts to emerge through the process of analysis, and reviewer reflexivity, allowing review development to emerge naturally (Bibb, Baker & McFerran, 2016). CIS, as it indicates, is an interpretive and iterative model of inquiry, which seeks to generate and shape theory rather than a cumulative process of information gathering and reports on subjective human experiences, and the creation of meaning (Dixon-Woods et al., 2006; Fossey, Harvey, McDermott & Davidson, 2002; Heaton, Corden & Parker, 2012). However, epistemologically there are interpretation barriers when attempting to accurately synthesise other researchers work. These barriers often lead to the quantification of findings, and a tendency to complete positivist aggregative synthesises, rather than a true interpretive epistemological systematic review (Weed, 2005).

CIS also has the benefit of being able to consider collating, analysing, and synthesising all data, and research design types; proposing that there should be no hierarchy, and offering an organic formulation of theory (Little et al., 2016). This is particularly useful in allowing the inclusion of quantitative data that would ordinarily be excluded in similar styles of review

(Dixon-Woods et al., 2006). When completing a CIS only seriously deficient papers, or studies that offer no relevance to the literature synthesis, will be excluded. However, to aid the author in the case of this review and synthesis, only English written papers were included. Also, a date of post 1991 (25-year search) was set, as there were very few studies of relevance which were written pre-1991 when a literature scoping review was completed.

# **Literature Search Strategy**

CIS unlike conventional systematic reviews does not require a comprehensive literature search, but instead utilises expertise of the subject from the reviewer, and others; seeking relevance in the sampling frame, rather than quantity (Dixon-Woods et al., 2006). This was aided by using the SPIDER framework, Table 1 (Cooke, Smith & Booth, 2012), which aided the formulation of a search topic, but also assisted the literature search by establishing search keywords and relevance to the exploratory review statement.

Table 1: Exploratory review question (and Search) Framework: SPIDER

| S  | Sample                 | People diagnosed with dementia.                        |
|----|------------------------|--|
| PI | Phenomenon of Interest | Suicidality.   |
| D  | Design                 | Interpretive review – Critical Interpretive Synthesis. |
| E  | Evaluation             | Factors associated with suicidality and dementia.      |
| R  | Research Type          | Qualitative, Quantitative, Mixed.                      |

(Cooke, Smith & Booth, 2012)

# **Inclusion Criteria**

Worldwide studies that include/consider suicide risk, or protective factors of suicide in people with a dementia diagnosis (ICD & DSM and/or cognitive measures/scales – evidence of diagnosis). All age, both genders, quantitative, qualitative and mixed studies/articles.

### **Exclusion Criteria**

Non-English written papers, studies/articles older than 1991 (25-year search). Specific dementia types (i.e. Frontal temporal dementia, Lewy bodies dementia, Korsakoff dementia) as a generic review dementia is being sought and not diagnosis specific. And also excluded is cognitive impairment due to stroke, acquired brain injury, or other neurological cause outside dementia.

The exclusion of non-English written papers and a 25-year search limit are omissions included to aid the single reviewer in shortlisting potentially useful articles; in what otherwise could be a daunting and very time-consuming task that could potentially add very little to the CIS. CIS is not trying in any way to prove scientific generalisability, but instead is interested in context and interpretation, which can get lost in the drive to create an exhaustive and comprehensive search of literature (Bales & Gee, 2012). The inclusion and exclusion criteria are deliberately open as the search does not wish to exclude articles that may otherwise be missed by a strict and defined by a set of inclusion rules. CIS combines the interpretive style of meta- ethnography, and the diversity of a realist synthesis to allow freedom in searches, and avoid well-defined and pre-determined conventional positivist searches, which test hypothesis alone (Dixon-Woods et al., 2006).

# **Key Words**

Key words selected were: suicide, suicidality, suicidal ideation/thoughts (suicid\*), dementia, cognitive (cogniti\*), (Including combinations and/or/not using Boolean (Boole 1854)

Operator and phrases). The single search included MeSH (Medical Subject Headings – US National Library of Medicine: NLM, 1999, updated 2015) keyword/term: Memory.

Keywords were selected by initially using the SPIDER framework (Cooke, Smith & Booth, 2012), and an exploratory statement was developed which focussed on the phenomenon and

cohort of interest, which was suicidality in people diagnosed with dementia. These two words were then used as a baseline, and searches were completed using these words, with Boolean operators (Boole, 1854), wildcard and truncation symbols (\*) and other words created by using MeSH (NLM, 1999, updated 2015) to find further keywords, as seen above in the keywords search.

### **Full Electronic Search**

Primo Central Index = BMJ Journals, Cochrane Library, CINAHL, MEDLINE/PubMed,
ProQuest, ScienceDirect Journals (Elsevier), SpringerLink, Taylor & Francis Online, Wiley
Online Library (not exclusive), Sage publications, Emerald Journals (Citation Search /
Reference chaining of all relevant papers).

# **Grey Literature**

Expert opinion, Age UK, Alzheimer's Society, Dementia Journals/websites, Department of Health, Google/Scholar, Joseph Rowntree Foundation, Office of National Statistics, Research Gate website (not exclusive as further literature will emerge as part of the iterative process)

# **Article Findings and Selection**

A one-off all-encompassing search is not an essential in CIS. Barnett-Page and Thomas (2009) argue that although CIS purports to offer an iterative literature review process, it does not clarify if this is a process which is fulfilled throughout the whole synthesis. This is however clarified by Dixon-Woods and her fellow authors in 2006 who state:

"The Processes of question formulation, searching, selection, data extraction, critique and synthesis are characterised as iterative, interactive, dynamic and recursive rather

than as fixed procedures to be accomplished in a pre-defined sequence". (Dixon-Woods et al., 2006, p.9.)

In the case of this literature review and synthesis the reviewer will aim to be iterative throughout the whole synthesis, as described by the originators of CIS quoted above.

However, a full electronic and grey literature search has taken place to aid the reader as well as offering clarity and transparency to the process of paper selection.

A full search of Primo Central Index and a secondary search of papers in grey literature, and through citation chaining and cycling found a total of 18,358 papers. The search indicated how a comprehensive and systematic search can create an unmanageable number of articles for one reviewer. To address the issues the reviewer completed a scan read for relevant titles, and then if appropriate, abstracts were read to include/exclude papers. This is where expert knowledge of the subject is particularly useful so as not to eliminate relevant papers (Dixon-Woods et al., 2006).

Table 2: Search Findings

| Search                    | Main Search Resource                                |
|---------------------------|---|
| Suicid* AND Dementia      | MEDLINE/PubMed (NLM) (7,853)                        |
| (ALL)                     | ScienceDirect Journals (Elsevier) (4,661)           |
| 16,410                    | ProQuest Business Collection (2,741)                |
| Suicid* AND Cog*          | MEDLINE/PubMed (NLM) (163)                          |
| 275                       | ScienceDirect Journals (Elsevier) (86)              |
|                           | Wiley Online Library (38)                           |
| Dementia AND Suicide      | MEDLINE/PubMed (NLM) (506)                          |
| 995                       | ScienceDirect Journals (Elsevier) (217)             |
|                           | ProQuest Business Collection (211)                  |
| Cognition AND Suicide 561 | MEDLINE/PubMed (NLM) (389)                          |
|                           | ScienceDirect Journals (Elsevier) (170)             |
|                           | ProQuest Business Collection (84)                   |
| Suicid* AND Dementia      | MEDLINE/PubMed (NLM) (34)                           |
| (Title)                   | ScienceDirect Journals (Elsevier) (17)              |
| 57                        | Cambridge Journals (Cambridge University Press) (4) |
| Suicide AND Memory        | MEDLINE/PubMed (NLM) (18)                           |
| (MeSH)                    | JSTOR Current Journals (5)                          |
| 38                        | JSTOR Archival Journals (5)                         |

Following the scan read search, elimination of repeat papers, and a scoping review of relevance, 38 papers were found which matched the sampling frame criteria. These papers were then reviewed to select 8 key papers were identified as a purposive sample (Dixon-Woods et al., 2006) for the CIS review. All eight papers met all the inclusion and exclusion criteria, but also once reviewed satisfied the authors quality, relevance, and data extraction standards for the exploratory review statement of 'dementia and its relationship with suicidality'.

# Relevance and Quality of studies

The Critical Appraisal Tool (CAT) developed by Hawker, Payne, Kerr, Hardey and Powell (2002) was adapted slightly to fit a CIS review and converted to a table to be used for the measurement of quality of the papers. The CAT was then added as it can be used to assess disparate and diverse studies/data, whilst also offering an overall score. This score will partially aid the decision making on how relevant the selected articles are, alongside the exclusion and inclusion criteria, and the reviewer's expert opinion of the topic.

However, the relevance and quality of the articles for the CIS will be indicated by how applicable and pertinent the content is to the synthesis, rather than the articles theoretical and methodical strength (Gough, 2007). The use of a quality appraisal tool will aid the reviewer and reader to follow the process of appraisal and why the key studies were selected; which in turn should offer articles that add value to the subject of dementia and its relationship with suicidality.

### **Data extraction**

The data, which was collected from a diverse set of articles, was collected and extracted into a set of written findings using Dixon-Woods et al., (2005) data extraction tool. The tool was modified slightly by the author and included the addition of the CAT as a quality scoring tool (Hawker, Payne, Kerr, Hardey & Powell, 2002) (Table 3). It has been argued that CIS data collection should be informal, and expansive, and not restricted by conventional synthesis methods (Dixon-Woods et al., 2006). Although a data extraction form was used the author did allow data to develop outside of the formal process, this allowed for a more pragmatic collection and collation of data, rather than perhaps offered in standard empirical systematic reviews (Dixon-Woods et al., 2005; Flemming, 2009). The data collected and analysed was also later screened, reviewed, and analysed reflexively in an iterative and inductive manner.

Table 3: Data extraction form; eight key papers

| Unique Paper Identifier   | A1  | A2   | A3  | A4  | A5   | A6  | A7   | A8   |
|---|---|--|---|---|--|---|--|--|
| Source of Paper   | International<br>Journal of.<br>Geriatric<br>Psychiatry                         | The American Journal of Geriatric Psychiatry   | International<br>Psychogeriat<br>-rics                                  | British Journal<br>of Psychiatry  | Alzheimer's & Dementia                           | Nursing<br>Standard   | International<br>Psychogeriat<br>-rics                         | Journal of<br>Affective<br>Disorders                           |
| First Two Authors   | Tsai, C.;<br>Tsai, S.   | Erlangsen,<br>A., Zarit, S.  | Haw, C,<br>Harwood, D   | Purandare, N,<br>Voshaar, R   | Seyfried, L<br>S., Kales, H.<br>C.               | Nicholson<br>L  | Draper, B.<br>M.   | Koyama, A.,<br>Fujise, N.                                      |
| Title of Article  | Chinese demented inpatients admitted following a suicide attempt: a case series | Hospital- Diagnosed Dementia and Suicide: A Longitudinal Study Using Prospective, Nationwide Register Data | Dementia<br>and suicidal<br>behavior: a<br>review of the<br>literature. | Suicide in<br>dementia: 9-<br>year national<br>clinical survey<br>in England and<br>Wales | Predictors of suicide in patients with dementia. | Risk of<br>suicide in<br>patients<br>with<br>dementia:<br>a case<br>study | Suicidal<br>behavior and<br>assisted<br>suicide in<br>dementia | Suicidal ideation and related factors among dementia patients. |
| Date of Publication   | 2007  | 2008   | 2009  | 2009  | 2011   | 2013  | 2015   | 2015   |
| Country of Study  | China   | Denmark  | UK  | England and Wales   | USA  | Scotland  | Australia  | Japan  |
| Quality 1. Abstract and title Good, Fair, Poor, Very Poor. 2. Introduction and aims | Fair (3)  | Good (4)   | Good (4)  | Fair (3)  | Good (4)   | Fair (3)  | Fair (3)   | Good (4)   |
| Good, Fair, Poor, Very Poor. 3. <b>Method and data</b>                              | Poor (2)  | Poor (2)   | Poor (2)  | Fair (3)  | Good (4)   | Poor (2)  | Good (4)   | Fair (3)   |
| Good, Fair, Poor, Very Poor.<br>4. <b>Sampling</b>                                  | Poor (2)  | Good (4)   | Fair (3)  | Good (4)  | Good (4)   | Fair (3)  | Good (4)   | Good (4)   |
| Good, Fair, Poor, Very Poor.<br>5. <b>Data analysis</b>                             | Fair (2)  | Good (4)   | N/A   | Good (4)  | Good (4)   | Fair (3)  | N/A  | Good (4)   |
| Good, Fair, Poor, Very Poor.<br>6. <b>Ethics and bias</b>                           | Poor (2)  | Good (4)   | N/A   | Good (4)  | Good (4)   | Poor (2)  | N/A  | Good (4)   |

| Good, Fair, Poor, Very Poor. 7. <b>Findings/results</b>                 | Very poor (1)  | Poor (2)  | Fair (3)   | Good (4)   | Poor (2)  | Very Poor (1)   | Poor (2)  | Fair (3)  |
|---|--|---|--|--|---|---|---|---|
| Good, Fair, Poor, Very Poor.  | Fair (3)   | Good (4)  | Good (4)   | Good (4)   | Good (4)  | Fair (3)  | Fair (3)  | Fair (3)  |
| 8. <b>Transferability/generalizability</b> Good, Fair, Poor, Very Poor. | Fair (3)   | Poor (2)  | N/A  | Fair (3)   | Fair (3)  | Poor (2)  | N/A   | Fair (3)  |
| 9. <b>Implications and usefulness</b> Good, Fair, Poor, Very Poor.      | Fair (3)   | Fair (3)  | Good (4)   | Good (4)   | Good (4)  | Fair (3)  | Fair (3)  | Good (4)  |
|   | (0)  | - 5.22 (0)  |  | , ,  | , ,   | - 3.22 (0)  | (0)   | ` '   |
| Quality? (Total Score)  | 21   | 30  | (20) N/A -<br>Review   | 33   | 33  | 22  | (16) N/A –<br>Review  | 32  |
| Relevance   | Fair   | Good  | Good   | Good   | Good  | Fair  | Fair  | Good  |
| Stated Aim of Study   | Explores the clinical and phenomenolog ical aspects and treatment of Chinese demented patients who have attempted suicide. | Examines the risk of suicide in persons diagnosed with dementia in hospital and the relationship to mood disorders. | To complete<br>a literature<br>review of the<br>research<br>literature to<br>share<br>risk factors<br>for suicidal<br>ideation,<br>self-harm<br>and suicide<br>in dementia | Describes<br>behavioural,<br>clinical and care<br>characteristics<br>of<br>people with<br>dementia who<br>died by suicide. | Patients with dementia who completed suicide & who did not by demographic characteristi c & severity of dementia at suicide | A case<br>study to<br>reflect on<br>risk<br>strategies<br>and ethics<br>of<br>suicide and<br>assisted<br>dementia<br>and carers<br>role | A systematic narrative literature review of suicidal behaviour and assisted suicide in persons with dementia. | Assess prevalence of suicidal ideation in dementia patients and relationship between ideation and other factors |
| Sample / Participants  Study Design/Data Type                           | 7 participants<br>with mild or<br>moderate<br>dementia   | All individuals aged 50+ living in Denmark (N=2,474,76 7)   | N/A Review of literature.  | Suicides - n=118 dementia patients n=492 non-dementia age/gender compared from total suicides n=11512 National clinical    | N = 294,952,<br>of which 241<br>committed<br>suicide.   | N=1 Case<br>Study   | N/A Review of literature.  A systematic   | N= 634<br>dementia<br>outpatients<br>and family<br>caregivers.  |
| Stady Design Data Lype  | presentations /<br>Demographic<br>data,  | Cohort<br>Study   | Review (nonspecific)   | Survey   | retrospective<br>cohort study   | - Case Study  | narrative<br>literature<br>review.  | comparative<br>design = 3<br>groups   |
| Analytic Approach   | Suicide  | Event-  | N/A  | Conditional  | chi-square  | States will   | N/A   | Two-tailed  |

|                                     | motives and<br>methods in the<br>form of<br>narrative/descr<br>iption.  | history<br>analysis<br>using time-<br>varying<br>covariates  | Literature review.  | logistic<br>regression.  | tests multivariate logistic regression Independent variables - Logistic model of variant.  | analyse<br>recommen<br>dations to<br>improve<br>care – no<br>approach<br>evident                             | Literature review.   | and the sig<br>levels<br>P<0.05.<br>Statistical<br>analyses<br>SPSS 21.0 J<br>across 3<br>groups  |
|-------------------------------------|---|--|---|--|--|--|--|---|
| Themes                              | Persecutory<br>delusions,<br>depression,<br>Jealousy,<br>Mild-mod<br>stage, anti-<br>psychotic<br>treatment.  | Depression,<br>hospitalisati<br>on, mood<br>disorder,<br>control and<br>treatment<br>factors.  | depression,<br>hopelessness<br>MCI,<br>insight, age<br>failure to<br>respond to<br>medication   | Depression,<br>suicidal<br>ideation/intent,<br>effects of early<br>diagnosis,<br>psychiatric<br>comorbidity  | Methods of suicide, stage of dementia, type of dementia, anxiolytic medication. Comorbidity  | Coping strategies, care input /planning, diagnosis support, risk assessment and euthanasia                   | Depression,<br>comorbidity,<br>young onset<br>dementia,  | BPSD, carer<br>burden,<br>depression,<br>onset of<br>dementia,<br>ageing,<br>quality of<br>life   |
| Findings                            | Suicidal ideation and behaviours are more likely present in mild to moderate stage of dementia, with or without depression. Worse with delusions; Treatment should be considered. | Hospitalisati<br>on added an<br>elevated risk<br>of suicide.<br>Preventive<br>measures<br>should focus<br>on suicidal<br>ideation<br>after initial<br>diagnosis. | The majority of studies reported increased rates of self-harm in dementia but only a few in MCI - Residential care increased risk and some dementia types | Most common method of Suicide in patients with dementia was self-poisoning, followed by drowning and hanging, Dementia Patients were also less likely to have a history of self-harm, psychiatric symptoms and admissions. | Higher risk when diagnosed with depression. anti-Anxiety medication a strong predictor of suicide. High rates of suicide in those with new dementia diagnosis. | The need for advanced directive / decisions and the maintenan ce of choice and dignity throughout life cycle | Added risk = presence of psychiatric comorbidity, mainly Depression + early / young onset when insight present. Assisted suicide needs discussion. | Higher rate of suicidal ideation with BPSD Carer burden increased by suicidal ideation of person with dementia, Depression = increased risk of suicidal ideation. |
| Future research/clinical suggestion | Further research on the effectiveness   | Future research is needed to   | Further research is needed to   | Suicidal intent<br>in dementia and<br>whether suicide  | Timely identification  | Advanced decision / directives   | To explore the evolving death  | Suicidal<br>ideation<br>assessment  |

|                      | of treatment | address the   | improve       | notes were       | and          | and         | wishes,       | is required   |
|----------------------|--------------|---------------|---------------|------------------|--------------|-------------|---------------|---------------|
|                      | options.     | influence of  | knowledge     | completed.       | intervention | maintenan   | suicidal      | for dementia  |
|                      | options.     | cognitive     | about         | completed.       | addressing   | ce of       | ideation, and | patients' and |
|                      |              | skills, stage | suicide and   |                  | the complex  | dignity by  | suicidal      | psychologica  |
|                      |              | of disorder.  | self-harm in  |                  | issues of    | considerin  | behaviour of  | 1 support and |
|                      |              | insight       | dementia /    |                  | depression   | g the use   | people at     | treatment     |
|                      |              | to disease on | MCI and       |                  | and          | of –        | risk of       | offered for   |
|                      |              | the risk of   | mechanisms    |                  | dementia in  | 'Five       | dementia to   | depression    |
|                      |              | suicide       | underlying    |                  | these        | Wishes'     | understand    | depression    |
|                      |              | among         | such acts.    |                  | patients may | (Aging      | the evolution |               |
|                      |              | elderly who   | sach acts.    |                  | help to      | with        | of end-of-    |               |
|                      |              | suffer from   |               |                  | mitigate     | Dignity     | life wishes.  |               |
|                      |              | dementia.     |               |                  | their        | 2013)       |               |               |
|                      |              |               |               |                  | increased    |             |               |               |
|                      |              |               |               |                  | risk         |             |               |               |
| Comments/Limitations | Very Small   | Findings      | Published     | Inability to     | Unable to    | One case    | Limited       | Carers were   |
|                      | study.       | cannot be     | research      | make causal      | assess the   | only– no    | scope of      | reliant on    |
|                      | -            | generalised   | reviewed      | inferences.      | effect of    | limitations | study.        | being told    |
|                      |              | to persons    | was           | Generalisability | disability   | disclosed   | Euthanasia    | about         |
|                      |              | with          | methodologi   | limited to       | resulting    |             | or assisted   | suicidal      |
|                      |              | dementia      | cally weak.   | patients         | from         |             | suicide       | ideation. The |
|                      |              | who have      | Lack of       | with dementia    | medical      |             | requires      | study only    |
|                      |              | not been      | standardized  | in contact with  | comorbidity. |             | public        | chose         |
|                      |              | hospitalised. | tools to      | mental health    | Registry     |             | discourse.    | specific      |
|                      |              |               | measure       | services. Cases  | data is      |             |               | dementia      |
|                      |              |               | MCI and       | included         | poorly       |             |               | types. The    |
|                      |              |               | organic       | undetermined     | recorded     |             |               | seriousness   |
|                      |              |               | disorders not | intent.          | data.        |             |               | of suicidal   |
|                      |              |               | separated.    |                  |              |             |               | ideation was  |
|                      |              | Diament West  |               | 5) 0 111         |              |             |               | not asked.    |

Dixon-Woods et al., (2005) & Hawker et al., (2002)

### Analysis

Dixon-Woods and her colleagues (2006) suggest the need for a process of Reciprocal Translational Analysis (RTA), Lines of Argument (LOA) Synthesis and Refutational Synthesis (Markoulakis & Kirsh, 2013; Noblit & Hare, 1988) when synthesising metafindings. The author adopted RTA and LOA methods of synthesis underpinned by CIS (Dixon-Woods et al., 2005). CIS was chosen rather than meta-ethnography as it considers all aspects of the review and not just the synthesis, as well as synthesising a diversity of literature; including quantitative studies (Barnett-Page & Thomas, 2009). Dixon-Woods et al., (2006) report a limited usefulness of RTA in the case of large and diverse literature reviews. However, as the author only selected eight papers RTA was thought to be useful for the purpose of theme mapping and interpretive synthesis.

Once a comprehensive examination and critique of the selected papers was completed and data was extracted, themes began to develop from individual papers, and in some cases, across papers. The emerging codes were checked, and rechecked, against the selected papers to allow the author to reflexively review emerging, recurring and reciprocal themes. This offered some protection from assumptions being made and established that the author's findings matched the papers abstracts and conclusions. Transparency and openness is an important factor is CIS, but the nature of qualitative analysis does not always allow this due to the freedom interpretive qualitative designs sometimes offer (Dixon-Woods et al., 2006). CIS in contrast offers the reader clarity and guidance of how all processes led from raw data to the concluding synthesis of findings (Sandelowski & Barroso, 2002). Aigen (2008) suggests that that this allows the reader to

make decisions on the value of the findings themselves guided by their own values and belief system.

# **Synthesis**

Once hundred and twelve codes (words and phrases) were developed iteratively and reflexively from the narrative data and were transposed manually onto a concept (mind) map. This process was used to commence the process of construct building. These emerging constructs, which included second order (reflexive) constructs, and LOA, were then formulated into 8 synthetic constructs and transferred onto a synthetic construct table, as shown below in table 4 (Dixon-Woods et al., 2006; Flemming, 2009). Finally, the eight synthetic constructs were considered closely and reflexively to construct two concluding synthesising arguments (Dixon-Woods., et al 2006): 'Comorbid risk factors of suicidality in dementia' and 'end of life decision making in dementia', as both relate directly to increased risks of suicidality in people with dementia.

Table 4: Synthetic constructs and associated codes

| Synthetic Constructs                                     | Contributing codes |
|--|--------------------|
| Insight into now and the future and knowledge sharing.   | 10                 |
| Age, stage, and onset of Dementia.                       | 24                 |
| Type of Dementia and associated cognitive presentations. | 9                  |
| Comorbid mental health diagnosis; past and present.      | 16                 |
| Loneliness, isolation and social / support and networks. | 8                  |
| Mental capacity and decision making; including advanced. | 11                 |
| Treatment potential, options, efficacy and choice.       | 19                 |
| Assisted suicide / euthanasia; discussion and ethics.    | 15                 |

# Comorbid risk factors of suicidality in dementia

Although the papers acknowledged that overall the rate of suicide is relatively low in dementia in comparison to the general population (Draper, 2015; Haw, Harwood &

Hawton, 2009), it was also acknowledged that there was also a significantly higher rate of coroner's open verdicts in cases of deaths in people with a dementia diagnosis (Purandare et al., 2009). Nevertheless, it was however understood and agreed across all eight of the studies, that there were particular 'risk factors' to be mindful of when giving a diagnosis of dementia.

One of the most evidenced and established risks factors which often led to suicidal ideations and behaviours in dementia, was the presence of depression (Draper, 2015; Erlangsen, Zarit, and Conwell, 2008; Haw, Harwood & Hawton, 2009; Koyama et al., 2015; Nicholson, 2013; Purandare et al., 2009; Seyfried et al., 2011; Tsai, Tsai, Yang, & Hwang, 2007). One paper felt this was a risk due to the correlation between depression, ageing, and other risks of suicide (Purandare et al., 2009). Whilst others reported that, those diagnosed at younger ages were at a higher risk of suicide, especially where there was co-morbid depression, and a family history of dementia (Draper, 2015; Seyfried et al., 2011). However, whatever the age or stage of dementia the presence of depression should not be ignored, and treatment should be always be considered and offered (Erlangsen, Zarit, and Conwell, 2008; Tsai, Tsai, Yang, & Hwang, 2007).

Other co-morbid mental health diagnoses of significance in the studies were anxiety (Haw, Harwood & Hawton, 2009; Koyama et al., 2015; Nicholson, 2013; Seyfried et al., 2011) and schizophrenia (Draper, 2015). However, a co-morbid schizophrenia diagnosis can also be considered a protective factor for suicide as there is a potential of compromised executive and planning skills associated with schizophrenia (Seyfried et al.,

2011). Whereas, some report in contrast the pathology of frontal lobe damage or disruption in dementia (also implicated in Schizophrenia) has the opposite effect, in increasing the risk of suicidality due to a potential increase in behavioural impulsivity (Draper, 2015; Haw, Harwood & Hawton, 2009).

# End of life decision making in dementia.

Nicholson's (Nicholson, 2013) case study explores the subject of advance decisions, and in the case of 'Mary', how she seeks answers to whether euthanasia or assisted suicide is an option open to her? The study explores how discussions on these subjects, and how advance care planning within the parameters of the law are important factors in reducing the risk of suicidality in dementia (Nicholson, 2013).

End of life decision making in dementia, and advanced directives are often deemed controversial (Draper, 2015). However, others encourage these discussions of paramount importance in maintaining the autonomy and dignity of the person in making end of life choices (Nicholson, 2013). Often, the question that arises is whether the person would make the decisions at later stages of dementia that they did in prodromal or early stages; what will be their "future self" be (Draper, 2015 p.1608).

Advanced directives, and end of life discussions, should perhaps also feature in future debates on euthanasia, or assisted suicide. In particular how advanced end of life planning would affect people with a dementia diagnosis who feel a 'burden' to others, their family, or indeed society as a whole (Erlangsen, Zarit, and Conwell, 2008; Haw,

Harwood & Hawton, 2009). In addition, to cases where carers' report 'carer burden'; bringing potential coercion into the decision process (Nicholson, 2013).

When exploring euthanasia Draper's paper notes that mental capacity, and a sound mind are requirements in jurisdictions where euthanasia is permissible (Draper, 2015). However, the person must also must be considered, "unbearable or hopeless suffering" (Draper, 2015 p.1606; Hertogh, 2009). Draper (2015) questions the difficult moral and ethical decisions that would need to be made in these cases; particular when having to measure what is 'quality of life' (QoL) at a late stage of dementia. This is especially the case in dementia care as planned treatments or interventions aimed at improving QoL requires a skilled consultation with the individual, differentiating between what elements of 'suffering' are due to permanent and progressive changes, and what is a treatable functional mental health need, particularly depression (Draper, 2015; Koyama et al., 2015; Nicholson, 2013; Purandare et al., 2009).

There are of course strong arguments from pro-choice campaigners about the 'right to die', often justified by substantial cost savings to health and social care services (Nicholson, 2013). However, the potential for any individuals to have improvements in their QoL should always be safeguarded and not be lost in money saving ideation and rhetoric (Nicholson, 2013).

### Conclusion

Suicide for any reason is a difficult subject to discuss for a multitude of reasons, and when this subject relates to people with a dementia diagnosis it is no easier. When reviewing the papers which address this subject, it was evident that one factor which

substantially increased the risk of suicide in those diagnosed with dementia was clinical depression (Draper, 2015; Erlangsen, Zarit, and Conwell, 2008; Haw, Harwood & Hawton, 2009; Koyama et al., 2015; Nicholson, 2013; Purandare et al., 2009; Seyfried et al., 2011; Tsai, Tsai, Yang, & Hwang, 2007). The increased risk of suicide however was less evident in other co-morbid mental health presentations, although anxiety and schizophrenia did present some concern, and should be considered when assessing and managing risk, alongside features of clinical depression (Draper, 2015; Haw, Harwood & Hawton, 2009; Koyama et al., 2015; Nicholson, 2013; Seyfried et al., 2011).

Finally, suicide in dementia cannot be truly discussed without entering into a debate on the ethics of choice (Nicholson, 2013); be that advanced directives of treatment, or conversations around assisted suicide and euthanasia (Draper, 2015; Erlangsen, Zarit, and Conwell, 2008; Haw, Harwood & Hawton, 2009). These discussions need to be opened up to allow all parties access to share their thoughts and feelings on the matter. However, this paper was not produced to establish conclusions on the subject of assisted suicide or euthanasia nevertheless it has arguably highlighted the need for future papers to explore the subject, especially with people with dementia and their care providers.

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