Understanding self-harm in the very old: A qualitative study with implications for clinical care and wider society.

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Understanding self-harm in the very old: A qualitative study with implications for clinical care and wider society.

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A thesis in fulfilment of the requirements for the degree of
Doctor of Philosophy

School of Psychiatry, Faculty of Medicine
University of New South Wales
Australia

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Thesis/Dissertation Sheet

Surname/Family Name	:	**Wand**
Given Name/s	:	**Anne Pamela Frances**
Abbreviation for degree as give in the University calendar	:	**PhD**
Faculty	:	**Medicine**
School	:	**Psychiatry**
Thesis Title	:	**Understanding self-harm in the very old: A qualitative study with implications for clinical care and wider society.**

Abstract

The population is ageing globally and the highest rate of suicide is in men aged 85+. The connection between suicide and self-harm in older people provides a window into understanding why older people die by suicide. Older people with cognitive impairment, advanced age, or from non-English speaking backgrounds are often excluded from research in this area, despite representing a significant proportion of the population.

Study 1 qualitatively examined why a cognitively and culturally diverse cohort of very old (aged 80+) adults self-harmed by interviewing the person, their nominated relative/friend, and by questionnaire completion by their General Practitioner (GP). The older people reported a myriad of biopsychosocial factors contributing to the self-harm, including relational factors in his/her clinical and familial systems such as perceived rejection, burdensomeness and helplessness. The carer perspective echoed that of the older person, as well as highlighting their own distress. GPs reported helplessness, professional isolation and therapeutic nihilism. The implications for requests for voluntary assisted dying were explored.

Study 2 followed-up the original cohort one year after the self-harm. Emergent themes from the three groups were triangulated. Patients and their relatives/friends described many contributing factors to self-harm persisting at follow-up, whereas GPs felt problems had been resolved and they understood the underlying reasons for self-harm. A conceptual framework for self-harm in late life, empirically derived, highlighted the relational context of the older adult with family, health professionals, and society, and opportunities for interventions to improve outcomes through prevention and aftercare.

Study 3 combined the results of the two previous studies in the development and evaluation of an educational intervention for primary care and hospital-based clinicians focused on understanding, assessing and managing self-harm in late life. Multidisciplinary clinicians attended the brief educational intervention. Significant improvements in attitudes, knowledge and confidence regarding self-harm in late life were found post-intervention.

In summary, this thesis presented novel insights into why the very old self-harm and the importance of relationships with family/friends and clinicians, which influence the decision to self-harm and outcomes. A brief educational intervention based upon this qualitative work had immediate impact on the knowledge and confidence of multidisciplinary clinicians.

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I hereby certify that all co-authors of the published or submitted papers agree to Dr Anne Pamela Frances Wand submitting those papers as part of her Doctoral Thesis.

Professor Carmelle Peisah

26 October 2019

Thesis by publication statement

Nine first-author papers are included in this thesis by publication. All papers have been accepted by peer-reviewed journals and are published or in press.

Professor Carmelle Peisah

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Philip Ward	5/11/19

Details of publication #1:
Full title: Rational suicide, euthanasia and the very old- two case reports.
Authors: **Wand APF**, Peisah C, Draper B, Jones C, Brodaty H.
Journal or book name: Case Reports in Psychiatry
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Date accepted/ published: 2016

Status	*Published*	*x*	*Accepted and In press*		*In progress (submitted)*	

The Candidate's Contribution to the Work
Dr Wand conceived the idea for the paper as she was developing the methodology for the main study. She was responsible for writing the paper, which the co-authors/supervisors then commented upon.

Location of the work in the thesis and/or how the work is incorporated in the thesis:
The paper in included in the Introduction (Chapter 1).

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Supervisor's name **Carmelle Peisah** *Date (dd/mm/yy)* 04/11/19

Details of publication #2:
Full title: Understanding self-harm in older people: A systematic review of qualitative studies.

Authors: **Wand APF**, Peisah C, Draper B, Brodaty H.
Journal or book name: Ageing and Mental Health
Volume/page numbers: 22(3):289-298.
Date accepted/ published: 2018

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Dr Wand conceived the idea for and performed the systematic review. She was responsible for writing the paper, which the co-authors/supervisors then commented upon.

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The systematic review constitutes Chapter 2 of the thesis and provides the background of the existing literature in the field at the time of commencement of the study.

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Details of publication #3:
Full title: Why do the very old self-harm? A qualitative study.
Authors: **Wand APF**, Peisah C, Draper B, Brodaty H.
Journal or book name: American Journal of Geriatric Psychiatry
Volume/page numbers: 26(8): 862-873.
Date accepted/ published: 2018

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Carmelle Peisah — 04/11/19

Details of publication #4:
Full title: Carer insights into self-harm in the very old: A qualitative study.
Authors: **Wand APF**, Peisah C, Draper B, Brodaty H.
Journal or book name: International Journal of Geriatric Psychiatry.
Volume/page numbers: 34:594-600.
Date accepted/ published: 2019.

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Supervisor's name — *Date (dd/mm/yy)*
Carmelle Peisah — 04/11/19

Details of publication #5:
Full title: How do general practitioners conceptualise self-harm in their older patients? A qualitative study.
Authors: **Wand APF**, Peisah C, Draper B, Brodaty H.
Journal or book name: The *Australian Journal of General Practice*.

Volume/page numbers: 47(3): 146-51.
Date accepted/ published: 2018

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Carmelle Peisah — 04/11/19

Details of publication #6:
Full title: The nexus between elder abuse, suicide, and assisted dying: The importance of relational autonomy and undue influence.
Authors: **Wand APF**, Peisah C, Draper B, Brodaty H.
Journal or book name: Macquarie Law Journal

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Dr Wand and Professor Peisah conceived the idea for the study. Dr Wand wrote the paper, which the co-authors/supervisors then contributed to.

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This paper appears as Study 1d in Chapter 4 of the thesis.

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Details of publication #7:
Full title: Self-harm in the very old one year later. Has anything changed?
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Carmelle Peisah — 04/11/19

Details of publication #8:
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This paper appears as Study 3a in Chapter 6 of the thesis.

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Supervisor's name — *Date (dd/mm/yy)*
Carmelle Peisah — 04/11/19

Details of publication #9:
Full title: Evaluation of an educational intervention for clinicians on self-harm in older adults.
Authors: **Wand APF**, Draper B, Brodaty H, Peisah C.
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This paper appears as Study 3b in Chapter 6 of the thesis

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Supervisor's name — *Date (dd/mm/yy)*
Carmelle Peisah — 04/11/19

PhD candidature – central outcomes

List of Publications

The thesis by publication comprises the following first-author publications:

Chapter 1 includes the publication (Paper 1):

> Wand APF, Peisah C, Draper B, Jones C, Brodaty H. Rational suicide, euthanasia and the very old- two case reports. *Case Reports in Psychiatry*. vol. 2016, Article ID 4242064, 5 pages, 2016. doi:10.1155/2016/4242064.

Chapter 2 includes the publication (Paper 2):

> Wand APF, Peisah C, Draper B, Brodaty H. Understanding self-harm in older people: A systematic review of qualitative studies. *Ageing and Mental Health* 2018; 22(3):289-298.

Chapter 4 has been published as a series of papers (Papers 3–6):

> Wand APF, Peisah C, Draper B, Brodaty H. Why do the very old self-harm? A qualitative study. *American Journal of Geriatric Psychiatry* 2018; 26(8): 862-873.
>
> Wand APF, Peisah C, Draper B, Brodaty H. Corrigendum to 'Why Do the Very Old Self-Harm? A Qualitative Study' [*American Journal of Geriatric Psychiatry* 26 (2018) 862–871], 2019, 27(2):211.
>
> Wand APF, Peisah C, Draper B, Brodaty H. Carer insights into self-harm in the very old: A qualitative study. *International Journal of Geriatric Psychiatry* 2019; 34(4): 594-600.
>
> Wand APF, Peisah C, Draper B, Brodaty H. How do general practitioners conceptualise self-harm in their older patients? A qualitative study. The *Australian Journal of General Practice* 2018; 47(3): 146-51.
>
> Wand APF, Peisah C, Draper B, Brodaty H. The nexus between elder abuse, suicide, and assisted dying: The importance of relational autonomy and undue influence. *Macquarie Law Journal* 2018; Volume 18, 79-92.

Chapter 5 has been published as (Paper 7):

> Wand APF, Draper B, Brodaty H, Peisah C. Self-harm in the very old one year later. Has anything changed? *International Psychogeriatrics* 2019; 31: 1559-1568.

Chapter 6 includes the publications (Papers 8 and 9):

Wand APF, Draper B, Brodaty H, Peisah C. Self-harm in late life. How can the GP help? *Medicine Today* 2019; 20(7): 33-36.

Wand APF, Draper B, Brodaty H, Hunt G, Peisah C. Evaluation of an educational intervention for clinicians on self-harm in older adults. *Archives of Suicide Research* 2020; 1-21.

Conference presentations arising from this thesis

Wand APF, Pesiah, C, Draper B, Brodaty H. Self-harm in the Very Old One Year Later: Has Anything Changed? (poster) 2019 American Association for Geriatric Psychiatry Annual Meeting, Atlanta, Georgia, USA, March 1-4, 2019.

Wand APF, Pesiah, C, Draper B, Brodaty H. Insights into late life suicide and self-harm: A qualitative study of older people who have self-harmed. International Association for Suicide Prevention Asia Pacific Regional Conference, Bay of Islands, New Zealand, 2018

Wand APF, Pesiah, C, Draper B, Brodaty H. How do general practitioners understand self-harm in their older patients? (poster) St George Hospital and Sutherland Hospital Community Health Services Medical Research Symposium, Sydney, 2017

Wand APF, Pesiah, C, Draper B, Brodaty H. Family context of late life self-harm: family responses and (mis)understandings. International Psychogeriatric Association, Queenstown, New Zealand, 2017

Wand APF. Family conflict, undue influence and suicide: A case study. 4th International Conference on Capacity. International Psychogeriatric Association, Queenstown, New Zealand, 2017

Wand APF, Pesiah, C, Draper B, Brodaty H. Why do older people self-harm? A systematic review of the qualitative literature. Faculty of Psychiatry of Old Age, Royal College of Psychiatrists, Bristol, UK, 2017.

Wand APF, McIntosh H. Decisions to die: rational suicide and request for euthanasia in older people. Annual National Conference Decision Making in Dementia. Sydney, 2016.

Invited talks/workshops arising from the thesis

Wand, Draper, Brodaty, Peisah. "Suicide, undue influence and elder abuse." The 6th International Capacity Conference. International Psychogeriatrics Association, Spain, Aug 2019.

Wand, Draper, Brodaty, Peisah. "Loneliness and Disconnection in self-harm in older adults." Symposium: Late Life Loneliness From Private Condition to Social Emergency. International Psychogeriatrics Association, Spain, Aug/Sept 2019.

"Self-harm in older people." South Western Sydney Primary Health Network Presents Older Person's Mental Health, Mittagong RSL, Australia, July 2019

"Suicide in the last 12 months of life in the very old: the role of professional hopelessness." Capacity Australia. Death on the Beach: The First World Conference on End of Life Psychiatry, Maroubra, Sydney, Australia, March 1 2018.

Workshop co-facilitated with Prof Draper. Assessing depression and suicide/risk in older adults. Dual Diagnosis Substance Misuse and Neurocognitive Disorders in Older People, St George Hospital, Sydney, Australia, June 2017

Research grants relating to my PhD research

2019 Wand A. Peisah C. The development of an online staff education tool for a suicide prevention and crisis support organization. Ageing Futures Institute/Lifeline. (AUD$26,000)

2019 Postgraduate Research Student Support Scheme (PRSS) Conference Travel Funds, UNSW, to support travel to the American Association for Geriatric Psychiatry Annual Meeting, Atlanta, Georgia, USA, March 1-4, 2019. (AUD$2,600)

Awards

1. Dr Wand won the Open Senior Division, 47th Annual Coast Association Tow Research Awards, 2019, with her presentation entitled "Understanding self-harm in the very old: A qualitative study with implications for clinical care and wider society." (AUD$1000, and additional funds towards conference travel to present the work.)
2. Dr Wand's PhD research was nominated for the 2019 Prince of Wales Hospital Foundation Research Medal. She was one of five finalists.

Acknowledgements

I had known for some years that I wanted to undertake a PhD but it took some time to come up with a question which really interested me. As a clinician it was no surprise that an idea would form at work. I was fortunate to have the close proximity of excellent clinical academic colleagues and mentors to help shape that initial idea into a doctorate. That I would find the ultimate "triumvirate of profs" was a blessing which made the process of learning well supported and enjoyable. I was fortunate enough to have collaborated with each of my three supervisors well before embarking on the PhD, which was a great way to test-drive working together on a long-term research project.

Firstly, I would like to thank Professor Carmelle Peisah, a psychiatrist of remarkable energy, warmth and wisdom. In appointing herself my mentor several years ago, Carmelle has helped me grow as a researcher, educator, clinician and person. Her enthusiasm, generosity of time and availability as my primary supervisor have enabled me to complete this work ahead of schedule. Her expertise in qualitative research and all things capacity were perfectly suited to the project and, as it turned out, its real-world implications for the complex area of voluntary assisted dying. Carmelle taught me how to find the gems and make connections in an ocean of data. She also helped me not lose sight of what's important and to balance research commitments with the rest of life. Carmelle was able to bring fun, light and hope to an otherwise potentially very dark subject matter.

I am also very grateful for my co-supervisors Professors Brian Draper and Henry Brodaty. It was a privilege to work with Brian, also a clinical colleague, an internationally renowned expert in late life self-harm and suicide. Brian's vast knowledge of the literature and ability to connect the study findings to existing theories and empirical research were extremely valuable. His astute reading of my draft manuscripts before submission provided prompt and pointed feedback, which I'm sure streamlined the process of review and in many cases was more challenging than any external reviewer. I also thank Brian for his mentorship as a senior clinician researcher of varied interests whose door was always open for me to run something past him early morning. I was also fortunate to have the guidance of Henry Brodaty, another prolific researcher with a wealth of experience. Henry's work in primary care, with the oldest old, and in nursing home settings were especially important in this study. Despite his busy research and clinical commitments Henry too was readily available

and responsive. His encouragement and support at my group supervision sessions were genuine and very welcome, especially at times of feeling swamped juggling various roles.

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My family have provided great support and grounding throughout this doctorate. I thank my wonderful children, Lucia and Francis, for coping with the times when I was busy with deadlines and even listening to some of my conference presentations providing hilarious and often helpful feedback. I hope I have shown them both how exciting research can be and the opportunities which can accompany it. I acknowledge the influence of my now 93-year-old Italian grandmother Anna, a courageous, strong and intelligent woman who helped raise me. She fostered within me with a love and respect for older people, which no doubt has influenced my career choices. I thank my mother Elizabeth for listening to me and backing me up emotionally and in practical ways when things became difficult. My parents' love of learning, reading and writing was clearly passed on to me. I have reflected upon how proud my father would be were he here to read this work; he too having embarked upon a doctorate many years ago.

Finally, I would like to thank my colleagues in older persons' mental health and consultation-liaison psychiatry. We have challenging clinical roles and there are always competing demands on our time. Thank you for supporting and encouraging me to pursue my research alongside the clinical work. To the patients, families, GPs and other health care professionals who participated in the study, many of whom were in a time of crisis, thank you for you candor and generously sharing your experiences- this work is for you.

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Abbreviations

ANOVA	Analysis of Variance
CALD	Culturally and Linguistically Diverse
CPD	Continuing Professional Development
GP	General Practitioner
MCI	Mild Cognitive Impairment
MOCA	Montreal Cognitive Assessment
NEO	Neuroticism, Extraversion, Openness
NSW	New South Wales
PHN	Primary Health Network
RUDAS	Rowland Universal Dementia Assessment Scale
UNSW	University of New South Wales
VAD	Voluntary Assisted Dying

Abstract

The population is ageing globally and the highest rate of suicide is in men aged 85 or more. The connection between suicide and self-harm in older people provides a window into understanding why older people die by suicide. Older people with cognitive impairment, advanced age, or from non-English speaking backgrounds are often excluded from research in this area, despite representing a significant proportion of the population. The aims of the thesis were to understand why very old people self-harm and to use the findings to inform and evaluate an educational intervention for clinicians.

Study 1 qualitatively examined why a cognitively and culturally diverse cohort of very old (aged 80+) adults self-harmed by interviewing the person, their nominated relative/friend, and by questionnaire completion by their General Practitioner (GP). The older people reported a myriad of biopsychosocial factors contributing to the self-harm, including relational factors in his/her clinical and familial systems such as perceived rejection, burdensomeness and helplessness. The carer perspective echoed that of the older person, as well as highlighting their own distress. GPs reported helplessness, professional isolation and therapeutic nihilism. The implications for requests for voluntary assisted dying were explored.

Study 2 followed-up the original cohort one year after the self-harm. Emergent themes from the three groups were triangulated. Patients and their relatives/friends described many contributing factors to self-harm persisting at follow-up, whereas GPs felt problems had been resolved and they understood the underlying reasons for self-harm. A conceptual framework for self-harm in late life, empirically derived, highlighted the relational context of the older adult with family, health professionals, and society, and opportunities for interventions to improve outcomes through prevention and aftercare.

Study 3 combined the results of the two previous studies in the development and evaluation of an educational intervention for primary care and hospital-based clinicians focused on understanding, assessing and managing self-harm in older people. Multidisciplinary clinicians attended the brief educational intervention. Significant improvements in attitudes, knowledge and confidence regarding self-harm in late life were found post-intervention.

In summary, this thesis presented novel insights into why the very old self-harm and the importance of relationships with family/friends and clinicians, which influence the decision to self-harm and outcomes. A brief educational intervention based upon this qualitative work had immediate impact on the knowledge and confidence of multidisciplinary clinicians.

Chapter 1 Introduction

1.1 Rationale

1.1.1 Unanswered questions

Worldwide, at least in middle and high income countries, suicide rates progressively increase in five year age bands from 60-64 up to 90-94 for men and to 85-89 for women (Shah *et al.*, 2016). In Australia and overseas, older men (aged 85+) have the highest prevalence of suicide across age groups (Australian Bureau of Statistics, 2017) and higher suicide rates compared with older women (Almeida *et al.*, 2016; Shah *et al.*, 2016). Postulated reasons for the gender disparity, despite shared risk factors (Canetto, 2017), are that men may be less psychologically equipped or have personality traits such as rigidity rendering it more difficult to cope with pain, physical illness, impairment and widowhood (Canetto, 2017; Li and Conwell, 2010).

Understanding of suicide and its prevention relies on an understanding of the related entity, self-harm. Self-harm has been defined as "any act of self-poisoning or self-injury carried out by a person, irrespective of their motivation" (The National Institute of Clinical Excellence, 2013, pp13), and may be direct or indirect, causing deferred damage or consequences over time (Mohl *et al.*, 2014). The definitions of self-harm are discussed further in Chapter 2.1. There are common risk factors shared by older people who die from suicide and those who have self-harmed (Shah *et al.*, 2016). Additionally, the ratio of self-harm attempts to completed suicide is very low in older people in comparison to younger cohorts (De Leo *et al.*, 2001). This is reflective of greater planning and intent to die, the high lethality of self-harm in older people, as well as factors such as relatively greater social isolation reducing the possibility of rescue after the attempt, and a higher burden of physical illness in older adults increasing the risk of self-harm resulting in death (Conwell *et al.*, 1998). As most self-harm research has been based upon people aged 60-80, there is a gap in understanding self-harm in the very old, an important proxy for understanding suicide in the latter population. In order to address the dearth of research in this population, this thesis focuses upon self-harm in the very old, defined as people aged 80 years or more. In this thesis, the terms older adults or late life refer to people aged 65 years or more.

Why do older people harm themselves? Research on suicide in late life has largely focused on epidemiological approaches identifying risk factors and variables associated with self-harm or suicide (Bonnewyn *et al.*, 2009; Conejero *et al.*, 2018; Conwell and Thompson, 2008; Fassberg *et al.*, 2016; Mezuk *et al.*, 2014; Sinyor *et al.*, 2016), rather than directly seeking the perspective of the older person themselves of why they have self-harmed and how they could be helped using qualitative methods (Van Orden and Conwell, 2016; Wand *et al.*, 2018). Furthermore, much of our understanding has been derived from psychological autopsy constructed from reports of others, often up to 12 months after the event (Conwell *et al.*, 1996; De Leo *et al.*, 2013; Snowdon and Baume, 2002). This approach has led to interventions largely focused on depression screening and treatment. However, while mood disorders represent an important target for suicide prevention in old age, diagnoses do not always remain significant in prediction models of late life suicide, resulting in a call for empirical exploration of other psychosocial, environmental, and general health risk factors (De Leo *et al.*, 2013; Fassberg *et al.*, 2016).

The psychosocial context and outcomes for older people who self-harm are not well known, particularly in relation to the original contributory factors to self-harm, experiences of care (clinically and in their social network), family relationships, and health outcomes. The importance of the relational context of older people who self-harm has been acknowledged in the "Interpersonal Theory of Suicide" (Joiner, 2005). This work has generated important unanswered questions about the interpersonal context of cognitions such as thwarted belongingness and perception of being a burden, and how they relate to known correlates of self-harm and suicide such as depression, social isolation, pain and functional impairment (Van Orden *et al.*, 2016). While our understanding of self-harm in later life is increasing, there are still missing pieces of the puzzle that remain elusive.

Further, the experiences of clinical care are especially important as most older people who die by suicide have had contact with a clinician prior to their death (De Leo *et al.*, 2013; Troya *et al.*, 2019), representing a key opportunity to intervene. Additionally, older people with cognitive impairment, from diverse cultural backgrounds, and the very old (>80 years) have been under-represented in research studies of self-harm (Sinyor *et al.*, 2016; Wand *et al.*, 2018).

While it is important to know which factors are associated with risk of suicide or self-harm, many of the identified factors (such as chronic pain, physical disability, depression) are common in older people in general, most of whom do not self-harm, so it is difficult to know who should be targeted for suicide prevention. The focus on quantifying risk factors

for suicide in late life has contributed to a literature which has been described as atheoretical (Van Orden and Conwell, 2016). Yet the meaning of various risk factors and how they interact with each other and the person's current context and past experiences remain unclear. A qualitative approach to research may extend knowledge of the thought processes, meaning and experiences of older people who self-harm (Wand *et al.*, 2018).

Accordingly, in-depth interviews with individuals following self-harm with suicidal intent (a suicide attempt) could be used therapeutically to help identify problems that may hinder recovery or precipitate another attempt (Crocker *et al.*, 2006) as well as enrich understanding of the psychological experiences of older people who have self-harmed (Van Orden *et al.*, 2015). Although there have been longitudinal quantitative studies of the outcomes of older people with major depression (Hinrichsen and Hernandez, 1993; Zweig and Hinrichsen, 1993), and a longitudinal study of older people who have attempted suicide who were asked their reasons for self-harm (Van Orden *et al.*, 2015), there are no comprehensive qualitative follow-up studies of older people who have self-harmed, to explore their experiences of (including gaps in) care and outcomes. Such information may reveal the interpersonal factors, and issues of communication and coordination of care, which are crucial to delivering quality clinical practice to this vulnerable group.

Important amongst the response of others both preceding and following self-harm in the older person, is the response of the family. However, this important psychosocial factor is not well understood. There has been a paucity of empirical investigation of family carers and self-harm in older people beyond an early prospective study of interpersonal factors prospectively associated with suicide attempts by older adults hospitalised with major depressive disorder (Zweig and Hinrichsen, 1993).This study is now over a quarter of a century old, featured the young-old, was more quantitative than qualitative, and was mainly a depression study, revealing a major gap in the literature.

This thesis redresses these gaps in knowledge by using data derived from this inclusive prospective, longitudinal qualitative study of the very old who have self-harmed and their relatives/friends, and General Practitioners (GPs).

1.1.2 Prologue – the story of my research interest

During a month in 2016 there were eight presentations to an acute general hospital in which I work of people aged over 80 who had self-harmed with suicidal intent. I was both saddened and surprised at this cluster of presentations and wondered what might be driving

their desperate actions. At that time I was not aware that from a population perspective very old men had the highest rate of suicide of any age group (Shah *et al.*, 2016), indicative that this constellation of presentations was representative. I also observed the responses of clinical staff to some of these older people and reflected upon whether all the issues relevant to the older person were being heard and addressed, or if there were degrees of therapeutic nihilism, ageism, and dismissal of the self-harm act as 'not serious.' These questions developed into my PhD research. My initial engagement with the literature was writing up two case reports from this cluster of older adult presentations with self-harm; both of whom had expressed a wish for euthanasia which was illegal in Australia at the time. Through this initial study I became more aware of the complexity of the contextual and interpersonal factors which may underlie self-harm in the very old. I also wondered about the relationship between requests for euthanasia and some suicide attempts. This was extremely timely given the current zeitgeist about voluntary assisted dying in Australia and internationally, necessitating an opportunistic use of the findings from this study to inform this hitherto neglected area.

PAPER 1:

RATIONAL SUICIDE, EUTHANASIA AND THE VERY OLD – TWO CASE REPORTS.

Reference

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Case Report

Rational Suicide, Euthanasia, and the Very Old: Two Case Reports

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Suicide amongst the very old is an important public health issue. Little is known about why older people may express a wish to die or request euthanasia and how such thoughts may intersect with suicide attempts. Palliative care models promote best care as holistic and relieving suffering without hastening death in severely ill patients; but what of those old people who are tired of living and may have chronic symptoms, disability, and reduced quality of life? Two cases of older people who attempted suicide but expressed a preference for euthanasia were it legal are presented in order to illustrate the complexity underlying such requests. The absence of a mood or anxiety disorder underpinning their wishes to die further emphasises the importance of understanding the individual's narrative and the role of a formulation in guiding broad biopsychosocial approaches to management.

1. Introduction

The population is ageing globally, particularly the proportion of those who are very old, and it is this group who appear most vulnerable to dying by suicide in most countries [1]. Epidemiological studies of community dwelling older adults have estimated that the wish to die has a point or recent (within the past two weeks) prevalence of 2–6% [2–4]. Suicidal ideation occurs in a smaller proportion. Various factors are associated with the wish to die, including depressive symptoms (major depression only occurs in a minority), social isolation, anxiety, pain, disability, and institutionalisation.

It has been hypothesised that death wishes and suicidal ideation might be "understandable" in some contexts and that such thoughts could emerge as positive solutions to regain control or provide release after an accumulation of life events or problems of ageing [2, 5]. Suicides in older people without psychiatric disorder that occur in these circumstances have been classified in some studies as "rational suicide" [6]. Rational suicide has been defined as occurring when a person is able to reason, possess sufficient information, have a realistic worldview, and act (to end their own life) according to their own essential interests [7]. Rationality is probably dimensional rather than dichotomous [8]. For example, having depression does not imply that a person's choice is irrational and, conversely, rationality cannot be assumed when depression or mental illness is absent. However, mental illness may influence decision making and, even in those who have previously attempted suicide whose acute depressive illness has resolved, there may be persistent impairment in decision-making capacity [9]. Compared to requests for euthanasia in people with a terminal illness, there

is additional complexity in evaluating the same request in someone with a mental illness. It has been argued that the request for euthanasia in this context may be a symptom of the illness itself, the prognosis of some mental illnesses may be less certain, the impact of the illness on decision making may be more variable, and there are no objective indicators for predicting response to treatment [9–11]. Additionally, the determination of rationality is subjective and influenced by one's personal view of ageing, older people, and the psychological effects of disability and chronic disease [8].

The wish to die has been explored qualitatively in the Netherlands where euthanasia is legalised [5] but not directly in Australia where euthanasia is not legal. Although suspected, it is unknown whether people expressing a wish to die differ from those who attempt suicide [5] or if there is a continuum from the wish to die to suicide attempts and completed suicide [3]. Moreover, these issues have not been explored qualitatively in the very old. We present two case reports of older people who attempted suicide and had requested euthanasia, in order to highlight the individual at the centre of the request, the complexity of the contextual factors contributing to wishes to die, and how these factors may guide personalised interventions to reduce distress. Both patients provided consent for publication.

2. Case Presentations

2.1. Case 1. Mrs. C, aged 88, was the sole carer of her frail older husband. She was a retired typist and then home maker. Her two daughters lived overseas. Mrs. C was admitted under geriatric medicine after a planned insulin overdose with intent to die. An aged care psychiatrist was asked to assess her on the medical ward. She revealed she had left a farewell note to her family, did not expect to be found, and wished she had died. Mrs. C had acute chronic back pain for which she had received various treatments without relief. Other medical comorbidities included diabetes, ischaemic heart disease, hypertension, osteoarthritis, and supraventricular tachycardia. Her husband relied upon her to maintain their household and to assist him with personal care, although her pain precluded this. She had become increasingly worried about her husband's mounting ill health and disability reaching a point where she would be unable to help him. She was worried about becoming a burden and dependent on others and the prospect of residential care, about which they were both strongly opposed. In recent weeks the couple's lives revolved around medical ailments and appointments. She had become more disheartened with each of her husband's recent unsuccessful surgical procedures. Pain and physical disability had reduced their mobility, limiting their ability to socialise.

Mrs. C only spoke of herself with reference to her husband and the help or hindrance she could provide him rather than seeing herself as an individual deserving of care and quality of life. Unable to fulfil her role as his carer, she had little reason to live. The couple had long discussed euthanasia as an option if ever they developed intractable symptoms and lost their independence. Mrs. C was frustrated euthanasia was not available to her. She had subsyndromal depressive symptoms, including a sense of hopelessness and helplessness. She was not anhedonic and denied reduced talkativeness or social withdrawal, self-pity, or pervasive pessimism, symptoms which are more specific for depression as opposed to somatic features in the context of medical illness [12]. She had been sleeping more to escape the pain. There was no past psychiatric history in her or her family. Her husband had not observed any change in her mood or other signs of depression or anxiety. No neuroimaging was performed.

On examination, Mrs. C was well groomed and maintained good eye contact. Rapport was tenuous and she appeared uncomfortable during the assessment. Mrs. C had difficulty describing her emotions but denied feeling depressed. Her affect appeared bland and detached, although reactive and with a full range. Her thought form was normal. She described feeling helpless and hopeless and still wished to die but did not have any specific plans to end her life. There were no anxious cognitions or psychotic symptoms. Mrs. C's cognition was normal on Mini Mental State Examination, as she scored 29/30 [13]. Aside from assistance with pain relief she did not identify any other problems or need for treatment.

The consulting psychiatrist noted the depressive cognitions but a lack of other symptoms necessary to reach a diagnosis of major depression. Minor depression was a differential diagnosis. The suicide attempt occurred in the context of acute chronic pain (associated with a sense of helplessness and hopelessness), disability, reduced mobility, and concern about her husband's deteriorating health. Her cognisance of their gradual loss of independence and her inability to continue her caregiver role contributed to the wish to die. She had few coping strategies or external supports to call upon to assist her.

The geriatrics team replaced Mrs. C's panadeine forte (paracetamol and codeine) with pregabalin, paracetamol, and oxycodone/naloxone, which led to minor improvement in her pain. She participated in sessions with the ward physiotherapists and was independent in activities of daily living, including mobility. She was offered but declined additional services to assist with domestic duties and care for her husband. Mrs. C was transferred to a private hospital for further optimisation of analgesia and declined psychiatric follow-up. The team discussed a step-wise plan for management of acute pain at home with Mrs. C. She was discharged home with her husband, with some increased domestic support at home and geriatric follow-up.

2.2. Case 2. Mr. B, aged 89, was a retired businessman and widower of 30 years who lived alone. He had two children who lived interstate. He was referred by his case manager for an urgent assessment due to disclosure of recent suicide attempts and an ongoing wish to die. He had been discharged from the Older Persons' Mental Health unit a few weeks prior, where he had been admitted for suicidal ideation disclosed to a mental health hotline. During the two-week admission his psychiatrist concluded that he did not have a major depressive illness, but he was found to misuse alcohol and

had an eighteen-month history of cognitive and functional decline. Cognitive impairment was noted on the Montreal Cognitive Assessment Test [14], with a score of 23/30. Points were lost for short-term memory, executive function, language, and orientation. Detailed neuropsychological assessment revealed significant impairment in executive function (especially inhibitory control, impulsivity, poor organisational skills, and impaired cognitive flexibility) and memory (new learning). He was advised not to drive and the Roads and Maritime Services (RMS, the State Drivers' Licencing Authority) was notified about his cognitive impairment and the need to review his licence. There were no acute medical issues identified, but his history was significant for previous myocardial infarction, coronary angioplasty, coronary artery bypass graft, mitral valve replacement, hypertension, diabetes, glaucoma, ulcerative oesophagitis, and an unrepaired inguinal hernia. Neuroimaging revealed moderate dilatation of the ventricles and subarachnoid cisterns and periventricular white matter hypoattenuation reported to be consistent with chronic small vessel ischaemia. Mr. B had declined follow-up with the drug health team and was precontemplative regarding viewing his alcohol use as problematic or contributory to his suicidality. Mr. B had rejected the option of living in a residential aged care facility primarily as he prioritised his independence and was fearful of becoming fully dependent as his mother did from the ages 92–100. He described her as existing like a "pot plant," possibly with underlying dementia. He also wanted to avoid causing grief and burden to his family who would feel obligated to visit him, as he had felt visiting his mother. A secondary concern was the cost of residential care, which he saw as exorbitant. He did not want to diminish the value of his estate, which he wanted to pass on to his children. His suicidal ideation self-resolved without any pharmacological treatment and he had been discharged with psychogeriatric follow-up and a weekly cleaning service.

Mr. B was assessed by an aged care psychiatrist at his home with his mental health case manager. He reported initially settling in well at home following discharge and had driven short distances to run errands. He received a letter from the RMS informing him that his drivers' licence had been cancelled. This, along with initial insomnia, led to resumption of drinking alcohol, three to four standard units per night. Without the ability to drive, he described lacking any usefulness or purpose in life as he could no longer babysit a friend's children or access the shops independently. There was no change in appetite or energy levels. He had come to feel old with the gradual development of difficulty walking, balance problems, and reduced exercise tolerance. He reflected that he would not achieve anything more in life. He was worried about becoming a burden on his children. Mr. B continued to enjoy social outings with his sister and visits from his neighbours, but he had found it hard to organise his day and often wandered his apartment wondering what to do.

He lamented that euthanasia was not legal and had therefore concluded the only solution was to end his life. A week earlier he had tried to end his life by covering his head with a plastic bag but aborted the attempt as the sensation of suffocation was too distressing, reminiscent of a near-drowning experience in childhood, and "the body fought it." A few days prior to the urgent assessment he had written an explanatory farewell note to his children, purchased extra-large garbage bags to include his head and torso, and repeated the suicide attempt. A similar involuntary response led to abandoning the attempt and he subsequently tore up the note. Mr. B had spent much time contemplating other ways of ending his life, including stabbing an artery, but was unsure how to go about it and did not want to try and fail.

Mr. B was engaging and developed a warm rapport but was easily distracted by items in his home. He walked holding onto furniture. He was spontaneous in conversation. He described his mood as bored and lost "like I'm floating around" although his affect was euthymic, reactive, and sometimes jovial. He was thought disordered; in particular he was overinclusive and circumstantial. He described himself as useless and lacking purpose given his age and loss of independence and felt hopeless. He had ruminating thoughts about how he could end his life. There were no delusions or perceptual disturbances. Although not formally reassessed cognitively, he was perseverative, misplaced items during the interview demonstrating poor short-term memory, and was dyspraxic. He maintained that he should be allowed to choose to die and was sceptical his situation might improve or there could be scope to find quality or meaning in his life.

It was again concluded that he did not have a depressive illness but rather cognitive impairment which, combined with his loss of independence, his role, and identity, had led to a loss of purpose and boredom. The alcohol was considered an important contributing factor which exacerbated his executive dysfunction, leading to even more impulsivity and disinhibition. Understimulation and the lack of skills to structure his day were likely factors leading to recurrent suicide attempts.

Mr. B returned to the mental health unit for further evaluation and exploration of management options which might reduce his wish to die. In hospital he revealed a further recent suicide attempt at home, by carbon monoxide poisoning. He had bought a hose and tested it out. He was treated with parenteral thiamine and placed on an Alcohol Withdrawal Scale and protocol. A capacity assessment was recommended to determine his ability to make decisions about his type of accommodation and the use of external services. His sister and children were contacted regarding his presentation.

On the ward Mr. B interacted with other patients, enjoyed watching the football, and ate well, and his sleep improved. No pharmacotherapy was initiated. Following a series of discussions with Mr. B and his family he decided that he would move into a residential aged care facility in another state to be close to his son. He identified having people to socialise with and a daily routine as positive aspects of this choice and that this would reduce some of his children's worries about him. Mr. B was optimistic about having an active role in his young grandchildren's lives. He was reassured about the financial implications of this decision and was able to participate in making decisions about the choice of facility and how he would fund this. He was pleased that he

would be assisted to organise the move as he found the task daunting.

3. Discussion

These cases illustrate that requests for euthanasia may occur in older people in the absence of a significant mood disorder. They highlight the unique interplay of biopsychosocial factors, such as cognitive impairment (including emerging dementia), low mood, substance misuse, pain, disability, and social impoverishment, which may underlie requests for euthanasia in very old people. Some of these individuals may be chronically bored, restricted in activity, and have little or no avenues to experience any pleasure in life, such that they are "waiting to die."

Physicians in the Netherlands estimated that approximately 17% of requests for euthanasia came from patients who were tired of living [15], a request which does not meet the country's legal requirement for euthanasia of a "medical cause." Although both patients had attempted suicide neither was thought to have major depression. Both were tired of life, struggled with the prospect of becoming dependent upon others, were scared of the prospect of institutional care, and could see no solution other than to end their lives. The cases also highlight the significance of perceived loss of role and purpose in late life. For Mrs. C the mounting disability and pain of her chronic medical conditions, loss of role as a carer, and illness in her frail older husband were important contributing factors, whereas in Mr. B's case his own negative views of ageing, perceived lack of usefulness as an older person, loss of his driving licence and independence, and his executive dysfunction limiting his ability to plan and structure his day and life had led him to conclude death was the only option. Others have similarly identified that some suicides in older people stem from the individual's perception that there is no other way out of an untenable situation [6].

Lindesay [16] suggested that elderly suicides are often explained as rational choices, especially if the person has physical illnesses, which may reflect ageism and therapeutic nihilism. Ageism, that is, stereotypes and assumptions about older people made purely on the basis of their age, may affect the ability of clinicians to detect the psychopathology that frequently underlies suicide in late life [8]. This may occur if depression is deemed understandable in the context of an older person's health and living circumstances if the potential reversibility of their depressive illness is underestimated or if suicidal thoughts are validated although previously unrecognised alternatives exist [8]. Indeed Mr. B himself had negative views of ageing as a state of being useless to society and unproductive compared to his working years. Arguably, in Mrs. C's case, therapeutic nihilism or ageism could have been present as clinicians initially took a less aggressive approach to pain management. The impact of such attitudes in staff highlights an opportunity to intervene with clinicians to improve the care of older patients before they reach the conclusion that nothing can be done to help their distress. In relation to requests for euthanasia from people with mental illness, it has been suggested that considering such requests may add to clinician pessimism and stigma about mental illness by reinforcing poor expectations of treatment effectiveness and ultimately resulting in clinicians giving up on treating some patients and reducing the impetus for improving psychiatric services [9, 11].

Medical paternalism is another potential form of ageism, where coercive life-prolonging measures may be implemented without consideration of the person's autonomy. With Mr. B, had he not had capacity to make a decision about his living arrangements, it is possible that guardianship and an accommodation order may have been sought by the team.

There are numerous studies elucidating population-level risk factors for suicidal ideation or completion in older people (see, e.g., [4, 17]). However, there is little formal literature to guide clinicians in how to help older people without major psychiatric illness who wish to die [18]. Although this lack of guidance is problematic for all jurisdictions, it is perhaps particularly relevant in settings where euthanasia is legal. For example, although depression was the most common diagnosis in a recent review of Dutch cases of euthanasia for people with psychiatric disorders, significant comorbidity was found with personality disorders, medical illness and functional impairment, loneliness, and social isolation [10]. Refusals of treatment were also common, confounding evaluation of the futility requirement [10]. The cases illustrate that interventions specific to the individual's needs may relieve suffering. In Rurup et al.'s [5] explanatory framework for how a wish to die may develop, the balance between wishes to die and to live derives from a complex interplay of life events, ageing, and illness combined with coping strategies, personality, social support, and issues of control. Clinicians need to have an open mind when evaluating psychological symptoms and comorbidity and treatability in the context of death wishes, emphasising that the wish to die may reflect a valid assessment of quality of life and means of regaining control [5].

The wish to die may be a passive thought quite distinct from the desire for euthanasia. A detailed narrative formulating the derivation and meaning of the wish to die may provide the person, their family, and treating team with targets for intervention. Accordingly, requests for euthanasia in the terminally ill have been considered "cries for help" from patients who are suffering or family members who have difficulty coping with the illness, which often resolve when a skilled clinician explores and addresses the real issues at hand [19] or in the depressed elderly when depression is treated [20]. Whilst in these two cases the recommendations to address their risk factors were not fully accepted by the individuals for various reasons, there is evidence that when treated for distressing symptoms or psychosocial problems some older people withdraw their request for euthanasia [18]. However, if a wish to die is prevalent and persistent in some [20], it may be an acceptable residual symptom if all treatable factors have been addressed.

Clinicians have several options for addressing the wish to die in their older patients. Crafting an advance care directive may give relief for some to know that their life will not be necessarily prolonged and provide an opportunity to exert some control over their lives. For others, exploration

of spiritual issues and facilitating pastoral care may be of value [21]. In practice, it may be the empathic, ongoing care and support provided by primary care clinicians that people want [21]. Children may find the development of dependency and proximity of mortality in their parent confronting. Long-held conflicts and disputes may reemerge as families grapple with these issues. Acknowledging and supporting both patients and their families during this time are necessary. As stress and social disconnection have also been associated with suicidal thoughts, social interventions to address these issues have been suggested too [4]. For example, a telephone welfare monitoring, emotional support, and emergency alarm service for older people resulted in fewer suicide deaths than expected [22]. For Mr. B, moving to an aged care facility provided structure as well as ready access to social interactions unavailable to him at home.

There must be a balance between therapeutic nihilism and acceptance of a phenomenon associated with increased longevity. Exploring the unique narrative for the older person presenting with a wish to die or following a suicide attempt provides foci for tailoring recovery based interventions, which go beyond merely assessing for a mood disorder, which is often not present. The request for euthanasia should never be considered "understandable" merely because a person is aged. By addressing the range of issues contributing to the individual's wish to die, distress and suffering may be reduced and requests for euthanasia withdrawn.

Disclosure

No commercial organizations had any role in the completion or publication of this paper.

Competing Interests

The authors declare that there are no competing interests regarding the publication of this paper.

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1.2 Aims of the thesis

The aims of this thesis are to understand in more depth the reasons why the very old self-harm in order to formulate interventions to prevent occurrence and improve post-self-harm care, specifically through an empirically-informed educational intervention for clinicians. This thesis qualitatively examined the perspectives of a culturally and cognitively diverse cohort of persons aged 80 years and over and their nominated carer (relative/friend) in relation to the reasons for self-harm and intent, and the consequences, including their experiences of care (clinically and in their social network). The perspective of the older person's GP was also sought in order to explore their understanding of the person's contributing factors to self-harm and how they might be helped. The outcomes for these older people one year after their self-harm were also examined, including their reflections on the self-harm, its consequences and the clinical care provided, and their objective outcomes (place of residence, repeat self-harm, contact with mental health services, psychiatric and cognitive diagnoses). The perspective of the older person's nominated carer and GP were also sought in order to triangulate data.

The findings have potential application to the clinical care of very old people who self-harm and their family carers. The findings may additionally inform interventions for the prevention of self-harm and suicide in late life. In the light of the legislative changes enabling Voluntary Assisted Dying (VAD) in some jurisdictions in Australia, the results may also inform understanding of the connections between family burden, undue influence and suicide or requests for assisted suicide.

1.2.1 Study 1

The aims of the first (baseline) study were to explore qualitatively the reasons why very old people self-harm, the consequences of the self-harm and perceptions of care from the viewpoints of the older person themselves, their carer (relative/friend) and GP. A qualitative approach facilitated understanding of the meaning of the self-harm for the patient and illuminated the importance of their interpersonal contexts. A further aim was to explore the relevance of these qualitative findings to requests for VAD. To the best of our knowledge the components of the study examining the perspectives of carers and GPs of very old people who have self-harmed and survived are the first of their kind, revealing important insights into the reasons for self-harm, and illuminating targets for prevention and management after self-harm including addressing the profound emotional impact on carers.

This approach was novel and revealed targets for medical education and improvement in communication and coordination of community care.

1.2.2 Study 2

The aim of the second (follow-up) study was to re-interview the original cohort of older people and carer dyads and to survey the patient's GP, one year after the self-harm in order to evaluate reflections on the self-harm, its consequences and the clinical care provided, and to assess their objective outcomes (place of residence, repeat self-harm, contact with mental health services, psychiatric and cognitive diagnoses).

1.2.3 Study 3

The aim of the final study was to use data from the preceding qualitative studies in combination with the quantitative literature to inform the development of an educational package for GPs and hospital staff on self-harm in the very old, and to evaluate the effectiveness and impact of such an educational intervention, in terms of clinician knowledge change, confidence and attitudes.

1.3 Thesis format and structure

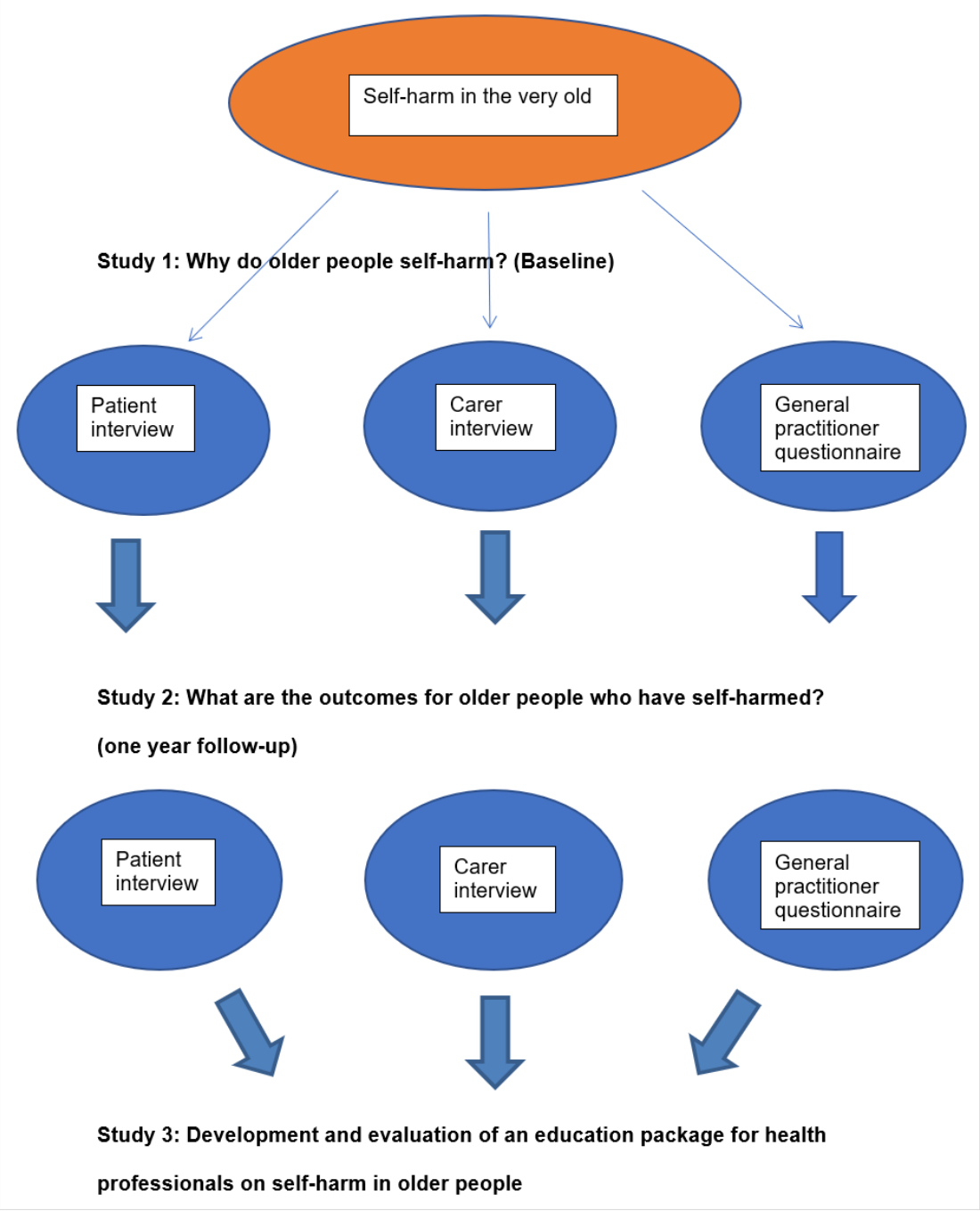

Figure 1.1 Overview of the thesis

An overview of the thesis is presented in Figure 1.1. This thesis is submitted as a series of publications including a literature review (chapter 2), and the findings of studies 1-3 (chapters 4-6), an introduction (chapter 1), methodology (chapter 3), and discussion chapter (7). Each publication includes an introduction, methods, results, discussion and reference section, and is formatted according to the requirements of the individual journal in which it is published. All the manuscripts included in the thesis have been externally peer-

reviewed prior to acceptance for publication. The thesis has been structured into Chapters (see Table 1.1).

This thesis meets the requirements of the Faculty of Medicine and the University of New South Wales, of a minimum of three publications (published or in press).

Table 1.1 Thesis structure - chapters, authorship and publication status

Chapter number	Chapter title	Publication details	Status
1	Introduction	**Wand APF**, Peisah C, Draper B, Jones C, Brodaty H. Rational suicide, euthanasia and the very old- two case reports. *Case Reports in Psychiatry*. vol. 2016, Article ID 4242064, 5 pages 2016. doi:10.1155/2016/4242064.	Published 2016 (Paper 1)
2	Literature review	**Wand APF**, Peisah C, Draper B, Brodaty H. Understanding self-harm in older people: A systematic review of qualitative studies. *Ageing and Mental Health*, 2018. 22(3):289-298.	Published 2018 (Paper 2)
		Combined with a review of the quantitative literature, not externally published	Included in thesis
3	Research methods and materials	Part of thesis, not externally published	Included in thesis
4	**Study 1** Why do older people self-harm? The older persons' perspective (Study 1A)	**Wand APF**, Peisah C, Draper B, Brodaty H. Why do the very old self-harm? A qualitative study. *American Journal of Geriatric Psychiatry*, 2018, 26(8): 862-873. **Wand APF**, Peisah C, Draper B, Brodaty H. Corrigendum to 'Why Do the Very Old Self-Harm? A Qualitative Study' [*American Journal of Geriatric Psychiatry* 26 (2018) 862–871], 2019, 27(2):211.	Published 2018 (Paper 3)
	Why do older people self-harm? The carers' perspective (Study 1B)	**Wand APF**, Peisah C, Draper B, Brodaty H. Carer insights into self-harm in the very old: A qualitative study. *International Journal of Geriatric Psychiatry*, 2019, 34:594–600.	Published 2019 (Paper 4)
	Why do older people self-harm? The General Practitioners' perspective (Study 1C)	**Wand APF**, Peisah C, Draper B, Brodaty H. How do general practitioners conceptualise self-harm in their older patients? A qualitative study. The *Australian Journal of General Practice*, 2018, 47(3): 146-51.	Published 2018 (Paper 5)

Chapter number	Chapter title	Publication details	Status
	Investigating the intersection between self-harm, suicide and voluntary assisted dying. (Study 1D)	**Wand APF**, Peisah C, Draper B, Brodaty H. The nexus between elder abuse, suicide, and assisted dying: The importance of relational autonomy and undue influence. *Macquarie Law Journal*, 2018, 18, 79-92.	Published 2018 (Paper 6)
5	**Study 2** One year follow-up of older people who self-harmed, their carers and GPs	**Wand APF**, Draper B, Brodaty H, Peisah C. Self-harm in the very old one year later. Has anything changed?" *International Psychogeriatrics*, 2019, 31, 1559-1568.	Published 2019 (Paper 7)
6	**Study 3** Development of an educational intervention for clinicians regarding self-harm in older people (Study 3A)	**Wand APF**, Draper B, Brodaty H, Peisah C. Self-harm in late life: How can the GP help? *Medicine Today*, 2019, 20(7): 33-36.	Published 2019 (Paper 8)
	Evaluation of an educational intervention for clinicians regarding self-harm in older people (Study 3B)	**Wand APF**, Draper B, Brodaty H, Hunt G, Peisah C. Evaluation of an educational intervention for clinicians on self-harm in older adults. *Archives of Suicide Research*, 2020, 1-21.	Published 2020 (Paper 9)
7	Synthesis and significance	Part of the thesis, not externally published	Included in thesis

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Chapter 2 Literature review

2.1 Definitions of self-harm in older people

The nomenclature around suicide and self-harm is complicated. Suicide refers to the voluntary act of intentionally ending one's life (Almeida *et al*., 2016). The term suicide attempt describes self-harm with the clear intent to die, but not resulting in death. Similarly, suicidal behaviours, refers to self-harm (of any type) associated with suicidal intent. Various definitions exist for self-harm, which is a broad term that has been variably defined. The lack of consistency in terminology complicates interpretation of the literature about why people self-harm (Edmondson *et al.*, 2016). Self-harm is an umbrella term which encompasses terms such as self-mutilation, self-injury, parasuicidal behaviour, non-suicidal self-injury, deliberate self-harm, and self-abuse, some of which refer to the intent of the behaviour (Klonsky *et al.*, 2011). However, there is no consensus or consistency in how these terms are used in the literature. Self-harm may be further categorised as direct or indirect, and with or without suicidal intent. Direct self-harm has been defined as a person deliberately harming themselves (regardless of intent) and includes overdose, cutting, hitting and burning (Chan *et al.*, 2007). Indirect self-harm is defined as an act that leads to damages which may or may not be an unintended by-product of the act. These damages are not realised immediately, but are deferred or long-term consequences, and the negative impact for the person unknown (Mohl *et al.*, 2014). Indirect self-harm includes behaviours such as refusal to eat, drink or take essential medications, and sometimes includes harmful behaviours such as substance misuse (Mohl *et al.*, 2014). Where used in this thesis, the term self-harm, does not imply any particular intent or motivation and encompasses both direct and indirect acts. This doctoral thesis focuses upon self-harm in the very old, defined as people aged 80 years or more. The term older adults in this thesis refers to people aged 65 years or more.

Individuals may vary in the intent of their self-harm. Importantly, not all self-harm is with suicidal intent. Although older adults who self-harm with suicidal intent and survive (i.e. attempt suicide) share many characteristics with older adults who die by suicide (Bonnewyn *et al.*, 2009), the two cohorts may also be quite distinct (DeJong *et al.*, 2010; Van Orden, 2018; Van Orden *et al.*, 2015). For example, personality traits may differ in older people who die by suicide compared to those who attempt suicide and survive (Bonnewyn *et al.*, 2009). In addition, rates of suicide increase with increasing age although rates of suicide attempts appear to reduce (Hawton and Harriss, 2008). In older adults who self-harm, determining

whether the self-harm was with suicidal intent may be less critical than in younger people, as there is a close link between those who attempt and those who die by suicide (Draper, 1996). This is supported by a literature in older adults describing greater intent to die as evidenced by more lethal choice of means, higher rates of completed suicide to self-harm ratios, the content of suicide notes and psychiatric assessment (De Leo *et al.*, 2001). An additional consideration is that the intent of self-harm may not be known, even by the person themselves (see for example, (Van Orden *et al.*, 2015)). In people with cognitive impairment it may be difficult to ascertain the intent of an overdose, including whether it was accidental (Mitchell *et al.*, 2015). Similarly, it may be hard to interpret the meaning of indirect self-harm such as refusing medical care or food (De Leo *et al.*, 2001). Thus care is needed in the terminology used in clinical research in this field. The complexity of these issues lends itself to the specific utility of qualitative approaches which directly seek the perspective of the older person in evaluating the meaning and intent of their self-harm (Van Orden, 2018).

The literature on self-harm and suicide is further complicated by a broad range of ideation and behaviours being clustered together. For example, thoughts of death (death ideation), wishing to die, and suicidal ideation are risk factors for suicide (Rowe *et al.*, 2006) and are often described as existing on a spectrum, although how they relate to each other is unclear (Pompili *et al.*, 2014). Further, wishing to die and death ideation are not uncommon thoughts in older people in general and may even be part of normal ageing, whereas for some they may signal the presence of psychopathology (Szanto *et al.*, 2013). How these different thoughts relate to suicidal behaviours is also unclear; thinking about suicide is not the same as attempting suicide or completing suicide (Almeida *et al.*, 2012). Suicidal ideation is much more prevalent in older people than suicide attempts or completed suicide (Lawrence *et al.*, 2000), and most people who contemplate suicide never act on those thoughts. However, suicidal thoughts almost always precede completed suicide (Waern *et al.*, 1999). There is some evidence for a hierarchy of suicidal thoughts and behaviours, i.e. ranging from wishing to die, to suicidal thoughts, suicidal plans, suicide attempts and completed suicide. The prevalence of each step in the hierarchy reduces and rates of psychopathology increase with more severe suicidal ideation and behaviours (Ojagbegmi *et al.*, 2013; Scocco and De Leo, 2002). However, whether a person dies after self-harm may also be determined by external factors (e.g. access to assistance, medical comorbidity), as well as by the degree of intent to die or other meaning underlying the behaviour (Barnow *et al.*, 1997).

2.2 Self-harm in older people- insights from the quantitative literature

Describing the epidemiology of self-harm in older people can be challenging with many studies combining a range of suicidal behaviours (e.g. the wish to die, thoughts of death, actual suicide attempts and suicide), not specifying the intent of self-harm or only evaluating self-harm which was clearly with suicidal intent, and small sample sizes. A recent systematic review of direct self-harm in older people reported annual rates of 19-65 per 100,000 people (Troya *et al.*, 2019). By comparison, the prevalence of indirect self-harm in various settings, especially in the general community or in hospitals, is largely unknown. An exception is a study in nursing homes which reported the point prevalence of indirect self-harm was 61%, compared to 14% for direct self-harm (Draper *et al.*, 2002).

A number of quantitative studies summarise the risk factors associated with suicidal behaviours in late life (Bonnewyn *et al.*, 2009; Conejero *et al.*, 2018; Conwell and Thompson, 2008; De Leo and Spathonis, 2003; Draper, 2014; Fassberg *et al.*, 2016; Mezuk *et al.*, 2014; Sinyor *et al.*, 2016), but fewer specifically evaluating older people who self-harm regardless of intent (Chan *et al.*, 2007; Troya *et al.*, 2019), and who indirectly self-harm (Draper *et al.*, 2002). Much of the literature on self-harm in older people has focused on attempted suicide rather than considering a broad range of behaviours (including indirect self-harm) and intents.

The sociodemographic correlates of self-harm in older people have been described (Chan *et al.*, 2007; Troya *et al.*, 2019). Of note, sex has not generally appeared to be a distinguishing factor, with male and female rates of self-harm converging in older people in comparison to suicide, where men are overrepresented. However, a recent systematic review found a slight female predominance (57%) in self-harm (Troya *et al.*, 2019). In terms of marital status, older people who are widowed or have never married have generally been found to have higher rates of attempted suicide (Chan *et al.*, 2007; Troya *et al.*, 2019), but this is not universal with studies in New Zealand (Beautrais, 2002) and Japan (Takahashi *et al.*, 1995) showing no significant difference in marital status between suicide attempters and non-attempters. Confounders such as cultural protective or facilitating factors are complex and beyond the scope of this thesis. Religion has been proposed as one possible explanation for the differences in rates of attempted suicide in different countries, but this is difficult to evaluate due to variations in the reporting of attempted suicide for cultural reasons (Chan *et al.*, 2007).

The psychiatric factors associated with self-harm in late life have been investigated. Older people who self-harm have a greater likelihood of having a past psychiatric history

and contact with mental health services (Draper, 1996; Murphy *et al.*, 2012). Although less frequent than in younger cohorts, a history of previous suicide attempt(s) has been noted as a risk for further self-harm and completed suicide in older people (Murphy *et al.*, 2012), but methodological limitations in such studies were noted such as biases introduced by the setting of the study (e.g. psychiatric inpatients) and source of information (e.g. incomplete medical records or relying upon informants rather than the older person themselves, who may not have disclosed previous attempts) (Chan *et al.*, 2007). In a systematic review of 30 studies of self-harm in older people, almost 30% of participants reported previous self-harm (Troya *et al.*, 2019). Mood disorders, especially major depression, have consistently been associated with late life suicide attempts (Chan *et al.*, 2007; Draper, 1996; Troya *et al.*, 2019). Psychotic illnesses such as bipolar disorder and schizophrenia are associated with late life suicide (Cohen *et al.*, 2010) and suicide attempts (Chan *et al.*, 2007), but the risk is lower than in younger people. There are mixed findings with respect to anxiety disorders and self-harm in late life (Draper, 2014). One empirical study evaluating self-harm (any intent) in a large primary care cohort of older people compared to a comparison group found that a history of mental illness was twice as prevalent in the self-harm group (Morgan *et al.*, 2018). Personality disorders, less prevalent in late life, are also associated with suicide attempts (Chan *et al.*, 2007). Alcohol abuse and dependence are associated with self-harm in older people (Neufeld *et al.*, 2015), with one review finding that 16% of participants had consumed alcohol at the time of self-harm (Troya *et al.*, 2019). Suicidal ideation and attempts have also been associated with opioid use in older people (Calati *et al.*, 2017; Ilgen, 2018).

Organic mood disorders and delirium have been associated with attempted suicide in older people, but findings are inconsistent regarding dementia as a risk factor (Chan *et al.*, 2007; Neufeld *et al.*, 2015). Most studies investigating cognition and self-harm are of people with major depression (Draper, 2016), and of the young old, with few examining people aged over 80. In a study of people aged 50 or more, hospitalised for self-harm by poisoning (intentional or unintentional), the hospitalisation rate for people with dementia was double that of people without dementia (Mitchell *et al.*, 2015). Impulsive suicide attempts in people with early dementia or mild cognitive impairment with frontal executive dysfunction have been reported (Draper, 2014). In older people with depression who have attempted suicide, cognitive factors such as executive dysfunction, including an impulsive approach to problem solving, a tendency to perceive life problems as unsolvable and threatening, or to ignore past experiences and neglect probable outcomes when decision making, have been reported (Dombrovski *et al.*, 2008; Draper, 2014; King *et al.*, 2000). It has been suggested that a lack

of cognitive inhibition and executive dysfunction result in a failure to control suicidal ideas and inhibit negative affects which trigger suicidal behaviours (Conejero *et al.*, 2018). Further, there may be a link between deficits in social problem solving, limited social networks and suicide attempts in older adults with depression, as demonstrated by a study in which impaired emotional recognition correlated with global cognitive dysfunction in older adults who had attempted suicide (Szanto *et al.*, 2012).

It has been proposed that self-harm in older people may be an early marker of cognitive decline and even of prodromal dementia (Draper, 2016). In one of the few studies to examine this connection longitudinally with an adequately powered sample size, a large cohort of older people (aged 65 years or more) who attempted suicide were compared to matched controls, and found to have significantly increased risk of dementia over the follow-up period (Tu *et al.*, 2016). The association remained significant even when demographic factors, depression and physical comorbidity were controlled for. None of the suicide attempters had a diagnosis of dementia at baseline, neither were they tested cognitively, so it is unknown whether there was any unrecognised dementia or cognitive impairment (in particular executive dysfunction), which may have accounted for the higher rates of developing dementia in the self-harm group (Draper, 2016; Tu *et al.*, 2016).

Physical illness and disability are more prevalent in older compared to younger adults (Paraschakis *et al.*, 2012), and have been evaluated as risk factors for late life self-harm and suicide (Fassberg *et al.*, 2016). Functional disability and specific diseases, such as malignancy, pain, neurological disorders, liver disease, male genital disorders, arthritis and chronic obstructive pulmonary diseases, have been associated with suicidal behaviours in older people (Fassberg *et al.*, 2016). In addition to pain and malignancy, tinnitus and diabetes have been associated with self-harm injury (of any intent) resulting in hospitalisation in older people (aged $\geq$ 50 years) after adjusting for mental illness, substance misuse and other comorbidities compared to those hospitalisation for non-self-harm injury (Mitchell *et al.*, 2017). Qualitative studies which were included in the systematic review by Fassberg and colleagues elucidated the meaning of physical illness highlighting the contributory role of frustration with pain, disability and illness, loss of autonomy or dignity, and unbearable suffering, to suicide attempts in older people (Fassberg *et al.*, 2016). Vascular disease, which is more likely in those with specific risk factors (such as smoking, diabetes, hypertension, hypercholesterolaemia and metabolic syndrome), may be a risk factor for late onset depression (Draper, 2014), which is in turn associated with self-harm and suicide. However, there is little support for a more direct association between cardiovascular diseases in general and suicidal behaviours (Fassberg *et al.*, 2016). It is noteworthy that the majority of studies

informing these associations were derived from populations of older people with direct self-harm and suicidal intent, which is not reflective of all self-harm (Troya *et al.*, 2019).

Various psychosocial factors associated with self-harm in older people have been evaluated. Risk factors such as social isolation, loneliness, loss of social connectedness, family discord, recent (for example, bereavement, financial problems) and distant life events (childhood adversity, parental neglect, physical and sexual abuse, other traumatic experiences), and living alone, are associated with suicidal behaviour in late life (Draper, 2014). Further, there may be a link between deficits in social problem solving, limited social networks and suicide attempts in older adults with depression, as demonstrated by impaired emotional recognition correlated with global cognitive dysfunction in older adults who had attempted suicide (Szanto *et al.*, 2012). Dissatisfaction with living arrangements and fear of nursing home placement have also been reported in older people who self-harm (Draper, 2014), but there is limited literature on anticipation of placement as a risk factor for self-harm (Mezuk *et al.*, 2014).

Indirect self-harm is often not included in quantitative studies of older people, but is of particular relevance to people living in nursing homes, where refusal to eat or drink or take medications, or to cooperate with staff, is not uncommon (Draper *et al.*, 2002). The intent of indirect self-harm may range from a distinct wish to die, to risking death, a wish to self-harm, or be unintentional/accidental (Draper *et al.*, 2002). In one Australian study, nursing home residents who were older, had dementia, greater functional impairment and higher degrees of behavioural disturbance were more likely to have indirect self-harm (Draper *et al.*, 2002). Unexpectedly, those nursing home residents with depressive symptoms had the least self-harm behaviours (Draper *et al.*, 2002). The authors concluded that indirect self-harm was more likely in people with dementia and overt psychiatric and behavioural disturbance, and that food refusal alone was uncommonly due to depression (Draper *et al.*, 2002). Other environmental factors in residential care settings such as staff turnover, facility size have been associated with suicide and self-harm (direct and indirect) (Osgood, 1992) and the type of facility ownership (religious, public, private, other) and lower per diem costs positively correlate with suicide (Osgood, 1992). Suicidal behaviours (direct and indirect) were also found to be more common in facilities with more design features for residents with frailty and dementia and those facilities with more intense security (Low *et al.*, 2004).

There have been studies examining the association between depression and a preference for Voluntary Assisted Dying (VAD) in older people. People with a terminal illness who request to hasten death have higher rates of psychiatric illness, particularly

depression (Chochinov *et al.*, 1995). A study examining preferences for euthanasia using hypothetical vignettes presented to older psychiatric inpatients with depression found that once depression was treated preferences for euthanasia markedly reduced (Hooper *et al.*, 1997). It is important to note that most older people who request or endorse euthanasia do not go on to pursue euthanasia and die by that method. However, it is unknown to what extent self-harm and suicide in late life may represent an alternative action in jurisdictions where euthanasia is unavailable.

The interpersonal theory of suicide (Joiner, 2005) is a model which has been applied to and investigated specifically in older adults (Van Orden *et al.*, 2016; Van Orden *et al.*, 2010). According to this framework suicide may be the result of two psychological states, thwarted belongingness and perceived burdensomeness, combined with an acquired (through habituation to physical pain and fear) capability for suicide (Van Orden *et al.*, 2010). The model explains risk factors associated with suicide in older people such as physical illness and functional impairment amplifying perceived burdensomeness and social isolation and depression increasing the risk of feeling disconnected and not belonging (Van Orden *et al.*, 2016; Van Orden *et al.*, 2010). Older adults who have attempted suicide have described old age as burdensome (Bonnewyn *et al*., 2014; Crocker *et al*., 2006; Kim, 2014) and feeling a burden on their families and society (Moore, 1997; Wand *et al*., 2016). These perceptions are reinforced by suggestions to ration healthcare resources on the basis of age (Callahan, 1987), public predictions of widespread economic disaster caused by longevity (Lagarde, 2012), and even suggestions that "elderly people have a duty to die and get out of the way" (Governor Richard Lamb in Colorado, quoted in Spring and Larson, 1988, p48). The related concept of thwarted belongingness, or social disconnectedness, a key evidence-based driver of suicide in older people (Conwell *et al*., 2011), may similarly be an indicator of ageism and societal response to older people. The current societal context is one which values beauty, youth, strength and health, characteristics not ascribed to older adults (Grant, 1996; Moore *et al*., 1997). However, qualitative studies have revealed that older people who have attempted suicide may themselves internalise ageist beliefs and negative stereotypes which contribute to feeling invisible, lonely and isolated (Crocker *et al*., 2006; Kim, 2014). Indeed, older adults who attempted suicide have described ageing as a state associated with dependency, loss of value and productivity (Crocker *et al*., 2006; Wand *et al*., 2016).

While quantitative studies provide important information on risk factors associated with self-harm in older adults, they are unable to explain their meaning to individuals and the relationships between various risk factors which culminate in self-harm (Bonnewyn et al., 2014; Stanley et al., 2016). Qualitative research methodology may help answer such questions.

2.3 Self-harm in older people- insights from the qualitative literature

PAPER 2:

UNDERSTANDING SELF-HARM IN OLDER PEOPLE:

A SYSTEMATIC REVIEW OF QUALITATIVE STUDIES.

Reference

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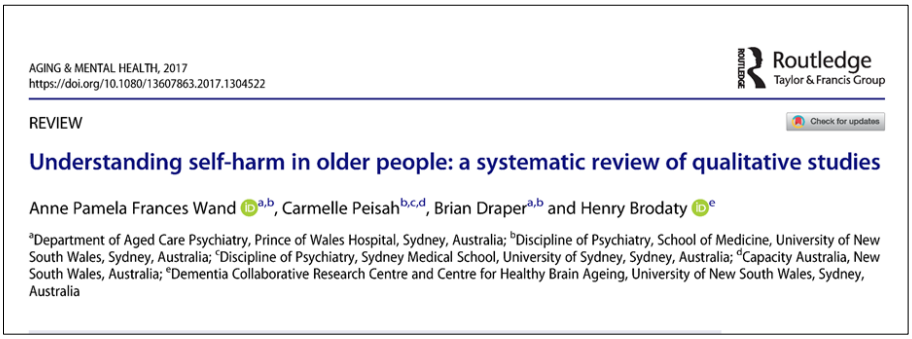

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REVIEW

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Understanding self-harm in older people: a systematic review of qualitative studies

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Declaration

I certify that this publication was a direct result of my research towards this PhD, and that reproduction in this thesis does not breach copyright regulations.

Anne Wand

Abstract

Objective: Rates of suicide in older adults are generally higher than other age groups. Although risk factors for suicide attempts, and self-harm more generally, in this population are well characterised, many of these vulnerabilities are common to older people and individual motivations are less well understood. Qualitative research may reveal more about the underlying thought processes, meaning and experiences of older people who self-harm.

Methods: A systematic review of qualitative studies examining the reasons why older people have self-harmed was undertaken by searching databases and screening the reference lists of articles. The quality of studies was critically appraised. A content analysis was performed to identify themes.

Results: The search yielded eight studies of variable quality which met the inclusion criteria; three pertained to indirect self-harm (refusal to eat or take medications and self-neglect) and five related to suicidal behaviour. Themes emerging from the analysis of studies of people who had self-neglected included control, impaired decision making and coping skills and threats to self-identity and continuity. In those who had suicidal behaviour, themes related to loss of and regaining control; alienation, disconnectedness and invisibility; meaningless and raison d'etre; and accumulated suffering and a 'painful life'.

Conclusions: There is scant literature evaluating self-harm in older people using qualitative methods. Nonetheless, this review suggests that active and passive self-harm should be considered as distinct entities as the underlying motivations and intents differ. Understanding individual perceptions and experiences which lead to self-harm may guide clinicians in delivering more sensitive, holistic interventions and counter ageism.

Keywords: qualitative; suicide attempt; self-injury; passive self-harm; indirect life-threatening behaviour

Introduction

Why do older people self-harm? Older people as a group have one of the highest rates of suicide (Shah, Bhat, Zarate-Escudero, DeLeo, & Erlangsen, 2016), perhaps due to choosing more lethal methods and reportedly greater suicidal intent (Hawton & Harriss, 2008; Sisask, Kolves, & Varnik, 2009). A history of attempted suicide or self-harm is an important predictor of completed suicide (World Health Organization, 2016). However, the intent associated with self-harming behaviours may be unclear to the clinician and even the individual patient. Thus it is important to understand the contributing factors underlying the spectrum of self-harm behaviours, from those with clear actions with intent to die, to more passive behaviours and accidental injury. The National Institute of Clinical Excellence defines self-harm as "any act of self-poisoning or self-injury carried out by a person, irrespective of their motivation" (National Institute for Health and Care Excellence, 2013, pp.13). Self-harm behaviours have been further categorised as direct (such as taking an overdose of medication or self-cutting) or indirect (such as refusing to take essential medications or to eat or drink) (Draper, Brodaty, & Low, 2002). In the elderly, indirect behaviour has been defined as "an act of omission or commission that causes self-harm leading indirectly, over time, to the person's death" (Conwell, Pearson, & DeRenzo, 1996).

There is a close relationship between self-harm and suicide in older people (Dennis & Owens, 2012). Specifically, hospital presentations of older people with non-fatal self-harm have been associated with markedly elevated risk of later suicide (Murphy et al., 2012); many predictors of suicide and self-harm in older people are shared (Dennis, Wakefield, Molloy, Andrews, & Friedman, 2007), the lethality of self-harm in older people is higher compared to younger people (De Leo et al., 2001) and older people who have self-harmed report high rates of suicidal intent (Dennis et al., 2007). Therefore exploring why older people self-harm may contribute to knowledge about late life suicide.

In defining self-harm, active or passive life-threatening behaviour, self-neglect and suicidal behaviour are not the same even though they are often lumped together. Nor does it serve our purpose, if we are seeking to understand and explore these behaviours in an idiographic manner, to see them as the same. Further, there may be a spectrum of suicidal behaviours from the wish to die, to thoughts of and plans for suicide, suicide attempts and completed suicide. This is evidenced by a reduction in prevalence of increasingly extreme behaviours (Ojagbemi, Oladeji, Abiona, & Gureje, 2013; Scocco & De Leo, 2002) and by the observation that higher scores of psychopathology are associated with more severe suicidal ideation and behaviours (Scocco & De Leo, 2002). Whether the outcome of self-

harm is death or not, may be determined by external factors, rather than the degree of intent to die or other meaning behind the behaviour (Barnow & Linden, 1997). There also appear to be common risk factors for different suicidal behaviours including completed suicide (Bonnewyn, Shah, & Demyttenaere, 2009).

However, the relationship between these behaviours is not straightforward. Rates of suicide attempts and suicidal ideation appear to decrease with increasing age whereas rates of completed suicide increase (Hawton & Harriss, 2008). Additionally, personality characteristics may differ in people who attempt suicide compared to those who complete suicide (Bonnewyn et al., 2009). Thus, it is possible that these occurrences are distinct entities rather than different manifestations along the same spectrum of suicidal behaviours (Bonnewyn et al., 2009). The relationship between these suicidal behaviours is clearly complex. Nonetheless, given the close relationship between self-harm and suicide in older people (Dennis & Owens, 2012), insights and opportunities for suicide prevention may be gleaned by in-depth interviews with those who survive self-harm.

The majority of literature relating to suicide in late life is quantitative and has focused upon determining the risk factors for completed suicide by methods such as psychological autopsy (De Leo, Draper, Snowdon, & Kolves, 2013), examination of secondary data such as hospital records (Lawrence, Almeida, Hulse, Jablensky, & Holman, 2000) or chart records (Sinyor, Tan, Schaffer, Gallagher, & Shulman, 2016) or large epidemiological studies (Turvey et al., 2002). Recent reviews have revealed that functional disability, pain and a number of specific physical illnesses (for example cancer) (Bonnewyn et al., 2009; Fassberg et al., 2016), are associated with suicidal behaviour in older adults. Completed suicide specifically has also been found to be associated with risk factors such as major depression and other psychiatric disorders, substance use disorders, recent bereavement, family conflict, financial problems, poor sleep quality, marital status (widowed or divorced), and previous suicide attempts (Bonnewyn et al., 2009; Sinyor et al., 2016). In relation to self-harm more broadly in older people, a large analysis of hospital record, administrative and residential care assessment data revealed that factors such as gender (male), younger age (60-74), indicators of probable depression, indicators of alcohol use and dependence, a psychiatric diagnosis, moderate to severe cognitive impairment, and psychotropic medication increased the odds of intentional self-harm (Neufeld, Hirdes, Perlman, & Rabinowitz, 2015). Protective factors, with a greater effect for men, included being married and having positive social relationships (Neufeld et al., 2015). A large population-based study of older people hospitalised for self-harm similarly found that

comorbid alcohol and psychiatric disorders were more common in people who had intentional self-harm compared to those with non-self-harm injury (Mitchell, Draper, Harvey, Brodaty, & Close, 2016).

Although the characteristics and outcomes of older people who self-harm have been described (Chan, Draper, & Banerjee, 2007; Mitchell et al., 2016), many of the identified risk factors for self-harm in the elderly, such as chronic pain, bereavement or disability, are common amongst older people in general, limiting their value to clinicians in identifying those who are vulnerable to suicide (Courage, Godbey, Ingram, Schramm, & Hale, 1993; Crocker, Clare, & Evans, 2006; Kjolseth, Ekeberg, & Steihaug, 2009). For example, it has been highlighted that although physical illness and disability are recognised risk factors for suicide in older people, there are few data about which individuals should be targeted for intervention and what at-risk older people with physical illness want in order to relieve their distress (Fassberg et al., 2016).

It is difficult to achieve an in-depth understanding of the perspective and experience of the older person themselves using quantitative methods alone. This has been partially addressed through studies where informants of those who have died by suicide have been interviewed (using mixed methods or qualitative techniques), which may develop our understanding of apparent motivations for suicide in late life (Kizza, Knizek, Kinyanda, & Hjelmeland, 2012; Kjolseth et al., 2009; Kjolseth, Ekeberg, & Steihaug, 2010).

Qualitative studies of self-harm move away from identifying and counting risk factors to emphasise the subjective experience of participants in an exploratory approach. The very nature of these studies allows for access to a person's narrative, thoughts, motivations and personal experience (Kjolseth et al., 2009). Such methods may reveal more about the process, meaning and experience of individuals leading to their self-harm behaviour (Bonnewyn, Shah, Bruffaerts, Schoevaerts, et al., 2014). Although the experience of suicidal ideation across the lifespan has been explored in a single systematic review of qualitative papers (Lakeman & FitzGerald, 2008), there are no reviews of qualitative studies of self-harm in the elderly. The aim of the present study was to systematically review the qualitative literature examining the reasons why older people self-harm.

Method

Search strategy

The Ovid MEDLINE (1946-October 2016), CINAHL (1988- October 2016), PsychINFO (1806- October 2016) and Embase (1974-October 2016) databases were searched using the following combinations of keywords "self-harm OR passive self-harm OR deliberate self- harm OR self-mutilation OR self-injurious behavio* OR self-destructive behavio* OR suicide attempt OR attempted suicide" AND "Qualitative"; "refusal to eat OR hidden suicide OR subintentional suicide OR indirect life-threatening behavio* OR indirect self-destructive behavio*". Searches were limited to articles in English. Each of the citations was examined to identify studies involving qualitative methodology which explored the reasons why older people (aged 60 years or more) had harmed themselves. A broad definition of self-harm was adopted, including both direct and indirect behaviours (as per (Draper et al., 2002). Citations were initially screened by title and abstract. If the abstract was ambiguous or the content indicated that the inclusion criteria were likely to be met, the full text was reviewed. The reference lists of included citations were screened for additional relevant studies.

Inclusion and exclusion criteria

The published and grey literature (e.g. conference abstracts and research dissertations) were reviewed to identify studies which:

- Included participants aged 60 years and over who had harmed themselves within the last 12 months; and
- focused upon examining the reasons for the self-harm by directly involving participants; and
- utilised qualitative methodology (broadly defined as studies which aim to "explore people's experiences and understandings through textual data from speech or observation" (Ring, Ritchie, Mandava, & Jepson, 2011, pp3).

Case reports/series were included if the description of cases was detailed and included direct interviewing of participants with an exploratory focus. Studies were excluded if they involved participants who had not self-harmed but had suicidal ideation or a wish to die, or data obtained from informants of those who had died by suicide. Surveys of participants using structured or semi-structured questionnaires were excluded as this is more consistent with topical surveys rather than thematic analyses characteristic of qualitative methodology

(Sandelowski & Barroso, 2003). Studies which included older adults but only as a minority within a diverse age cohort or which did not link emergent themes specifically to the older participants were also excluded.

Assessment of quality

The quality of included studies was appraised using the checklist developed by Attree and Milton (2006) and used by Lakeman and FitzGerald (2008). This checklist was designed for qualitative systematic reviews and evaluates the research background, aims and objectives, context, appropriateness of design, sampling, data collection, data analysis and findings, reflexivity (i.e. reflection upon the relationship between the researcher and the participants and of the researcher's own perspectives and how they may interact with the data), usefulness and value, and ethical considerations using clear criteria (Attree & Milton, 2006). A quality rating is assigned to each of the checklist items from A (no or few flaws), B (some flaws), C (considerable flaws, but the study still has some value) to D (significant flaws which threaten the validity of the whole study). Studies with a quality rating of D were to be excluded, consistent with the recommendations of Attree and Milton (2006), due to significant methodological issues limiting the validity of results. The overall quality score (A-D) for the study is based upon the grade for the majority of sections. Additional recommendations for assessing the methodological quality of qualitative studies were sourced from published guidelines (Elliott, Fischer, & Rennie, 1999; Ring et al., 2011).

Data gathering and synthesis

The first author reviewed all included papers and performed the quality ratings. The second author independently performed quality ratings on all of the papers. Results were compared and differences of opinion discussed and resolved by consensus. All authors reviewed the data synthesis.

The findings of studies were evaluated using conventional content analysis (Hsieh & Shannon, 2005). With this technique initial categories emerge directly from the data, rather than using preconceived categories. Immersion in the data, via repeated reading of the data, develops a sense of the whole. Codes emerge from reading the data word by word. Initial thoughts and analysis are recorded and the process continues, refining codes and then grouping them into categories (Hsieh & Shannon, 2005). In a variation of this technique described by Lakeman and FitzGerald (2008), initial coding categories were then combined into overarching themes. Both the first and second author independently coded the papers to

generate categories and finally, overarching themes. A consensus-based approach was used to generate the final content analysis.

Results

There were 1457 citations identified from the database searches and other sources. Overall eight citations met the inclusion criteria (see Figure 2.1. PRISMA flow diagram: Results of literature search). Four studies were from Northern America , two from Europe, one from Asia and one from Australia (see Table 2.1.). Studies fell into two groups; those focusing on participants who had clearly attempted to end their lives (Bonnewyn, Shah, Bruffaerts, Schoevaerts, et al., 2014; Crocker et al., 2006; Kim, 2014; Moore, 1997; Wand, Pesiah, Draper, Jones, & Brodaty, 2016), and participants with indirect self-harm (Bozinovski, 2000; Finestone & Blackmer, 2007; Thibault, 2007). The forms of indirect self-harm described included self-neglect (not specified for individual participants but including any failure to self-care: i.e. not adequately maintaining food, clothing, shelter or medical care or not managing financial affairs; (Bozinovski, 2000), partial or total refusal to eat (Finestone & Blackmer, 2007; Thibault, 2007), and medication refusal (Thibault, 2007).

One of the included studies primarily explored the life experiences of participants *after* the suicide attempt; however, in exploring this topic participants discussed their reasons for the suicide attempt (Kim, 2014). Only these themes are discussed in the present review. One study of indirect self-harm (refusal to eat post-stroke) was primarily concerned with determination of capacity to decide not to eat, but described factors underlying this behaviour (Finestone & Blackmer, 2007), and so was included.

The findings of the review and quality ratings for each study are summarised in Table 2.1. Three of the studies received the highest quality rating; each of which were a dedicated qualitative study, with a majority of quality ratings of ‘A’ on the Attree and Milton (2006) quality appraisal checklist, in contrast to case report papers, which were all rated as C. Specific methodological strengths and weakness are presented in Table 2.1. There were no identified studies with a quality rating of ‘D’.

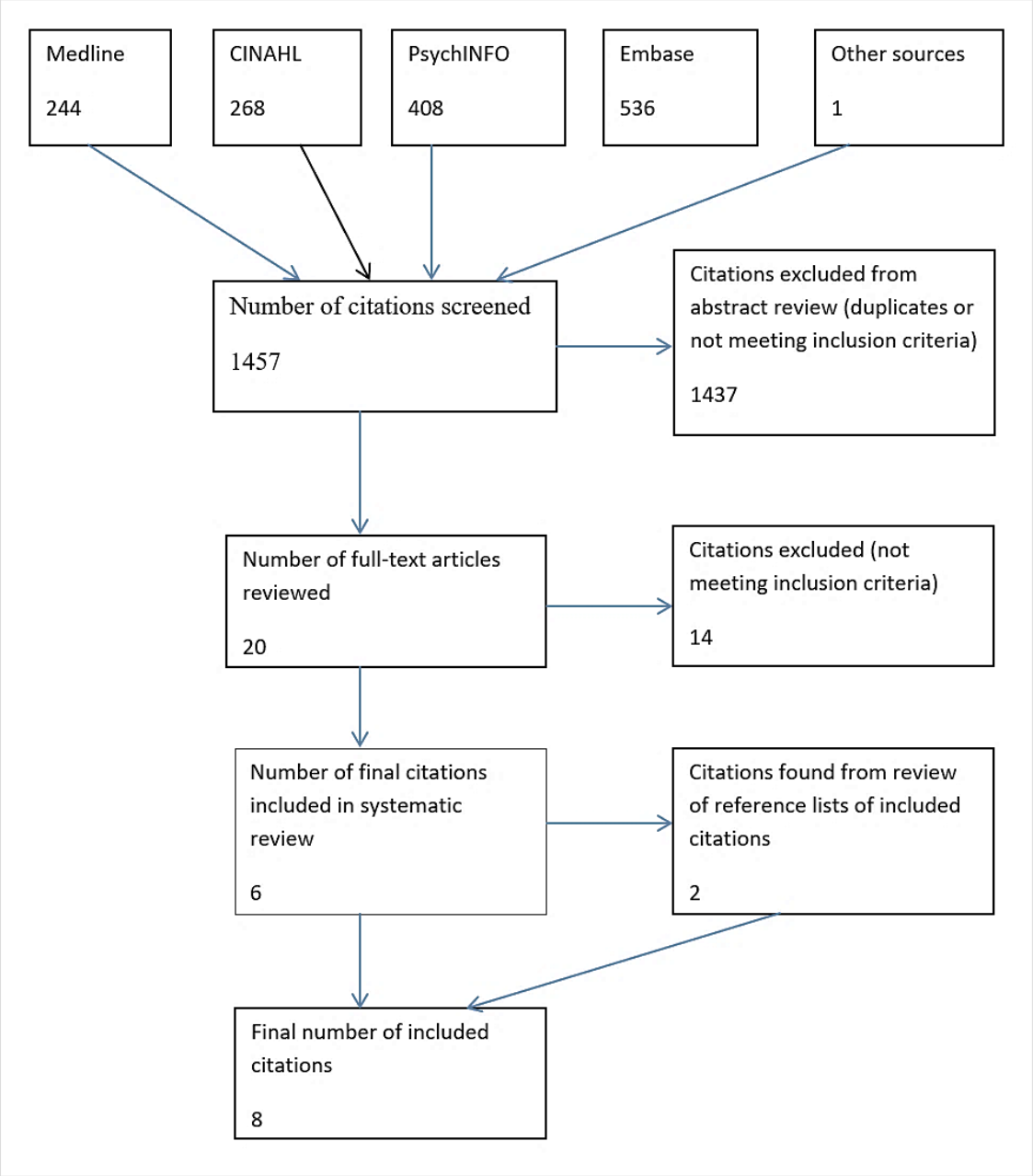

Figure 2.1 PRISMA flow diagram: Results of literature search

Table 2.1 Summary of reviewed studies

Study (country)	Quality rating and comments	Design and methodology	Participants and setting	Summary of emergent themes
Bonnewyn, Shah, Bruffaerts, Schoevaerts, et al., 2014 *(Belgium)*	**A** Independent coding of transcripts, reflexivity demonstrated, Saturation of data Data not triangulated Limitations acknowledged	In depth interview less than 30 days from the suicide attempt Grounded theory NVivo for data management	N=8, 6 female Ages 66-86 (mean 71.7) 'Able-bodied' MMSE >24 Inpatients in a psychiatric unit	Life and self disrupted by loss Loneliness Insomnia and physical exhaustion Loss of control Unwillingness to continue Anxiety symptoms and being overwhelmed
Crocker et al., 2006 *(United Kingdom)*	**A** Range of cases; reflexivity demonstrated; Credibility checks; data not triangulated	Semistructured in depth interview five days to 20 weeks post-suicide attempt Interpretative phenomenological analysis	N= 15, 9 female Ages 65-91 (mean 69.5) All had depression MMSE ≥24 Setting: an inpatient older person's psychiatric unit, medical ward or participant's home Excluded if psychosis or euthanasia	Life and ageing as a struggle Control- loss of or attempt to regain Visibility and connection- loss of or attempt to regain
Kim, 2014 *(Korea)*	**A** Member checking; trustworthiness demonstrated; Triangulation of data Peer review of data; unclear whether saturation of themes; limitations unacknowledged	In depth interview within one year of suicide attempt and review of social worker's field notes Content analysis	N= 35, 26 female Age 64-89 (mean 73.7) Excluded dementia or psychosis Community dwellers	Suicide to end pain and suffering Despair and lack of hope Mismatched cultural expectations- familial roles

Study (country)	Quality rating and comments	Design and methodology	Participants and setting	Summary of emergent themes
Moore, 1997 *(Canada)*	**B** Sampling unclear (inclusion criteria were inpatients from psychiatric units who expressed suicidal ideation, unclear how many had attempted suicide and when; at least one had attempted hanging); data saturation uncertain; Collaborative analysis team Data triangulated and clear audit trail; Trustworthiness demonstrated; limitations unacknowledged	In depth interview, field notes and methodological journal Hermeneutical phenomenological approach	N= 11 (gender not reported) Age 64-92 Excluded dementia or psychosis Inpatients in a psychiatric unit, six were waiting for ECT	Sadness and despair "Psychache" Feeling unloved "nobody cares" Powerlessness Cultural context - devaluing the aged
Bozinovski, 2000 *(USA)*	**C** Major limitations in data analysis which was more theory than data-driven (e.g. few quotes and not linked to individuals; results and discussion mixed - unclear what was theory and what was derived empirically), reflexivity not met; ethical concerns (no description of consent process or institutional ethical approval).	In-depth interviews of clients of adult protective services (categorised as self-neglecters) and adult protective services caseworkers; review of case notes and environmental and participant observation Constructionist grounded theory NUDIST for data management	N= 30 clients (gender not reported); n= 20 adult caseworkers; n= 15 caseworker supervisors Clients aged ≥ 60 Included people with dementia, mental illness and 'incapacity'	Maintaining continuity: preserving and protecting oneself; interpersonal problems; turning points in life Impaired role taking in relation to societal expectations

Study (country)	Quality rating and comments	Design and methodology	Participants and setting	Summary of emergent themes
Finestone & Blackmer, 2007 *(Canada)*	**C** Case series not true empirical study; aims not clearly stated; Triangulation of data; data analysis sound Lack of trustworthiness and reflexivity	Detailed case description from interviews of people refusing to eat and their relatives.	N= 3 (2 female) Age ≥ 65 (65-81) Inpatients post-stroke Cognition not evaluated	Distinguishing depression versus ill health Disability
Thibault, 2007 *(USA)*	**C** Case series not true empirical study Limitations in sampling- selected to illustrate predetermined theory; Triangulation of data; Trustworthiness demonstrated	Detailed case series from interviews of women categorised as self-neglectful	N= 3 (all female) Age 84-92 Community dwelling (one in own home, 2 in residential care) MMSE ≥ 24	Behavioural responses to negative stimuli or aversive events (loss of control): solving a problem, avoiding the problem, or not coping
Wand et al., 2016 *(Australia)*	**C** Case series not true empirical study Limitations in sampling- selected to illustrate predetermined theory; two cases only with no data saturation. Triangulation of data in only one case. Lack of trustworthiness and reflexivity. Limitations not acknowledged	Detailed case description of two people who had attempted suicide.	N=2 Age 88 and 89. Both participants were community dwellers hospitalised for self-harm. One had cognitive impairment.	Control- loss of or attempt to regain Disability and dependency Boredom, loss of usefulness and purpose in life Old age as burdensome Alcohol and cognitive impairment

MMSE= Mini-mental Status Examination score

Quality scores A-D derived from Attree and Milton (2006). A: no or few flaws, B: some flaws, C: considerable flaws, but the study still has some value, D: significant flaws which threaten the validity of the whole study.

The detailed results of the content analysis are presented below highlighting the common and interrelated themes which emerged from the studies.

It was evident from both the content and the quality analysis that there was a distinct difference between the conceptualisation of self-neglect (e.g. ranging from hoarding, to refusal to eat and non-compliance with medications) and suicidal behaviour, the active attempt to terminate one's life. Indeed one study made this distinction explicit: *The present cases clearly show that stroke patients who refuse to eat may not be conveying a "wish- to-die" message* (Finestone & Blackmer, 2007, p1477). For this reason we have presented two separate analyses for the papers describing subjects with self-neglect and those describing subjects with suicidal behaviour.

Themes for self-neglect

Self-neglect was conceptualised as an adaptive or defensive behaviour in response to threat, albeit with a maladaptive outcome. This is not always an attempt to destroy the self (Finestone & Blackmer, 2007; Thibault, 2007), but rather an attempt to solve a problem (Thibault, 2007) as illustrated by the following themes:

Control

Self-neglect can be conceptualised as a response to threats of control over personal freedom and/or living situations, often seen in residential care environments. A range of threats to personal control were identified including chronic illness, loss and interpersonal problems such as perceived abandonment and betrayal (Bozinovski, 2000). That such unintentionally self-destructive behaviour is chosen rather than positive life enhancing responses is due to the loss of bargaining power and narrowed repertoire of available reinforcers in such environments, conceptualised by Thibault (2007) as "reinforcement loss."

Impaired decision-making and coping skills

For some, self-neglect is a manifestation of impaired problem solving due to cognitive impairment. In such cases the consequences of behaviour such as refusing to eat, drink, or take medications, is not understood by the person and needs to be addressed by either supported or proxy decision making (Finestone & Blackmer, 2007; Thibault, 2007). For example, a woman hospitalised repeatedly for exacerbations of heart failure due to nonadherence to medications believed that "she was taking too many pills…. And feared they might actually do her harm" (Thibault, 2007, p155). In the absence of effective coping skills, self-neglect can sometimes be an attempt to save the self by adopting actions which arouse the attention, guilt or fear of caregivers (Thibault, 2007).

Threats to self-identity and continuity

Self-neglect as manifested by failure in self-care or care of the home was conceptualised by Bozinovski (2000) as a maladaptive attempt to maintain self-identity and continuity. Distrust of others and threats to self were precipitated by turning points such as loss of a spouse, forced and unwanted relocation or life-long relationship failure or disappointments. This was manifest by comments that people are "just out to get you" and "want to use you" (Bozinovski, 2000, p45). By adopting customary control-orientated behaviours and resisting threats of change and assistance from care workers, "self-neglecters" preserve a sense of continuity (Bozinovski, 2000).

Themes related to suicidal behaviours

The following themes were generated from analysis of the papers focusing on suicidal behaviour or self-harm.

Loss of and regaining control

As with self-neglect, powerlessness and loss of control were associated with suicidal behaviour. Powerlessness arose from a reduction in independence and autonomy and changing life circumstances associated with ageing. This included losses related to death of loved ones, physical ill-health, pain, immobility, relationship disappointments, social status and social support (Bonnewyn, Shah, Bruffaerts, Schoevaerts, et al., 2014; Crocker et al., 2006; Kim, 2014; Moore, 1997; Wand et al., 2016). In one study all eight respondents described a specific life event preceding their suicide attempt, culminating in a feeling of "losing hold on life" (Bonnewyn, Shah, Bruffaerts, Schoevaerts, et al., 2014). Symptoms such as fatigue, anxiety and insomnia contributed to the sense of loss of control thereby fuelling despair (Bonnewyn, Shah, Bruffaerts, Schoevaerts, et al., 2014; Wand et al., 2016). For one older man, a return to alcohol misuse after losing his drivers' licence exacerbated his pre-existing cognitive impairment, diminishing his control through further impulsivity and disinhibition (Wand et al., 2016, p3).

As with self-neglect, self-harm for some provided a means of problem-solving in the face of losses and powerlessness; finding a solution or taking control in a situation where they felt helpless. Suicide could avoid the need for much feared residential care placement and the associated costs, which would diminish the estate inherited by family (Wand et al., 2016). In some instances a suicide attempt redressed the loss of control by facilitating treatment of the underlying cause; namely, medical care for pain, anxiety, depression or

physical symptoms (Bonnewyn, Shah, Bruffaerts, Schoevaerts, et al., 2014; Crocker et al., 2006). In another study physical pain, weakness and financial problems worsened after the attempt and iatrogenic problems with dependence upon prescribed medication were created (Kim, 2014). For others, self-harm was an act of giving up (Crocker et al., 2006), or a solution to intractable physical symptoms and dependency (Wand et al., 2016). That survival represented a failure to problem solve or regain control explains why people often feel worse, angry or even diminished further after a failed attempt (Crocker et al., 2006; Kim, 2014). One participant reflected on their suicide attempt thus, "I was actually ashamed of myself. If I was going to do it (laughs), I should have done it properly" (Crocker et al., 2006, p643).

Alienation, disconnectedness and invisibility

A common theme expressed by older adults who had self-harmed was their sense of alienation from others - family and society in general (Bonnewyn, Shah, Bruffaerts, Schoevaerts, et al., 2014; Crocker et al., 2006; Kim, 2014; Moore, 1997). "Broken connections" (Moore, 1997, p34) were observed not only with family, but also with nurses and other health care providers. This was related to a strong perception that "nobody cares", particularly people "who should care" (Moore, 1997, p32; Kim, 2014, p1395). Akin to these perceptions was the sense of loneliness, isolation or invisibility, usually based on internal cognitive sets rather than necessarily social isolation (Crocker et al., 2006). Such perceptions were often fuelled by negative internalised ageist stereotypes and beliefs (Crocker et al., 2006; Kim, 2014). There were strikingly disparaging descriptions of older people such as "one foot is in the grave", "Somebody who is not terribly astute and on the ball" (Crocker et al., 2006, p641) and of advanced age and dependency akin to existing like a "pot plant" (Wand et al., 2016 p3). The sense of alienation was felt particularly acutely by elderly Korean suicide attempters in the face of cultural shifts of marginalisation and changes in the family unit and the role of elders (Kim, 2014). Particularly challenging was the mismatch between expectations and social reality for Korean elders who had not expected to be living alone in their old age, assuming that cultural traditional values of family care would operate rather than the emergent societal emphasis on self-reliance and independence.

For some, losses imposed a sense of being abandoned, left to their own devices or being alone in the world (Bonnewyn, Shah, Bruffaerts, Schoevaerts, et al., 2014). Again, this was not always caused by real abandonment, and loneliness and invisibility may have been self-imposed. Some actively pursued self-isolation, by rejecting social opportunities and approaches by family or not sharing thoughts or feelings with others (Bonnewyn, Shah,

Bruffaerts, Schoevaerts, et al., 2014). Lack of routine and social activities, as well as a diminishing social circle contributed to loneliness, but also represented opportunities to redress this problem (Crocker et al., 2006; Wand et al., 2016). Similar to some cases of self-neglect, the suicide attempt had the effect of increasing visibility – not always intentionally - by mobilising support systems and help that was hitherto unavailable (Crocker et al., 2006).

For others, perceived dismissive, angry or rejecting responses by family or staff merely served to exacerbate alienation (Crocker et al., 2006; Kim, 2014). For example, one woman cried recalling her son's angry response to her overdose "Why did you take those pills? You should have taken more if you really wanted to die" (Kim, 2014, p1395). Some of the narratives reflected upon the experience with healthcare workers which included being perceived as time wasters (Crocker et al., 2006), shown lack of interest or care from clinicians (Moore, 1997), and being dismissed with tablets and no inquiry as to why they tried to end their lives (Kim, 2014).

Meaningless and a raison d'etre

An important theme due to its potential role for remedy was the sense of meaningless for older people who attempted suicide. Narratives reflected the perception of being no longer able to give to others or to achieve anything more in life, and a desire to feel useful and needed (Moore, 1997; Wand et al., 2016). Some older people feared becoming a burden upon family due to increasing dependency with nothing to offer in return (Wand et al., 2016). In the absence of meaning, life was an obligation (Bonnewyn, Shah, Bruffaerts, Schoevaerts, et al., 2014), or boring and rudderless (Wand et al., 2016), and some people searched for a reason to live after their attempt (Kim, 2014). One participant particularly highlighted this point "If there was anything good in my life, I wouldn't want to die" (Kim, 2014, p1396).

Accumulated suffering and a "painful life"

A minor but categorically distinct theme found in a single study in a culturally specific setting, was the notion of accumulated suffering (Kim, 2014). Although a culturally-shaped version of the interpersonal experiences of self-neglecters (Bozinovski, 2000), the kind of suffering experienced by ageing Koreans who attempted suicide included difficulties during Japanese colonialism, past spousal abuse, deaths of adult children and feelings of remorse for a life that had failed to meet expectations (Kim, 2014). Suicide was thus seen as a way of escaping a "painful life" (Kim, 2014, p1394). The role of abuse and violence in suicidal behaviour amongst women was particularly noted (Kim, 2014).

Discussion

We undertook the first systematic review of qualitative studies examining the reasons for self-harm in older people, using a recognised critical appraisal tool for qualitative research. Despite casting a wide net of databases over an extensive time period, this review yielded only eight studies, of which three were small case series. This occurred despite a deliberately broad definition of self-harm, which encompassed clear suicide attempts, refusal to eat and self-neglect. Three of the eight studies received consensus-based quality ratings of no or few flaws.

Notwithstanding the small numbers of papers evaluated and the variability of quality ratings, the content analysis of the papers yielded a richness of data that gave depth and meaning to the innumerable risk factors associated with suicide in later life. While a plethora of factors such as gender, age, mental illness and mostly depression, physical illness, pain, death ideation, past suicide attempts and wish to die have all been associated with suicidal behaviour (Bonnewyn et al., 2009; Fassberg et al., 2016) little is known about how these factors relate to each other in terms of pathways to suicide in later life (Bonnewyn, Shah, Bruffaerts, & Demyttenaere, 2014; Stanley, Hom, Rogers, Hagan, & Joiner, 2016).

From the content analysis it was evident that self- neglect, a syndrome of behaviours driven by an array of intents including, but not restricted to, self-harm but also self – preservation, differed from suicidal behaviour, the intent of which was usually self-destruction or termination of suffering. The analysis of the three qualitative studies or case series focusing on self-neglect elucidated the following themes: (i) control; (ii) threats to self-identity and continuity; and (iii) impaired decision-making and coping skills. Clearly this is not the whole picture in regards to self-neglect. These findings reflect some of the methodological shortcomings of the papers studied, including sampling with no data saturation using very small case series in restricted settings. No doubt, self-neglect is also driven at times by a desire for self- destruction akin to suicidal behaviour, as much as it is, as demonstrated in these studies, a dysfunctional attempt at problem solving.

In relation to the separate construct of suicidal behaviour, the themes generated were: (i) meaningless and absence of a raison d'etre; (ii) alienation, disconnectedness and invisibility; (iii) accumulated suffering and a "painful life"; and (iv) loss of and regaining control. Notwithstanding the small number of studies and the largely Western perspective, the salience of these themes and the commonality with the findings from the single Asian setting was striking. Loss of control is ubiquitous with ageing and it is not surprising that it featured

in the narratives of both people who showed self-neglect and those with suicidal behaviour. Notable was the relevance of internalised ageism to suicide amongst older people which can be perceived as an act of self-induced permanent invisibility and voluntary extrusion from a society which values youth, beauty, health and strength (Moore, 1997). Meaninglessness and lack of purpose have been previously associated both with wishes to die (Bonnewyn, Shah, Bruffaerts, & Demyttenaere, 2014; Stanley et al., 2016) and mortality (Krause, 2009). The therapeutic benefits of providing a role or purpose for a depressed older person has been described previously (Peisah, 2006). Similarly, the previously described perception of older depressed persons that the family would be better off without them (Zweig & Hinrichsen, 1993) is now, in the face of ageism, echoed by society.

Comparison with the quantitative literature

Quantitative studies have identified associations with suicidal behaviour in late life, including physical illness and disability, psychiatric illness and social isolation (Bonnewyn et al., 2009; Fassberg et al., 2016; Neufeld et al., 2015). This qualitative review enriches our understanding of *why* these factors may be important to older people who self-harm by directly inquiring about their meaning and significance. For example, physical illness and disability impact upon one's sense of control and may reinforce negative internalised stereotypes of aging as a state of dependency and loss of productivity and value (Crocker et al., 2006; Wand et al., 2016). Some types of physical illness may also impair decision making leading to self-harm, sometimes inadvertently (Finestone & Blackmer, 2007). Psychiatric illnesses, especially depression, have similarly been identified as important risk factors for suicidal behaviour in both quantitative and qualitative studies. This is perhaps not unexpected as suicidal ideation or behaviour is part of the diagnostic criteria for major depression. However, the qualitative studies which included participants with depression, highlight the personal experiences of alienation, lack of purpose and meaning, and suffering as key elements underlying suicidal behaviours in older people with depression (Moore, 1997). Lack of marital and social relationships more broadly may mediate suicidal behaviours through a sense of invisibility and disconnection (Moore, 1997), with particular relevance in light of shifting cultural normal and expectations (Kim, 2014) and internalised ageism (Crocker et al., 2006; Kim, 2014). Thus these very different but complimentary research methodologies may expand our understanding of this complex area of self-harm in older people.

Comparison with psychological autopsy studies

Qualitative psychological autopsy studies of informants of older people who died by suicide have revealed similar insights to the findings of this review. For example, a Dutch cohort of 63 informants (family doctors, close relatives, carers) of 23 older people who had died by suicide (Kjolseth et al., 2010) reported themes such as life as a burden (through illness, loss, disability and mental illness), akin to the theme of a "painful life"; meaningless and loss of reason to live; and loss of the self through ageing related changes, dependency and loss of physicality, akin to the themes of invisibility and loss of control which emerged in this review. In another psychological autopsy paper describing this cohort of elder suicides, the informants described personality traits of the deceased including a need to control others and the self, inflexibility, being emotionally closed (and therefore unable and/or unwilling to access help from others and isolation) and action-orientated achievers (Kjolseth et al., 2009). These personal characteristics correspond well to the themes of this review, in particular of disconnection, loss of control and having no raison d'etre. Kjolseth et al. (2009) suggested that suicide in this cohort reflected an inability to accept and adapt to age-related loss of physicality, productiveness and function in older people for whom self-esteem was closely linked to productivity and maintaining control.

In line with the findings of the Korean study (Kim, 2014), a Ugandan psychological autopsy study also identified the importance of cultural expectations (particularly of family members), a painful life and accumulated suffering, and inescapable stress in older people who ended their lives (Kizza et al., 2012). Informants of Ugandan men aged 18-85 (five of whom were over 60 years old) who had died by suicide were interviewed. They reported that for older men, changes in the socioeconomic and cultural milieu resulting from two decades of conflict was thought to have contributed to the decision to end their lives (Kizza et al., 2012). The traditional patrilineal culture of the older men who died by suicide had been disrupted by the loss of other men (providers) and sons (protectors of the aged and family lineage) through conflict, and the resulting considerable burdens upon the older man's economic resources. As was found in the present review, informants identified alienation and social isolation, loss of meaning, self-worth and social value as contributory to the decision of the older man to end his life (Kizza et al., 2012). One point of difference with the current review was the theme of failure to live up to the responsibilities entrusted by others and associated shame and embarrassment (Kizza et al., 2012). As this review was largely based upon studies in Western populations, the importance of sociocultural context to older people requires further examination.

Qualitative psychological autopsy studies may reveal considerable information about why people end their lives. However, they are limited by the fact that they rely upon the interpretations of others, whose perspectives may be shaped by their relationship with the deceased and their responses to the suicide; they are conjecture, not the thoughts and words of the person themselves (Kjolseth et al., 2010). The studies discussed here interviewed at least two informants for each person in order to triangulate data and amplify common key observations.

Limitations

Aside from the small number of included papers, of variable quality, there are various factors limiting the generalisability of results from this review. We acknowledge that one of the identified papers was written by our group (Wand et al., 2016), and recognise the limitations of self-review. However, the study met our inclusion criteria and objective quality criteria were applied to all studies. As stated previously, the cultural focus was very narrow with one exception, perhaps as only papers written in English were included. We are aware of one qualitative study published in Korean which employed in-depth interviews in four older people who had attempted suicide (Im & Kim, 2011) and another qualitative study in Norwegian of suicide in the elderly (Kjolseth & Ekeberg, 1997) both of which may have been relevant to this review. In light of variations in demographics of late life suicide across different settings (Shah et al., 2016), sociocultural factors are strong determinants of pathways to suicide and this needs to be explored with a cross cultural comparative review. Additionally, only two (Bozinovski, 2000; Wand et al., 2016) of the qualitative studies reviewed included people with dementia or cognitive impairment (although in one of these studies this was not quantified and the study was significantly methodologically flawed (Bozinovski, 2000); and there was relatively less representation of the oldest old (aged $\geq$ 80) than the younger old (65-79). Although both hospital inpatients (five studies) and community dwellers (three studies) were included, people in residential care were under-represented (only two patients in one case series, (Thibault, 2007)). It is not known if there is a difference in the motivations and reasoning behind self-harm in people who remain in the community, or indeed how caregivers respond to their self-harm behaviours, compared to those who are consequently admitted to hospital, but some difference in severity might be expected. Further, the time course of self-harm behaviours in community-dwellers was not commonly described. Only one study clearly documented a timeline of the onset of self-harm (neglectful) behaviours, with the duration of behaviours varying from a year to three months (Thibault, 2007). With regards to severity and symptoms of mental illness, this was only reported in one case series study described here (Wand et al., 2016). It is thus difficult to

disentangle symptoms of a depressive illness per se, from other remediable reasons for suicide. The extent to which cognitions were tainted by negative depressive state and more importantly, psychotic thinking, was not discussed in any of the studies. Notably, in one study, half of the participants were waiting for ECT and one withdrew because she felt worthless to contribute, which was attributed to the theme "psychache" (Moore, 1997). Surprisingly, only one study identified a participant with substance misuse and considered the effects upon cognition and suicidal behaviours (Wand et al., 2016). Additional studies are needed to explore the influence of various settings, cultural factors, cognitive impairment and the perspective of the oldest old, giving voice to the latter being particularly relevant in light of recent increased suicide patterns (Shah et al., 2016).

Conclusions

"The profile" of older people who self-harm includes an abundant list of identified risk factors empirically proven to be associated with self-harm. We now need to understand the individual experiences and pathways to self-harm to inform and enrich our interventions. This systematic review has highlighted the importance of loss of control, threats to identity and continuity of self and impaired decision making as contributory factors in self-harm by older people. For those with suicidal behaviour, perceptions of meaninglessness and lack of raison d'etre, disconnectedness, invisibility, accumulated suffering and a painful life, as well as losing and trying to regain control, underpinned decisions to self-harm.

When health care professionals identify self-neglect or suicidal behaviour in older patient they should neither: (i) dismiss a person with a script for an antidepressant without enquiry about "why"; nor (ii) fail to assist the person to regain a sense of control and/or a raison d'etre. Most importantly we cannot reinforce ageism by our clinical stance.

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2.3.1 Updating the qualitative literature

A further systematic review of the literature was conducted to identify any additional empirical qualitative studies following our original review (Wand *et al.*, 2018b). The search yielded only one study meeting the inclusion criteria (Van Orden *et al.*, 2015); namely studies with participants aged 60 or more who had harmed themselves within the last one year; focusing upon the reasons for self-harm through direct involvement of participants; and using qualitative methodology. In this study 101 older people who had attempted suicide and attended an Emergency Department were asked why they attempted suicide (Van Orden *et al.*, 2015). There were no follow-up questions or prompts, which limited the depth of the analysis. The emergent themes regarding the reason for the attempt included wanting to escape life (28.7%), loss of function and autonomy (23.8%), psychological problems (in particular anxiety and depression, 23.8%), physical illness and pain (15.8%), perceiving themselves a burden (12.9%), social problems (not belonging and family conflict) (12.9%), lack of meaning in life (7.9%), wanting to die without a specific reason (12.9%) and not recalling or understanding why (7.9%). Most of the sample (94%) met criteria for a mood disorder, although the role of depression was not weighted highly as a reason for the suicide attempt. Only 12 (12%) had cognitive testing. Those participants who cited social problems as underlying their suicide attempt were more likely to repeat suicidal behaviour over the one year follow-up period than those people without this reason (Van Orden *et al.*, 2015). Overall, the results were consistent with the themes which emerged from our initial review (Wand *et al.*, 2018b), in particular the importance of loss of and regaining control (autonomy), disconnection and alienation (social problems and not belonging), and loss of meaning. In contrast to our review, accumulated suffering and a painful life were not themes of the Van Orden study, perhaps because the methodology and acute setting did not allow detailed discussion about such potentially sensitive topics.

In addition, one study of professional caregivers working in nursing homes was identified that qualitatively explored barriers to suicide prevention in that setting (Couillet *et al.*, 2017). Nurses, nursing aides and care assistants with direct daily caring roles were individually interviewed about suicide in older adults, two-thirds of whom had experienced suicide attempts by residents and almost half who had faced resident suicide (Couillet *et al.*, 2017). Key themes which emerged included professional caregivers viewing suicide as an expression of autonomy, especially for residents unable to express themselves verbally and with dementia. Another theme was suicide as an answer, which some caregivers felt was legitimate, to the suffering accompanying ageing (i.e. bereavement, isolation, chronic

illness and functional decline). Professional caregivers felt helpless to ease the mental suffering of residents themselves and noted difficulty accessing psychiatric care, which they perceived as sometimes ineffective. The third theme was of society's exclusion and devaluation of older adults, to the point where suicide was considered by their relatives as a normal and acceptable end of life, and old age as a 'time to leave'. Professional caregivers reflected that entering a nursing home was traumatic, often 'brutal', with new residents sometimes unprepared, uninformed, losing their liberty and personhood and experiencing a "deathly" atmosphere.

The perspectives of professional caregivers in this specific nursing home setting highlighted negative concepts of ageing including loss of autonomy, helplessness, suffering, loneliness and devaluation by society (Couillet *et al.*, 2017). Some of the themes resonated with those emerging from our systematic review of studies directly canvassing the views of the older person who had self-harmed (Wand *et al.*, 2018b), notwithstanding few participants were from nursing home settings. The professional caregivers interpreted self-harm as a way of regaining control (autonomy); the alienation, disconnection and invisibility of older people in society; and accumulated suffering (Couillet *et al.*, 2017). Professional caregivers in nursing homes appear to understand key issues underlying suicide and self-harm in nursing home residents, but perceived themselves to be impotent to effect change for the resident, especially as orientation to the environment itself was poor, relatives were absent and there were scant time or resources to deliver personalised care (Couillet *et al.*, 2017). This sense of helplessness in professional caregivers of older adults who self-harm was a recurring theme, emerging in both Study 1 (Wand *et al.*, 2018a; Wand *et al.*, 2018c; Wand *et al.*, 2019b) and 2 (Wand *et al.*, 2019a).

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Chapter 3 Research methods and materials

3.1 Ethical approval

Approval was granted by the South Eastern Sydney Local Health District Human Research Ethics Committee for the study to be conducted across two hospitals and associated community service sites. Amendments to the original Ethics application were subsequently approved to include the General Practitioner (GP) component of the study (Study 1C and 2) and the educational intervention (Study 3B). The ethical approval was also ratified by the University of New South Wales Human Research Ethics Committee (see Appendix for copies of letters of ethical approval). There was no funding for this study. The doctoral candidate and co-investigators had no conflicts of interest.

3.2 Selection criteria

Three groups of participants: patients (very old people who have self-harmed), their nominated closest relative or friend (hereafter referred to as carers in the manuscripts), and the patient's GP were included in the empirical studies. Patient participants were people aged 80 years or more who had self-harmed (regardless of intent) within one month of recruitment (Study 1, baseline). All consecutive referrals of very old people who self-harmed during the data recruitment period were eligible for inclusion. They were recruited from two main teaching hospital campuses and their associated community services. Patient participants were recruited through any department of these two campuses, including Emergency Departments, geriatrics services, older persons' mental health services, and any wards of the two general hospitals, as well as nursing homes and patient's homes, providing a diverse sample. The participants included people who do not speak English, people with mild cognitive impairment, and people with dementia. Professional healthcare interpreters were used to facilitate communication in baseline and follow-up interviews with patients when needed. Reasons for non-participation are outlined in the three Study 1 papers (patient (Wand *et al.*, 2018c), carer (Wand *et al.*, 2019b) and GP (Wand *et al.*, 2018a)). The sample size was determined in Study 1, when saturation of themes was reached at baseline analysis of patient interviews (Wand *et al.*, 2018c). Patient participants were asked to nominate a close family member or friend (denoted as his/her carer) to be involved in the study. The nominated carers were then separately invited to take part in the qualitative study (Wand *et*

al., 2019a; Wand *et al.*, 2019b). Professional healthcare interpreters were used to facilitate communication in baseline and follow-up interviews with carers when needed.

The patient's GP was invited to take part in the study by completing a written questionnaire regarding the patient's self-harm and their clinical care at baseline and one year follow-up (Study 1 and 2)(Wand *et al.*, 2018a; Wand *et al.*, 2019a).

3.3 Aims and hypotheses

An exploratory qualitative study investigated the psychosocial contexts of older people who have self-harmed and focused upon uncovering the strengths and gaps in their care. In summary, the aims of the studies were:

Study 1: To explore qualitatively the reasons why very old people self-harm, the consequences of the self-harm and perceptions of care from the viewpoints of the older person themselves, their carer (relative/friend) and GP.

Study 2: To re-interview the original cohort of older people and carer dyads and to survey the patient's GP, one year after the self-harm in order to evaluate reflections on the self-harm, its consequences and the clinical care provided, and to assess their objective outcomes.

Study 3: To use data from the preceding qualitative studies in combination with the quantitative literature to inform the development of an educational package for GPs and hospital staff on self-harm in the very old, and to evaluate the effectiveness and impact of the educational intervention.

Qualitative research is hypothesis-generating and seeks to explore and question rather than to prove or disprove (Corbin and Strauss, 2015). Therefore, hypotheses regarding the experiences of care and outcomes for very old people who have self-harmed will emerge from the qualitative interview data gathered with patient participants and their relatives/friends, and the questionnaires from GPs.

3.4 Mixed methods

3.4.1 Qualitative methodology

Grounded theory methodology was chosen for this study as it was best suited to investigate the research questions. This form of qualitative research was developed by

sociologists (Glaser and Strauss, 1967). Concepts which develop from a grounded theory approach are derived from data collected during the research study rather than chosen before the study commences (Corbin and Strauss, 2015). The other key feature of grounded theory is that data collection and research analysis are interrelated. The researcher analyses initial data, and the concepts which emerge from this analysis form the basis for subsequent data collection (Corbin and Strauss, 2015). Data are analysed using constant comparisons, a process whereby data are simplified into components, with each component compared for similarities and differences (Corbin and Strauss, 2015). Data that are similar in concept are grouped together under the same conceptual heading. With further analysis, the researcher groups together concepts to form themes (or categories). The properties of each theme are developed, and eventually the different themes are integrated around a core category, or major theme of the study. There is an ongoing cycle of data collection and analysis throughout the research process (Corbin and Strauss, 2015).

A qualitative approach was taken for the patient and carer interviews (Studies 1 and 2), utilising narrative inquiry. Open-ended questions were employed to assist the patient participant and, separately, his/her relative or friend in forming a narrative about their reflections upon the self-harm, the outcomes of the self-harm, and perceptions of care (clinically and within their social network) (Peters *et al.*, 2013). The audio recordings of in-depth interviews were replayed and the transcripts checked for accuracy.

a. Thematic analysis

Thematic analysis was used to analyse the content of the in-depth interviews and GP questionnaires. Interview transcripts were imported into the qualitative data management program QSR N-VIVO Pro 11 for analysis. The primary data analysis was undertaken by the doctoral candidate, Dr Wand, who read and coded the transcripts using QSR N-VIVO Pro 11 (Armstrong *et al.*, 1997). Dr Wand attended a formal course in conducting qualitative analysis using N-VIVO at the University of New South Wales (UNSW) in 2016. Professor Peisah independently coded the transcripts. The two assessors thereafter discussed their coding and themes, with the final categorisation based upon consensus findings of both (Braun and Clarke, 2006).

The methods for thematic analysis described by Corbin and Strauss (2015) were utilised. Specifically, this involved each interview being read and re-read in its entirety, followed by a detailed line-by-line analysis to code the text into themes and subthemes. As subsequent interviews were transcribed an iterative approach was used to re-

examine previously analysed data in light of emergent themes (Braun and Clarke, 2006). The results were compared and discussed with all authors until agreement is reached. Data were triangulated through the three sources - patient participant, their nominated carer (relative or friend) and their GP.

b. Methodological rigor of the qualitative studies

Various techniques were employed to ensure the methodological quality of this qualitative study as outlined by Attree and Milton (2006) in their Quality appraisal checklist (Attree and Milton, 2006). Specifically, the background of the research was provided and the study connected to the existing body of knowledge in the field of self-harm and older people; aims and objectives were defined; the setting and context of the study were described, and the appropriateness of the qualitative approach justified. The sampling strategy and inclusion/exclusion criteria were specified at the outset, and the sample size was determined when there was saturation of themes in the patient interview data (Morse, 2000). Data saturation may be defined as the point where no new relevant themes or categories emerge in the analysis, but also entails the researcher having explored each theme or category in depth and qualifying its dimensions and properties (Corbin and Strauss, 2015, p139). The procedures for data collection, the form of data (audio-recordings and subsequent verbatim transcripts or GP questionnaires) and data sources (triangulation of data from the three groups of patient, carer and GP) were reported. Ethical issues such as consent, confidentiality/anonymity, and managing distress in participants were addressed in meeting Ethics Committee requirements.

The quality of data analysis and findings in qualitative research may be assessed in several ways (Attree and Milton, 2006). In the present study there was a clear description of how the analysis was conducted (see above, section 3.4.1.a). Data were provided in the form of verbatim quotations from participants in the empirical published studies (from Study 1 and 2) to support findings. The demographic details of participants who provided relevant quotations used to support the findings were provided (e.g. age, gender, relationship to patient, as appropriate). The subjective meaning attributed by participants is emphasised in the findings.

Another important aspect of quality in qualitative research is the trustworthiness or credibility of findings. Trustworthiness is evaluated by procedures such as triangulation (the use of multiple data sources or methods to develop a comprehensive understanding; (Patton, 1999); peer review or debriefing; prolonged engagement and

persistent field observations; inclusion of negative cases (those which do not fit the pattern); addressing researcher bias (also referred to as self-awareness); member checks (participant or responder validation); thorough description; and external audits (Creswell, 1998). This study utilises triangulation, peer review by old age psychiatrists, prolonged engagement with the participant, inclusion of negative cases, addressing researcher bias, discussing limitations of individual studies and how they may impact the findings, and thorough description, as outlined in the empirical published manuscripts of Study 1 and 2.

A reflexive approach was taken throughout the study to ensure that the relationship between the researchers and participants is considered. Reflexivity refers to consideration of the relationship between the researchers and participants, and whether the researchers reflect upon their personal experiences, biases, and views that they bring to the research setting (Finlay, 2002). The doctoral candidate, an old age psychiatrist, conducted all of the interviews. A contemporaneous journal of preconceptions and reflections was maintained during and after the interviews and noting the clinical role (as the treating or consulted old age psychiatrist) in some of the patient/relative dyads, and how these factors might influence the interpretation of the data and analysis.

Finally, the usefulness or value of qualitative research should be clear. In the publications derived from Study 1 and 2 (Wand *et al.*, 2018a; Wand *et al.*, 2019a; Wand *et al.*, 2018b; c; 2019b), the implications of the findings for the assessment and management of older people who self-harm, their carers, and GPs are discussed. There is also discussion of how the qualitative findings relate to existing theories, such as the interpersonal theory of suicide (Joiner, 2005). Implications for policy and practice are similarly discussed in the papers.

3.4.2 Quantitative methodology

The evaluation of the educational intervention (Study 3) utilised quantitative statistical methods. The pre/post questionnaires contained 16 identical questions; a combination of multiple choice (single correct answer) and true/false questions. The post-intervention questionnaire additionally included one question about the perceived impact of the educational intervention and one open response question inviting feedback and/or comments. Written comments in the post-intervention questionnaire were summarised for qualitative feedback on the education session.

Quantitative data were analysed using SPSS version 25 (Nie *et al.*, 1970). Descriptive statistics were expressed as simple means, frequencies, percentages and standard deviations. Group differences were assessed using one-way Analysis of Variance (ANOVA) and Pearson chi-square test for independence. Pre-post educational intervention comparisons were made using paired- *t*-tests for continuous variables and chi square analysis for categorical variables using the McNemar test for paired variables. This test does not consider the pairs with the same outcome; it is based on discordant pairs (e.g., those who differ in their responses between evaluations). Statistical significance was defined by probability (P) values <0.05.

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Chapter 4 Why do older people self-harm? (Study 1)

4.1 Preamble

As outlined in Chapters 1 and 2, there is a close relationship between self-harm and suicide in older adults. Thus, qualitatively exploring why very old people have self-harmed, its consequences and the experiences of clinical care can provide some important insights into the driving factors for both late life self-harm and suicide and provide some guidance on prevention and management. While there are psychological autopsy studies which seek to answer the question of why older people self-harm by examining their lives through the lens of family and clinicians (Snowdon and Baume, 2002), often many months after the death by suicide, there have been few studies which examine late life self-harm by directly speaking to those who have survived the experience (Van Orden and Conwell, 2016; Wand *et al.*, 2018c). This study aims to redress this absence in the literature.

Many older people, as a result of medical comorbidity, disability and frailty, may be dependent upon their relatives for care. Yet there is a dearth of information about family carers of older people who have self-harmed. In fact, the doctoral candidate was unable to find any studies examining self-harm in an older person from the perspective of their carer. Psychological autopsy work has shown that carers know much about risk factors for suicide in their relatives (Draper *et al.*, 2018), however the impact of self-harm on family relationships and carers is unknown, as was therefore a target of inquiry in this study.

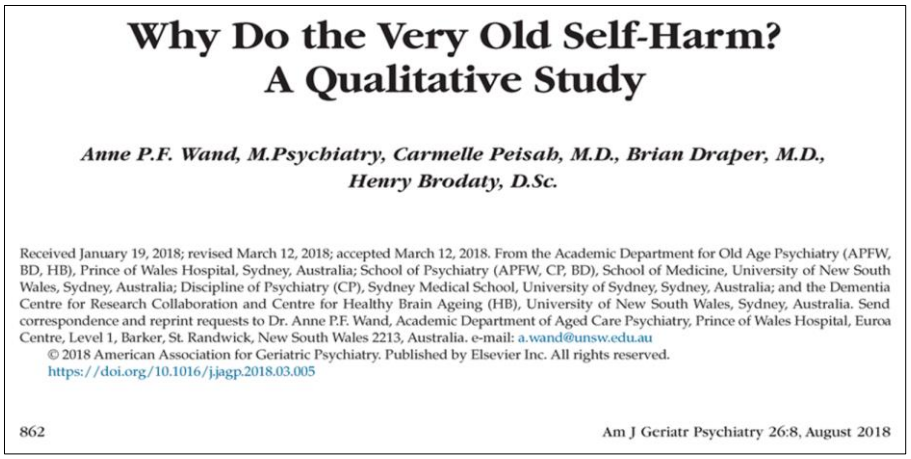
The general practitioner (GP) will most often be the primary health care professional involved with an older person. A significant proportion of older people who die by suicide have seen a health care professional in the month before their death including his/her GP (Cheung *et al.*, 2018; De Leo *et al.*, 2013a). It has been suggested that this encounter is therefore an opportunity to intervene to prevent suicide (Cheung *et al.*, 2018; De Leo *et al.*, 2013a). It is less clear what proportion of older people who self-harm and survive had contact with a health professional prior to the self-harm (Troya *et al.*, 2019), and what understanding the GP has of the reasons for self-harm. In this study the perspective of the GP was sought within a few weeks after the older patient's self-harm. Qualitatively assessing this primary care viewpoint, combined with that of the patient and their close relative can provide rich insights into why very old people self-harm and important related factors such as barriers to help-seeking, consequences of self-harm and clinical responses. The following three papers detail the results of qualitative studies derived from each of these three groups.

PAPER 3:
WHY DO THE VERY OLD SELF-HARM?
A QUALITATIVE STUDY. (STUDY 1A)

Reference

Wand APF, Peisah C, Draper B, Brodaty H. Why do the very old self-harm? A qualitative study. *American Journal of Geriatric Psychiatry*, 2018, 26(8): 862-873.

Wand APF, Peisah C, Draper B, Brodaty H. Corrigendum to 'Why Do the Very Old Self-Harm? A Qualitative Study' [*American Journal of Geriatric Psychiatry* 26 (2018) 862–871], 2019, 27(2):211.



Why Do the Very Old Self-Harm?
A Qualitative Study

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Declaration

I certify that this publication was a direct result of my research towards this PhD, and that reproduction in this thesis does not breach copyright regulations.

Anne Wand

Abstract

Objectives: To examine the perspectives of people aged 80 years or over who self-harmed regarding their reasons for self-harm and its consequences, and their perceptions of care.

Design: A qualitative study using in-depth interviews.

Setting: Participants were recruited from two teaching hospitals and associated community services.

Participants: People aged 80 or more who had self-harmed within the previous month.

Method and Measurements: Structured psychiatric assessment including cognitive testing, DSM-5 diagnosis and an in-depth qualitative interview focusing upon the reasons for and consequences of self-harm. Narrative enquiry was used to guide the discussion. All interviews were undertaken by a geriatric psychiatrist, audio recorded, transcribed verbatim and subjected to thematic analysis using N-VIVO.

Results: Themes which emerged for the reasons for self-harm included 'enough is enough'; 'loneliness'; 'disintegration of self'; 'being a burden'; 'cumulative adversity'; 'hopelessness and endless suffering'; 'helplessness with rejection'; and 'the untenable situation'. Themes for the consequences of self-harm were 'becoming engaged with or distanced from family'; 'the problem was solved'; 'gaining control'; 'I'm worse off now'; 'rejection by health professionals'; and 'tension in the role of the inpatient clinical environment'.

Conclusions: Self-harm may communicate a need which cannot otherwise be expressed. An individualised person-centred approach is required to respond to self-harm, including a combination of practical, medical and psychological approaches as indicated. Involvement of families in the process of understanding the meaning of and responding to self-harm through education and family therapy, as well as education of health care professionals beyond risk factor notation may be indicated.

Key words: old age; self-harm; suicide; suicidal behaviours; consequences; cognitive impairment; depression

Objectives

Worldwide suicide rates progressively increase in late life with those over the age of 80 at greatest risk.[1] Additionally, there is higher lethality of self-harm in older compared with younger cohorts,[2] and older people who self-harm or suicide share common risk factors.[3] As much of this research has been based on people aged 60-80, there is a gap in understanding self-harm and suicide in the very old.

Research on suicidal behaviour in late life has largely focused on epidemiological approaches, identifying associated risk factors. Quantitative approaches may not reveal the meaning of relationships between risk factors and how they interact. Thus there is little to guide clinicians about which at-risk individuals to target for intervention. Few studies have qualitatively explored the perspective of older persons as to why they self-harmed and how they could be helped, particularly the very old, those with cognitive impairment, and those from minority groups.[4, 5]

Our systematic review of qualitative studies focused upon the experience or meaning of self-harm to the older person.[5] Themes such as loss of control, threats to self-identity and continuity, alienation, accumulated suffering, meaninglessness, and lack of raison d'etre were identified.[5] We concluded that a detailed understanding of the personal experiences and cognitions which contribute to the decision to self-harm could guide sensitive, individualised and holistic clinical care.

Little is known about perceptions of the systemic response to suicidal behaviour in older people, including perceptions of clinical care and barriers to seeking help,[6] the latter being important targets for proximal suicide prevention given the frequency of clinical contact prior to suicide.[7]

To address these gaps in understanding, we aimed to explore qualitatively the perspectives of a culturally and cognitively diverse cohort of persons aged 80 years and over in relation to their reasons for self-harm and the consequences of the self-harm, including their perceptions of clinical care.

Methods

Participants

Participants were people aged 80+ who had self-harmed within the last month, by direct (e.g. overdose, cutting) or indirect acts (e.g. refusal to eat), and were recruited consecutively from December 2016-December 2017 from two teaching hospital campuses (Emergency department, geriatric, general medical and geriatric psychiatry ward) and associated community services (community, residential care) settings. Thirty-five percent of residents aged over 65 in the geographical catchment area of the study hospitals were born in non-English speaking countries.[8]

Procedures

Participants provided signed informed consent or their person responsible provided written consent to take part in the study if the participant was assenting but lacked capacity to give informed consent. Participants with delirium were interviewed after its resolution. Professional healthcare interpreters were used to facilitate communication when required.

A geriatric psychiatrist (AW) conducted structured psychiatric assessments and in-depth interviews. The structured assessment derived psychiatric (DSM-5) and medical diagnoses, medication, cultural, drug health and family psychiatric histories, and cognitive screening (MOCA- Montreal Cognitive Assessment[9] or RUDAS- Rowland Universal Dementia Assessment Scale[10] for persons from non-English speaking backgrounds). The in-depth interview of the participant focused on self-harm using a qualitative approach employing narrative inquiry. Open-ended questions assisted the participant to form a narrative about their reflections upon the self-harm and perceptions of care (clinically and within their social network).[11] A predetermined list of broad, open-ended questions was developed by the research team based up our review of the qualitative literature.[5] These included: (1) What were the factors that led to you harming yourself? (2) What were you hoping would happen as a result of the self-harm (intent)? (3) Had you spoken to anyone about how you were feeling? (4) Is there anything that if it were different would have stopped you harming yourself? (5) What has been your experience of clinical care following the self-harm? Questions were asked in a flexible manner in order to facilitate responses from participants with cognitive impairment and/or major mental illness. Interview duration was flexible and determined by the participant's responses. The interviews were audio-recorded and content transcribed verbatim. The sample size was determined when saturation of themes was reached during thematic analysis.

In order to triangulate data and consider a variety of perspectives, the participant's nominated closest first-degree relative or friend was interviewed separately (manuscript in preparation) and their general practitioner (GP) was invited to complete a questionnaire regarding their perceptions of the self-harm.[12]

Data Analysis

The demographic and clinical characteristics of the participants were summarised using descriptive statistics. Interview transcripts were imported to the qualitative data management program QSR N-VIVO Pro 11 for analysis. Patterns in responses were identified, analysed and described using thematic analysis.[13] Interview transcripts were read twice, then analysed line-by-line and organised (coded) into themes and subthemes. As subsequent transcripts were analysed an iterative process was employed to re-examine data in light of evolving themes. Two authors (AW and CP) independently analysed interview transcripts, with disagreements resolved by re-examining data and discussion until agreement. Secondary analyses were performed to explore whether there were different themes in those with suicidal intent compared to those without, and whether there were different themes in people with or without dementia.

Methodological rigor

A reflexive approach was undertaken throughout the study to ensure that the relationship between the researchers and participants was considered. The first author kept a contemporaneous journal of her preconceptions and reflections during and after the interviews and noted her clinical role with some of the participants, and how these elements might influence both recruitment in terms of any perception of obligation or even coercion, and the interpretation of the data and analysis. A second researcher (BD) was a clinician also involved in the care of some participants.

The study received ethical approval from the South Eastern Sydney Local Health District Human Research Ethics Committee.

Results

Of 39 people referred to the study, 30 (77%) consented to participate before saturation of themes was reached. Reasons for non-participation included lack of interest in the project (n=6), interpreter unavailability (1), and caregiver refusal (2). The interviews ranged from 9-55 minutes (mean 28) and took place on average 14 days after the self-harm (range 1-30 days). Direct self-harm was most common (n=26, 87%). Four participants had indirect self-harm (all had refusal to eat and one also refused medication). The self-harm was with suicidal intent in 9/14 (64%) of participants with dementia, 10/13 (77%) of those with mild cognitive impairment (MCI), and 1/3 (33%) participants with no cognitive impairment. Overdose was the most common self-harm; 10/13 (77%) of participants with MCI; 5/14 (35.7%) participants with dementia, and 1/3 (33%) participants without cognitive impairment. One participant was inadvertently interviewed during a resolving delirium. Nine participants had direct clinical input from the geriatric psychiatrist who also conducted the interview. Demographic and clinical characteristics are outlined in Table 4.1.

We present results of the thematic analysis in relation to (i) perspectives on why the self-harm occurred; and (ii) perceptions of the consequences of self-harm. There was no distinction in themes for people with direct or indirect self-harm and for people with and without cognitive impairment. Six participants had no psychiatric diagnosis; five had prominent physical symptoms (e.g. pain, insomnia), but no unique themes. A summary of the emergent themes is presented in Table 4.2.

Table 4.1 Demographic and clinical characteristics of participants

Characteristic	Mean (%) max n= 30
Age	86.5 (range 80-102)
Gender	15 females (50%)
Non-English speaking	13 (43%) Cultural background included Australian (6), Chinese (5), Dutch (2), Serbian (2), Greek (3), Croatian (2), Slovenian (1), Italian (3), Macedonian (1), Egyptian (2), Portuguese (1), Scottish (1), Hungarian (1)
Marital status	Married 11 (36.7%); widowed 14 (46.7%); single 4 (13.3%)
Accommodation prior to self-harm	Community 24 (80%); residential care 6 (20%)
Cognitive test score	MOCA (13 people)= 17 (7-24) RUDAS (17 people)= 16 (0-26)
Prior self-harm	13 (43%)
Psychotropic use prior to self-harm	Any: 17 (56.7%)* Antidepressant 13 (43.3%) Antipsychotic 4 (13.3%) Mood stabiliser 1 (3.3%) Benzodiazepine 10 (33.3%) 10 people were on > 1 psychotropic
Prior recent involvement with mental health services	4 (13.3%)
Type of self-harm (number, proportion with suicidal intent)	Overdose 16 (14, 88%); cutting 5 (2, 40%); refusal to eat 4 (1, 25%); hitting 3 (1, 33%); suffocation 2 (2, 100%); CO poisoning 1 (1, 100%); biting 1 (0, 0%) * 2 people had 2 types of self-harm (one of these participants had suicidal intent)
Self-harm was reported as a suicide attempt	20 (66.7%)
Hospital admission Length of admission	29.2 (0-194 days)
Depression	13 (43%) Major depression n = 9 Major depression with psychosis (n = 3*): delusional themes were of persecution (2) or guilt (1) Minor depression = 1 *bipolar disorder n = 1
Dementia (major neurocognitive disorder)	14 (46.7%)
Mild cognitive impairment (MCI) (minor Neurocognitive disorder)	13 (43.3%)
Other diagnoses	Alcohol use disorder 2; delirium 3*; anxiety disorder 1; very late onset schizophrenia like psychosis 1; mixed manic/depressive episode 1 *2 participants were delirious at the time of self-harm, but not interview; 1 had a resolving delirium when interviewed
No psychiatric diagnosis	6 (20%) (includes people with MCI but not dementia)

MOCA: Montreal Cognitive Assessment; RUDAS: Rowland Universal Dementia Assessment Scale

Table 4.2 Summary of themes emerging from the analysis of interview transcripts

Reasons for self-harm	Enough is enough Loneliness and not belonging Disintegration of self- my ageing body is letting me down Being a burden Cumulative adversity Hopelessness and endless suffering Helplessness with rejection The untenable situation
Consequences of self-harm	Becoming engaged with or distanced from family The problem was solved Gaining control I'm worse off now Rejection by health professionals Tension in the role of the inpatient clinical environment (i) I'm a prisoner here (ii) I'm safe now

Personal perspectives of reasons for self-harm

1. *"Enough is enough"*

Being of advanced age, many participants had a sense of life completion, reflecting that their long life was over. In some, this was expressed with a loss of raison d'etre, with nothing more to be achieved, nothing to do, and no reason to continue:

- "I had no use to continue living in this world….. I got nothing to live for." Male, 84

For some, this lack of meaning and purpose was seen through a retrospective lens of regret. For others, this was seen through a positive reflection on their life lived, a "good life" which had gone on long enough.

- "Oh well, it's my birthday. I'm going to be 94. I've had a good life." Female, 93

2. *Loneliness and not belonging*

Loneliness, isolation and perceived loss of value to and disconnect from society were prominent:

- "I'm worthless to society." Male, 84
- "I have no friends. I have nobody." Female, 102

This sense of alienation was compounded for migrants, especially if their English was poor:

- "I have nobody here [in Australia]." Female, 83

3. *Disintegration of self: my ageing body is letting me down*

Older people perceived the loss of autonomy associated with ill-health as an unbearable loss:

- "I am not self-sufficient now because I can't walk properly. I have that [frame] over there and went into a nursing home. Wee wee and poo poo, the nurses have to attend to me… Because of stroke, wasn't able to move. Can't even remove my clothing…. I am here waiting for death." Male, 82

A related subtheme was the desperate wish to avoid residential care:

- "That morning I just woke up and I saw that it [eyesight] was getting worse and worse and then I just thought I really don't want people to feed me. I don't want to go to a nursing home." Female, 80

4. *Being a burden*

Some participants tried to end their lives as they felt they were a burden to their loved ones.

- "I have been very, very lucky with my family but I couldn't help thinking that I was going to be a damned nuisance to them in my latter years. So I thought I would - in a moment of depression - I suppose it was - I decided I would terminate the whole thing….. I love them but I just didn't want to become a weight around their neck." Male, 89

5. *Cumulative adversity*

Some related self-harm to early aversive experiences, and of migration, including being stuck in the hardship, having survived it and the cumulative effects:

- "I was homesick for 10 years and that triggers it off too you see and that was very hard for me to leave my country …. My mum cried and I still that…. You don't forget....." Female, 83

6. *Hopelessness and endless suffering*

Endless suffering came from depression, physical illness and pain:

- "I was feeling very, very depressed and I started thinking to meself 'well, I can't put up with this anymore.'" Male, 86
- "The last time I went to the hospital with it [nausea] was just a few days back and they just couldn't seem to help me. I think that's what upset me more thinking 'Oh. I won't be able to go to hospital then to get help.'" Female, 90

7. *Helplessness with rejection*

Many participants experienced helplessness, sometimes echoed by the clinician, often inhibiting disclosure of self-harm intent.

- "Because I am always there. And the doctor saw me and then he said 'Why? Why? Why you have depression?'" Female, 84
- "I saw [nurse] sort of brushed off what I was asking her about and I didn't ask anybody else. I'd get the same result wouldn't I?" Male, 88

One older lady sought help from both her GP and son, but felt invalidated by both:

- "I never talk with my son about that, because he said like, 'Everything's going to be fine.' He thinks it's nothing. I told him once that I am a lot of stressed and he said 'Mum, you can't have stress.' And then I thought 'I don't have anybody to talk to.' No one believed me." Female, 83

8. *The untenable situation*

Some older people faced untenable situations, for example family conflict, abuse, or perceived betrayal, for which self-harm seemed the only solution.

- "Look, I was unhappy lately because my son became impatient and all my friends one after each other … they dying because they were sick… and if I ask something or if I decide something he [son] said 'you are stupid …" Female, 80

The consequences of self-harm

Themes relating to perceived consequences of self-harm are summarised in Table 4.2.

1. *Becoming engaged with or distanced from family*

   The response of the older person's family to the self-harm was described as either facilitating closeness or rejection.

   - "Well I'm seeing just how beautiful my family is with the care and attention that I'm getting whilst here. They seem to want me to live….., so it's a pretty good reason to stay alive." Male, 89
   - "My daughter started to go off to sleep… She said 'I've heard those, what you are telling me dad, that many times I don't want to hear them currently.' … She's here [in hospital] trying to help me and saying those things.' I felt deflated." Male, 82

2. *The problem was solved*

   For some participants the self-harm led to a better understanding of the original problem (e.g. in the case of receiving a diagnosis) or the problem being addressed (e.g. by resolving family conflict, receiving treatment or gaining practical help).

   - "Yes, and then I felt happy. Definitely that's the right thing and now I go home with assistance and my son help …. I'm satisfied." Female, 83

3. *Gaining control*

   The ability to have control over the end of one's life in the form of an Advance Care Directive was an important solution for some:

   - "let me die in peace, which is my only wish. …. There was a social worker I think who approached me with an advanced care program thing. I read that and studied that one and I signed it with an agreement that I didn't want my life prolonged if I had some serious illness." Male, 86

4. *I'm worse off now*

   Others felt worse off following self-harm:

   - "[I survived]. See, that's where I'm sorry. ….I woke up in hospital, and I realised that my sight was even worse that what it was before- 'cos I wasn't as bad as this… and I couldn't walk…. 'Cos before I could walk without a stick in the house. I was OK ….. I went through all that to no good and I'm worse off." Female, 93

5. *Rejection by health professionals*

Rejection emerged as both a precipitant to self-harm (see above) and a consequence, manifest through the responses of clinicians:

- "One of the nurses…. She was always very cranky …. And suddenly the day after [the overdose] she said to me 'you shouldn't have done that.' She was real cranky … to take my own life." Male, 81

6. *Tension in the role of the inpatient clinical environment.*

Of those admitted to hospital, two subthemes emerged regarding the impact of clinical care:

i. I'm a prisoner here

Hospitalisation was analogous to being in prison for some participants, with locked wards being a particular indignity:

- "… I don't like being here. I'm a self-made man. I don't like being dependent on other people and I don't like being locked up. I don't like having my family frisked when they come. That's an indignity I put them through." Male, 89

ii. I'm safe now

Other participants had a positive experience of hospitalisation:

- "I liked the people around me … in the medical business. I felt safe." Male, 88

Secondary analyses

Themes for participants with suicidal intent

Certain themes regarding the reasons for self-harm were only mentioned by participants for whom self-harm was with suicidal intent, including having lived a good life but feeling 'enough in enough'; 'being a burden'; and 'cumulative adversity'. Two participants with suicidal intent highlighted euthanasia not being available as a contributing factor to self-harm:

- "I didn't dream there was something that exists that a person can't die if they want to." Male, 92

Unique themes for the consequences of self-harm in those with suicidal intent included, 'becoming engaged with or distanced from family'; 'I'm worse off now'; 'the problem was solved'; and 'tension in the role of the inpatient environment'.

Themes for participants with or without dementia.

Three participants with dementia described untenable situations (including two who perceived their children as abusive, and one with a disabled daughter needing lifelong care) as reasons for self-harm. The theme of 'being worse off now' after the self-harm only emerged in participants without dementia.

Discussion

We report qualitative interviews with a culturally diverse, and predominantly cognitively impaired, cohort of older people who had recently self-harmed. Unique insights into their intrapsychic experiences and relationships with family carers and professionals emerged. The analysis has endorsed and enriched current theoretical understandings in this area derived from psychological autopsy and epidemiological approaches.[14] This study "connects the dots" of the risk factors associated with suicide in the elderly, and the very plethora of themes identified shows how this final picture differs between individuals.

Many factors fuel the older person's loss of raison d'etre, sense of alienation and disconnection, key themes that form Joiner's[15] interpersonal theory of suicide and the notion of thwarted belonging,[16, 17] confirmed by our systematic review.[5] It is not surprising that these factors operated amongst the very old in our sample, as such losses increase with age. Furthermore, we have demonstrated the relevance of these issues amongst older migrants, consistent with a psychological autopsy study.[18] Importantly, these factors also operated amongst the cognitively impaired, comprising 90% of our cohort, usually excluded from qualitative research of self-harm,[5] although clearly able to articulate their concerns. Furthermore, similar themes emerge from people regardless of whether self-harm is direct or indirect, perhaps different expressions of the same experiences amongst the very old.

The relational context of self-harm in late life has emerged strongly in our study with perceived and actual rejection fuelling the decision to self-harm, these factors operating as both antecedents to and consequences of self-harm. This was most relevant where self-harm was with suicidal intent. With family conflict, the older person may feel that their family are better off without them.[19] Certainly the role of perceived burden features prominently in previous theoretical formulations of suicide in older life.[17] Older people may be responding with projective identification of an unexpressed wish for their death by family burdened and exhausted by care.

Another important factor in the crucible for suicidal behaviour identified here in people with dementia, and by others,[18, 20] is the untenable situation, sometimes created by dependency on a child perceived as oblivious, uncaring or abusive.[5] People with dementia may be especially vulnerable as cognitive impairment affects problem solving. A similar bind existed for those with insight into their functional dependency, and fear of placement, which may have amplified perceptions of loneliness, abandonment, and nihilism. Depression may be both a consequence of an untenable situation, and contribute, with personality, to the perception of such.[18] Personality traits such as high neuroticism have been associated with suicide in older people,[21] and disinhibition, impulsivity and poor problem solving associated with cognitive impairment[4] or substance misuse compound risk.

Early life adversity also emerged as a theme in those with suicidal behaviours, consistent with literature which demonstrated the role of early abuse,[14] accumulated suffering in late life suicide,[22] growing up in invalidating environments,[23, 24] and the challenges of migration,[18] possibly acting as sensitising factors to subsequent loss.

Most importantly, we have highlighted difficulties older people have in asking for help, including lack of emotional language or communication ability, depression, previous invalidation of concerns, rejection/non-responsiveness of family and/or clinicians, and lack of privacy to disclose abuse. Whether intentionally or not, self-harm was seen by some as a means of obtaining help otherwise unavailable, and for those with suicidal intent it sometimes led to problem resolution whilst others perceived themselves worse off. Hopelessness was both a contributing factor and an impediment to seeking help, long recognised as such.[25]

While sometimes suicidal behaviour "solves problems" by eliciting care, at other times it exacerbates rejection and alienation by the family or clinical system.[5,22, 26] The differentiating factor here was whether individual needs were identified and met. With regards to clinical systems, while some participants reported feeling safe and cared for, even relieved, in hospital, others experienced shame and a sense of punishment for their self-harm that was not psychotically-driven. Many participants strongly opposed nursing home care which was akin to further incarceration.

Implications for management

This study suggests self-harm in older people may be communicating needs not otherwise expressed indicating a need for an individualised person-centred response, akin to the model used for behavioral and psychological symptoms of dementia. The role of

professionals, to be communicated to family carers, is to interpret this need. Clinical pathways should be informed by strategies which address the negative reinforcement loops of invalidation and rejection unwittingly perpetrated by family and professional systems both before and after the self-harm.

In addition to the "big items" of Axis 1 diagnoses of mood, anxiety, psychotic and neurocognitive disorders, psychosocial factors, often dismissed as "small things" also matter- for example, loneliness, burdensomeness, fear of placement, unremitting pain or nausea.[17] These factors are of equal import in the crucible of late-life self-harm, although being less tangible or considered beyond the remit of health care, they are often more difficult to tackle. Nihilistic, helpless, or hopeless responses of heath care professionals do not help; nor do invalidating, guilt-driven responses of families.

This is all grist for the mill for shaping family psychoeducation and therapy following a suicide attempt[19, 27] to facilitate a needs-driven and sensitive response, while acknowledging the challenges of the caregiving role and facilitating caregiver support.[27] For the older person, emergent themes such as being trapped in an untenable situation, and loss of raison d'etre and meaning, suggest a role for cognitive-behavioural therapies. Structured problem solving, for example, which includes caregivers[27] might improve depression, wellbeing and independence.[28, 29] Cognitive therapy has been proposed to counter dichotomous thinking for people describing themselves as a significant burden on others[30] and has been modified for suicidal older people.[31]

Contrary to the policy and focus of many mental health services on risk-based solutions to self-harm, such as risk assessments and containment in secure environments, personalised care and addressing contributory factors to self-harm may be more effective responses.[32] System responses which are perceived by older people as simply aimed at safety and preventing repetition may actually reinforce alienation, hopelessness and rejection, which originally led to the self-harm, potentially (and unintendedly) increasing risk through reinforcement of negative feedback loops.

Strengths and limitations

We deliberately included participants who are often excluded from qualitative research; those who are very old, do not speak English, have psychosis or have dementia- amplifying their voices and subjective experiences. The inclusion of a detailed psychiatric and personal history provided an important context for interpretation and the in-depth interview design

and open-ended questions facilitated the richness of data elaborated. A further strength was the proximity of the interview to the self-harm, reducing recall bias.

The theoretical distinction between non-lethal self-harm and suicide should be borne in mind when interpreting the present study, although previous findings indicate similar risk factors.[18] The use of clinician researchers, albeit considered reflexively, may have inhibited responses, although this suggestion is countered by breadth of emergent themes regarding challenges of the hospital environment.

Conclusions

Self-harm may communicate needs which cannot be otherwise expressed. An individualised person-centred approach, addressing practical, medical and psychological needs, will inform both family and clinical systems. The benefits of safety versus the potential negative consequences of hospitalisation and confinement need consideration.

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Corrigendum to 'Why Do the Very Old Self-Harm? A Qualitative Study' [American Journal of Geriatric Psychiatry 26 (2018) 862–871]

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The authors regret that they have discovered two errors in the above article. In Table 1 (page 865), in the row marital status, the numbers should read married 13 (43.3%), widowed 13 (43.3%), single 4 (13.3%). In the row accommodation prior to self-harm, the numbers should read community 22 (73.3%), residential care 8 (26.7%).

The authors would like to apologise for any inconvenience caused.

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Carer insights into self-harm in the very old: A qualitative study

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Objective: To examine the insights of carers to better understand self-harm in their older relatives.

Methods: An in-depth interview was conducted with the nominated relative/friend (carer) of a person over 80 who had self-harmed within the last month. Carer interpretation and experience of the self-harm and clinical care were explored qualitatively. Audio recordings were transcribed and the content thematically analyzed using N-VIVO.

Results: Thirty-two carers of 30 older people who self-harmed were interviewed. Physical, social, and psychological issues were identified as contributory to self-harm. Themes relating to the perceived barriers to seeking help included "they can't communicate," "suicide and secrets," and "invalidation." Themes for the intent of self-harm were "attention seeking" and "wanting to die." Themes which emerged for consequences of self-harm for carers were "anger," "guilt and self-blame," and "it made us ill." Themes for solutions to address the underlying factors leading to self-harm were "more practical support and structure," "improving communication," "removing means of self-harm," "advance care directives as a solution for suffering," and "ignoring self-harm." Clinical care themes were "shared shame and stigma," "safety and supervision vs being locked up," "clinicians dismissing the carer," and "relief and support."

Conclusions: Validation of carer perspectives and understanding family dynamics may improve communication at various system levels and inform interventions for older persons, concurrently support families, and potentially reduce risk of repeat self-harm. Good care must be holistic, be person-centred, and relieve carer burden. A shared understanding and psychotherapeutic approaches to management of self-harm in late life should be considered.

KEYWORDS

aged, family, old age, relative, self-harm, suicidal behaviours

1 | INTRODUCTION

Self-harm and suicide in older people are recognized as major public health concerns, with suicide rates increasing until age 94 in men and 89 in women.[1] Self-harm may be direct, resulting in immediate pain, injury, or death (eg, overdose) or indirect, which over time may cause harm or death (eg, refusing to eat or drink).[2] Biological, psychological, and social risk factors for self-harm in older people and their interactions have been identified.[3-5] Theoretical mapping of late life suicidal behaviour incorporates systemic factors such as perceived burdensomeness and not belonging.[3] However, empirical study of the family and systemic context is limited, despite the function

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carers play in the system and their potential role as resources to the older person.[6,7]

Most studies have focused on warnings given to relatives, general practitioners (GPs) and home-care nurses prior to suicide[6,8] and their understanding of risk factors contributing to such, with little focus on self-harm.[9] Notable is the lack of communication between members of the system,[6,9] and families' perceptions of the health system as unsupportive, invalidating, and inadequate.[8,10] Furthermore, the psychological effects of self-harm on families are rarely acknowledged or understood.[8]

We have previously reported the reasons for self-harm and its consequences from the perspective of older persons[4] and their GPs.[7] Key themes underlying self-harm described by the older person included loneliness, being a burden, hopelessness, endless suffering, and helplessness with rejection. The themes for consequences of self-harm included becoming closer to, or more distant from family, solving the problem, gaining control, and rejection by health professionals.[4] General practitioners identified individual patient factors contributing to self-harm but did not see themselves as having a role in addressing them.[7] They described particular challenges to care including diagnosing and treating depression (especially in the cognitively impaired) compounded by their own sense of hopelessness and therapeutic nihilism.

The aims of this study were to explore (1) the perspectives of relatives/friends of older people who had self-harmed regarding the reasons for self-harm and potential interventions and (2) the effects on the relatives/friends of the self-harm.

Key points

- Suicidal secrets are common in the family and systemic context of the very old.
- Clinicians, carers, and patients do not talk, and clinicians do not obtain the right information.
- Carers experience considerable distress when their older relative self-harms.
- Understanding the family-carer system may improve communication at various system levels and inform interventions for the older person, including support for the family, potentially reducing risk of repeat self-harm.

2 | METHODS

2.1 | Participants

Participants were nominated relatives or close friends of 30 patients aged 80+ who had self-harmed in the previous month recruited from two tertiary general hospitals and affiliated community centres in Sydney, Australia, in a region where 35% of people aged 65+ were born overseas in non-English speaking countries,[11] as described previously.[4] One participant was interviewed per patient, unless an additional carer requested to take part.

2.2 | Procedure

Individual interviews with both patient[4] and carers were conducted within a month of the self-harm. A questionnaire requesting reflections about the self-harm was sent to the patient's GP.[7]

The relative or friend, hitherto referred to as carer, was interviewed by an old age psychiatrist, and their demographics and relationship to the patient recorded. Given that there was a clinical relationship with the researcher with some of the patients, measures were taken to facilitate open responses from carers. The sensitive nature of the interview content was acknowledged. Specifically, qualitative interviews were temporally and explicitly separated from clinical interactions, reassurance given that honest responses were welcomed without judgement, would be de-identified and would not affect care. Qualitative methodology was utilized.[12] Open-ended questions assisted carers to form a narrative about their experience and interpretation of the older person's self-harm and clinical care.[8] Carers were asked what they thought were the contributing reasons preceding the self-harm. Open-ended questions enquired about help-seeking prior to, and purported intent of, the self-harm, the effect of the self-harm on the carer, potential approaches to addressing the contributing factors, and perceptions of clinical care. Interview duration was determined by the carer's responses. Health care interpreters assisted non-English speaking participants.

All interviews were audio-recorded, and the interviewer took supplementary contemporaneous notes, with audio-recordings transcribed verbatim and the transcripts checked for accuracy.

2.3 | Thematic analysis

The qualitative data management program QSR N-VIVO Pro 11 was used to organize data for analysis. Interview transcripts were uploaded to N-VIVO, and data analysis was undertaken independently by two of the authors (A.W., C.P.). The method of thematic analysis described by Braun and Clarke[13] was used. Specifically, this involved each interview being listened-to and the accompanying transcript read and re-read in full (familiarization with the data), followed by a detailed line-by-line analysis to code the text into themes and subthemes. An iterative approach was used to re-examine previously analyzed data in light of emergent themes. Themes were reviewed, defined, and named. Finally, results between the two analysts were compared and discussed with all authors until agreement was reached.

2.4 | Methodological rigor

A reflexive approach was adopted enabling consideration of the relationship between two of the researchers (A.W., B.D.) and participants. The interviewer (A.W.) maintained a journal noting her clinical role in some of the patient/relative dyads, and memos of her

preconceptions and reflections, and how these factors might influence data interpretation and analysis. Prolonged engagement with the transcripts enhanced trustworthiness of data.[14]

Ethics approval was provided by the South Eastern Sydney Local Health District Human Research and University of New South Wales Ethics Committees.

3 | RESULTS

3.1 | Participants

Thirty-one relatives and one friend of 30 older persons who had self-harmed were interviewed. Two carers were interviewed for two patient participants. Carer demographic details are presented in Table 1. The clinical characteristics of the older adults who had self-harmed, described previously,[4] included a mean age of 86.5 (range 80-102); 50% female; 13 (43.3%) married (an additional 13 people were widowed, four were single), 22 (73.3%) community dwellers, and 13 (43%) non-English speaking. Medication overdose was the most frequent type of self-harm (16, 53.3%) and suicidal intent observed in 20/30 (66.7%). The most common DSM5 psychiatric diagnoses were major depression (13, 43%), dementia (14, 46.7%), and mild neurocognitive disorder (13, 43.3%). Six (20%) patient participants had no psychiatric diagnosis. Most had been admitted to hospital after their self-harm (26, 86.6%).

Carer interviews were conducted on average 17 days after the self-harm (range 1-30). Length of interviews ranged from 14 to 36 minutes (mean 23.5). Results of the thematic analysis of carer interview transcripts are presented as (1) perceived reasons for self-harm; (2) barriers to seeking help prior to self-harm; (3) intent of self-harm; (4) consequences of self-harm; (5) potential solutions; and (6) perceptions of clinical care.

3.1.1 | Perceived reasons for self-harm

The individual contributing factors to self-harm were reflected in the heterogeneity of reasons postulated by carers. Emergent themes included physical illness (eg, chronic pain, vision loss), social issues (eg, interpersonal conflict, carer burden, inadequate practical support, loneliness, avoidance of residential care), psychological distress (eg, anger, early adversity, boredom, loss of meaning/raison d'etre, bereavement), elder abuse, and mental illness. Loss of raison d'etre was prominent:

- "She was fed up with life. She said 'what's the point?' She says, 'I'm not going to get better. I'm just going to get worse. I've lived my life'." [son]

TABLE 1 Characteristics of carer participants

Characteristic	*N* = 32
Relationship to older person who self-harmed	Adult child 24 (75%) Spouse 5 (15.6%) Sibling 1 (3%) Grandchild 1 (3%) Friend 1 (3%)
Sex	Male 15 (46.9%)
Non-English speaker	3 (9.4%)
Co-resident with older person who self-harmed	5 (15.6%)

3.1.2 | Barriers to seeking help prior to self-harm

Carers reported a range of attempts made by the older person to seek help prior to self-harm, with key themes below:

'They can't communicate'

Difficulties communicating were multifactorial, often real and pragmatic such as being non-English speaking or aphasic post-stroke.

- "It might be different if he was a Westerner, but because there is a language barrier as well it's also putting an interface between them [clinicians] and him. So they're not able to actually pick up from the more subtle language signals." [son-in-law]
- "I understand this is what she says 'hm, hm' [gestures with her hands pressing down] 'down, down' with her hands. She wants to go down, down- to die." [daughter]

This was compounded by the difficulty expressing emotion and stoicism of this cohort:

- "..it's never anything that's been verbalised and I think that's the generation. They're just different, so it's always this 'You've gotta be strong', 'you've gotta appear strong' ". [son]

Combining these factors, one relative perfectly captured the recipe for "communication disaster":

- "they actually don't talk about feelings and so they actually don't have the language skills of being able to put their feelings into words … .. And then you interface that with an interpreter [laughs] and it's just a recipe for disaster.", [son-in-law]

Suicide and secrets

Carers observed a lack of communication. Clinicians, patients, and relatives do not talk, and clinicians do not get the right information. Notably, there was a marked discordance between what patients told families and what they told clinicians, with associated assumptions:

- "She's always going to the doctor. So I thought that [depression] was being managed somehow through her constant visits to the doctor and he ordered tests and nothing seemed out of the ordinary." [son]
- "When the nurse from [the hospital], psychiatrist or whatever, went to see him before he told them "I really don't want to kill myself …. I want to get a better service." But he told our relatives, basically, "I don't want to live". [daughter]

Carers understood fear of disclosure:

- "I don't think he would have confided in [the GP] in regards to the self-harm because I think if he did [the GP] would act, or he would do something, or he would tell us". [son]

Some carers facing lack of disclosure actively sought communication with the health care professional.

Invalidation

Carers acknowledged their own invalidation of the older person and the impact of this:

- "… the first time she went into hospital [after an overdose] …. she did say I should go to a nursing home. I just dismissed it basically and said 'Oh, don't be silly'". [son]
- "… she mentioned … 'it's not worth living like this' …. Maybe I didn't take her as seriously as I should of have but I didn't think that was a serious indication that she was thinking about taking her life … just another example of her complaining." [son]

Others expressed frustration at invalidation and dismissal by health care professionals:

- "Well he asked that many times [for medication for dizziness], and she [GP] sort of blew him off. And then, when all this happened [self-harm] …. the first thing she [GP] said …. was 'I'll give you that prescription for Serc that you've been asking for.' Now why didn't she damn well give them to him months ago? And this wouldn't have happened." [wife]

3.1.3 | Perceived intent of self-harm

Carers had a range of attributions for the intent of self-harm including attention-seeking and wanting to die.

3.1.4 | Consequences of self-harm for the carer

The self-harm had direct effects upon carers' wellbeing and attitude toward the older person, as well as practical implications. Key themes were as follows:

Anger

Carers felt angry with the older persons for harming themselves and struggled to empathize:

- "I've been through all those stages of anger, you know, and grief and sadness and all that stuff 'cos it just felt so selfish, but then I don't understand what's going on with him to think that and for him to say that it's the easy way." [son]

Guilt and self-blame

Carers blamed themselves for either not removing the means of self-harm or being unable to care "enough" for the older person.

- "Maybe it's my fault leaving the tablets to her." [daughter]
- "It's my fault. If I hadn't sent her to respite maybe none of this would have happened because she was very happy living at [my] home." [daughter]

(3) 'It made us ill'

The self-harm had a marked effect on family members, with carers describing feeling shocked, exhausted, depressed, and impotent to help their loved ones.

- "The first thing I said is forget about myself. I just try because there is nobody else, it's me … it is very tiring … I find myself that I must also get my energy and not to lose my sanity." [brother]
- "It is having a big impact for my family especially.... Every single time I try to bring the positive energy to sort of change him … but the thing is you can only do so much, talking, talking. After a while he goes back to the same square one. Oh my God! You feel depressed." [daughter]

3.1.5 | Potential solutions

Emergent themes regarding solutions to the factors underpinning self-harm are listed below.

(1) More practical support and structure

The self-harm communicated to carers that the person needed more support, ranging from practical assistance to having more company and stimulation.

- "But now that a routine is starting to establish itself, she is becoming better. They also have somebody else to speak to in the house other than just themselves." [daughter]
- "He's a very bright guy but I think the depressing nature of having no, not necessarily intellectual, I mean no mental stimulus whatsoever must be enormous." [friend]

Improving communication

Carers described their difficulties communicating with clinicians prior to the self-harm and identified this as an important area to be improved upon.

- "So I think it would be a good idea [that] the GP can coordinate into this and keep contact with the family member. … So if some issue happening I can reach him at least." [daughter]

They also encouraged the older person to have more open communication with their clinicians.

- "I said "Dad, don't just tell the doctor what you want him to hear. Tell him what happened. You need to tell him you're struggling …. looking after mum [with dementia]." [daughter]

Removing the means of self-harm

Carers wanted to ensure the self-harm did not recur and suggested practical ways of removing the means of self-harm.

- "When she bite her finger before, take the dentures out so she won't bite anymore." [husband]
- "I'm not gonna leave tablets for her like that." [daughter]

Advance care directives (ACD) as a solution for suffering

Carers identified ACDs both an antidote to their own hopelessness about the person's wish to die and a way of reassuring the older person that their longevity and suffering would not be indefinite and uncontrolled:

- "We did the advanced care directive, which he was actually really pleased about … I guess it gives him that sense of control back." [daughter]

Some carers felt that with no quality of life the person was better off dead, and therefore euthanasia (if legal) appropriate.

- "If we gave people the dignity to end their own lives, I'm pretty much 100% sure that he would take that option". [son]

Ignoring self-harm

For some carers, in the absence of solutions, conscious denial was preferred:

- "In the last time [overdose], we decided to pretend we don't hear … .. And they suggest me 'brother, don't take any notice of him. He's old man …. Only way you can survive like that and calm yourself." [son]

3.1.6 | Perceptions of clinical care

Key themes relating to negative aspects of care were:

Shared shame and stigma

Carers described the stigma of their relative being admitted to a psychiatric ward following self-harm.

- "I've got to be very secretive now, to people who don't know that he did this [overdose]. … .because, you can't tell them the truth … .." [son]

Safety and supervision vs being locked up

There was tension between the carer's desire to keep the person safe and prevent further self-harm through hospitalization, and acknowledgement of the cost to the person's autonomy and dignity. Admission contained carer anxiety:

- "In hospital what has been positive is just having around-the-clock watching of him. Because he does actually need that supervision … he can't be trusted at the moment." [son-in-law]

However, carers acknowledged the cost to the person's freedom and their perception of being imprisoned:

- "His two biggest fears are he doesn't want to end up in a looney bin- in his words- in a mental institution nor does he want to go to a nursing home." [son]
- "He hates being locked up in this place." [son]

Clinicians dismissing the carer

The carer's personal knowledge of the older person was seemingly not valued by clinicians, causing frustration:

- "I did call the Emergency …. they says 'oh, he's OK', you know that he will go home. And I say 'wait a minute. This person is depressed, he wants to hurt himself'." [brother]
- "One doctor I spoke to … he was really dismissive … dismissing with a wave of the hand the observation of someone who'd known him [patient] for a long time." [friend]

Relief and support

Relief emerged from carers who perceived that the person was receiving good holistic care.

- "I feel like finally there's all these little pieces which are being put together …. So there's doctors looking at the liver disease, people looking at the depression. I've got a social worker that I talk to. Now I feel like I'm in one place." [daughter]

4 | DISCUSSION

To our knowledge, this is the only qualitative study of carers of older people who have self-harmed and survived. The carer perspective so contemporaneous with the self-harm echoes and endorses the perspectives of the older persons themselves[4] and enriches our understanding of the family and systemic context of late life self-harm. Carers identified key targets for suicide prevention, including the difficulties that older people have in articulating their distress and seeking help, which may in part relate to not speaking English or communication through an interpreter.[15] This contributes to their lack of engagement with, and sense of invalidation by, health care professionals and even their own carers, amongst whom they perceive a strong sense of helplessness.[4] Our study of GPs of these patients, demonstrated their sense of professional isolation, lack of support and therapeutic nihilism, further reinforcing the carers' and older persons' perceptions.[7]

There were similarities between themes of communication difficulties which emerged in relation to both carers and health professionals. Taking a systemic perspective,[16] these appear to be echoes

of frustration and hopelessness within the system, which we suggest acts synergistically to reinforce the patient's sense of invalidation and hopelessness. This is not surprising given the wider systemic context of ageism, context with perceptions of old age as depressing and associated with loss and loneliness.[17] This triangulation of data means, we cannot dismiss the older person's perception of alienation and rejection,[4] as merely a manifestation of depressive guilt or shame because it was reiterated by carers. Similarly, we cannot dismiss the carers' perception of suicidal secrets and dismissal by health care professionals as projected carer guilt, because it was endorsed by the patients themselves.[4]

The findings from this carer study are consistent with psychological autopsy studies regarding lack of communication between members of the system and the perceptions of unsupportive health systems.[6,8,9] We have demonstrated that compounding this lack of communication is a raft of assumptions and expectations of carers, including that clinicians would communicate self-harm risk to carers.

Equally important is understanding that the family-carer system, while an important source of information for risk factor identification,[9] is also a target for care and support both before and after self-harm. Whether the grief and needs of relatives bereaved by elder suicide[8,18] are also relevant to relatives where elders survive self-harm is unclear, and most research on the impacts of self-harm focus on younger people.[19] Our findings illustrate the adverse personal impact of self-harm on carers, including feelings of anger, guilt, depression, and exhaustion. This is compounded by new physical, psychological, and social burdens imposed by the act itself and necessary responses of changes to supervision, routine, and caregiving arrangements for the older person.

Understanding family distress may also inform suicide prevention. Our study has further illustrated the circular relationships between family burden, anger, helplessness and invalidation, and self-harm in older people. In younger people, suicide communication preceding suicide attempts triggers anger, hopelessness, and fear in significant others and may unearth the carer's own psychic conflicts.[20] We have previously proposed that self-harm in some older people may be a projective identification of their exhausted carer's unexpressed or unconscious wish for the patient's death or an end to their suffering.[4] Carer responses here support this conjecture, by giving voice to understandable carer validation of the person's wish for death and euthanasia. Insights into these family and intrapsychic dynamics can only inform intervention in this setting.

4.1 | Targets for interventions with families and health professionals

Insights from this study inform interventions for both carers and older persons at risk of self-harm. Firstly, the considerable carer distress and its potential impact on the older person themselves provide an impetus for clinicians to include carer "first aid" as part of routine response to late life self-harm. This response should include an opportunity for carer ventilation; with validation of anger, stigma, and self-blame; establishing foundations for a collaborative working relationship. Once intense psychological responses are understood, addressed, and attenuated, hitherto helpless and powerless carers can be better engaged by health professionals instilling hope.[21] Further, narrative approaches, for both carers and patients, may provide insight into relationships, help identify relational difficulties and inform problem-solving approaches, guiding interventions and potentially identifying risks.[22] Narrative production may also be therapeutic for carers of people with dementia,[23] a significant proportion of the present study, and assist service development.[24]

Secondly, information from carers should be valued, not dismissed, by clinicians. This study demonstrated their astute understanding of the needs of older persons who self-harmed, especially the need for raison d'etre, reiterated by the voices of the persons themselves.[4] Carers recognized barriers to care and identified person-centred solutions, often previously dismissed as "small or irrelevant,"[4] but nonetheless useful in countering feelings of helplessness in health care professionals.[7] Carers may also act as conduits for communication between clinicians and older people. Crucially, carers expect health professionals to communicate to them any concerns about mental illness and suicide risk in older people, and education should address barriers to this such as clinician concerns about confidentiality.

Communication problems emerged as key issues operating at various levels of the system, suggesting a role for techniques which facilitate understanding amongst family members and clinicians if not psychotherapy.[16] Family therapy may be under-utilized for older people, despite established associations between interpersonal conflict and mental distress.[16,22,25] Family approaches may highlight the potential roles of family members across generations and stages of the life cycle in understanding the cause and maintenance of problems, such as self-harm in the older person, as well as inform treatment.[16,25] Benbow and Sharman[22] suggest a pyramid starting with family therapy techniques, progressing to formal family therapy in dementia practice, depending on need.[16] Understanding carer projections onto health professionals of carer burden, guilt, and inadequacy may enable more sensitive and effective responses of clinicians.[25] Previous work has focused on carer burden in isolation, rather than based within a family system.[25,26]

4.2 | Limitations

Two authors (A.W., B.D.) were treating psychiatrists for 12 patients, and one author (A.W.) interviewed their relative/friend. This unequal position with the carer could potentially have affected carer responses by influencing their narrative (for, eg, paraphrasing the clinician's formulation or providing expected or socially sanctioned responses), or inhibiting responses. However, the breadth of responses suggests otherwise. These clinical relationships may have affected data analysis and interpretation; this was mitigated by the use of a reflective journal, regular research team discussions during analysis, and independent thematic analysis by an author not clinically involved. We note that the carer group was heterogeneous and that the issues facing carers will differ depending on their relationship to the older person (eg, spouses versus children), whether the person has dementia, their culture, and their language. Further studies should examine these groups to tailor interventions better.

5 | CONCLUSION

Carer insights into the reasons for self-harm in older people illuminate important targets for management, namely better communication between patients, families, and health professionals; avoidance of invalidating/rejecting responses of older people and carers alike; and addressing the significant psychological distress of carers. Psychotherapeutic approaches towards care of all parts of the system, especially understanding the family context, are needed. Ultimately, a goal is to eliminate self-harm as a means of communication between older people and their carers and clinicians.

CONFLICT OF INTEREST

Two of the authors were the treating psychiatrist for some patient participants; potentially representing a conflict of interest.

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PAPER 5:
HOW DO GENERAL PRACTITIONERS CONCEPTUALISE SELF-HARM IN THEIR OLDER PATIENTS? A QUALITATIVE STUDY. (STUDY 1C)

Reference

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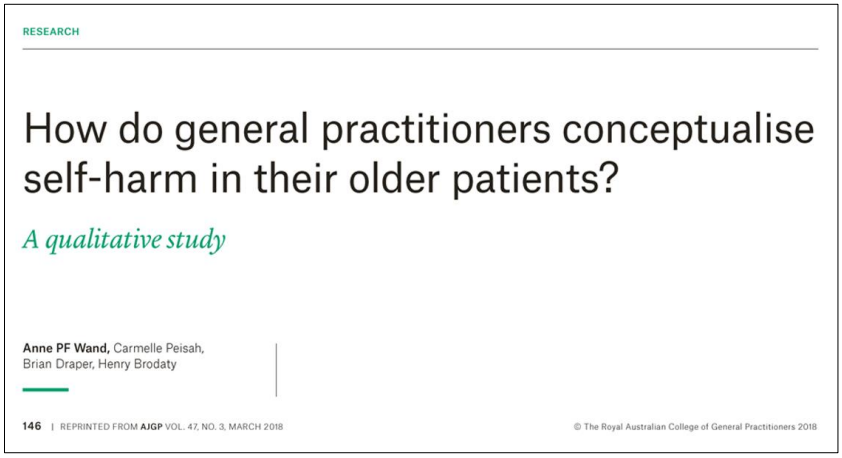
RESEARCH

How do general practitioners conceptualise self-harm in their older patients?

A qualitative study

Anne PF Wand, Carmelle Peisah, Brian Draper, Henry Brodaty

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Declaration

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Anne Wand

How do general practitioners conceptualise self-harm in their older patients?

A qualitative study

Anne PF Wand, Carmelle Peisah, Brian Draper, Henry Brodaty

Background and objectives
Little is known about how general practitioners (GPs) conceptualise self-harm in older people. The aim of this study was to explore GPs' understanding of the reasons for recent self-harm in an older patient.

Method
Short questionnaires were sent to the GPs of patients aged 80 years or older who had recently self-harmed and were participants in a qualitative study about self-harm. Questions evaluated GPs' understanding of the self-harm. Thematic analysis was used to identify and analyse themes.

Results
Thirteen GP responses were analysed. GPs could identify multiple factors contributing to self-harm in their patients but did not see a role for themselves in addressing these issues. They feared repetition of self-harm if these underlying contributory factors, including depression, did not change.

Discussion
Targeted education and practical options for GPs regarding management of the issues underlying self-harm in older people are needed. Families and carers may be underused allies in management. These strategies may serve to counter therapeutic nihilism and clinician isolation.

GENERAL PRACTITIONERS (GPs) are at the front-line of healthcare for older people. Most older people who have died by suicide have seen a GP in the preceding three months,[1] representing a potential opportunity to intervene, an imperative in an ageing population with high rates of suicide, particularly among men.[2]

Self-harm and suicide are closely related in older people, with common risk factors such as depression, pain and social isolation. After an episode of self-harm, there is a high risk of subsequent suicide. Self-harm, which is any self-injurious act carried out by a person regardless of intention, may be direct (eg cutting, overdose) or indirect (eg refusing to eat or drink).[3] A recent psychological autopsy study (which uses informants to reconstruct the lived experience and circumstances of the deceased leading up to their suicide) demonstrated that GPs and carers know much about risk indicators for suicide in their patients and loved ones, with carer knowledge being greater but, often, not communicated to GPs.[4] Several of these risk factors for suicide are potentially remediable and GPs are well placed to identify and manage them.

The understanding and attitudes of GPs to self-harm in older patients have been little studied. One study compared physician responses to hypothetical vignettes involving an employed man aged 38 years and a retired man aged 78 years, both of whom were depressed and suicidal, to explore age biases in management.[5] Physicians detected depression and suicide risk in both vignettes, but they were less willing to treat the older patient and more likely to evaluate suicidal ideation in the older patient as more normal, acceptable and rational.[5]

A qualitative study found that primary care practitioners (GPs and nurses) considered depression in older people as part of a range of psychosocial issues, such as loneliness, dependence and poor social support, rather than a distinct diagnostic category, and that depression was 'justifiable' and 'understandable'.[6] Associated with this was the sense that 'nothing could be done' (therapeutic nihilism), lack of active management, and limited expectations of treatment.[6] While the primary care practitioners identified depression as being within their scope of practice, they reported that they lacked skills, resources and referral pathways for these patients. Others postulated that reasons for the under-recognition and under-treatment of depression in old age[7] include negative attitudes of GPs, inadequate training and ineffective treatment approaches.[8]

Our primary aims were to explore qualitatively GPs' understanding of factors contributing to self-harm in their older patients who had recently self-harmed and how these factors could be addressed; and perceptions of the intent of the self-harm and their concerns about repetition. Secondary aims were to identify potential targets for GP education.

Methods

Ethics approval was granted by South Eastern Sydney Local Health District Human Research Ethics Committee and University of New South Wales (application number 16/269).

Patient participants were aged 80 years and over, had self-harmed in the previous month, and had been recruited to a qualitative study of self-harm in which

Table 1. The clinical and demographic characteristics of patients who had self-harmed

Characteristic	n = 25
Age	Mean 86, range (80–93)
Gender	12 (48%) female
Non–English speaker	11 (44%)
Living arrangement prior to self-harm	Home 18 (72%) Residential aged care facility 7 (28%)
Involved with mental health service/clinician immediately prior to the self-harm	6 (24%) 3 (12%) had recently refused mental health care
Type of self-harm	Overdose 12 (48%) Cutting 5 (20%)* Biting 1 (4%) Refusal to eat 3 (12%) Suffocation 1 (4%) Hitting oneself 3 (12%)* Carbon monoxide poisoning 1 (4%)
Hospital admission post self-harm (where discharged from)	Total: 22 (88%) Psychiatry 13 (52%) Geriatrics 6 (24%) General medicine 3 (12%)
Previous self-harm	11 (44%)
DSM-5 diagnosis	Major depression 10 (40%) Alcohol use disorder 2 (8%) Minor depression 1 (4%) Delirium 1 (4%) Anxiety disorder 1 (4%) Very late onset schizophrenia like psychosis 1 (4%) No psych illness or cog imp 1 (4%)
Dementia	10 (40%)
Mild cognitive impairment	9 (36%)

**NB one patient's self-harm was both hitting and cutting*

they were interviewed by a psychiatrist (AW) about their reasons for self-harm. Patients nominated their primary GP and consented to them being contacted. This study reports data obtained from the GP study. All GPs were contacted by email or facsimile. A questionnaire was developed and included basic demographic information (age, gender, years they have known the patient, how they learned about the self-harm) and open-response questions eliciting their perception of contributing factors to the patient's self-harm, how these factors could be addressed and by whom, their reflections on the intent or purpose of the self-harm and thoughts about the possibility of repetition. Consent to participate was implied by completion of the questionnaire. If not returned, the questionnaire was re-sent. GPs who did not respond were contacted to confirm receipt of the questionnaire and offered telephone completion of the questionnaire. All responders chose written responses.

Data collection and analysis

The study design was qualitative. Thematic analysis was used to identify, analyse and describe patterns in GP responses to open questions.[9] For each of the open-response questions the text was analysed line by line and then grouped into themes and subthemes. An iterative process was used to re-examine previously analysed data in light of emergent themes. Two researchers (AW and CP) independently analysed the GP responses. Where there was disagreement, data were re-examined and discussed until consensus was reached. Descriptive statistics were used for the demographic characteristics of the GPs and patients.

Results

Twenty-five patients who had self-harmed within the previous month consented to take part in the study. Clinical and demographic characteristics are shown in Table 1. Thirteen (13/25, 52%) GPs returned questionnaires. Reasons for declining to participate included lack of interest, not having seen the patient for a while, feeling uncomfortable about commenting, concerns about the validity of patients' consent for non–English speaking patients, citing 'sensitive issues', lack of time and immediate clinical demands.

The mean age of the GPs was 51 years (range 43–63). Nine (69%) were male and most had known their patient for several years (range two weeks to >30 years, mean 15 years excluding the GP who had assumed care of his patient two weeks previously). Two of the 13 GPs did not know that their patient had self-harmed; the remaining 11 had been informed by hospital staff, either directly (8) or via discharge summaries (3); one GP was additionally informed by a patient's family member.

Qualitative analysis

The following themes emerged from the analysis of the responses:

1. Factors contributing to self-harm

1.1 Physical and mental illness
Only two of the 13 GPs failed to identify reasons for self-harm. Typically, GPs identified a raft of possible reasons, including both mental and physical illnesses such as depression, anxiety, delirium and Alzheimer's dementia, sometimes several in one individual. One GP listed 'advanced age' as a contributing factor among a mix of other factors, including chronic pain, depression and early cognitive impairment. A typical list was:

> *Chronic pain; coronary disease; metastatic cancer; fungating cancer – very unsightly, painful, bleeding smelly; worsening arthritis/immobility ...* – GP 21

GPs were less likely to identify cognitive and mood disorders than the psychiatric interviews.

1.2 Psychosocial problems
Social issues, including stress as a carer, isolation, loneliness and bereavement, were also identified. Threats to independence were mentioned as precipitants to self-harm and seen as potentially ameliorable, and moving to residential care was seen as both a trigger to, and a consequence of, self-harm:

> *Concerned about moving to a nursing home ... Addressed by reassurance and organising a carer – NOT moving to a NH* [nursing home] – GP 7

> *Patient was sent [to a nursing] home for future care.* – GP 20

1.3 Hopelessness
Loss of hope, especially that engendered by other practitioners, was identified as a trigger for self- harm. GPs identified the importance of maintaining hope for their patient and how this could be achieved:

> *Has deterioration of vision. Was told via ophthalmologist that week that vision will deteriorate more to total blindness.* – GP 5

A tentative suggestion of how to address the hopelessness engendered by others was offered:

> *Stating [that it was] hard to assess degree of blindness in future, rather than say will be totally blind?* – GP 5

Conversely, some GPs shared, and possibly fuelled, their patient's sense of hopelessness:

> *Nothing could be done – he refused cancer treatment, counselling, antidepressants ... It is unlikely that antidepressants would have helped him anyway.* – GP 21

2. How to address the contributing factors to self-harm

2.1 Someone else
An emergent theme regarding who could address contributing factors was 'someone else' (or 'not me'). GPs generally did not identify themselves as having a role in coordinating their patient's care in relation to self-harm. Only two GPs thought they might have a role in discussing mental health issues with the patient. Another suggested his patient would have received more consistent and continuous care had they seen the same GP at each visit. GPs listed specialists (eg ophthalmologists, psychiatrists), the family, hospital pain clinics, community care providers, dementia support services and local mental health services as potentially helpful to intervene. One GP could not identify anyone who could help the patient.

2.2 Helplessness: I don't know what to do next
Another emergent theme was a perceived lack of treatment strategies. Few specific treatments, such as reassurance and education, were identified, but it was unclear whom GPs thought would be the providers. Practical suggestions were made, including pharmacy-packaged medications and increasing supervision. There were few references to any psychological strategies. One GP asked:

> *How do you deal with depression?* – GP 19

Not all GPs felt powerless. Some had a clear formulation of the problem and how risk of repetition could be mitigated:

> *Early identification of delirium and treat any reversible causes. Early attention to any patient call for help. Provide psychological intervention if patient still has insight or receptive.* – GP 1

Another GP suggested:

> *Coping skills to deal with medical issues* – GP 17

3. Intent of the self-harm
The GPs' perceived purpose or intent of the patient's self-harm included the wish to die, a cry for help, an impulsive behaviour, or a direct expression of depression or frustration. A number of GPs indicated they did not know what the intent of the self-harm might have been.

4. Repetition of self-harm

4.1 If I can't fix the contributing factors they will self-harm again
Most GPs (8/13) were concerned that their patient would self-harm again, particularly if supportive strategies were withdrawn, or the original triggers and contributory factors persisted, especially depression and isolation. Difficulties identifying and treating depression were particularly prominent:

> [Referring to a patient with dementia and recurrent delirium] *Hard to identify depression* – GP 1

> *Ongoing rather resistant depression, social isolation* – GP 11

> *She remains depressed, has low motivation to change and still lives alone ...* – GP 2

In one case the self-harm had continued:

> *Patient is still refusing eating* – GP 19

GPs who were not concerned about repetition felt that the contributing factors to the self-harm had been definitively addressed, cited the absence of any previous self-harm, or noted the patient had promised not to self-harm again.

> *Impulsive action. Spoke to her again. Will not do it.* – GP 17

Discussion

To the best of our knowledge, this is the only qualitative study of GPs of older patients who have self-harmed and survived. Most GPs, having known their patient for well over a decade, recognised the often multiple psychological, social and medical factors underlying self-harm, although their role in addressing these factors was less clear.

Key themes that emerged were GPs' sense of hopelessness and the perception that they had neither a leading role coordinating nor providing care for older patients with self-harm and often complex medical and social needs. Some GPs, seemingly isolated and overwhelmed by their patient's difficulties, expressed therapeutic nihilism, a known impediment to managing depression and suicide in later life.[6,10] Such GP responses may have reflected feelings of guilt or grief at being unable to prevent their patient's self-harm. Consistent with previous research, while GPs identified numerous potential contributing factors to the self-harm, most nominated other clinicians, services or family to address the issues.[11] This may have been feasible if there were a close and continuing relationship between GP, family and/or mental health services; our data suggest otherwise. Only one family member communicated the self-harm to the GP; most (19/25, 76%) of the older patients in this study were not being seen by mental health services prior to their self-harm.

We do not know whether GPs contacted families. It is possible that this did not occur because of misunderstandings about the limits of confidentiality in the therapeutic relationship, although self-harm and suicide risk are valid reasons for waiving confidentiality. Next-of-kin know much about their relatives' suicide risk indicators, but rarely communicate this information to GPs.[4] This represents a missed opportunity to identify patients who may have disclosed suicidal ideation to carers but not health professionals,[12,13] or may have other potentially remediable suicide risk factors.[4] Communication with carers could also have provided support, instilled hope and validated the family's role.[4,14] Similarly, few GPs mentioned referral to, or communication with, mental health services, which could have been helpful especially for patients with apparent treatment resistance.

We confirmed that, often, when depression is identified in older people, GPs lack confidence and feel a sense of therapeutic helplessness.[6,7,15] GPs highlighted difficulty identifying depression in people with cognitive impairment, and lack of knowledge and skills in treating depression in older people previously identified.[5,8,10]

Dementia and cognitive impairment were similarly under-detected by GPs or perhaps not recognised as relevant to self-harm, which is in contrast to the psychiatrist's assessment. What impact the presence of cognitive impairment/dementia has on GP concepts of self-harm is unknown.

One way to address these barriers would be through better education on cognitive impairment and depression in later life, particularly non-pharmacological options. The recognition of patients' hopelessness as an important risk factor should also be highlighted. The lack of GP references to psychological strategies to improve coping or treat mental illness was surprising, especially given the Australian Government's subsidised scheme for improving access to psychological treatments – the Better Access to Mental Health Care Program.[16] However, patients in residential aged care facilities (28% in this study) cannot access psychologists through the Medicare Benefits Scheme, but people with dementia and self-harm may access behavioural assessment and management programs through Dementia Support Australia.[17] Another explanation for the infrequent mention of psychological strategies may have been the high proportion of non–English speaking patients (44%), a recognised barrier to accessing psychological interventions.

The GP responses indicate the value of long-term therapeutic relationships with older patients. Their responses suggested warmth, empathy and compassion for the challenges facing their patients who had self-harmed, although possibly to the point of over-identification with their hopelessness. This holistic understanding and therapeutic alliance confirms what patients want from primary care in relation to depression.[18] An Australian study also found that the empathy and openness of GPs to discussing emotional concerns in their older patients played a pivotal part in reducing ideas of self-harm, perhaps more so than treatment of depression.[19] Patients have emphasised the importance of interpersonal aspects of their interactions with GPs, including empathising, listening and understanding, along with technical competence.[18]

Reflexivity, strengths and limitations

There were a number of limitations to this exploratory pilot study. First, the brief questionnaire format by correspondence (a more superficial qualitative typology), together with the small numbers, precluded a more comprehensive exploration of GP perspectives and data saturation. Second, in such a sensitive area, there may have been responder bias – it is possible that those with more interest in, and understanding of, self-harm replied, thereby leading us to overestimate GP competency. Social bias in responses is possible,[20] although inaccurate reconstruction of events and attributions are less likely in this study, with data gathering so proximate to the self-harm.

Two of the authors were involved in the care of some of the patients recruited to the study. Therefore, they may have had contact with the participants' GPs, potentially influencing their responses. Another limitation is that GP responses might also have been enriched by interactions with mental health services following the self-harm. However, the converse may be true, that involvement with secondary health services impeded GPs' connection with their patients and their families – for example through blame, poor communication, or lack of collaboration.

Implications for general practice

Potential targets for GP education include:

- management of depression in older people, particularly when comorbid

with cognitive disorders and suicidal ideation[5,6,8,21]
- instilling hope and optimism in GPs regarding treatment of depression and self-harm in older people, while at the same time exploring GPs' self-blame and the realities of risk prediction,[22] and ensuring accurate understanding that patient confidentiality may be validly breached in situations of disclosures of self-harm or suicide
- effective approaches to reducing depression and suicidal behaviours in older primary care patients, including a program involving practice audit and personalised feedback, written materials, and educational newsletters,[19] and providing GPs with clinical algorithms for treatment of depression in the elderly combined with depression care managers.[23] A depression care manager supervised by a primary care expert and psychiatrist who provides education, support and practical guidance to GPs with the treatment of depression in late life (brief psychotherapy or medication) is also effective in reducing depressive symptoms, improving rates of depression treatment, and improving patient quality of life and function.[24]

Support and sharing responsibility in care plans

- While GPs are the coordinators of care for their older patients, this should not mean isolation and sole responsibility for managing their complex needs. Many of the multifactorial contributing factors to self-harm can be broken down into specific simple interventions to meet the patient's unique needs.
- Practice nurses and primary health networks (PHNs) may also have a key role in care coordination and follow-up.
- GP contact with families and carers should be encouraged, as they are underused informants and allies in treatment[4,13] who could potentially co-manage the reversible factors for self-harm in older people and help monitor suicide risk.[25]
- GPs' sense of alienation and helplessness provide strong justification of the need for enhanced communication, including between specialist mental health services and primary care.
- Peer review groups and supervision (either with peers or psychiatrists) may provide a forum to present professional challenges and help prevent the development of negative attitudes and concern about failure of treatment.[26]

Roles for primary health networks

- The aim of the Australian Government's PHNs was to increase effectiveness and efficiency of medical services for patients through better coordination of care.[27] Suicide prevention initiatives were specifically highlighted as targets for PHN focus in funding and practice.[28] Primary mental healthcare activities targeted for funding included care coordination and clinical support, support for GPs with assessments and directing referrals to the most appropriate service for the patient's needs, and liaison with Local Health Networks and other organisations for follow-up care after a suicide attempt.[29]
- The PHN documents assert that GPs have a fundamental role in providing primary mental healthcare; in assessment, treatment, developing care plans and referral to other services commissioned by PHNs,[29] which conflicts with GP responses here.
- As not all patients who self-harm want, can, or will receive mental health case management, one potential solution would be for the PHNs to develop care coordinator roles. The GP, having identified the contributory factors to their patient's self-harm, could then inform the care coordinator of individual patient needs to facilitate domiciliary assessments and support, specialist aged care, dementia and other clinical services, and appropriate follow-up and monitoring.

Conclusion

GPs have a broad understanding of why their patients may have self-harmed, and often have the benefit of a therapeutic relationship over many years. However, GPs did not nominate themselves as having a role in addressing the contributing factors to self-harm. Particular challenges identified were diagnosing and treating depression, especially with comorbid cognitive impairment, therapeutic nihilism and hopelessness. Educational interventions should target identified gaps in knowledge, practical pathways to address the complex biopsychosocial needs of older patients, and opportunities for better communication, support and referral to specialist services. Additionally, it is within the remit of PHNs to assist with care planning and coordination across services. The importance of engaging family carers in management is emphasised. We plan to test some of these strategies in future work on GP education about self-harm in older people.

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4.2 What are the implications of the self-harm in the very old study for assessing requests for Voluntary Assisted Dying?

While it is important to understand why older people harm themselves, there is also a need to examine why older people may ask others to assist them to die, and whether there are links between the two. This concept evolved some years ago in psychological autopsy work in late life suicide (Snowdon and Baume, 2002). In this study which explored the perceived reasons for suicide a category of understandable (possibly rational) suicide emerged. People who died by suicide in this category perceived life as unbearable due to discomfort, pain or disability or perceived themselves as imposing an excessive enduring burden on their carers due to physical health problems (Snowdon and Baume, 2002). Further, these people had commonly stated that they would have requested euthanasia were it legal in Australia. Some owned the book *Final Exit*, which explores the means by which a terminally ill person may end their lives (Humphry, 1991). It was noted that a majority of suicides in this category with physical illness had comorbid depression, a condition which can affect judgement, making the term 'rational' problematic (Snowdon and Baume, 2002). More recently, a psychological autopsy study of people aged 60 or more reported that 8.5% of suicides belonged to a euthanasia advocacy group, with older suicide cases (aged 60 years or more) significantly more likely to have such membership compared to middle aged cases (35-59 years), and sudden death controls (De Leo *et al.*, 2013b).

In clinical settings, old age psychiatrists, palliative care physicians and geriatricians may assess people who express a preference for euthanasia or have self-harmed because they want to die, but cannot legally access Voluntary Assisted Dying (VAD). Two such cases are described in this thesis (Wand *et al.*, 2016). The two older people (aged 88 and 89) had vastly different reasons for their serious suicide attempts, but both said they would have requested VAD had it been an option. One case, a socially isolated woman, had acute on chronic pain associated with functional disability and was facing the prospect of being unable to fulfil her role as a carer for her husband, which would consequently lead to nursing home placement, an outcome that the couple feared. In the other case, a man had executive cognitive impairment, declining mobility, alcohol misuse and had recently lost his driver's licence, which led to social isolation, boredom and loss of role and purpose. He saw himself as a burden on his children.

An overlap between the drivers of suicide and requests for euthanasia or VAD makes intuitive sense, especially in people with serious medical illness (Fassberg *et al.*, 2016). In Oregon, 80% of people who died under the Death with Dignity Act were over 65 (median 74 years) and the majority had cancer (62.5%) (Oregon Public Health Division, 2019). There were considerable resonances between the themes derived from our qualitative

studies of self-harm in the very old and the reasons cited by those who died under the Oregon Death with Dignity Act, where the most common end of life concerns were loss of autonomy (92%), being less able to participate in activities which made life enjoyable (91%) and loss of dignity (67%) (Oregon Public Health Division, 2019). The potential connection between euthanasia and suicide has been infrequently explored from the perspective of the suicide literature (Fassberg *et al.*, 2016).

These issues have come to the fore in Australia with the passage of the Victorian *Voluntary Assisted Dying Act 2017* and its subsequent commencement in June 2019, and with active bills and parliamentary inquiries in New Zealand, Australian Capital Territory and Western Australia. The public discourse about this issue has included the highly publicised case of Dr David Goodall, a 104-year-old Australian man who wanted assistance to die and finally died by VAD in Switzerland (ABC News 10 May, 2018[1]). Of note, Dr Goodall did not have a terminal illness, but cited poor quality of life in old age as underpinning his decision. He was supported by his family and was hailed by the media as a champion of rights (Guardian online 10 May 2018[2]).

The *Voluntary Assisted Dying Act 2017 (Vic)* requires that an adult must have "decision-making capacity in relation to voluntary assisted dying" to be eligible to receive assistance to die (s 9(1)(c)). More pertinently to the doctoral candidate's body of work, in addition to assessing capacity, the Act also required that the two doctors involved in assessing the person are satisfied that the person is "acting voluntarily and without coercion" (s 20(1)(c), s 29(1)(c)). Clearly the role of undue influence of others on the decision to die was recognised by those crafting the legislation. This is of particular import for older people who, by virtue of their interpersonal contexts, and greater rates of dependency and medical comorbidity, may be especially vulnerable to various psychological pressures to request VAD. Specifically, the findings from our qualitative study showed that perceptions of being a burden upon family and/or society, accumulated suffering and functional dependency, disconnection from others and not belonging, hopelessness, and rejection and invalidation by both health care professionals and carers are relevant to decisions to self-harm, two-thirds of which was with suicidal intent (Wand *et al.*, 2018a; Wand *et al.*, 2018d; 2019).

The potential for VAD legislation to be used as an instrument for elder abuse prompted the doctoral candidate to raise awareness of this issue using the qualitative findings from this thesis (Wand *et al.*, 2018b).

[1] http://www.abc.net.au/news/2018-05-10/david-goodall-ends-life-in-a-powerful-statement-on-euthanasia/9742528 Accessed 13.10.19

[2] https://www.theguardian.com/australia-news/2018/apr/30/david-goodall-australia-oldest-scientist-to-end-own-life-in-switzerland Accessed 13.10.19

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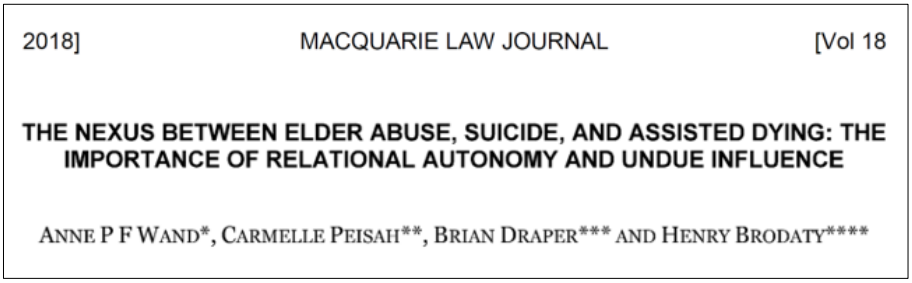
PAPER 6:

THE NEXUS BETWEEN ELDER ABUSE, SUICIDE, AND ASSISTED DYING: THE IMPORTANCE OF RELATIONAL AUTONOMY AND UNDUE INFLUENCE. (STUDY 1D)

Reference

Wand APF, Peisah C, Draper B, Brodaty H. The nexus between elder abuse, suicide, and assisted dying: The importance of relational autonomy and undue influence. *Macquarie Law Journal*, 2018, Volume 18: 79-92.



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THE NEXUS BETWEEN ELDER ABUSE, SUICIDE, AND ASSISTED DYING: THE IMPORTANCE OF RELATIONAL AUTONOMY AND UNDUE INFLUENCE

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Declaration

I certify that this publication was a direct result of my research towards this PhD, and that reproduction in this thesis does not breach copyright regulations.

Anne Wand

THE NEXUS BETWEEN ELDER ABUSE, SUICIDE, AND ASSISTED DYING: THE IMPORTANCE OF RELATIONAL AUTONOMY AND UNDUE INFLUENCE

ANNE P F WAND*, CARMELLE PEISAH**, BRIAN DRAPER*** AND HENRY BRODATY****

The term elder abuse encompasses a wide range of acts or lack of action (neglect) which cause harm or distress to an older person and occur within trusted relationships. Harm may occur when older people are unduly influenced to make decisions, including to end their lives. With the legalisation of assisted dying in Victoria, there is an urgent need to consider the relevant aspects of decision-making in this setting. Assessment of the social and relational context of older individuals is essential in evaluating whether decisions for assisted dying are autonomous or potentially an extreme form of elder abuse, or anywhere in between.

I INTRODUCTION

With the introduction of the *Voluntary Assisted Dying Act* 2017 (Vic)[1] ('the Act') in Victoria, and active bills and parliamentary inquiries into assisted dying in New Zealand, New South Wales, the Australian Capital Territory and Western Australia, there is an urgent need to discuss the potential implications of such legislation for elder abuse. Notably, s 5(1)(i) of that Act specifically acknowledges 'there is a need to protect individuals who may be subject to abuse'.[2] Implicit to such 'protection', and arguably the safe and effective functioning of any assisted dying legislation, is the recognition and mitigation of risks of such abuse.

Older people, the age group with the highest rate of suicide internationally,[3] may be particularly vulnerable to abuse under this legislation[4] given their interpersonal contexts, especially the frequently dependent nature of their relationships and comparatively greater health burden, combined with other psychosocial factors such as perceived burdensomeness influencing decision making.

According to the World Health Organisation, elder abuse can be defined as

> a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an *expectation of trust* which causes harm or distress to an older person.[5]

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1 *Voluntary Assisted Dying Act 2017* (Vic). Notably when using the term 'assisted dying' we use the definition from the Act, namely 'the administration of a voluntary assisted dying substance and includes steps reasonably related to such administration'. Euthanasia is not a legal term and does not have a universally accepted definition, so is not otherwise used in this paper unless specifically used by the reference source.

2 *Voluntary Assisted Dying Act 2017* (Vic) Pt 1 s 5(1)(i).

3 Ajit Shah, Ravi Bhat, Sofia Zarate-Escuredo, Diego DeLeo and Annette Erlangsen, 'Suicide Rates in Five-Year Age-Bands after the Age of 60 Years: The International Landscape' (2016) 20 *Aging and Mental Health* 131, 138.

4 *Voluntary Assisted Dying Act 2017* (Vic).

5 World Health Organization, *A Global Response to Elder Abuse and Neglect: Building Primary Health Care Capacity to Deal with the Problem Worldwide* (2008), 1 <http://www.who.int/ageing/publications/ELDER_DocAugusto8.pdf>.

Elder abuse can take various forms such as physical, psychological or emotional, sexual and financial abuse.[6] It can also be the result of *intentional or unintentional neglect*. This definition clearly includes harm and distress incurred within the context of a relationship where there is exploitation of trust and vulnerability, a key factor distinguishing abuse of older adults and that of younger adults.[7] One means of incurring harm is to adversely influence decision making, otherwise conceptualised as undue influence,[8] a prominent target of Articles 12 and 16 of the Convention on the Rights of Persons with Disability.[9] Hitherto used in the context of will-making and the execution of contractual documents,[10] but also in reference to treatment consent (see *Re T*),[11] undue influence has relevance to both suicide and assisted dying.

Decisions to suicide or to request assisted dying are never undertaken in a vacuum. Relational autonomy[12] suggests that autonomy emerges within and because of relationships,[13] and the corollary of this is that decision-making occurs within and because of relationships. There is evidence of the impact of relationships on the decision to die by suicide,[14] but little attention has been given to the impact of relationships on requests for assisted dying. Clarification of these issues is of upmost importance with the passage of the *Voluntary Assisted Dying Act 2017* (Vic).[15]

The aim of this paper is to explore the ways in which relationships can cause harm mediated by suicide or requests for assisted dying, which by definition constitute elder abuse. We firstly discuss how interpersonal (relationship) factors relate to abuse and suicide. Secondly we explore concepts of undue influence and relational autonomy in the context of suicide and assisted dying in older people; and thirdly, criminal prosecutions. Finally, the implications for policy and guidelines in regards to requests for assisted dying are discussed.

II UNDERSTANDING RELATIONSHIPS, ABUSE AND SUICIDE

People rarely exist in isolation, but function within various interacting social and family systems, which are inextricably linked with mental health. Most older adults with functional and/or cognitive impairment are in dependent relationships with family members and carers, rendering them vulnerable to abuse. Carers may feel stressed and burdened by their caregiving role and the shift in family roles,[16] with anger and conflict culminating in abuse[17] of a myriad of psychological, physical, neglect and financial varieties.[18]

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6 Ibid.

7 Rae Kaspiew, Rachel Carson and Helen Rhoades, 'Elder Abuse: Understanding Issues, Frameworks and Responses' (Research Report No 35, Australian Institute of Family Studies, February 2016) 8.

8 Carmelle Peisah et al, 'The Wills of Older people: Risk Factors for Undue Influence' (2009) 21(1) *International Psychogeriatrics* 7, 15.

9 *United Nations Convention on the Rights of Persons with Disabilities*, opened for signature on 30 March 2007, A/RES/61/106 (entered into force on 3 May 2008).

10 Peisah et al, above n 8, 7.

11 *Re T (An Adult): Refusal of Medical Treatment* [1992] All ER 649.

12 Carolyn Ells, Matthew R Hunt and Jane Chambers-Evans, 'Relational Autonomy as an Essential Component of Patient-Centered Care' (2011) 4(2) *International Journal of Feminist Approaches to Bioethics* 79, 101.

13 Jennifer Nedelsky, 'Reconceiving Autonomy: Sources, Thoughts and Possibilities' (1989) 1(7) *Yale Journal of Law and Feminism* 7, 36.

14 Gustavo Turecki and David A Brent, 'Suicide and Suicidal Behaviour' (2016) 387 *The Lancet* 1227, 1239. This review paper describes the social, including relationship factors associated with suicide, such as living alone, interpersonal stressors, loss and bereavement.

15 *Voluntary Assisted Dying Act 2017* (Vic).

16 Carmelle Peisah, 'Practical Application of Family and Systems Theory in Old Age Psychiatry: Three Case Reports' (2006) 18(2) *International Psychogeriatrics* 345, 353.

17 Susan Kurrle, Paul Sadler and Ian Cameron, 'Patterns of Elder Abuse' (1992) 157(10) *Medical Journal of Australia* 673, 676.

18 Ibid. Kurrle and colleagues describe the frequency of various forms of elder abuse in a sample of community dwelling older people.

In a more indirect way, family relationships have an impact on suicide in older people. The interpersonal theory of suicide[19] recognises the role of relationships in the decisions to end one's life. According to this theory, three factors of thwarted belongingness, perceived burdensomeness and capability for suicide must be present for the decision to suicide. There is empirical evidence to support this hypothesis in older people. Van Orden and colleagues found that greater perceived burdensomeness and painful and provocative experiences were associated with suicide case status.[20] The sense of being a burden to loved ones and/or society has also been identified in quantitative studies of risk factors for suicide,[21] as well as in qualitative work on why older people have self-harmed.[22] This includes our own empirical work that demonstrated the combined effects of feeling like a burden to others, and often compounded by the very helplessness of family and professional caregivers alike.[23] As such, carer stress may amplify the older person's internalised perceptions of burdensomeness.[24] When a carer's burden culminates in an older person's suicide in order to relieve the carer of that distress, it clearly does not constitute abuse. However, it shows the relational pathways of decision making in suicide, which at their extreme can constitute abuse, as will be discussed.

In depressed older adults, the psychiatric and physical health of their carers, and reported difficulties caring, increase the risk of suicidal behaviours in older adults.[25] How this is mediated is unclear, although it has been postulated that the older person may become demoralised by viewing their own depression as burdensome to the family carer and their relationship with them.[26] This demoralisation may lead them to conclude that their family member would be better off without them. On the other hand, it may be that when the family caregiver is not coping they are unable to provide social support to their depressed older relative, increasing the risk of a suicide attempt.[27] It is likely that both possibilities contribute to suicide risk, but passively so. In our own qualitative work on late-life self-harm we have empirically confirmed that the relational context is important, with perceptions of family and caregiver rejection acting as both a trigger for, and consequence of, self-harm.[28] The older person's self-harm may reflect a defensive response of projective identification (when a person projects, onto another, unacceptable feelings or impulses that the recipient adopts as their own), whereby the older person acts out their burdened caregiver's unexpressed wish for their death.[29]

Another mechanism for family relationships culminating in suicide or influencing the decision of an older person to end their life is the untenable situation. In some cases, older people are

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19 Thomas E Joiner, *Why People Die by Suicide* (Harvard University Press, Cambridge, Massachusetts, 2005).

20 Kim Van Orden et al, 'A Case Controlled Examination of the Interpersonal Theory of Suicide in the Second Half of Life' (2016) 20(3) *Archives of Suicide Research* 323, 335.

21 Jerome Motto and Alan Bostrum, 'Empirical Indicators of Near-Term Suicide Risk' (1990) 11(1) *Crisis* 52, 59.

22 Van Orden et al, above n 20, 324; Anne Wand et al, 'Understanding Self-Harm in Older People: A Systematic Review of Qualitative Studies' (2018) 22(3) *Ageing and Mental Health* 289, 298; Joiner, above n 19.

23 Anne Wand et al, 'Why Do the Very Old Self-Harm? A Qualitative Study' (2018) *American Journal of Geriatric Psychiatry* <https://doi.org/10.1016/j.jagp.2018.03.005>.

24 Kimberley Van Orden et al, 'The Interpersonal Theory of Suicide' (2010) 117(2) *Psychological Review* 575, 600.

25 Gregory A Hinrichsen and Nancy A Hernandez, 'Factors Associated with Recovery from and Relapse into Major Depressive Disorder in the Elderly' (1993) 150(12) *American Journal of Psychiatry* 1820, 1825; Richard A Zweig and Gregory A Hinrichsen, 'Factors Associated with Suicide Attempts by Depressed Older Adults: A Prospective Study' (1993) 150(11) *American Journal of Psychiatry* 1687, 1692.

26 Zweig and Hinrichsen, above n 25, 1692.

27 Ibid.

28 Wand et al, above n 23.

29 Projective identification is a defence mechanism or interpersonal communication whereby subtle interpersonal pressure from the carer is placed upon another [older] person to take on the feelings/thoughts of an aspect of the carer – in this context the wish their elder relative was dead. The older person who is the target of that projection then begins to think, feel and behave in the way the carer projected, ie 'I want to die'.

'bullied' into suicide. Family conflict, elder abuse, and complex interpersonal dynamics may lead to untenable situations, whereby suicide is perceived by the older person to be their only option. The following situation illustrates this outcome.

Mrs B was an 86 year old widow with dementia who had recently moved to a nursing home after a prolonged medical admission following a fall. She was referred to an aged care psychiatry service for assessment due to continued refusal to eat and take medications. She was largely mute upon review, but her daughter, a geriatrician and nursing home staff provided a history of massive weight loss (20kg in four months), low mood, reduced talkativeness, and poor engagement with staff. Her daughter had been her primary co-resident carer for the preceding two years. Mrs B's son had learned his sister, and not he, was appointed their mother's representative under Power of Attorney (POA). This was perceived as an unforgivable slight against his expected role as the male of the family in their cultural context. He was also angry his mother had chosen to live with his sister and not move to a nursing home, concerned this would diminish his inheritance. He became increasingly hostile, accusatory and abusive towards his mother for choosing his sister for the POA role. This involved him shouting at her, abruptly stopping and starting the car when driving with her, throwing her rosary beads, accusing his sister of taking advantage of her, and verbally threatening his mother. Her daughter explained: 'Sometimes she'd rush at me [after outings with her son] and just sob and I was powerless to do anything.' The abusive behaviours occurred when Mrs B was alone with her son on weekly scheduled outings. Mrs B's daughter offered her mother an excuse of being 'unwell' to protect against having to experience the weekly visits, but she declined saying 'he's my son and I love him'.

When Mrs B was admitted to hospital after a fall she developed a delirium (an acute confusional state) during which time she voiced paranoid ideas about her son electrocuting her and coming to 'throw me in the Nile'. She was increasingly withdrawn and started to refuse food, most fluids and medication. Her son's abusive behaviours continued in hospital and escalated to the point where he had to be escorted from the building by security staff. Mrs B refused to look at or speak to her son. Subsequently, he was allowed to visit his mother for short periods, and was reportedly quiet and non-confrontational towards her, with no further accusations made about her finances. Mrs B's delirium resolved, but her cognitive and functional impairment had progressed to the point where she needed nursing home care. Upon discharge to a nursing home her oral intake improved, but it was noted she would not eat after her son visited.

Mrs B's indirect self-harm (refusal to eat and take medications) emerged in the context of an untenable situation – elder abuse from her son whom she simultaneously loved and feared. Although she would withdraw during his visits and was visibly distressed afterwards, she was unable to voice this and would not agree to suggested measures to stop him visiting. This response derived from her role as a mother, and also culturally, as he was the eldest child and a man, and as such his position was the head of the family. The indirect self-harm inadvertently served to solve this problem as her son's accusations and overt hostility stopped when she stopped speaking, eating, and taking medications. Mrs B's daughter and others were aware of the abuse, but felt unable to protect her, understanding the complexity of the interpersonal dynamics of the situation for Mrs B. As her daughter summarised, 'She would put up with anything and just wanted to see him because she loves him. He's her son.' Her daughter, the nursing home staff, geriatrician and GP all felt torn between respecting Mrs B's apparent wish to maintain contact with her son and wanting to protect her from her son's abuse. Notably there was no requirement for the abuse to be reported or clear guidelines for how they should respond. Moreover, the reluctance of the older person to cease contact with or prosecute the perpetrator is a common phenomenon for several reasons.[30]

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30 Australian Law Reform Commission, *Elder Abuse—A National Legal Response*, Report No 131 (2017) 209.

Other situations perceived as untenable which have been implicated in the suicide deaths of older adults analysed by psychological autopsy include loss of self-esteem following migration to a different culture, guilt, shame, rejection by spouse, financial disaster and inability to stop drinking alcohol.[31]

III UNDUE INFLUENCE AND RELATIONAL AUTONOMY IN RELATION TO ELDER ABUSE, ASSISTED DYING, AND SUICIDE

A *Undue Influence*

The legal construct of undue influence is usually applied to testamentary undue influence,[32] but it has much broader application. O'Neill and Peisah argue that the concept should be extended to consideration of how relationships may influence decision making, particularly in people with cognitive impairment, who may be influenced by others to make a range of legal decisions in the other person's favour.[33] Undue influence is also relevant to discussions about euthanasia and suicide, particularly when the decision making of individuals is recognised as bound to their relationship context. Peisah and colleagues described several risk factors or 'red flags' for undue influence in will-making, which remain relevant to other areas of decision making.[34] The red flags relate to the social environment, the social circumstances, and vulnerability of the person (testator):[35]

(i) The social environment includes consideration of the relationship with the 'influencer', such as a relationship between an older cognitively impaired person and a family member, helpful neighbour or friend, carer, distant relative, a 'suitor'/de facto partner or spouse (often younger and not cognitively impaired), and professionals (doctors, lawyers, clergy etc).

(ii) The social circumstances that may indicate risk include the presence of family conflict, loss of favour of previously trusted relatives or friends, psychological and/or physical dependency on a carer, and isolation and sequestration.

(iii) The personal factors that render a person vulnerable to undue influence include: physical illness, disability and/or sensory impairment; substance misuse; mental illness (eg depression, schizophrenia, paranoid ideas) and cognitive disorders (delirium, dementia, intellectual disability); psychological factors including mourning and grief, personality disorders; and impaired neuropsychological functions required for decision making capacity (eg problems with judgement and reasoning, apathy/passivity).

B *Relational Autonomy*

Many older people are burdened by these risk factors outlined in the previous section. An understanding of how these factors affect decision-making can be drawn from the concept of relational autonomy, which proposes that the autonomy of individuals is founded upon their social connections and context.[36] Our identity is shaped by social environments and our interactions with other people. Nedelsky suggested that autonomy emerges within and

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31 John Snowdon and Pierre Baume, 'A Study of Suicides of Older People in Sydney' (2002) 17(3) *International Journal of Geriatric Psychiatry* 261, 269.

32 Peisah et al, above n 8, 6.

33 Nick O'Neill and Carmelle Peisah, *Capacity and the Law* (Australasian Legal Information Institute (AustLII) Communities, 2nd ed, 2017).

34 Peisah et al, above n 8, 10.

35 Ibid.

36 Ells, Hunt and Chambers-Evans, above n 12, 86.

because of relationships.[37] According to this concept, self-identity and decision making capacity are dynamic and change with the individual's network of relationships, and their cultural and social context.[38] For example, in Maori people (and some other indigenous peoples), decisions about an individual may be made as part of a family group in a cultural context: *taha whanau* (family health).[39] In relation to decision making specifically, a relational autonomy approach promotes understanding and incorporating a person's interpersonal context when assisting them to make choices in line with their sense of self and values.[40]

A related concept in evaluating whether a decision is made autonomously is authenticity. Conditions for authenticity stipulate that the persons' decisions, beliefs, values and commitments are identified as their own, coherent with their sense of self and identity.[41] Thus, even though most tests of decision making capacity focus upon procedural aspects (ie understanding, retaining and weighing up relevant information and then communicating a decision) and emphasise capacity being decision-specific, the context of the person should also be considered to ensure the decision is autonomous.[42] This context includes authenticity, consistency and social dimensions – that decisions are made in line with the persons' values, commitments and beliefs and in continuing interactions with others.[43] As we are social beings, we are accountable for these decisions and must be able to explain the reasons for making decisions and take responsibility for them and their consequences. Understanding undue influence and relational autonomy may be the key to understanding why some older people decide (or not) to attempt suicide or, in the future, request assisted dying.

Long term abuse and family violence also affect autonomy and decision-making through the insidious undermining of self-esteem and identity. When a person has a mental disability, including vulnerability in terms of sense of self and identity, more time must be spent understanding their values and decisions and exploring aspects of authenticity, accountability and social context necessary for autonomy.[44] One example is the following case of Mrs H, as discussed by Mackenzie:

> Mrs H is a woman with an aggressive bone cancer who has had a leg amputation as part of treatment. Her husband has just left her due to her disability, disfigurement and the anticipated burden she would pose on him. She is a woman who has a poor sense of self, with a practical identity determined by norms of traditional femininity, such that her husband's leaving her results in her feeling worthless and with no reason to live. [45]

This self-concept informs her decision to decline further treatment and to tell the treating team that she wants to die.[46] It is not difficult to see how her position could extend to a request for assisted dying. The difficulty in assessing the autonomy of decision making here is that her sense of self or identity and the values she endorses seem to stem from an oppressive social relationship.[47] Mackenzie suggests that Mrs H's autonomy in the decision to stop treatment, and potentially to go on to request assisted dying, is therefore compromised. This is because her capacity to reflect has been impacted by distorting influences, and the appropriate response for the medical team would be to try and shift Mrs H's perception of her situation,

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37 Nedelsky, above n 13, 36.
38 Ells, Hunt and Chambers-Evans, above n 12, 86.
39 Tane Ora Alliance, *Taha Whanau – Family Health* <https://www.maorimenshealth.co.nz/te-whare-tapa-wha-health-whare/taha-whanau-family-health/>.
40 Ells, above n 12, 87.
41 Catriona Mackenzie and Wendy Rogers, 'Autonomy, Vulnerability and Capacity: A Philosophical Appraisal of the Mental Capacity Act' (2013) 9(1) *International Journal of Law in Context* 37, 52.
42 Ibid 44.
43 Ibid 45.
44 Ibid 50.
45 Catriona Mackenzie, 'Relational Autonomy, Normative Authority and Perfection' (2008) 39(4) *Journal of Social Philosophy* 512, 533.
46 Ibid 526.
47 Ibid 518.

for example, by helping her explore whether she could see her life as having value within a broader social network (other than just her husband) and identifying sources of self-esteem around which she could reconstruct her identity.[48] Thus patient autonomy can be supported by attention to the relational context.[49]

The issue of autonomy and requests for assisted dying are complex. On the one hand, if ever there was a decision that had to be autonomous it should be the request to end one's life. On the other hand, we have previously encouraged discussion and family consultation about such decisions.[50] In reaching an informed decision to end one's life, we have suggested that the person requesting assisted dying should demonstrate that they have considered the potential adverse impact of their death on their loved ones.[51] Distorted perceptions of relationships and how their death might affect family and friends are relevant here. Discussion with family also allows an opportunity to explore these perceptions, and potentially resolve issues underlying the decision to request assisted dying. Rabins has also pointed out that whether there is a 'good reason' to die by suicide, family and friends are often permanently and seriously damaged by such a death of their loved one.[52] Whether this is also the case in assisted dying remains to be seen, although some families have reported feeling pressured to accept a relative's wish for assisted dying when repeatedly threatened with the alternative prospect of their suicide.[53]

The reality is that notwithstanding burdened carers and a failing sense of self, a decision for assisted dying is never made in a vacuum, nor should it be. Principles of relational autonomy may be used to protect older people from this most serious potential form of abuse. Constraints on the competence condition for autonomy may come from influences which distort capacity for reflection and self-awareness. Cognitive impairment in older people is an obvious cause of such. Traditionally, this has been interpreted narrowly, in terms of impairments in the practical operation of capacity, through compromised functions such as understanding and appreciating information, weighing up the pros and cons of various options and applying these to one's situation and values, and then arriving at a decision.[54] However, cognitive impairment may also impede accurate appraisals of relationships and consequently guide decisions through mechanisms such as changes in personality or family alliances, persecutory ideas, and apathy/passivity.[55] Christman gives other examples of distorting influences such as overpowering emotions, depression or other mental illness, being subject to physical, emotional or verbal abuse, being under the influence of substances which distort perception, or being deprived of educational and social opportunities to develop skills in reasoning, criticism and reflection.[56] Lack of self-esteem or self-confidence, often the end result of longstanding abuse, impair one's capacity to understand his or herself and to respond in a flexible way to life changes. Autonomy is compromised by lack of self-esteem because it is hard to make a decision if one does not think his or her life and activities are worthwhile.[57] Given the array of potential factors described by Christman which may distort self-awareness in younger adults, the additional challenges faced by older adults are particularly sobering. These challenges include impaired cognition causing passivity, impaired reasoning and

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48 Ibid 526.
49 Ells, Hunt and Chambers-Evans, above n 12, 95.
50 Cameron Stewart, Carmelle Peisah and Brian Draper, 'A Test for Mental Capacity to Request Assisted Suicide' (2010) 37(1) *Journal of Medical Ethics* 34, 39.
51 Ibid 38.
52 Peter V Rabins, 'Can Suicide be a Rational and Ethical Act in Persons with Early or Pre-Dementia?' (2007) 7 *American Journal of Bioethics* 47, 49.
53 Claudia Gamondi, Murielle Pott, Sheila Payne, 'Families' Experiences with Patients Who Died after Assisted Suicide: A Retrospective Interview Study in Southern Switzerland' (2013) 24(6) *Annals of Oncology* 1639, 1644.
54 *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 All ER 819.
55 O'Neill and Peisah, above n 33; Carmelle Peisah et al, 'Family Conflict in Dementia: Prodigal Sons and Black Sheep' (2006) 21(5) *International Journal of Geriatric Psychiatry* 485, 492.
56 John Christman, 'Relational Autonomy, Liberal Individualism and the Social Constitution of Selves' (2004) 117 *Philosophical Studies* 143, 164.
57 Mackenzie, above n 45, 525.

reflection, and the disintegration of a sense of self, which is conferred not only by impaired cognition but also by disintegration of the body.

C *Elder Abuse and Undue Influence*

These concepts of undue influence and relational autonomy are highly pertinent to elder abuse in general, as well as to decisions for assisted dying and suicide in older people. Firstly, we deal with elder abuse. Older age often comes with more ill health, which impacts on a person's view of themselves, their needs within relationships, and how they respond to maltreatment in these relationships.[58] Dementia, for example, is more prevalent with increasing age and has been associated with greater risk of elder abuse compared to people without dementia. The risk of elder abuse increases incrementally with the degree of cognitive impairment.[59] Several reasons have been proposed for this increased risk of elder abuse in dementia, including greater ill health, frailty and dependency on family/carers for support, and less ability to defend oneself from physical and verbal abuse.[60] Neglect may occur due to the dependency upon others for activities of daily living and personal self-care (eg continence management). People from culturally and linguistically diverse communities may be at heightened risk of abuse due to language difficulties if their primary language is not English due to dependency on family members for support with instrumental activities of daily living (eg paying bills, seeking health care) and social contact, and potential conflict from different expectations of care between generations.[61]

Abuse in older people may also be long standing, such as 'domestic violence grown old'.[62] For some families and couples, conflict and abuse may be well entrenched patterns of relating which simply persist into old age (thus called domestic violence grown old), rather than arising for the first time in late life. Cognitive or functional changes and ill health in older age may shift the balance of needs in a relationship, for example, with a long-term victim of abuse struggling to provide care for the perpetrator.[63] Additionally, perpetrators of domestic violence may not make good carers, as a poor premorbid relationship may lead to elder abuse.[64] Furthermore, long-term domestic violence is associated with depression and anxiety and the undermining of confidence and self-esteem, capability for independence, opportunities for success and personal development and resilience. Additionally, it may promote isolation.[65] Many of these consequences are also risk factors for undue influence. As discussed above, individuals make decisions in the context of their social environment, personal factors (physical, psychological and cognitive) and significant relationships. Decisions are also guided by how people conceptualise themselves, which may be distorted by abusive interpersonal relationships and social structures, thus impairing autonomy.[66] Therefore, as in the circumstance of making wills, these factors may interact to render an older person vulnerable to undue influence and abuse within their significant relationships.

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58 Lucy Knight and Marianne Hester, 'Domestic Violence and Mental Health in Older Adults' (2016) 28(5) *International Review of Psychiatry* 464, 474.

59 Xinqi Dong et al, 'Decline in Cognitive Function and Elder Mistreatment: Findings from the Chicago Health and Aging Project' (2014) 22 *American Journal of Geriatric Psychiatry* 598, 605.

60 Knight and Hester, above n 58, 466.

61 Dale Bagshaw, Sarah Wendt and Lana Zannettino, 'Preventing the Abuse of Older People by their Family Members' (Stakeholder Paper 7, Domestic Violence Clearing House, 2009) 16 <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.843.2682&rep=rep1&type=pdf>.

62 Chanaka Wijeratne and Sharon Reutens, 'When an Elder is the Abuser' (2016) 205(6) *Medical Journal of Australia* 246, 247.

63 Knight and Hester, above n 58, 466.

64 Claudia Cooper, 'Abuse of People with Dementia by Family Carers: Representative Cross Sectional Survey' (2009) 338 *British Medical Journal*, 583, 586.

65 Knight and Hester, above n 58, 469.

66 Mackenzie, above n 45, 526.

D *Assisted Dying and Undue Influence*

Assisted dying is potentially a fertile ground for undue influence, and this has been recognised in the recent Victorian legislation.[67] Eligibility for assisted dying under the *Voluntary Assisted Dying Act 2017* (Vic) requires a person: to have lived in Victoria for a minimum of one year; to be over the age of 18; to have decision making capacity in relation to voluntary assisted dying; to have a condition which is incurable, advanced, progressive and will cause death; to have six months to live (or 12 months if suffering from particular neurodegenerative conditions such as motor neurone disease which they are expected to die from with 12 months); and experience suffering which cannot be relieved in a manner perceived as tolerable to the individual.[68] Apart from the formal three-step request process, which mandates two independent medical assessments and a written declaration from the person requesting assisted dying, the legislation includes safeguards to protect vulnerable people from coercion and abuse. Requests will be subject to review by a dedicated board.[69] Notably, the Act also requires that the two doctors involved in assessing the person are satisfied that they are 'acting voluntarily and without coercion'.[70] It is also clearly stipulated that a person whose primary reason for requesting assisted dying is a mental illness (as defined under the *Mental Health Act 2014* (Vic)) or a disability (as defined by the *Disability Act 2006* (Vic)) *alone* is ineligible.[71]

Thus, in addition to assessing decision making capacity in relation to assisted dying, clinicians must assess or screen for undue influence. In a proposed legal test for competence to request assisted suicide, we previously emphasised both components of the assessment task. Specifically in relation to undue influence, we suggested that the decision must be made by the person him or herself and not one he/she feels compelled to make, or coerced by others involved in their care into making, in order to relieve them of burden.[72] The possibility of making a voluntary and informed decision despite the likely presence of dependent relationships with carers was noted.[73] The person's strength of will and the degree of pressure upon them to request assisted suicide should also be considered when assessing for undue influence. The same assessment could be usefully applied to the determination of their capacity to request assisted dying.

Terminal illness is of itself a risk factor for undue influence, and it is conceivable that people suffering from the associated physical and psychological symptoms would be more vulnerable to pressure, whether express or implied, from significant others. The definition of a terminal illness is in itself complex. There is a clear difference, for example, between someone with a condition that confers a very short life expectancy and someone with a diagnosis of early Alzheimer's dementia. Whilst a person with early dementia has a statistically shorter life expectancy than someone without dementia of the same age, there is uncertainty about when or how they will die many years before their death. Knowledge of having, or even fear of developing, dementia may confer anxiety about the imagined experience of functional and cognitive decline, which is not often realised.[74] Notably, the *Voluntary Assisted Dying Act* specifies that, for a person to be eligible for access to voluntary assisted dying, they must have a disease that is expected to cause death within weeks or months, not exceeding six months,[75] which is perhaps a protective measure for those contemplating assisted dying in early dementia.

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67 *Voluntary Assisted Dying Act 2017* (Vic).
68 Ibid s 9.
69 Ibid pt 9.
70 Ibid ss 20(1)(c), 29(1)(c).
71 Ibid ss 9(2)–(3).
72 Stewart, Peisah and Draper, above n 50, 38.
73 Ibid.
74 Brian Draper et al, 'Early Dementia Diagnosis and the Risk of Suicide and Euthanasia' (2010) 6 *Alzheimer's and Dementia* 75, 82.
75 *Voluntary Assisted Dying Act 2017* (Vic) ss 9(1)(d), (3).

Depression is not uncommonly comorbid with terminal illness and may influence decision making capacity. It may compound perceptions of hopelessness, isolation and burdensomeness,[76] especially when accompanied by a poor prognosis. For example, depression in patients with cancer with a poor prognosis of less than three months life expectancy was found to be associated with requests for euthanasia.[77] Further, the wish for euthanasia may be state-dependent, as preferences for euthanasia in depressed older people mostly resolved upon treatment for depression.[78] Depression can be screened for in the terminally ill, and there is evidence that treatment is effective and can improve quality of life.[79] It is worth noting, however, that the presence of depression does not automatically preclude decision making capacity, a point which has been raised elsewhere.[80]

E *Suicide and Undue Influence*

Older people, especially those reliant on carers, may feel obliged to end their lives by suicide to reduce care giver burden, for similar reasons to those proposed to potentially underlie euthanasia requests. We have previously described two cases of older people who requested euthanasia, but as it was not legal in their jurisdiction, they attempted suicide instead. In one case, an 88-year-old woman who was the primary carer for her frail older husband took an overdose with suicidal intent in the context of acute chronic pain. She had previously expressed a wish to die by euthanasia should she ever lose her independence. The acute pain was a trigger to her suicide attempt as she could no longer perform her caregiving role for her husband and feared both placement in residential aged care facility and becoming a burden on her family. In the other case an 89-year-old man with cognitive impairment and alcohol misuse who lived alone made multiple attempts to end his life. He stated he would have opted for euthanasia were it legal, and concluded that the only solution was to take matters into his own hands. With some awareness of his declining cognition, death for him meant avoiding becoming a burden on his family, nursing home placement and dependency. Avoiding placement also meant that his children would receive the full amount of his estate.[81]

In both of these cases, although there was no apparent external undue influence, it was the interpersonal or relational factors that underpinned their requests for euthanasia and ultimately, as it was unavailable, their decisions to attempt suicide.

IV ASSISTED DYING AND CRIMINAL PROSECUTIONS

Manslaughter and homicide are extreme manifestations of elder abuse. However, the line between assisting a person to die if they ask for help to end their life and abuse or criminal behaviour is not always clear. According to Australian law,[82] aiding and abetting a suicide is a crime. We have previously discussed *R v Justins,*[83] an Australian case of involuntary euthanasia due to incapacity.[84] Two women, Justins and Jennings, were found guilty of the manslaughter of Graeme Wylie, a man with severe dementia and depression who had

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76 Van Orden et al, above n 24, 600.
77 Marije L van der Lee et al, 'Euthanasia and Depression: A Prospective Cohort Study among Terminally Ill Cancer Patients' (2005) 23 *Journal of Clinical Oncology* 6607, 6612.
78 Stuart Hooper et al, 'Preferences for Voluntary Euthanasia during Major Depression and Following Improvement in an Elderly Population' (1997) 16(1) *Australasian Journal on Ageing* 3, 7.
79 Lauren Rayner et al, 'Antidepressants for the Treatment of Depression in Palliative Care: Systematic Review and Meta-Analysis' (2011) 25(1) *Palliative Medicine* 36, 51.
80 Stewart, Peisah and Draper, above n 50, 37.
81 Anne Wand et al, 'Rational Suicide, Euthanasia, and the Very Old: Two Case Reports' [2016] *Case Reports in Psychiatry* 1, 2-3.
82 *Crimes Act 1900* (NSW) s 31C.
83 *R v Justins* [2008] NSWSC 1194 (12 December 2008).
84 Stewart, Peisah and Draper, above n 50, 37.

requested euthanasia but lacked capacity to suicide. Justins was Wylie's long term de facto partner and Jennings was a friend of the couple and a member of the voluntary euthanasia organisation Exit International. Wylie had made suicide attempts and expressed to friends and family a wish to end his life rather than succumb to the inevitable stages of decline in dementia.[85] He did not prepare an advance directive outlining his wishes at the end of life in the event that he had lost capacity or give any indication as to who should make health care decisions for him. An application to visit the Dignitas clinic[86] for euthanasia was written by Jennings on behalf of Wylie in 2005. Dignitas rejected his application due to concerns about his capacity to consent to assisted suicide. Following this rejection, Wylie unsuccessfully attempted suicide again, whilst Justins – who was aware of the attempt – was out of the house at his request. Jennings then visited Mexico in order to procure Nembutal (pentobarbitone), after reading about the effectiveness of the drug for euthanasia, and gave it to Justins upon her return. In the same month Justins took Wylie to his solicitor to change his will which substantially increased her proportion of his estate. The couple had a medical certificate stating Wylie was competent to make his own decisions. Justins testified that she left the open bottle of Nembutal on the table in front of Wylie, which he then poured into a glass. She left the house. Wylie then drank from the glass. Justins returned and found him deceased. An autopsy revealed the Nembutal in his system and confirmed the presence of Alzheimer's disease. The prosecution rejected the women's offer to plead guilty to assisting suicide and a jury subsequently found both women guilty of manslaughter. Jennings killed herself before sentencing and Justins was sentenced to periodic detention. The verdict rested on two key issues: Wylie's capacity to decide to end his life by taking the Nembutal, and whether a reasonable person in Justins' position would have known he had the capacity or explored whether he had the capacity to end his life.[87]

Justins subsequently successfully appealed her conviction in 2010 in the Court of Criminal Appeal (CCA),[88] with a key element in the determination being that a decision to commit suicide need not necessarily be informed in order to be competent.[89] Specifically, Johnson J (with Simpson J agreeing) held that:

> [4] The concept of 'an informed decision' is not apt to an assessment of the capacity of a person to decide to commit suicide. Nor is it useful to speak of a rational decision for which a good reason may be ascribed or identified.
>
> [5] A person possessing capacity may decide to commit suicide on a basis that is ill-informed or not supported by reason, but it may be the reasoned choice of the person, which the law accepts will render the act of suicide the act of the person and not another person who provides the means of death.[90]

It is important to note that the CCA found that, in suggesting a sequential set of capabilities the deceased must have in order to have capacity, the trial judge fell into error because these transformed factual propositions into legal requirements.[91] Notwithstanding these findings, which disconnected clinical criteria for capacity from the determination of whether the act of suicide was the act of the person or the other providing the means of death, the case highlighted the relational context of assisted suicide, notably the question of aiding and

85 Thomas Faunce, 'Medical Law Reporter: *Justins v The Queen*: Assisted Suicide, Juries and the Decision to Prosecute' (2011) 18(4) *Journal of Law and Medicine* 706, 715.

86 Dignitas is an association founded in Switzerland in 1988 with the objective of ensuring a life and death with dignity for its members. They offer services to people internationally, including the possibility of assisted suicide for people making a reasoned request in the context of medical proof and cases of terminal illness, pain or disability.

87 Stewart, Peisah and Draper, above n 50, 37.

88 *Justins v R* (2010) 79 NSWLR 544.

89 Faunce, above n 85, 706.

90 *Justins v R* (2010) 79 NSWLR 544 [4]–[5].

91 Ibid [2].

abetting a suicide or manslaughter,[92] an important distinction in the discourse about assisted dying.[93]

It is unclear what constitutes aiding and abetting in suicide in Australia as there have been no tested cases and, unlike the UK,[94] there are no guidelines for prosecution. The six public interest factors against prosecution that comprise the Policy for Prosecutors in Respect of Cases Encouraging or Assisting Suicide ('the Policy') for prosecuting assisted suicide cases in England emphasise the following: the importance of the victim reaching a determined, voluntary, settled and clear informed decision to end their life; the accused being motivated by compassion; the accused trying to dissuade the victim from ending their life; the minor and reluctant encouragement or assistance to the victim; and the reporting of the suicide to police and assisting in the investigation of the circumstances of the suicide.[95] The emphasis is on the motivation of the accused who assisted the suicide, not the victim. The Policy also suggests that it is not in the public interest to prosecute someone who has reluctantly and compassionately assisted in the suicide of a competent and determined adult.[96]

Assisting suicide will include conduct where the defendant supplies an instrument or drug that a person then uses to kill herself or himself. It can also consist of advice on methods which help the suicidal person in his or her task. If the assistant takes a more active role and actually kills the person (for example, by injecting the patient with drugs), the charge of murder or attempted murder may apply. This was the question in Kate Gilderdale's case.[97] Gilderdale's daughter Lynn had myalgic encephalomyelitis that resulted in a form of chronic fatigue syndrome. She had consistently asked for help to end her life, had attempted suicide and made an advance directive indicating she refused life-sustaining treatment. After Lynn tried and failed to end her life by morphine overdose, Gilderdale administered morphine and injected air into her daughter's veins. She pleaded guilty to assisting a suicide but was found not guilty of attempted murder. The jury expressed much sympathy for Gilderdale's case, deeming her role in the suicide to be compassionate. She was sentenced to 12 months' conditional discharge.[98]

The motivation of the person assisting the suicide is an important determinant for prosecution. In contrast to the Gilderdale case, that in the case of *McShane* is a clear case of (elder) abuse.[99] Mrs McShane was in serious financial difficulty and was convicted under the *Suicide Act 1961* for trying to persuade her mother to kill herself.[100] McShane was video recorded instructing her mother to take an overdose and cautioning her mother, before she took the overdose, not to tell anyone of her (McShane's) role in assisting the suicide in case she would lose her inheritance claim. Her mother did not want to end her life and did not make an attempt. *McShane* illustrates malevolent motivation leading to coercion and pressure on a potential victim, in direct contrast to someone who makes an informed and voluntary decision to end their life,[101] having asked for the assistance of another.

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92 *R v Justins* [2008] NSWSC 1194 (12 December 2008).

93 Faunce, above n 85, 710.

94 Director of Public Prosecutions, *Suicide: Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide* (October 2014) Crown Prosecution Service <http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html>.

95 Ibid.

96 Alexandra Mullock, 'Overlooking the Criminally Compassionate: What Are the Implications of Prosecutorial Policy on Encouraging or Assisting Suicide?' (2010) 18 *Medical Law Review* 442, 470.

97 'Mother Cleared of ME Daughter's Attempted Murder', *BBC News* (online), 25 January 2010 <http://news.bbc.co.uk/2/hi/uk_news/england/sussex/8479211.stm>.

98 Afua Hirsch, 'Kay Gilderdale Case: A Clear Verdict on the Law's Confusion on Assisted Suicide', *The Guardian UK* (online), 26 Jan 2010 <https://www.theguardian.com/uk/2010/jan/25/kay-gilderdale-case-expert-view>.

99 (1977) 66 Cr App Rep 97; R Huxtable, *Euthanasia, Ethics and the Law: From Conflict to Compromise* (Routledge-Cavendish, 2007) 60.

100 *Suicide Act 1961* (UK).

101 *McShane* (1977) 66 Cr App Rep 97 [43(3)].

V IMPLICATIONS FOR POLICY AND GUIDELINES FOR ASSISTED DYING

We have previously recommended an approach to assessing mental capacity to request assisted suicide.[102] The proposed criteria for assessment include evaluating the following: the person's understanding of their conditions and prognosis; their perceptions of quality of life; their ability to give informed consent (including comprehending and retaining relevant information on the potential risks and likely result of taking a drug for assisted suicide, and feasible alternatives); their reasons for requesting physician assisted suicide; and their process of reasoning (weighing up the information and arriving at a decision).[103] Consistency in decision-making should be present over time and in line with past expressed wishes and the person must be able to communicate their wish. Focus was also given to the patient's mental status, mood (and possible mood disorders), general and interpersonal functioning, the presence of internal or external coercion; and

> [t]he decision must be free from undue influence. While patients will still be able to make competent decisions when they are highly dependent on others for care, their decisions must truly be ones that they have made, rather than decisions which they have been forced to make or feel they should make to relieve others of burden. Undue influence must be assessed by having regard to both the patient's strength of will and level of pressure being placed on the patient by others to commit suicide.[104]

In addition, we have highlighted how concepts of relational autonomy are relevant to the assessment of requests for assisted dying. Whilst such a decision must be autonomous, the person must be considered in the context of their relationships, with the accompanying complexity. Where possible, people requesting assisted dying should be encouraged to discuss this decision with their friends and family, not only for support or to ensure they understand the broader effects of this decision on others, but to safeguard against abuse.

Noting the reference in the Act to the need to protect individuals who may be subject to abuse,[105] we propose that a robust set of guidelines be developed to support this and indeed all of the other principles of capacity assessment for the purposes of that Act. Such guidelines need to be promulgated amongst all health practitioners involved in assessments for the purposes of the legislation in line with the principles of training embodied within it.[106] It is the responsibility of all health practitioners involved in assessments for the purposes of the Act to understand the importance of determining capacity and undue influence and the potential for abuse in this context. It is important for the implementation of this legislation that health practitioners understand the legislation and their responsibilities under the legislation. Active policy regarding such specific education is essential given what is already known about the gaps amongst medical practitioners in understanding capacity in general[107] and other key provisions pertaining to end of life, such as withholding and withdrawing life-sustaining medical treatment.[108]

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) published a Position Statement on Physician Assisted Suicide.[109] It was recognised that the practice was illegal at the time of publication and the emphasis was on the ethical issues inherent in physician-assisted suicide, particularly in relation to psychiatrists. Several key points were

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102 Stewart, Peisah and Draper, above n 50, 38.
103 Ibid.
104 Ibid.
105 *Voluntary Assisted Dying Act 2017* (Vic) ss 5(1)(i), 12.
106 Ibid ss 4(b), 17, 18.
107 Greg Young, Alison Douglass and Lorraine Davison, 'What Do Doctors Know about Assessing Decision-Making Capacity?' (2018) 131 *New Zealand Medical Journal* 58, 71.
108 Ben White et al, 'Doctors' Knowledge of the Law on Withholding and Withdrawing Life-Sustaining Medical Treatment' (2014) 201(4) *Medical Journal of Australia* 1, 4.
109 Royal Australian and New Zealand College of Psychiatrists, Physician Assisted Suicide, Position Statement No 67 (2016) 1, 4.

raised: the rights of people with mental illness and that psychiatric illness should never be the justification for physician-assisted suicide; the rights of older people, especially those with dementia; misconceptions about older people and factors underpinning high suicide rates in older people; and the right of doctors to determine whether or not they will be involved in physician-assisted suicide.[110] The RANZCP concluded that the main role of doctors in end of life care is to promote good quality, comprehensive, accessible patient-centric care; that psychiatric assessment and treatment should be provided for people requesting physician-assisted suicide; and that psychiatrists should add their expertise to the debate. Noting the reference to psychiatric expertise in the Victorian legislation,[111] we would add the requirement that psychiatrists be trained in capacity and undue influence assessment.

VI CONCLUSION

With assisted dying now legal in one state of Australia, there is an urgent need to consider how capacity to request assisted dying should be assessed, including the potential for undue influence and abuse. We are social beings and, as such, decision-making capacity, including for assisted dying, must be considered within a relational autonomy framework. Older people are at particular risk of undue influence in decision-making, and we know that relational factors drive decisions to self-harm and suicide in older people. Relationships would therefore be expected to influence requests for assisted dying.

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110 Ibid 2.
111 *Voluntary Assisted Dying Act 2017* (Vic) s 18(1).

Chapter 5 The reflections and outcomes of late life self-harm one year later – what happens? (Study 2)

5.1 Preamble

Little is known about the mental state of very old people who have self-harmed and their outcomes over time. High rates of repetition of self-harm in older people and of completed suicide have been reported (Troya *et al.*, 2019). However, the reasons for these outcomes have been explored mostly quantitatively, by evaluating factors associated with self-harm (Draper, 2014; Fassberg *et al.*, 2016; Fassberg *et al.*, 2012; Troya *et al.*, 2019; Van Orden and Conwell, 2016) rather than by open enquiry with the person themselves and their carers (relatives/friends) and/or health care professionals. Study 2 aims to redress these gaps in the literature by following up the same cohort of patients, carers and GPs one year later using qualitative methodology (interviews and questionnaire data).

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PAPER 7:
SELF-HARM IN THE VERY OLD ONE YEAR LATER.
HAS ANYTHING CHANGED? (STUDY 2)

Reference

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Self-harm in the very old one year later: has anything changed?

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Declaration

I certify that this publication was a direct result of my research towards this PhD, and that reproduction in this thesis does not breach copyright regulations.

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Abstract

Objectives: To follow-up a cohort of older people who self-harmed, their carer, and general practitioner (GP) and examine their reflections on the self-harm, care experiences, and outcomes.

Design: Qualitative in-depth interviews.

Setting: Two teaching hospitals and associated community services.

Participants: Twelve-month follow-up of participants aged 80 or older who self-harmed, their nominated carers, and GPs.

Measurements: A geriatric psychiatrist gathered data through patient and carer interviews using a narrative inquiry approach and from medical records. Interviews were audio recorded and transcribed. N-VIVO facilitated data organization for thematic analysis. Questionnaires sent to the patient's GP examined their perspectives and aspects of care relating to the self-harm.

Results: Nineteen patients (63% baseline sample), 29 carers (90.6%), and 11 GPs (36.7%) were available at follow-up. Themes emerging from patients were "denial and secrets;" "endless suffering;" "more invalidation;" "being heard;" and "miserable in care." Themes from carer interviews were "denial and secrets;" "patient's persistent wish to die;" "abandonment by clinicians;" "unending burden for the carer;" and "distress regarding placement." General practitioner themes were "the problem is fixed;" "the troops have arrived;" and "I understand."

Conclusions: Factors contributing to self-harm persisted at follow-up. Positive and negative responses were identified in the older person's system, highlighting areas for potential intervention. A conceptual framework for understanding self-harm in the very old was derived that emphasized the importance of understanding individual needs, the interpersonal context of the older person, and carer burden. Interventions should improve communication, facilitate shared understanding of perspectives, and provide support at all levels.

Key words: aged care, self-mutilation, suicide, carers, qualitative research

Introduction

The sequelae of self-harm amongst the very old is not well understood. Previous self-harm regardless of intent (De Leo *et al.*, 2002) is strongly associated with subsequent death by suicide (Morgan *et al.*, 2018; Murphy *et al.*, 2012). This may be because older people use more lethal methods, have greater intent to die, and less physiological resilience to self-harm (Bradvik and Berglund, 2009; Finkelstein *et al.*, 2015; Miret *et al.*, 2010). Therefore, studies of older adults who self-harm may usefully inform suicide prevention strategies.

Qualitative approaches that seek the perspective of the older person in understanding the meaning and intent of their self-harm may be especially informative (Van Orden, 2018). In our baseline qualitative studies, 30 people aged 80+ who had self-harmed, their carers, and general practitioners (GPs) were interviewed within a month following self-harm (Wand *et al.*, 2018a; Wand *et al.*, 2018b; Wand *et al.*, 2019). Reasons for self-harm included

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communicating unmet and unarticulated needs, loneliness, disintegration of self, being a burden, helplessness with rejection, hopelessness, and endless suffering (Wand *et al.*, 2018b). While the self-harm facilitated resolution of problems for some, others felt worse off and experienced more rejection, particularly by being "imprisoned" in psychiatric wards. Carers and GPs identified physical, psychological, and social issues that echoed patient perspectives (Wand *et al.*, 2018a; Wand *et al.*, 2019). Carers identified barriers to help-seeking for the older person including invalidation, difficulty communicating with, and being dismissed by clinicians, as well as describing their own intense distress following the self-harm (Wand *et al.*, 2019). Accordingly, carers suggested a range of solutions to assist the older person. GPs largely understood reasons for self-harm but saw others as having a role in addressing them; their own role dismissed with therapeutic nihilism, hopelessness, and helplessness (Wand *et al.*, 2018a).

Despite this work and others (Lebret *et al.*, 2006; Wiktorsson *et al.*, 2010) having elucidated much about the antecedents of self-harm, we know little about the sequalae of self-harm in older people. A study of one-year outcomes using data linkage and medical records showed that older adults who expressed thwarted belongingness at baseline following a suicide attempt were more likely to reattempt suicide during follow-up (Van Orden *et al.*, 2015). Future qualitative studies were recommended to better understand reasons for further suicide attempts.

Equally important, yet also poorly understood, is the impact of self-harm on carers beyond the immediate effects as we have investigated (Wand *et al.*, 2019), and in turn, the impact of carers on subsequent self-harm in older people. Relatives and friends of older people who self-harmed (Testoni *et al.*, 2018) or died by suicide (Harwood *et al.*, 2002) have reported experiences of shame, stigma, and rejection. Further, Zweig and Hinrichsen (1993) found more psychiatric symptoms, relationship strain and difficulty caring amongst relatives of older depressed persons who attempted suicide over a one-year follow-up (Zweig and Hinrichsen, 1993).

The aim of this study was to follow-up our original cohort of older people who self-harmed, their carers, and GPs one year later and to qualitatively examine their reflections on the self-harm, experiences of care, and outcomes.

Methods

We undertook a one-year follow-up of a baseline cohort of 30 people aged 80 or older who had self-harmed; 32 of their nominated carers; and their GPs. Participants were originally recruited consecutively within a month of self-harm from two teaching hospitals and associated community services in Sydney, Australia (Wand *et al.*, 2018b). Self-harm was broadly defined including direct and indirect methods, regardless of intent (Draper *et al.*, 2002), and included, in order of frequency, overdose, cutting, refusal to eat, hitting, suffocation, CO poisoning, and biting (Wand *et al.*, 2018b). The sample size of the baseline cohort was determined by saturation of themes on thematic analysis. Consent for follow-up was obtained at baseline interview and all 30 of the baseline patient cohort, all 32 of the carer cohort, and the 30 patient GPs were contacted by telephone.

Data for this follow-up study were obtained by face-to-face structured psychiatric interviews by a geriatric psychiatrist, review of medical records, and questionnaires sent to the GP. Outcomes such as recurrence of self-harm, all-cause mortality, hospitalization, contact with mental health services, and place of residence were assessed.

The patients and carers were interviewed separately to explore reflections and outcomes of self-harm and perceptions of care one year later. A qualitative approach was taken, involving open-ended questions to assist patients and carers in forming narratives about their reflections (Peters *et al.*, 2013). The duration of the interview was flexible and determined by the participant's tolerance and responses. Interviews were audio-recorded and transcribed verbatim.

The follow-up GP questionnaire evaluated clinical progress (including repeat self-harm), whether contributing factors to the self-harm had been addressed, involvement of and communication with other care providers/services, and use of resources. The effect of the older person's self-harm on the GP's subsequent care with that patient and other patients, and GP preferences for the mode of education on self-harm in late life were explored.

Interview transcripts and GP questionnaires were imported to the qualitative data management program QSR N-VIVO Pro 11 for thematic analysis. Data analysis was undertaken by two authors, who read and coded the transcripts independently. The method of thematic analysis has been described previously (Braun and Clarke, 2006; Corbin and Strauss, 2015; Wand *et al.*, 2018b). The results were compared and discussed with all authors until agreement reached. Secondary analyses were undertaken to explore differences in themes between those with and without suicidal intent and those with repetition of self-harm.

Methods used to enhance methodological rigor included triangulation of patient, carer, and GP data (Corbin and Strauss, 2015). The first author also kept memos of observations made during interviews

and a reflective journal on perceptions and decisions made throughout the study. Trustworthiness of data was ensured through prolonged engagement with transcripts, observations of participants, reflective journaling, and peer discussion (Lincoln and Guba, 1985). Reflexivity was established by consideration of the effect of author clinical roles on participant responses as well as how personal perspectives, beliefs, and values may impact the research.

The study was approved by the South Eastern Sydney Local Health District Human Research Ethics Committee.

Results

Sample and demographics

Nineteen (19/30, 63%) patients were available for follow-up; seven patients died of natural causes (none by suicide); two patients and two proxy consents for cognitively impaired patients declined interview. Five (16.7%) patients repeated self-harm. Other patient characteristics are presented in Table 1.

Twenty nine carers (90.6%) (including six of patients who had died during follow-up period) were available for follow-up; one carer died; one declined to participate; and one could not be contacted. Of the 29 carers, 14 were males. Children (22) or children-in-law (2) of the patient were most commonly interviewed, followed by two spouses, one grandchild, one friend, and one nephew.

The interview duration ranged from 4–34 minutes (mean 16) for patients and 7–46 minutes (mean 18.5) for carers, the duration determined by participants' responses and tolerance of the interview. Interviews were curtailed by irritability or poverty of ideation in patients with cognitive impairment.

Eleven GPs (11/30, 36.7%) aged 30–76 (mean 50 years) returned follow-up questionnaires. Eight were male. Two patients of participating GPs had repeated self-harm in the follow-up period; two other patients died of natural causes.

Qualitative results

Patient themes

At follow-up, patient themes were redolent of those identified at baseline, namely: (i) denial and secrecy; (ii) endless suffering, hopelessness, and further invalidation from clinicians (see Table 2 for themes and illustrative quotes). Patients perceived that nothing could be done to help them and felt mistrusted, invalidated, or ignored by clinicians. As identified previously, patients still felt rejected by and a burden to carers. Eight patients (32%) had a persistent wish to die. An additional and new theme was misery in care, as a consequence of being placed in residential care for greater vigilance (see Table 2). Patients described feeling miserable, defeated and waiting to die, and lacking appropriate care.

A divergent theme was "being heard." Some patients felt well-supported or perceived that the

Table 1. Characteristics of patient participants at follow-up

Characteristic	Number/Mean (%): 19 patients
Age	86.2, range 81-94
Female sex	12 (63.2%)
Died during follow-up period	7/30 (23.3%) none by suicide
Persistent wish to die	8/25 (32%)*
Repeat self-harm	5/30 (16.7%)
	2 by cutting; 1 overdose, 1 self-hitting, 1 attempted jumping from height
	3/30 (10%) were readmitted for self-harm
Dementia	17/26* (65.4%)
	3 converted from mild cognitive impairment at baseline
Major depression	3/22* (13.6%)
Change in accommodation during follow-up period	12/30 (40%)
	11 moved into residential care
	1 was transferred into a hospice
Living in a nursing home	17/30 (56.7%)
Readmission	
Psychiatric ward	3/30 (10%), each was a single admission
Medical ward	17/30 (56.7%), range 0-6 admissions per patient
Contact with mental health services after self-harm	23/30 (76.7%)
Mean duration of contact	12.3 weeks (range 0-52)
	2 patients were still clients of mental health services at follow-up
	4 people newly residing in a nursing home after self-harm had no follow-up

*The denominator varied according to availability of information

Table 2. Themes from patient interviews

Core theme	Illustrative quote
(i) Denial and secrets	"If you ask me anything about suicide, I can't remember anything." 90F
	"... [I] cut my arm when I came here. No one knows. I haven't said anything ... this was my little secret." 94F
(ii) Endless suffering	"I can't be helped. The vision can't improve in any way. My memory is dreadful .... I'm terrible." 94F
	"Why they old people have to live? ... I pray that I don't wake up in the morning." 94F
	"I want to go. I want to die." 90F
(iii) More invalidation	"I guess I was under surveillance. Everybody here was concerned or, if not concerned, at least watching me, which I don't find enjoyable." 87M
	"I don't sleep at all good .... They don't give me anymore sleeping tablets." 94F
	"The doctor knows. They don't have a good solution ... It's pointless to tell them [my problems]." 82M
	"The GP never discussed it [self-harm]. Never brought it up, but I know he knew ... maybe he's thought he doesn't want to get into that." 87M
	"That I did it [self-harm] and twice! We had lots of arguments. Then I got sicker." 85F
	"I said 'darling, could I come home and see you?' She said to me 'I never want to see you in my home again! ... I haven't got a wife anymore." 83M
	"They [children] are helping me quite a bit and they go way beyond what I think I deserve ..... It's just that they are busy and they've got things to do." 86F
(iv) Being heard	"I was very happy that I could stay at my daughter's house ... They are helping me quite a bit." 86F
	"In the past they [facility staff] pushed, they pulled ... Now their attitude is better." 82 M
(v) Miserable in care	"Life here is not much of a life for me .... like a prison, you know. I'm here and that's it." 87M
	"It's a nursing home, but no one gets out alive. You gotta die to get out of here." 94F
	"I think my daughter should come and see me and take me home .... I lost everything." 82F
	"No clinical care ... no one here. They just give me my tablets." 94F
Divergent subtheme: Good care	"It is better, you know, that somebody looks after me ... you have the help and you meet people." 84F

problem was fixed or that the self-harm had resulted in successfully eliciting a caring response from others, including being placed in residential care (see Table 2).

Secondary analysis

No unique themes were identified in the five patients who repeated self-harm; all were nursing home residents, four of whom were newly placed after the initial self-harm, and one of whom subsequently died of natural causes.

Carer themes

With a strong synergism between themes identified by patients and carers, the following themes emerged from carers: (i) denial and secrecy; (ii) patient's persistent wish to die; (iii) abandonment by clinicians; (iv) unending burden for the carer; and (v) distress regarding placement (see Table 3 for illustrative quotes). Secrecy manifested as collusion with the patient in failing to inform clinicians of self-harm. Sometimes this was fueled by the carer's perception of being ignored and invalidated, and even excluded, by clinicians, particularly specialist mental health clinicians whose support may have terminated after discharge from the admission for baseline self-harm. Seven patients were not followed-up at all by mental health services; including four patients newly discharged to a nursing home. Carers expressed concerns about untreated depression in their relative and ageist responses from clinicians. Furthermore, their own distress was often ignored resulting in recourse to finding their own psychological support, all of which culminated in a practical and psychological burden for carers. Notably, as with patients, a divergent theme identified from carers was a sense of relief and satisfaction with care (see Table 3).

Themes from GPs

Three themes emerged from the GP questionnaires: (i) the problem is fixed; (ii) troops have arrived; and (iii) I understand (see Table 4 for illustrative quotes). Perceiving that patients' depression had resolved, all but one GP was unconcerned regarding repeat self-harm. Notwithstanding this, GPs described better awareness of the issues contributing to the individual's self-harm, and a variety of services had been newly engaged including older adult mental health teams, social workers, nurses, private psychiatrists, and community aged care packages. All GPs endorsed liaison between these services and themselves. Seven GPs had spoken to carers about the patient's self-harm. Dementia support services, psychiatrists, and social workers were assessed as most helpful in the aftercare of their patients (see Table 4). There were mixed responses regarding whether the GP felt

Table 3. Themes from carer interviews

Core theme	Illustrative quote
(i) Denial and secrets	"He's never really admitted that to me about harm. He's never spoken about that." Nephew
	"They didn't know when he tried to kill himself. I didn't tell them." Wife [repeat SH]
	"They [facility staff] did have some sort of inkling that she did attempt something, but they didn't know exactly what it was [i.e. cut her wrists], and I didn't let on either." Son [repeat SH]
(ii) Patient's persistent wish to die	"He just keeps talking about it. Talking about 'I don't want to live'." Daughter
	"ever since the overdose, she just wanted to go … she'd wake up in the mornings and say 'Oh no! Not another day!'" Daughter
(iii) Abandonment by clinicians	"The nursing home staff [and the family] had voiced their concerns about Dad's possibility of self-harm and it was being ignored [by mental health] as well." Son-in-law
	"The whole impression they [NH staff] gave was that they regarded some of their charges a bit of a damned nuisance and that they didn't really want to know." Friend
	"Everyone dropped off as soon as she was released [from hospital]." Daughter-in-law
	"The doctor and the case worker, I didn't really get a lot of feedback from them. They didn't really involve me all that much and when they did come round for mum … they preferred that I wouldn't be there." Son
	"She had people talk to her, but we don't know what she said or how she came across. I think maybe if we had of been spoken to more maybe we could have given it a better holistic look…" Daughter
	"He struck me as depressed indisputably." Friend
	"She didn't really improve … she progressively worsened in the sense that she was more distant and her depression was worse." Daughter
	"I find that sometimes [GPs] don't have the experience with the elderly. So, I don't know if they are aware of ways to manage, other than to just say 'well look she's old.'" Daughter-in-law
	"[ambulance officer] said, 'look we'd be really concerned if someone was about 26, but at dad's age and with his condition; he's in pain, he can't walk, he's got your mum with Alzheimer's … it's [self-harm] not such a terrible thing." Daughter
	"I have mentor and friends, so I have been able to talk about it ….. I understand good systems for help… and I have had to have breaks too." Son
Divergent theme: Relief and satisfaction with care	"It seemed as though anyone that had anything to do with mum wasn't just doing it as part of their work. They seemed to have a genuine interest and a genuine caring for people in mum's position." Daughter
	"A warm friendly relationship with a couple of nurses who he talks to and who treat him politely, respectfully, friendly, but I think that is of positive benefit." Daughter
	"But for me and my sister it is a great weight lifted off us, because to see her and to see that she is cared for, knowing that she participates and she even sings and does all sorts …" Daughter
	"There was a lot of transparency which was good." Son
(iv) Unending burden for the carer	"… there [should be] more help to the actual partners, the spouses… Even if there was like a partners' group…. Support groups for the partners of suicide [attempt] victims." Son
	"I need to come here every day. I have to otherwise he will just become unwell." Wife
	"I've never been anywhere over night, but it's always on my mind…. I was expecting to come home and see him [dead]. Son
	"…but just half an hour later [seeing my father] my spirit, emotional will go down so much ….. I have to cheer myself [up] otherwise I'm running down the same path [depression]." Daughter
	"She could get so much more help, but she has turned it down." Daughter
(v) Distress regarding placement	"He had been crying and complaining, wanting to go home. So the nursing home didn't allow family to visit him for a couple of weeks." Wife
	"She cry all the way through every time I come here to visit her. She followed me up to the gate. She bang the gate…. She throw herself [on the ground]." Daughter
	"He would just be in a room by himself. I think they could have been far more proactive in involving him …. Not to leave just because people are being passive and not complaining. … don't assume they are OK." Friend
	"He is worried ….[he says] 'what about if I poo myself, I wee myself? No one cares. No one is coming to check.'" Daughter

Table 3. Continued

Core theme	Illustrative quote
	"He wasn't happy there. . . . he lost all his sparkle." Friend ". . . of course she cried when she saw him [husband] or when she saw us [children]. He felt guilty and all the rest of it." Daughter "As a daughter, I still fight with an unreasonable guilt that I could have done something else . . . . .I know how much she loves her home." Daughter

that their clinical practice with the patient and others had changed as a result of the self-harm. Some recognized changes included involving community services earlier, increased surveillance, and greater awareness of issues contributing to self-harm. All but two GPs felt confident managing self-harm in older adults, especially when they received assistance from mental health services. GP confidence in management also depended upon the patient's supports. GPs welcomed further education on self-harm in older people, preferring online modules.

Discussion

This study is the first to qualitatively examine and triangulate themes related to the sequelae of self-harm amongst older patients, carers, and GPs a year after self-harm. The triangulation of themes strongly validated our findings. As a prospective study, few patients were lost to follow-up, despite their advanced age and the sensitive nature of inquiry. The in-depth interviews allowed participants to discuss personal interpretations and the issues salient to their self-harm. A further strength was that participants could speak about their behaviors in an open and unstructured way (Van Orden, 2018). Importantly, the flexible interview manner, albeit curtailed at times, allowed the voices of older people with dementia to be captured, consistent with the contemporary push to include people with dementia in research from which they would benefit (Black *et al.*, 2013; Dunn and Jeste, 2001; Peisah *et al.*, 2012). The study also adds to the scant literature available on outcomes for nursing home residents who self-harm (Mitchell, 2018).

We found few changes over a year for older people who have self-harmed. Their suffering, hopelessness, and depression persist as does their carers' burden. Patients continue to perceive rejection from carers and clinicians alike; the perception of abandonment by clinicians was shared by carers. Yet, ideally self-harm would lead to better engagement of the patient, not the reverse. Notably GPs' perceptions of understanding the patient, confidence in care provision, and risk resolution were at odds with the negative appraisals of clinicians by patients and carers, of invalidation, ageism, poor communication, and therapeutic nihilism. There may have been a sampling bias in that GPs who reported shame, isolation, and therapeutic nihilism at baseline (Wand *et al.*, 2018a) may not have responded at follow-up. However, the perceived rejection may relate to mental health services rather than GPs, as few patients had ongoing mental health care, particularly those placed in residential care. It is possible that mental health services consider placement as "problem solved," an assumption at odds with the evidence that most suicides occur in the 12 months before and after nursing home admission (Murphy *et al.*, 2015; Murphy *et al.*, 2018). Perhaps the GP responses are a manifestation of a systemic denial in response to this overwhelming problem and wider societal perspectives that old age is inevitably negative (Berger, 2017); reflected also in a carer's recollection of a comment from an ambulance officer that "at his age we wouldn't be so concerned [sic: about suicide]" (Table 2, abandonment

Table 4. Themes from GP questionnaires

Core theme	Illustrative quote
(i) The problem is fixed	"Overcame her depression" GP7 "Now in a more supervised environment [i.e. nursing home]." GP24
(ii) The troops have arrived	"[The hospital], follow-up older [persons'] mental health." GP1 "Clinical nurse specialist, heart support team- has helped [patient] with Advanced Care directive." GP9 "Trying to involve community services earlier. Use of Quick Response Team." GP24
(iii) I understand	"More aware of environmental stimuli contributing to agitation." GP1 "Feels that at 95 she has lived long enough. But is not suicidal/or self harm" GP9

by clinicians). This "what do you expect" societal attitude possibly fuels patient, carer, and GP nihilism and leads to a passive tolerance of suicide in older people.

Regardless, the disconnect between patients, carers, GPs, and specialist mental health services was strongly evident and still manifested by frank "suicidal secrets" as we (Wand *et al.*, 2019) and others (Draper *et al.*, 2018) have identified previously, as well as avoidance, denial, and the difficulty asking for help. Such problems recognizing, communicating, or understanding emotions have been associated with both delay in seeking help for mental health problems (Epstein *et al.*, 2010) and with suicide attempts in middle-aged populations (Levi *et al.*, 2008).

We confirmed previous observations that relatives of older people who attempted suicide experience interpersonal stress, carer burden (including psychiatric symptoms), and difficulty caring for the patient (Zweig and Hinrichsen, 1993), which are often unnoticed and untreated. Distressed and poorly adjusted family members may be unable to provide essential social support for the older person, which in turn increases risk for the older person (Zweig and Hinrichsen, 1993).

A key finding was the distressing effects of residential care placement as an outcome following self-harm. Previously recognized as a significant life event (Murphy *et al.*, 2018), transition to residential care is associated with psychosocial losses (Tanner, 2003) and negative connotations (Boyle, 2005; Forbes-Thompson and Gessert, 2006). In our study, themes of defeat and waiting to die, misery, and difficulties with care predominated. Over half of the patients, admittedly of advanced age and predominantly cognitively impaired, were living in a facility one year later; eleven of these as a consequence of self-harm. Moving to residential care was often perceived as further rejection and invalidation, echoing contributory reasons for the initial self-harm (Wand *et al.*, 2018b), contrary to the perception that the problem is solved or with the evidence base (Murphy *et al.*, 2015; Murphy *et al.*, 2018). This supports the call for resources dedicated to meeting the social and emotional needs of older people both transitioning into and living in residential aged care (Kendall and Reid, 2017; Murphy *et al.*, 2018). Psychiatric services and carers should also be mindful that their responses to self-harm are not solely surveillance and supervision, which may reinforce the patient's sense of powerlessness.

Implications for intervention

It is not surprising that older people have a continued, often unexpressed, wish to die in the face of such disrupted communication in their systems and persistence of factors contributing to self-harm, illustrated by themes such as burden, invalidation, and hopelessness. Patients and carers do not disclose to GPs, and GPs do not routinely communicate with carers or know how to engage better support from specialist services (Wand *et al.*, 2018a), echoing findings from psychological autopsy studies (Draper *et al.*, 2018). An empirically-derived conceptual framework for the direct and wider systemic context of self-harm in the very old was developed by triangulating the themes in responses from patients, carers, and GPs at baseline (Wand *et al.*, 2018a; Wand *et al.*, 2018b; Wand *et al.*, 2019) and this follow-up study (Figure 1).

The systemic context of the older person includes their carer(s), GP, and the broader society; the latter resoundingly echoing the kind of ageist responses articulated by our carers, that self-harm in older people is "understandable" and "not so bad" (Wand *et al.*, 2019). When the older person self-harms, the responses of the system including their carers, GP, and mental health services potentially either help to resolve (e.g. themes of person-centered holistic care, good communication) or reinforce (e.g. hopelessness in clinicians, secrecy and denial, perceptions of burden, rejection and invalidation in patients and carers) self-harm (Figure 1). This conceptual framework is consistent with and builds upon the Interpersonal Theory of Suicide in late life, which emphasizes underlying factors such as perceived burden, thwarted sense of belonging, and pre-existing vulnerability (increased pain tolerance and reduced fear of death) (Van Orden and Conwell, 2016; Van Orden *et al.*, 2010).

Key opportunities for intervention at various points in the systems influencing self-harm in older people are highlighted in the conceptual framework (Figure 1). Strategies aimed at changing attitudes, knowledge, and clinical confidence (and competence) could occur through improving education and support in primary and specialist care, as well as encouraging communication to reduce secrets and denial regarding self-harm and more nuanced (sensitive) responses to risk management. For example, the study reinforces findings that depression (which may contribute to perceived hopelessness, nihilism, and burden) must be detected and treated in older people (Draper, 2014). Yet GP responses in the baseline study demonstrated both a lack of knowledge and optimism about the treatment of depression in older people, especially if comorbid with cognitive impairment (Draper *et al.*, 2010; Mitchell, 2018; Wand *et al.*, 2018a). To some extent, this is reflected in the limited efficacy of antidepressants in dementia and depression (Dudas *et al.*, 2018) where non-drug treatments are first-line

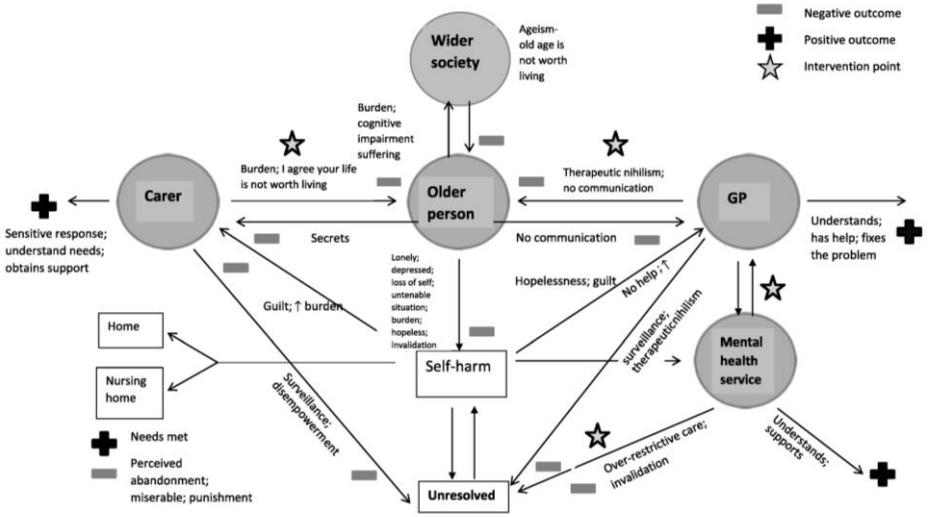

Figure 1. Conceptual framework for self-harm in late life.

interventions (O'Connor *et al.*, 2015; Ortega *et al.*, 2014), although the provision of such by mental health services seemed limited in our study, suggesting scope for improvement. GPs originally identified professional isolation too (Wand *et al.*, 2018a), suggesting a need for better linkage with geriatric psychiatry and other specialist aged-care services. However, at follow-up, GPs were much more positive and noted their involvement and liaison with supporting services as instrumental in addressing issues underlying self-harm. Clearly, there must be more effort to support GPs earlier before self-harm occurs, such as focusing upon prevention rather than a solely reactionary approach to self-harm. We have previously identified strategies such as targeted GP education, support and monitoring from practice nurses, enhancing contact between GPs and carers (the latter who may be helpful informants as well as allies in implementing treatment plans), improving communication between specialist mental health services and GPs, and in Australia, coordination of patient care roles through geographically established Primary Health Networks (Wand *et al.*, 2018a). This study echoes the recognition by others of the importance of follow-up with older adults who self-harm (Lebret *et al.*, 2006), given their ongoing vulnerability and risk of repetition. Better linkage between primary care and specialist aged-care services is important, given the medical, functional, and social issues underlying self-harm in older people (see Figure 1).

Surprisingly, there are no guidelines for how clinicians should approach the medium to long-term care of older people who self-harm. Whether the provision of evidence-based interventions to this cohort over 12-months would reduce repetition and improve perceptions of care and quality of life is unknown and worthy of study.

The conceptual framework emphasizes the relational context of older people who self-harm. Just as older patients who have self-harmed warrant follow-up to ensure the issues underlying their self-harm are addressed, their carers too must be supported. Carer burden was influential in both the older person's decision to self-harm and a consequence of it and persisted a year later. Unravelling the relationship dynamics in families and ensuring that the emotional needs of carers are addressed may be important in addressing elder self-harm (Zweig and Hinrichsen, 1993).

Limitations

It is possible that involvement in the study facilitated better follow-up and support of participants. Two authors were the treating geriatric psychiatrist for some patients, potentially inhibiting or influencing (in the case of shared clinical formulations) participant responses. This may have been particularly evident in the small and potentially biased sample of GP respondents at follow-up. GPs who felt isolated, guilty, nihilistic, and/or disengaged may have been under-represented. Nonetheless, patient and carer responses were broad and largely negative, providing a counterpoint to potential clinician bias, and research measures such memo-keeping, use of a reflective journal, and reflexivity were utilized to enhance methodological rigor. Participant numbers precluded quantitative analysis of outcomes such as repetition of self-harm, suicide, and mortality. We considered patient, carer, and

GP perspectives at a group level. A qualitative exploratory study of patient, carer, and GP triads would add further to the context of old age suicide.

Conclusions

This qualitative study of one-year outcomes of self-harm in older people and the interactions with carers and GPs demonstrated the persistence of many negative themes identified at baseline. A conceptual framework regarding self-harm in the very old was developed that identifies opportunities for interventions to improve outcomes. Ultimately, we need to understand and support all elements of the system as well as the older person who self-harms.

Conflict of interest declaration

None.

Description of authors' roles

A. Wand designed the study, collected and analyzed the data, and wrote the paper. C. Peisah assisted in developing the research question, supervised data collection, analyzed the data, and assisted in writing the article. B. Draper and H. Brodaty assisted in developing the research question and assisted with writing the article. All authors reviewed multiple drafts of the paper and the final version.

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Chapter 6 The educational intervention (Study 3)

6.1 Preamble

The qualitative studies of this thesis provided rich data on self-harm in the very old from the perspective of older persons themselves (Wand *et al.*, 2018c), their relatives/friends (denoted as the carer in the PhD publications) (Wand *et al.*, 2019b) and general practitioners (GPs) (Wand *et al.*, 2018a) both contemporaneous with their self-harm and one year later (Wand *et al.*, 2019a). These data complement existing quantitative research which describes the demographic, social, medical and psychiatric factors associated with self-harm and suicide in older people (Draper, 2014; Fassberg *et al.*, 2016; Mezuk *et al.*, 2014; Troya *et al.*, 2019). The qualitative data derived from this thesis provide insight into the role and interaction of these various risk factors for self-harm in the very old, particularly their meaning for the older person. This is important as many of the identified risk factors are common in older people in general, most of whom do not self-harm (Courage *et al.*, 1993; Crocker *et al.*, 2006; Kjolseth *et al.*, 2009), making it difficult for health care professionals to know where to prioritise assessments and resources and how to intervene. Specifically, the hopelessness in dealing with self-harm in older people identified amongst health care professionals is possibly driven by a lack of understanding of the phenomenon. Hence, there is an imperative to disseminate the findings of this thesis.

General practitioners who participated in this study identified areas where they lacked knowledge, confidence, and practical options for the care of older people who self-harm (Wand *et al.*, 2018a). Specifically, GPs noted difficulty and lacked skills and knowledge in identifying and managing depression in older people *per se*, but particularly in those with cognitive impairment. Combined with this was their therapeutic nihilism in addressing issues underlying late life self-harm and a perceived narrow scope of treatment options. Non-pharmacological strategies for treating depression in older people were absent from their armamentarium, predominantly because of an underestimation of the role of psychosocial factors in the genesis of late life depression and suicide. The absence of communication with the patient's relatives and perceived lack of support from mental health services further compounded the GPs' sense of helplessness and professional isolation (Wand *et al.*, 2018a; Wand *et al.*, 2019a). These findings highlight the need for synthesised, practical, evidence-based information on late life self-harm in primary care.

The qualitative data which emerged from the thesis was combined with the current evidence from the quantitative literature (see Chapter 2) to inform a practical written educational resource for GPs on assessment and management of late life self-harm (Paper 8), with accompanying questions for Continuing Professional Development (CPD) points which the doctoral candidate was invited to write.

PAPER 8:
SELF-HARM IN LATE LIFE:
HOW CAN THE GP HELP? (STUDY 3A)

Reference

Wand APF, Draper B, Brodaty H, Peisah C. Self-harm in late life. How can the GP help? *Medicine Today*, 2019, 20(7): 33-36.

Accompanying Continuing Professional Development assessment. July 2019 issue, Module 1 (CPD). The questions in this module are based on the article 'Self-harm in late life. How can the GP help?' (*Medicine Today*, 2019, 20(7): 33-36), which should be read before attempting the module.


PEER REVIEWED FEATURE 3 CPD POINTS

Self-harm in late life

How can the GP help?

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Declaration

I certify that this publication was a direct result of my research towards this PhD, and that reproduction in this thesis does not breach copyright regulations.

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In late life, self-harm and suicide are closely associated. Thus, good assessment and management of self-harm may prevent suicide. GPs, with their knowledge of the medical, social and psychological issues of their patients, are well placed to intervene and co-ordinate care with relatives and with healthcare and community services. Moreover, GPs are often the first port of call for the older distressed person, and the next port of call after discharge from hospital.

KEY POINTS

- Self-harm is any act of self-injury or self-poisoning, regardless of motivation. This includes indirect self-harm, such as refusing to eat or drink or to take essential medications.
- Self-harm in an older patient should be a red flag for GPs (and all clinicians) to consider suicide risk.
- Understanding what is driving an individual to self-harm may direct intervention.
- The acuity and intent of an individual's self-harm thoughts or actions, access to means and the resources available to him or her will help determine the setting of care and an appropriate response.
- Problems underlying self-harm may be broken down into areas for action by healthcare professionals and other service providers, with the GP in a co-ordinating role.
- Carers are an integral part of effective patient care and are individuals who require support in their own right.
- GPs of older patients who have self-harmed may experience feelings of helplessness. Peer support and resources that promote self-care for medical practitioners are important.

Self-harm occurs predominantly in younger people, often as a way to cope with intense stress or emotional pain rather than with intent to die.[1] However, older people self-harm too, and when they do it is more likely to be with suicidal intent. In fact, suicide rates globally peak in older men. In Australia in 2017, the death rate from suicide was 32.8 per 100,000 men aged 85 years or more – the highest rate of any age group.[2] Suicide rates progressively increase across five-year age bands from 60-64 to 90-94 years for men and become higher at the age band 85-89 years for women.[3] Overall, the most common means of suicide in older people is hanging, followed by firearms/explosives, drug poisoning and nondrug poisoning (e.g. motor vehicle carbon monoxide).[4]

When older people self-harm it should be a red flag for GPs (and all clinicians) to consider suicide risk. Older people who self-harm and those who die by suicide share common risk

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1. FACTORS ASSOCIATED WITH SELF-HARM IN LATE LIFE[6,12-14]

- Living alone, limited social support
- Previous suicide attempts or self-harm
- Psychiatric illness or symptoms: mood disorders (especially depression, but also bipolar disorder), anxiety (including health anxiety), schizophrenia
- Alcohol misuse
- Cognitive impairment (early cognitive decline)
- Physical illness (e.g. chronic worsening disability, chronic pain, delirium, malignancy, neurological disorders, liver disease, male genital disorders)
- Life events (e.g. childhood adversity, physical and sexual abuse, recent bereavement)
- History of limited coping skills in adversity

factors.[5] Self-harm in older people is associated with greater intent to die, higher lethality attempts and subsequent death by suicide.[5,6] A large Australian community study of adults aged 60 years or more found that the two-week prevalence of suicidal ideation was 4.8%.[7] By comparison, a Canadian study of people aged 55 years or more found a one-year prevalence of suicidal ideation of 2.2%; the prevalence of a suicide attempt over the same period was 0.13%.[8] The estimate of lifetime suicidal thoughts was 8.7% and of suicide attempts was 1.8%.[8]

This article focuses on how to assess and manage self-harm in older people in primary care. A previous article, published in the August 2018 issue of *Medicine Today*, dealt with repetitive self-harm in younger people.[1]

What is self-harm?

Self-harm is any act of self-injury or self-poisoning carried out by individuals, regardless of their motivation.[9] Obvious to most clinicians is direct self-harm, namely acts such as taking an overdose, self-cutting or hanging. Ingestion of drugs is by far the most common method of self-harm in older adults, followed by self-cutting and other methods.[10] What is often not thought of, but still considered self-harm, is indirect self-harm – that is, an act of omission or commission that indirectly causes self-harm over time leading to death (e.g. refusing to eat or drink or to take essential medications). Indirect self-harm in nursing homes is more likely in older people with dementia, greater functional impairment and more behavioural and psychiatric disturbance.[11]

Why do older people self-harm?

In epidemiological studies, various demographic, psychiatric, medical and psychosocial risk factors have been associated with self-harm in late life (Box 1).[6,12-14] Although men and women are equally likely to self-harm in late life, men are more likely to die by suicide, one reason being that the means chosen tend to be more lethal.[13]

Many of the risk factors for self-harm identified through quantitative approaches, however, are common to most older people. The relationship between these factors is poorly understood and their meaning may vary between individuals, so it is difficult to know where to focus clinical interventions. Qualitative studies have helped answer these questions. When older people themselves have been asked why they have self-harmed, important themes have emerged (Box 2).[15-19] There is a myriad of personal reasons underlying self-harm in older people, and understanding what is driving an individual may directly inform points of intervention.

Interestingly, carers and GPs of older people who have self-harmed identify similar reasons to patients for the self-harm, but carers may not communicate their concerns to GPs.[20,21] Carers may, often erroneously, assume their relative has disclosed depression or suicidal ideation to their GP.[21] This is especially telling because psychological autopsy studies have similarly revealed that although carers can identify suicide risk factors in their older relative – and more so than the patient's GP – this knowledge was not communicated, suggesting that strategies for strengthening communication represent a key opportunity for change in practice.[22] Even one year after self-harm these 'secrets' may persist, with patients and carers not disclosing repeat self-harm to GPs and mental health professionals.[23]

2. WHY DO OLDER PEOPLE SELF-HARM? THEMES FROM QUALITATIVE STUDIES[15-19]

- Feeling disconnected from others; loneliness
- 'Enough is enough' – a long life has been lived
- 'My ageing body is letting me down', 'I'm falling apart'
- Feeling like a burden
- Cumulative adversity (e.g. migration, early trauma, death of adult children)
- Hopelessness and endless suffering
- Helplessness, with rejection or invalidation from relatives and/or clinicians
- Untenable situations (e.g. elder abuse, family conflict, need for nursing home placement)
- Loss of and regaining control

Clinical assessment and management

Preventing self-harm in older patients

Older people may have physical health comorbidities that bring them to their GP regularly, often resulting in long-lasting therapeutic relationships. Given the myriad of reasons for self-harm in late life, this clinical encounter represents an opportunity for GPs to deal with distressing symptoms and to screen for psychiatric illness, social stressors, and cognitive and functional impairment, especially as patients may not present with self-harm or suicidal ideation. It is important to understand the meaning of the problem to the older person in light of the themes outlined above (Box 2), as this may guide management.

Older people who have self-harmed have described invalidation of their concerns, lack of privacy to disclose abuse or an untenable situation, perceived rejection or non-responsiveness by clinicians and family, and hopelessness as barriers to receiving assistance before self-harm occurs.[18] Thus the

responses of the GP (and other healthcare professionals) to an older person's issues can serve to reinforce or diminish the distress. Comprehensive multidisciplinary and palliative management of distressing physical and psychological symptoms in older people may prevent despair and a sense of abandonment by healthcare professionals. Practical tips for clinical assessment are presented in Box 3.

Responding to disclosures of self-harm thoughts or action

If an older person reveals thoughts of being 'better off dead', self-harming or suicide then a more detailed assessment is needed. This includes exploring when and why these thoughts or plans have arisen. Patients should be asked what they have considered doing and if there has been any action on these thoughts. Careful questioning might determine if they have a means of self-harm or suicide, if they have decided when they would act or if they have made any arrangements in anticipation of their death (e.g. completing a will, giving away possessions). If a patient has means for self-harm then plans should be made urgently to remove access, including by enlisting carer assistance.[24]

It is important to know if a patient has a history of self-harm or suicide attempts, as there is a high risk of repetition.[25,26] The interpersonal supports and personal strategies that a person has to cope with his or her situation and distress should be explored. Unhelpful coping strategies such as substance misuse (especially depressant drugs such as opioids, alcohol or benzodiazepines), which may exacerbate distress or lead to impulsive self-harm, should be highlighted and discussed with the patient. Plans should be made to reduce access (e.g. by removing or limiting the supply of such medication or alcohol in the home) and encourage alternative coping mechanisms. Beware sudden calm in a previously distressed person because this may indicate his or her decision to die by suicide. If there is acuity of risk and intent to self-harm then an immediate plan should be made to address safety (Box 4).

Involving carers

Patients should be encouraged to permit the GP to communicate with their carer, but if they do not and there are disclosures suggesting risk of self-harm or suicide, a breach of confidentiality may be justified.[27,28] This should be explained sensitively to the patient and time should be allocated to speak to the carer separately about their concerns and the GP's regarding self-harm. Carers may be a good source of corroborative history about the patient (and often know much about suicide risk factors), and generally want to be involved and informed about clinician plans.[21,22] They can also be allies in treatment, informing the management plan, knowing what is realistic and possible, assisting in reducing access to means of self-harm, helping monitor symptoms and co-ordinating services for the older person. An open approach helps address the secrecy and poor communication known to occur in self-harm in older people.[23]

Carers of older people who have self-harmed describe intense emotional responses to the self-harm including anger, difficulty empathising, guilt and self-blame that the self-harm occurred, and their own emotional distress (shock, exhaustion, depression and helplessness).[21] They may also experience additional carer burden after self-harm in their relative, through concerns about repetition of self-harm leading to greater supervision or need for practical assistance. Carers of older people who attempted suicide may have difficulty caring for the patient, become distressed, have difficulty coping and feel unable to support the older person, so increasing the older person's risk.[21,29] This suggests that GPs should routinely be asking about the emotional responses of carers and their feelings of burden and offering appropriate avenues of support.

New nursing home residents

Older people may be placed in a residential aged care facility following self-harm. Placement is a major life event often with negative associations and psychosocial losses.[30-33]

3. TIPS FOR CLINICAL ASSESSMENT OF SELF-HARM IN OLDER PEOPLE

- See the older person on his or her own
- Review the impact of the older person's symptoms on quality of life, mood and function
- Acknowledge distress associated with even 'the small things', such as pain or loss of vision
- Identify areas of suffering – physical, psychological, social or spiritual
- Ask directly about thoughts of or actual self-harm – a positive response should elicit more detailed assessment
- Screen for comorbidities – such as depression, substance misuse (alcohol, benzodiazepines and opioids in particular) or cognitive impairment – and flag the importance of managing comorbidities
- Convey optimism that the problem can be managed; be wary of reinforcing hopelessness
- Be wary of ageism: 'What do you expect at your age?'
- Involve specialist services where needed to assist with management
- Encourage the older person to allow his or her carer to be contacted for sharing of information and involvement in management
- Agree on a plan for treatment that focuses on alleviation of suffering
- Schedule another appointment to review progress

This outcome may be due to perceived or actual inability to manage the factors underlying self-harm in the home environment, a healthcare or family response intended to reduce recurrent self-harm (through greater supervision and reduced access to means), or recognition of functional impairment and high-care needs.

Some older people who have self-harmed and subsequently move into nursing homes describe feelings of defeat, misery, demoralisation, 'waiting to die' and difficulties accessing care.[23] The helplessness and invalidation experienced by some older people before self-harming may be reinforced by placement for 'containment of risk', in turn increasing their distress

4. RESPONDING TO SELF-HARM/SUICIDAL IDEATION, PLANS OR ACTION

Acute risk

- Consider the most appropriate setting of care. Does the older person need to be assessed by a mental health clinician in a hospital emergency department or by an acute care team* with a view to admission or can the risks be managed at home with existing support (family, community services) and additional acute outpatient support?
- Assess the patient's level of insight, judgement and willingness to address their issues. If there is ongoing intent to self-harm and symptoms of mental illness combined with unwillingness to accept treatment, consider whether involuntary mental health assessment and treatment are needed (e.g. use of the Mental Health Act).
- Consider whether there is a need to break confidentiality in the interest of patient safety. Speak to carers about the disclosures of suicidal/self-harm ideation and gauge their willingness and/or ability to support the patient (e.g. closer supervision, removal of means of self-harm, assisting to meet the patient's unmet needs).†

Subacute risk (after resolution of self-harm/suicidal ideation or after self-harm)

- Match the underlying factors for self-harm identified in the patient's initial assessment to specific components of a plan to address them.
- Engage specialist medical help to address each of the contributing factors – e.g. geriatric services for medical problems; older persons mental health services; community aged care services for home support.
- Consider whether a psychologist may help with anxiety or depression, ongoing interpersonal difficulties and poor coping through a Mental Health Care Plan. Family therapy may also be indicated to help address ongoing conflict or interpersonal dynamics contributing to patient distress.
- Consider whether there is a need for more domiciliary support or services to meet the patient's needs. Is a My Aged Care referral needed?
- Remember that advance care directives may empower a patient who perceives that they have no control over poor health and chronic symptoms.
- Perform ongoing review of symptoms and enquiry about self-harm/suicidal ideation because there is a high risk of repetition.

* The mental health crisis phone numbers differ between states and territories (www.healthdirect.gov.au/crisis-management).
† For a more detailed discussion regarding the issues of confidentiality and consent in mental health care, see the editorial *Communication, confidentiality and consent in mental health care* (2014).[27]

and potentially driving further self-harm.[18] In fact, people who enter residential care are at greatest risk of self-harm in the year before and after placement.[33,34] Paradoxically, placement of an older person who has self-harmed may be considered by mental health services as solving the problem and specialist care be withdrawn, at the very time they are most at risk and need more support.[23] In addition, the patient's (often long-term) GP may change when they move into care, reinforcing the person's sense of abandonment. Nursing home residents who have self-harmed are therefore a key group for active social and emotional support and follow up from general practice and mental health services.[35]

GP care

For GPs, understanding their own responses to self-harm in their patients is important. GPs of older patients who have self-harmed often feel helpless in supporting their patients and preventing further self-harm.[20] Loss of hope, often engendered by other clinicians, makes this worse (e.g. 'Nothing can be done for your pain, or blindness, or walking difficulty, or ...'), as does a sense of abandonment by mental health services experienced by some GPs.[20] The GP's response needs to be understood, acknowledged and contained before it is conveyed to the patient. We strongly endorse peer support and other self-care initiatives for GPs, such as the RACGP's *Keeping the doctor alive: a self-care guidebook for medical practitioners* (www.racgp.org.au/FSDEDEV/media/documents/Running%20a%20practice/Practice%20resources/Keeping-the-doctor-alive.pdf).[36]

Conclusion

Self-harm in older people is often multifactorial and complex and may communicate needs that the individual otherwise cannot express. Key to management is listening to the patient and understanding the underlying issues. The acuity of self-harm thoughts or actions and resources available to the older person will help determine the setting of care. Carers are an integral part of effective patient care, in sharing information and providing a corroborative history, as allies in management and as people requiring support in their own right. There should be a low threshold to involve specialist mental health services in the care of older people who have self-harmed. Problems underlying the self-harm may be broken down into areas for action and community, specialist and domiciliary services engaged to assist, with the GP in a co-ordinating role. MT

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A list of references is included in the online version of this article (www.medicinetoday.com.au).

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Learning outcomes

- Identify contributing factors in an older patient who has self-harmed
- Tailor management strategies for self-harm in older patients to their life circumstances
- Manage an emergent risk of self-harm in an older person
- Implement strategies to reduce the impact on yourself, as a clinician, when an older patient self-harms

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Question 1

What are some of the factors associated with self-harm in late life? Choose the three most correct answers.

a. Mood disorder
b. Previous self-harm or suicide attempts
c. Cognitive impairment
d. Being married

a,b,c. Correct	Factors associated with self-harm in late-life include psychiatric illness, cognitive impairment and a history of self-harm or suicide attempts.
d. Incorrect	Being married is not associated with self-harm in late life. A marital status of single is associated with higher risk of self-harm.

Case Study 1

Yvonne is a 68-year-old Aboriginal woman. She lives with her daughter and three grandchildren. She is overweight and has type 2 diabetes; she quit smoking six months ago. She has usually been good at taking medications, and when her adherence recently declined you assessed her and diagnosed her with mild dementia. Today you notice that she has lost 5 kg since her last visit a month ago, but she says she has not done anything intentionally to lose weight.

Question 2

Is the following statement true or false?

'Yvonne may be engaging in indirect self-harm.'

a. True
b. False

a. Correct — Yvonne may be engaging in indirect self-harm – that is, an act of omission or commission that indirectly causes self-harm over time leading to death (e.g. refusing to eat or drink or to take essential medications).

b. Incorrect — The statement is not false.

Case Study 1 (cont)

You perform a mental state examination for Yvonne and diagnose depression.

Question 3

Why do older people self-harm? List at least three common reasons or underlying factors.

[MODEL ANSWER]

There is a myriad of personal reasons underlying self-harm in older people. Themes that have emerged from qualitative studies include the following:

- Feeling disconnected from others; loneliness;
- 'Enough is enough' – a long life has been lived;
- 'My ageing body is letting me down', 'I'm falling apart';
- Feeling like a burden;
- Cumulative adversity (e.g. migration, early trauma, death of adult children);
- Hopelessness and endless suffering;
- Helplessness, with rejection or invalidation from relatives and/or clinicians;
- Untenable situations (e.g. elder abuse, family conflict, need for nursing home placement);
- Loss of and regaining control.

Question 4

Is the following statement true or false?

'Older people who have self-harmed have described perceived rejection or nonresponsiveness by clinicians and family as a barrier to receiving assistance before self-harm.'

a. True
b. False

a. Correct — Older people who have self-harmed have described invalidation of their concerns, lack of privacy to disclose abuse or an untenable situation, perceived rejection or nonresponsiveness by clinicians and family, and hopelessness as barriers to receiving assistance before self-harm occurs. Thus the responses of the GP (and other health professionals) to an older person's issues can serve to reinforce or diminish the distress.

b. Incorrect — The statement is not false.

Question 5

After an older person discloses self-harm thoughts or actions, what should be the first response of a clinician? Choose one correct answer.

a. Ask the individual about the reasons for the self-harm
b. Schedule the person under the Mental Health Act
c. Contact the person's next of kin
d. Transport the person to the local hospital emergency department

a. Correct — After safety has been addressed, the first response of a clinician to self-harm in an older person should be to ask the individual about the reasons for the self-harm.

b. Incorrect — The first response of a clinician to a disclosure of self-harm thoughts or actions in an older person is not to schedule the person under the Mental Health Act.

c. Incorrect — The first response of a clinician to a disclosure of self-harm thoughts or actions in an older person is not to contact the person's next of kin.

d. Incorrect — The first response of a clinician to a disclosure of self-harm thoughts or actions in an older person is not to transport the person to the local hospital emergency department.

Case Study 1 (cont)

Yvonne tells you that she has no plans to take active steps to harm herself. However, she is grieving after attending several recent funerals for people in her community and she says she cannot shake the thought that 'my time has come too'. She says she cannot see the point of eating.

Question 6

List at least three elements of an appropriate response to subacute risk of self-harm in an older person.

[MODEL ANSWER]

An appropriate response to subacute risk for self-harm or suicidal ideation includes the following:

- Match the underlying factors for self-harm identified in the patient's initial assessment to specific components of a plan to address them.
- Engage specialist medical help to address each of the contributing factors
- Consider whether a psychologist may help with anxiety or depression, ongoing interpersonal difficulties and poor coping through a Mental Health Care Plan. Family therapy may also be indicated to help address ongoing conflict or interpersonal dynamics contributing to patient distress.
- Consider whether there is a need for more domiciliary support or services to meet the patient's needs.
- Remember that advance care directives may empower a patient who perceives that that they have no control over poor health and chronic symptoms.
- Perform ongoing review of symptoms and enquiry about self-harm/suicidal ideation because there is a high risk of repetition

Case Study 1 (cont)

Yvonne gives you permission to share your concerns and plans with her daughter, Joanne, who is in the waiting room.

Question 7

Which two statements are most true regarding the carers of older people who have self-harmed?

a. Carers may have difficulty empathising with an older person who has self-harmed
b. Carers may experience anger after self-harm in their relative
c. Carers usually contact clinicians for advice when learning about thoughts of self-harm in their relative
d. Carers generally do not want to be involved in the clinical care of their relative

a,b. Correct	Carers may experience intense emotional responses to the self-harm, including difficulty empathising and anger.
c. Incorrect	Carers of older people do not usually contact clinicians if concerned about self-harm in their relative.
d. Incorrect	Carers of older people generally want to be involved in the clinical care of their relative.

Case Study 1 (cont)

Joanne is upset but supportive. She says she knew that 'something wasn't quite right with Mum after all this Sorry Business'.

Question 8

Briefly describe how carers can help in the creation and implementation of a management plan for an older person who has self-harmed.

[MODEL ANSWER]

Carers may be a good source of corroborative history about the patient (and often know much about suicide risk factors), and generally want to be involved and informed about clinician plans. They can also be allies in treatment, informing the management plan, knowing what is realistic and possible, assisting in reducing access to means of self-harm, helping monitor symptoms, and co-ordinating services for the older person.

Question 9

Is the following statement true or false?

'It is inappropriate for a GP to ask about the emotional needs of carers.'

a. True
b. False

b. Correct — Carers of an older person who has attempted suicide may have difficulty caring for the patient, become distressed, have difficulty coping and feel unable to support the older person, so increasing the older person's risk. This suggests that GPs should routinely be asking about the emotional responses of carers and their feelings of burden and offering appropriate avenues of support.

a. Incorrect — The statement is not true.

Case Study 2

Jim, aged 75 years, is a longstanding patient of yours. Recently he attempted suicide by hanging. He was rescued and, after an involuntary inpatient mental health unit admission, he was moved to a residential aged care facility.

Question 10

In late life, self-harm and suicidal intent are closely associated. Which of the following populations has the highest rate of suicide? Choose one correct answer.

a. Women aged 25 to 30 years
b. Men aged 85 years and over
c. Women aged 60 to 64 years
d. Men aged 35 to 40 years

b. Correct	The highest rate of suicide is in men aged 85 years and over. In late life, self-harm and suicidal intent are closely associated.
a. Incorrect	The highest rate of suicide is not in women aged 25 to 29 years.
c. Incorrect	The highest rate of suicide is not in women aged 60 to 64 years.
d. Incorrect	The highest rate of suicide is not in men aged 35 to 39 years.

Question 11

Is the following statement true or false?

'Jim will now certainly be safe because he is in a residential care facility.'

a. True
b. False

b. Correct — People who enter residential care are at greatest risk of self-harm in the year before and after placement.

a. Incorrect — The statement is not true.

Question 12

Which of the following are risk factors for indirect self-harm in nursing homes? Choose the two most correct answers.

a. Dementia
b. Functional impairment
c. English as a second language
d. Older age

a,b. Correct — Indirect self-harm in nursing homes is more likely in older people with dementia or greater functional impairment, and also in people with more behavioural and psychiatric disturbance.

c. Incorrect — English as a second language is not a recognised risk factor for self-harm in a nursing home environment.

d. Incorrect — Older age is not a recognised risk factor for self-harm in a nursing home environment. Rates of indirect SH have been found to be higher in younger nursing home residents.

Question 13

Residents of aged care facilities who are admitted because of previous self-harm are a key group for active social and emotional support. Briefly explain why this is the case.

[MODEL ANSWER]

The feelings of helplessness and invalidation experienced by some older people before self-harming may be reinforced by placement for 'containment of risk', in turn increasing their distress and potentially driving further self-harm. An individual with a history of self-harm or suicide attempts is at high risk of repetition.

Case Study 2 (cont)

You get a distressed phone call from one of Jim's cousins, who is visiting him in the home. Jim is threatening to jump out of a window when the visit ends. The cousin asked who he should call for help and Jim gave him your phone number.

Question 14

What is the most important step to take now? Choose the single best answer.

a. Phone Jim's new GP and hand over care to him
b. Phone an ambulance and tell the paramedics that you are scheduling the patient
c. Phone the home's registered nurse and advise him or her to call the mental health crisis number for your state or territory
d. Phone the local police

c. Correct	When faced with an acute risk of self-harm, appropriate response includes: considering the most appropriate setting of care (including whether the person can be adequately supported and safely managed in their home); assessing the patient's level of insight, judgement and willingness to address their issues; considering whether there is a need to break confidentiality in the interest of patient safety.
a. Incorrect	The most important step to take is not phoning Jim's new GP to hand over care to him.
b. Incorrect	The most important step to take is not phoning an ambulance and telling the paramedics that you are scheduling the patient.
d. Incorrect	The most important step to take is not phoning the local police.

Question 15

For GPs, understanding their own responses to self-harm in their older patients is important. How might GPs care for themselves in this situation? Select as many answers as you think appropriate.

a. Discuss such cases in a peer-review group
b. Seek supervision with a psychiatrist
c. Involve other services and clinicians in the co-management of the patient (matched to the patient's needs)
d. Other – please write the strategies you use in the box below

All of the above answers are correct. There is no one correct answer. The purpose of this question is for you to consider and provide practical ideas and methods by which your practice systems can be improved or streamlined.

6.2 An educational intervention for health care professionals

While written resources and guidelines have an important place in education for health care professionals, these are rarely sufficient to change knowledge and practice (Young and George, 2003). Educational strategies for health care professionals which have been shown to be effective in changing clinical practice and patient outcomes include patient-mediated interventions, opinion leaders, audit and feedback, reinforcement and reminders (Davis *et al.*, 1995; Heffner, 2001). With this in mind, the final study of the thesis sought to use an opinion leader as the educator, and to reinforce evidence-based educational content through facilitated discussions of patient vignettes and pre/post-assessment. The content of the face-to-face interprofessional education sessions was derived by bringing together the findings of the first two qualitative studies (Wand *et al.*, 2018a; Wand *et al.*, 2019a; Wand *et al.*, 2018c; 2019b) with quantitative data from the self-harm literature, for example (Conejero *et al.*, 2018; Draper, 2014; Troya *et al.*, 2019). Interprofessional education, that is learning from, with and about each other with the aim to improve collaborative patient care (Buring *et al.*, 2009), makes intuitive sense in late life self-harm. We have demonstrated that managing self-harm in older people requires a team approach and the contribution of different services, disciplines and professions to address underlying issues holistically. Interprofessional education already has a strong theoretical and research evidence base for developing collaborative skills across disciplines and professions in complex areas such as delirium (Sockalingam *et al.*, 2014).

In developing the educational intervention for health care professionals on self-harm in older adults (Study 3B), a multimodal model was developed which combined didactic teaching for theoretical components and facilitated case-based discussion to stimulate multidisciplinary participation, shared dialogue and practical application of acquired knowledge. The educational intervention was designed to be interprofessional given the potential benefits of team learning for the provision of collaborative holistic care in late life self-harm (Buring *et al.*, 2009; Sockalingam *et al.*, 2014).

PAPER 9:
EVALUATION OF AN EDUCATIONAL INTERVENTION ON SELF-HARM IN OLDER ADULTS (STUDY 3B)

Reference

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Evaluation of an Educational Intervention for Clinicians on Self-Harm in Older Adults

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Declaration

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Anne Wand

Abstract

Clinicians may lack knowledge and confidence regarding self-harm in older adults and hold attitudes which interfere with delivering effective care. A one-hour educational intervention for hospital-based clinicians and general practitioners (GPs) was developed, delivered and evaluated. Of 119 multidisciplinary clinicians working in aged care and mental health at two hospitals, 100 completed pre/post-evaluation questions. There were significant improvements in knowledge, confidence in managing, and attitudes regarding self-harm in late life, and the education was rated as likely to change clinical practice. No GP education sessions could be conducted. A brief educational intervention had immediate positive impacts for hospital-based clinicians albeit with high baseline knowledge. The sustainability of these effects and effectiveness of the intervention for GPs warrant examination.

Keywords

education; suicidal behaviours; doctors; allied health; geriatrics; learning

Introduction

In most countries, rates of suicide are highest in older men (World Health Organisation, 2017), rendering suicide prevention in the elderly a global priority for public health initiatives. Rates of self-harm in older adults (aged 60+) vary from 19.3-65/100,000 per annum (Troya *et al.*, 2019). Many people have contact with health professionals before fatal or non-fatal self-harm, especially general practitioners (GPs) (Cheung, Merry, & Sundram, 2015; De Leo, Draper, Snowdon, & Kolves, 2013; Troya *et al.*, 2019), representing important opportunities to intervene with people at risk (Stene-Larsen & Reneflot, 2019; Suominen, Isometsa, Martunnen, Ostamo, & Lonnqvist, 2004). This is especially true in people over 50 years of age, in whom rates of contact with primary care in the month before suicide are 32-77% (Stene-Larsen & Reneflot, 2019). However, health professionals report difficulties working with people who self-harm, such as lack of technical skills, emotional distress, relational and communication challenges, issues working with families and logistic difficulties, and vary in terms of their knowledge, exposure to training and confidence in managing self-harm (Rothes, Henriques, Leal, & Lemos, 2014). It has been highlighted that suicide knowledge and intervention skills are not the same thing, and that risk assessment must occur in the therapeutic and relational context of clinician confidence in practice (Inman, Bascue, Kahn, & Shaw, 1984; Rothes *et al.*, 2014). The attitudes of health professionals towards people who self-harm are also relevant, and likely to influence behaviour (Rothes & Henriques, 2018). For example, negative clinician attitudes such as lack of empathy and stigmatisation towards people who self-harm have been associated with patient distress, poorer quality of care provided, and missing a key opportunity to prevent further self-harm and suicide (Pompili, Girardi, Ruberto, Kotzalidis, & Tatarelli, 2005). How these parameters differ in health professionals working specifically with older people who self-harm, whether it is direct or indirect and regardless of intent, is poorly understood.

Although there are several clinical practice guidelines for suicide prevention and assessment (Bernert, Hom, & Roberts, 2014), discrepancies have been identified in a number of specific areas, including recommendations for clinician training, discussion of confidentiality, ethical and legal issues, safety planning and outpatient management tools (Bernert *et al.*, 2014). Further, guidelines are passive educational tools quite distinct from training clinicians to achieve competency in knowledge and practice (Silverman & Berman, 2014). It has been highlighted that clinical practice guidelines may not change health professional behaviours and there is a significant knowledge gap regarding implementation

of guidelines and demonstration of effectiveness in terms of patient outcomes (Kredo *et al.*, 2016). By comparison, clinicians who receive specific training on suicide may be more likely to undertake comprehensive risk assessments and involve a patient's family, than clinicians without training (Rothes & Henriques, 2018).

Targeted educational interventions may have direct clinical impact. There have been some studies of educational interventions to improve knowledge of self-harm and suicide, predominantly for clinicians working in Emergency Departments, with the majority reporting improvements in knowledge post-intervention (see review by (Saunders, Hawton, Fortune, & Farrell, 2012)). One study investigated a 12-hour continuing education workshop on the assessment and management of suicidal behaviour for mental health professionals in the Air Force using a multifaceted approach (lectures, role-play of clinical scenarios, question and answer sessions and problem solving). This demonstrated that 83% of clinicians reported change in practice for suicide management and improved confidence assessing and treating suicide risk six-months later (Oordt, Jobes, Fonseca, & Schmidt, 2009). Another study which trained GPs to identify and treat depression demonstrated a reduction in community suicide rates (Szanto, Kalmar, Hendin, Rihmer, & Mann, 2007). The need for suicide risk assessment and prevention measures targeted for different at risk populations has been recognised (Silverman & Berman, 2014); older adults should be one of these populations.

There have been studies of attitudes towards patients who self-harm (including suicide attempts) in nurses working in both hospital-based (Kishi, Kurosawa, Morimura, Hatta, & Thurber, 2011; Neville & Roan, 2013) and community settings (Wang, Anderson, & Mentes, 1995), and in mental health and non-mental health multidisciplinary clinicians (Srivastava & Tiwari, 2012). However, we were unable to find any studies specifically evaluating attitudes of clinicians towards older people who self-harm. A systematic review of the attitudes of clinicians towards people (of all ages) who self-harm found that general hospital clinicians, especially doctors, had more negative attitudes towards people with repeated self-harm, while mental health clinicians across hospital and community settings had comparatively more positive attitudes (Saunders *et al.*, 2012). Similar findings were reported in a study of attitudes towards suicide prevention in healthcare professionals including GPs, with medical specialists holding the most negative views; postulated to relate to inadequate knowledge and skills managing suicidal patients (Draper, Krysinska, De Leo, & Snowdon, 2014). Notably, training interventions appear to consistently improve knowledge and attitudes regarding patients who self-harm, although it was acknowledged that no studies evaluated the impact on actual behaviour in clinical practice (Saunders *et al.*, 2012).

Given the importance of self-harm in late life as a major risk factor for suicide and the relative lack of data on the effectiveness of educational interventions for multidisciplinary health professionals in suicide in late life, this study sought to design and evaluate an educational intervention on this topic. The aims were to improve the knowledge, attitudes and confidence in clinical practice of multidisciplinary health professionals working in hospital, community and GP settings with respect to self-harm in older adults. We hypothesised that mental health professionals, having self-selected to work with people with mental health problems including self-harm, would have greater knowledge and confidence regarding assessment and management, and more positive attitudes towards self-harm in late life than non-mental health professionals.

Methods

Participants and Procedures

Potential participants were clinicians of any discipline (i.e. medical, nursing, social work, occupational therapy, physiotherapy) working in a hospital or community setting based at two large university teaching hospitals in Sydney, and GPs attending an educational session on self-harm in late life. For hospital-based staff the educational sessions were held within work hours and as part of embedded in-service programs without additional advertising or specific invitations for attendance. Sessions for GPs were arranged through five area-based Primary Health Network (PHN) education coordinator or consultant or through discussion with ten individual Practice Managers and direct invitation from the primary investigator at mutually convenient times (in or after hours).

The educational intervention

For hospital and community based clinicians, a one-hour education session focusing on self-harm in late life was organised for clinicians working in general mental health, aged care psychiatry, and geriatrics, as part of their routine education programs (i.e. grand rounds for mental health, aged care psychiatry and aged care, and general mental health nursing in-services). All sessions were conducted by the same aged-care psychiatrist who worked across both hospital sites (AW). The focus was on understanding the individual issues underlying self-harm in an older adult, collaborating with and supporting carers and demonstrating opportunities for improved communication. The content was informed by previous work conducted by our group on self-harm in late life (Wand, Peisah, Draper, & Brodaty, 2018; Wand, Draper, Brodaty, & Peisah, 2019a; Wand, Peisah, Draper, &

Brodaty, 2018; Wand, Peisah, Draper, & Brodaty, 2019) and the broader epidemiological and quantitative literature (De Leo *et al.*, 2001; Fassberg *et al.*, 2016; Troya *et al.*, 2019). An outline of the content of the educational intervention is provided in Appendix 1 and further content detail is provided in an accompanying clinical practice paper for primary care (Wand, Draper, Brodaty, & Peisah, 2019b).

The educational intervention was a combination of didactic/theoretical information and working through a facilitated interactive case vignette (see Appendix 1). The theoretical content was identical for all education sessions and included dispelling myths about ageing, definitions and prevalence of late life self-harm, how self-harm in late life differs from that in younger adults, epidemiological risk factors and qualitative insights into why older people self-harm (patient, carer and GP perspectives), barriers to help-seeking, consequences of self-harm for patients and carers (immediate and at one-year follow-up), potential solutions, individualising after care plans and a unifying conceptual framework for self-harm in late life (see (Wand, Draper, *et al.*, 2019a)). The case vignette presentation sought clinician (audience) participation in working through the assessment of suicide risk, understanding the reasons for self-harm, taking a targeted psychiatric history, identifying key signs on mental state examination, identifying the appropriate setting of (e.g. inpatient, outpatient) and legal framework for care (e.g. Mental Health Act, Guardianship), aspects of collaborative care (with other healthcare professionals and family) and developing an individualised management plan. The proposed sessions for GPs were 80-90 minutes in duration, with identical theoretical content to that delivered to hospital/community based clinicians but two community-based vignettes.

Measures

As there was no existing tool specifically addressing clinician knowledge, attitudes and confidence regarding self-harm in late life a 16-item questionnaire was developed, and administered before and immediately after the educational session (see Appendix 2). Twelve questions were knowledge-based; two evaluated attitudes/beliefs and two evaluated confidence regarding self-harm in late life. Questions were a combination of multiple choice (7) and true/false (9). Correct responses for the twelve knowledge questions were given a score of one and summed to provide an overall total score for the pre and post-evaluations. Demographic data were requested pre-intervention including age, gender, profession, setting of work (mental health, geriatrics, community or hospital), previous clinical role with an older person who self-harmed and educational experiences regarding self-harm and specifically self-harm in late life. The post-intervention questionnaire had an additional two

questions; i) whether the education session would change clinical practice and ii) free-text space for additional comments or feedback on the educational session. The questionnaires were distributed in randomly numbered pre-post pairs (e.g. 5a; 5b) and given to participants before the education in order to anonymously evaluate intra-individual change. Pre-intervention questionnaires were collected prior to commencement of the education session.

The questionnaire was piloted with eight clinicians, four of the study authors, all old age psychiatrists, and four other clinicians (a general psychiatrist, clinical psychologist, registered nurse and medical educator/psychiatrist) and was modified based on feedback prior to use.

Ethical approval was obtained from the South Eastern Sydney Local Health District Human Research Ethics Committee.

Data Analysis

Data were analysed using SPSS version 25. Descriptive statistics are expressed as simple means, frequencies, percentages and standard deviations (SDs). Group differences were assessed using one-way ANOVA and Pearson chi-square test for independence. Pre-post educational intervention comparisons were made using paired- *t*-tests for continuous variables and chi square analysis for categorical variables using the McNemar test for paired variables. This test does not consider the pairs with the same outcome; it is based on discordant pairs (e.g., those who differ in their responses between evaluations). Statistical significance was defined by probability (P) values <0.05. Fifteen evaluation forms were returned with a missing/blank item for one of the twelve pre or post knowledge questions. These were re-coded as incorrect responses for purposes of the analysis. Written comments in the post-intervention questionnaire were summarised for qualitative feedback on the education session and categorised as positive or negative/neutral according to content.

Results

Education sessions and demographic data

Five educational sessions were conducted across two teaching hospitals (two to general mental health staff, one to aged care psychiatry, one to the department of geriatrics and one was a dedicated general mental health nursing in-service). Sessions were held over a one month period in March/April 2019. The number of attendees per session varied from 12 to ~50. One hundred and nineteen clinicians (all post-qualification) completed pre, post or

both questionnaires (see Table 6.1), representing an estimated 95% of participants attending the sessions. The exact response rate was not determined due to variable arrival and departure times of participants. Nineteen subjects returned forms with more than one missing value and these were considered non-completers and evaluated separately to the 100 respondents who completed forms pre and post-evaluation. Their demographic characteristics are shown in Table 6.1.

Table 6.1 Demographic data for all participants
(N=119)

Demographics and previous education	Mean or subject number (N)	Percent*
Age years: Mean ± SD	38.6 ± 11.9	
(range)	(20-66)	
Gender:		
Female	74	68
Male	33	30
Other/non-binary	1	2
Missing (N=11)		
Profession:		
Doctor	35	40
Nurse	25	28
Allied health	27	31
Other	1	1
Missing (N=31)		
Works in mental health?	60	57
Missing (N=13)		
Works with older people?	93	85
Missing (N=9)		
Work setting:		
Hospital or hospital outpatients	99	88
Community	13	12
Missing (N=7)		
Had a clinical role in the care of an older person who self-harmed		
Missing (N=17)	67	66
Education:		
Received some education on self-harm	90	78
Missing (n=17)		
Received education on self-harm specifically in older people	26	23
Missing (n=4)		
Completed all pre education session questions (AQ1-16)	110	92
Completed all post education session questions (BQ1-16)	104	87
Completed both question sets with no missing values	100	84

*Calculated as proportion of those with data for the item

General practitioners (GPs)

Five Primary Health Networks (PHNs)[1] in the Sydney metropolitan and greater-Sydney areas were contacted and offered educational sessions for GPs on self-harm in late life between January and June 2019. The practice managers of ten urban large group general practices were offered free in-practice education sessions at flexible times convenient to the GPs. Due to various practical and administrative reasons and low registrations no sessions were conducted.

Questionnaire completers versus non-completers

There were no significant differences in demographics, work settings or educational histories between participants who completed the questionnaires (n=100) compared to the nineteen subjects returning incomplete evaluation forms; non-completers were less likely to been involved in the clinical care of an older person with self-harm (Table 6.2). There were no significant differences between completers and non-completers and the number of correct responses to the 12 knowledge items prior to the educational intervention.

Table 6.2 Completers vs. non-completers who did not return evaluation sheets

	Completers (n=100)	Non-completers (n=19)	Probability
Age (Mean ± SD)	38 ± 11.6	41 ± 13.3	NS
Gender: females, %	64 (69%)	10 (67%)	NS
Works in mental health	49 (54%)	11 (69%)	NS
Works with older people	81 (86%)	12 (75%)	NS
Work Setting: Hospital or hospital outpatients	83 (87%)	16 (100%)	NS
Had a clinical role in care of an older person who self-harmed	63 (69%)	4 (36%)	P=0.03*
Received some education on self-harm	77 (79%)	13 (72%)	NS
Received education on self-harm specifically in older people	24 (25%)	2 (13%)	NS
Mean pre-score (knowledge items only, range, 12 max)	8.3 ± 0.16 (5-12)	8.4 ± 0.50 (6-10)	NS

NS, not significant (P>0.05).
*Some probabilities not applicable due too expected cell counts less than 5.

[1] Primary Health Networks (PHNs) were established by the Australian government in 2015 with the aim of increasing the effectiveness and efficiency of medical services for patients. Mental health and aged care were two of six areas that PHNs were mandated to prioritise, with suicide prevention a specific target. The PHNs are intended to better coordinate care, support GPs with assessments, assist in directing referrals to best meet patient needs, and provide education to GPs as part of continuing professional development.

Knowledge on self-harm in late life

Overall, there was a significant improvement in clinician performance on the 12 knowledge-based items (Table 6.3, Q1-5; 8-14) after the intervention. The mean group score pre-evaluation was 8.3 (SD, 1.6, max=12) and after the evaluation it significantly rose to 10.6 (SD, 1.2, paired t=13.85, df = 99, p<0.001). Five questions showed much improvement post-evaluation (see Table 6.3, Q1, 2, 4, 10, and 14). The other knowledge questions did not increase, but this was likely due to ceiling effects where more than 85% or the responses were correctly identified prior to the intervention.

Table 6.3 Pre-post evaluation of knowledge items
Completers (n=100)

Question number ***Correct answer (multiple choice)***	**Pre Correct N**	**Post Correct N**	**Incorrect pre to correct post N/Prob***
Q1. Highest suicide rate? *A. Men aged 85-89*	51	98	47 .001
Q2. True for ageing. *C. Satisfaction with life increases*	21	69	48 .001
Q3. Those with cognitive impairment self-harm. *A. True*	87	96	12 #NS
Q4. Self-harm in older people associated with *B. Use of lethal means*	48	80	38 .001
Q5. Which items contribute to self-harm. *D. All of the above*	93	98	6 #NS
Q8. Which is most true for older people? *B. There are effective treatments for depression*	76	85	16 NS
Q9. Self-harm can usually be managed by GPs. *B. False*	90	97	10 #NS
Q10. Confidentiality in an older person with self-harm. *A. True, carers may be contacted*	58	75	25 .005
Q11. Important considerations addressing hopelessness. *D. All of the above*	94	98	4 #NS
Q12. Self-harm is rare in nursing homes. *B. False*	94	98	6 #NS
Q13. Carer burden is a primary factor in self-harm. *A. True*	90	95	8 #NS
Q14. Which is true, A or B? *A. Carers commonly understand why older person feels this way*	30	73	45 .001

*Probability was based on McNemar test.
#NS statistics invalid for six questions due to ceiling effect (high percentage correct pre-test) resulting in low expected cell counts in 2 x 2 Table.

There were no significant effects of gender or profession on any of the individual knowledge items or sum scores. Specifically, there were no significant differences in the change in correct responses to the 12 knowledge questions between those working in mental health and those who did not work in mental health pre and post intervention (8.6 vs 8.4 respectively pre-intervention and 10.8 vs 10.5 post-intervention; Table 6.5). It was not possible to meaningfully evaluate whether there was a difference in the performance of general mental health (n=13) compared to old age mental health clinicians (n=33) or whether there was a difference in those who worked in hospital/hospital outpatient settings (n=99) compared to community (n=13) due to low numbers in some groups.

Table 6.4 Pre-post evaluation of attitudes/beliefs and confidence items
Completers (n=100)

Question number ***Desired response designated as correct (true/false)***	**Pre Correct N**	**Post Correct N**	**Improvement (incorrect pre, correct post) N/Prob***
Q6. I feel helpless dealing with self-harm in an older person (false)	57	83	32 .001
Q7. Older people who self-harm are just seeking attention (false)	100	100	0 #NS
Q15. I feel confident assessing self-harm in an older person (true)	33	70	37 .001
Q16. I feel confident talking to families about self-harm (true)	39	77	38 .001
Q17. The education session will change my practice (true)	-	94	-

*Probability was based on McNemar test.
#NS statistics invalid for six questions due to ceiling effect (high percentage correct pre-test) resulting in low expected cell counts in 2 x 2 Table.

Table 6.5 Demographic data and responses based on current work in mental health (MH) setting

Completers (n=91*)

Variable	Works in mental health (MH) (N=49)	Does not work in MH (N=42)	P
Gender:			NS
Male	17 (37%)	11 (28%)	
Female	29 (63%)	28 (72%)	
Missing	*3*	*3*	
Profession:			NS
Doctor	18	14	
Nurse	13	5	
Allied health	10	10	
Missing, n=21			
Works with older people, Yes	33 (72%)	42 (100%)	.001
Missing	*3*		
Works in hospital or hospital outpatients	45 (96%)	33 (81%)	.024
Missing	*2*	*1*	
Had a clinical role in care of an older person who self-harmed	32 (73%)	26 (63%)	NS
Missing	*5*	*1*	
Education:			
Received some education on self-harm	44 (94%)	29 (69%)	.003
Missing	*2*	*9*	NS
Received education on self-harm specifically in older people	13/47 (28%)	21%	
Missing	*2*		
AQ6. I feel helpless in dealing with self-harm in older persons (Pre)	12 (25%)	26 (62%)	.001
BQ6. I feel helpless in dealing with self-harm in older persons (Post)	3 (6%)	12 (29%)	.004
AQ15. I feel confident assessing self-harm in an older person (Pre)	26 (53%)	10 (24%)	.004
BQ15. I feel confident assessing self-harm in an older person (Post)	41 (84%)	22 (52%)	.001
AQ16. I feel confident talking to families about self-harm in their older relative (Pre)	26 (53%)	10 (24%)	.004
BQ16. I feel confident talking to families about self-harm in their older relative (Post)	42 (86%)	29 (69%)	.056
BQ17. This education session will change my clinical practice	45 (92%)	40/41 (98%)	NS

*Nine cases did not respond to the question regarding whether they work in mental health.

Attitudes on self-harm in late life

Following the intervention participants as a group were less likely to feel helpless dealing with self-harm in an older persons (Table 6.4, Q6, 43% vs 17%, p=0.001). This was especially true for clinicians not working in mental health (Table 6.5). Pre-intervention, clinicians with previous education on self-harm in older people (n=24) were less likely to feel helpless dealing with self-harm in an older person (Q6, 4/24= 16.7% vs 38/70= 54.3%, X2; df=10 = 10.233, p<0.001). There was no difference on this item post-intervention. For the other attitudinal question (Table 6.4, Q7), none of the participants, pre- or post-intervention, indicated that older people who self-harm are just seeking attention from others.

Confidence regarding assessment and management of late life self-harm

There was a significant improvement in the two confidence items post-intervention (Table 6.4, Q15 and Q16, p<0.001). Confidence in assessing self-harm in an older person was significantly higher in those working in mental health compared to those who did not, but improved in both groups post-intervention (Table 6.5, Q15, pre: 53% vs 24% p=0.004 and post: 84% vs 52%, p<0.001). Similarly, confidence in talking to families about self-harm in their older relative was significantly higher in mental health clinicians prior to the intervention (Table 6.5, Q16, p=0.004) and improved in both groups as a whole post-intervention. Pre-intervention, clinicians with previous education on self-harm in older people (n=24) were more likely to report confidence assessing self-harm in an older person (Q15, p=0.002) and talking to families about self-harm (Q16, p<0.001) compared to clinicians without this educational experience (n=72, 4 had missing data). However, these differences were not significant post-intervention.

Ninety-four percent felt the education session would change their clinical practice (Table 6.4, Q17) and this was similar for mental health clinicians and those not working in mental health (Table 6.5, Q17).

Qualitative results; Open-ended responses

Thirty-one participants (31%) provided comments. These were overwhelmingly positive (n=25) such as;

- “It has increased my awareness and I will be more vigilant in looking for signs” (anonymous)
- “well presented - excellent slides. The case worked very well to illustrate previous points.” (female, general mental health)

- "I feel much more confident about approaching this issue now if faced with this e.g. in ED" (female doctor, mental health)
- "made me aware of need to convey hope to elderly patient" (female, general mental health)
- "I have a better understanding of the diversity of issues and risk factors underlying self-harm" (female, allied health, aged care mental health)

There were a couple of negative or neutral comments (n=6), for example:

- "a good session but already a familiar topic" (male doctor, mental health)
- "Getting patient assessed by mental health is impossible unless there is a crisis of self-harm and follow-up post event is sporadic - hence patient/carer/GP nihilism" (female doctor, geriatrics)

Discussion

A brief educational intervention had immediate impact in terms of improving knowledge, attitudes and confidence of hospital and community-based multidisciplinary health professionals regarding the assessment and management of self-harm in older adults. Strengths of the study were the low cost and brevity of the intervention, uniform implementation of the intervention (same clinician presenter and content), and opportunistic delivery of the intervention within existing continuing education programs, increasing accessibility to health professionals. The inclusion of clinicians from a variety of professional backgrounds and settings (geriatrics, mental health, emergency department, hospital and community) was also a strength as older people with self-harm may present to any of these contexts and benefit from encountering trained clinicians. The multidisciplinary participants in most of the sessions also provided an opportunity for inter-professional learning, a method with identified benefits in other aspects of aged care (Sockalingam *et al.*, 2014).

In contrast to prior research (Oordt *et al.*, 2009) many participants had received prior education on self-harm, but only a minority had specific education regarding older people; despite this being mandatory training for public mental health clinicians in New South Wales (Ministry of Health NSW, 2016). This was notable given the high rates of clinical contact with older people who had self-harmed, including in staff from non-mental health backgrounds. Health professionals in this study had high rates of baseline knowledge about self-harm in late life as demonstrated by high overall pre-test scores and significant

improvement in only five questions post-intervention. This was not wholly unexpected as a longitudinal project on self-harm in late life had been conducted across both hospital sites (Wand, Draper, *et al.*, 2019a; Wand *et al.*, 2018; Wand, Peisah, *et al.*, 2019) with requests to recruit patients and associated education on self-harm in late life (attended by many participants in the present study) therefore raising awareness of late life self-harm amongst clinicians, as well as high rates of prior education on self-harm in general in participants. Indeed, knowledge translation may have therefore been underestimated as those with prior training were not excluded from the study. Thus in clinicians with less baseline knowledge the intervention may result in even more knowledge gain than observed here.

Nonetheless, those items where participant knowledge improved highlight the gaps in knowledge, namely in the epidemiology of suicide, assumptions about ageing (ageist or negative assumptions were more common pre-intervention), how self-harm differs in older compared to younger people (lethality of means), consent and confidentiality issues, and the knowledge and behaviour of carers. General knowledge about the prevalence of and risk factors for self-harm in late life improved post-intervention. Such knowledge is fundamental for clinicians to consider and detect aspects of risk when working with older adults. Participant responses that cognitive impairment or depression is expected in late life or that quality of life declines with ageing suggest negative assumptions about ageing which may affect care. Previous work has identified that primary care professionals may see depression as 'understandable' or 'justifiable' in older people, with significant implications for detection and management (Burroughs *et al.*, 2006). Prior to the intervention health professionals made assumptions that carers would inform clinicians if concerned about risk of self-harm in their relatives. We have previously shown that knowledge of risk factors for suicide and risk concerns are often not communicated between clinicians, carers and patients (Wand, Draper, *et al.*, 2019a; Wand, Peisah, *et al.*, 2019) (Draper, Krysinska, Snowdon, & De Leo, 2017). Pre-intervention, health professionals lacked knowledge about the limits of confidentiality and disclosure of information against a patient's consent in this context. This is a complex but important area of clinical practice in late life self-harm with clear implications for patient safety (and also human rights), acknowledged as poorly understood (Ryan, Callaghan, & Large, 2014).

There was a significant change in attitudes of clinicians following the intervention. Our previous work has highlighted that helplessness and hopelessness in older patients who have self-harmed (Wand, Draper, *et al.*, 2019a; Wand *et al.*, 2018) is echoed and possibly fuelled by their carers (Wand, Draper, *et al.*, 2019a; Wand, Peisah, *et al.*, 2019) and their

GPs (Wand *et al.*, 2018). However, what was most notable in this study, was that this very helplessness (and possibly therapeutic nihilism) can be addressed by an education intervention such as this. This is encouraging as working with suicidal people has been associated with greater likelihood of mental health clinicians conducting an evidence based suicide risk assessment and adequate management practices with patients with suicidal ideation (Roush *et al.*, 2018). The lack of agreement with the statement that older people who self-harm are attention seeking may reflect differential attitudes towards older and younger self-harm, although this has not been borne out when attitudes to suicidal behaviours by age group were directly compared in non-clinicians (Segal, Mincic, Coolidge, & O'Riley, 2004). However, mid-to-high degrees of empathy and sympathy towards older people who attempted suicide have been demonstrated in homecare nurses, although the nurses disagreed with their actions (Wang *et al.*, 1995).

Unsurprisingly, and consistent with our hypothesis, confidence in assessing self-harm in an older person and talking to families about self-harm in their relatives was lower in non-mental health professionals compared to mental health professionals; both groups improved post-intervention. This may reflect self-selection of mental health professionals choosing to work with and more frequently encountering people who self-harm (although the latter was not significant in the present study)(Roush *et al.*, 2018), having greater access to education on self-harm, and perhaps (not assessed) having more access to related clinical supervision and support (Saunders *et al.*, 2012). Confidence in talking to families about self-harm was low in both professional groups, echoing the results of another study in mental health professionals (Roush *et al.*, 2018) and reflecting the experience of carers of older people who self-harmed (Wand, Peisah, *et al.*, 2019). Clearly working with carers is a key target for clinician education given the demonstrated lack of engagement and communication between clinicians and carers and the importance of carer responses to self-harm in late life (Wand, Peisah, *et al.*, 2019), also reflected in clinical guidelines for suicide prevention (Bernert *et al.*, 2014).

Similar to other studies educating mental health professionals to assess and manage suicidal behaviour, the training was highly valued (Oordt *et al.*, 2009) and deemed likely to change clinical practice. Others have recommended that all clinicians who look after people who self-harm should have access to formal training (Rothes *et al.*, 2014) which addresses knowledge, self-awareness, attitudes, communication and behaviour (Saunders *et al.*, 2012) and promotes evidence-based practice for suicide prevention (Rothes & Henriques, 2018).

The lack of uptake of the educational sessions by general practice was surprising and concerning given the potential opportunities for GPs to intervene with older people at risk of suicide when they present for care (Conejero, Olie, Courtet, & Calati, 2018; De Leo *et al.*, 2013; Troya *et al.*, 2019). There were administrative and practical barriers to implementation of GP education sessions, including lack of audiovisual equipment, no space within education programs, and reluctance to ask GPs attendees to complete pre/post questionnaires on top of (or in lieu of) other continuing professional development requirements. Other factors may have also been relevant such as time-pressure on GPs, competition with other suicide-prevention training initiatives (for example, through the concurrent Lifespan project[2]), perceived knowledge and competence regarding the topic, perceived lack of relevance to clinical practice- especially if some GPs do not perceive themselves as having a role in addressing the contributing factors to late life self-harm (Wand *et al.*, 2018), lack of interest, a preference for online learning (Yee, Simpson-Young, Paton, & Zuo, 2014), or educational 'gate-keepers' (practice managers/PHN education coordinators) not perceiving the topic as important. Engagement of GPs in educational initiatives may be more effective when targeted to identified gaps in knowledge (e.g. depression with comorbid cognitive impairment) and clinical practice (i.e. focusing on clinical pathways and care coordination with other services) (Wand *et al.*, 2018). For example, a different approach to Australian GP education about depression and self-harm in older people which involved printed educational material, practice audit and personalised feedback was associated with a 10% reduction in two-year prevalence of depression and self-harm in older patients (Almeida *et al.*, 2012).

Limitations

The data obtained were cross-sectional taken immediately pre and post-intervention and the sustainability of the effect is unknown; an important consideration for evaluating the cost-effectiveness and benefits of healthcare interventions (Proctor *et al.*, 2015) and with other studies highlighting diminishing endurance of effect over time (Gask, Dixon, Morriss, Appleby, & Green, 2006; Moore, Cigularov, Chen, Martinez, & Hindman, 2011). Although improved attitudes and self-appraisals of confidence post-intervention are encouraging and important in clinical care (Oordt *et al.*, 2009; Roush *et al.*, 2018) they do not necessarily equate to behavioural change and improved clinical practice, which requires objective measurement. The high proportion of correct answers at pre-test may reflect the high baseline

[2] https://www.blackdoginstitute.org.au/research/lifespan

knowledge of mental health clinicians, perhaps in part due to ongoing clinical research in late life self-harm, other lectures and workshops occurring at the study hospitals, the presence of international clinical academic experts on staff, or the questionnaire being too easy. This made it more difficult to detect knowledge gained though the single educational intervention. Additionally, there were only two items in the questionnaire evaluating the key constructs of confidence and attitudes, the latter only really evaluated by one question given that all participants gave the same response. Finally, some participant responses may have reflected socially desirable answers rather than true attitudes (Oordt *et al.*, 2009). However, the paired questionnaires were completed anonymously in an effort to minimise this potential bias. As no GPs received the educational intervention we are unable to comment on effectiveness in this group, an important target population for training in suicide prevention.

Conclusions

A brief educational intervention had immediate impact on knowledge and confidence in relation to understanding, assessing and managing self-harm in late life in both mental health and non-mental health (geriatric) multidisciplinary clinicians. In a group of clinicians with high baseline knowledge particular areas for education included challenging negative beliefs about ageing, engaging with carers, confidentiality and consent.

The study highlights areas for further study including whether the effects of the intervention are sustained over time and/or whether repeated sessions are needed to maintain benefits, whether the format works for GPs and whether there is actual objective behavioural change or improvements in patient outcomes as a result of the intervention. We do not know how the demographics of our older population (such as the high proportion of linguistic and cultural diversity) may influence clinician attitudes to self-harm and patient care. Similarly, we do not know whether the content should be adapted for clinicians of other institutions where there may be less baseline knowledge on self-harm in late life. Future research could identify the core components of educational interventions for clinicians regarding self-harm in older people in order to devise the most time and cost effective approaches. Education should be broadly based given that older people at risk may present to a variety of healthcare professions including primary and secondary care, mental health, general hospital, geriatrics and emergency settings.

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Appendix 1. Outline of the content of the educational intervention

Objectives: To improve knowledge and confidence in relation to the assessment and management of self-harm in older people and to improve "post-self-harm care."

- Summary of key objectives- for health care professionals to understand the individual issues behind a person's self-harm; to support carers; to show carers how to support the older person; to demonstrate opportunities for improving communication
- Debunking myths about ageing
- Definitions of self-harm: direct and indirect
- Statistics regarding the prevalence of self-harm across the lifespan
- How does late life self-harm differ from in younger people?
- Factors statistically associated with direct and indirect late life self-harm (i.e. those derived from quantitative epidemiological studies)
- The reasons for late life self-harm which have been derived from qualitative research with the older person themselves, their carers (relatives and friends) and general practitioners
- The barriers to older people asking for help (perspectives of the older person themselves, their carers and GP)
- The consequences of self-harm for the older person and their carer
- Potential solutions- including clinicians as needs interpreters; practical support and structure; removing the means of self-harm; Advance Care Directives as a solution for suffering; better communication; having clinical pathways informed by strategies which address negative feedback loops of invalidation and rejection; clinician education (including the intersection of cognitive impairment with self-harm); use of psychological strategies in older people; sharing patient care (GPs, family carers, and specialist services) and clarifying concerns about confidentiality.
- Practical strategies for aftercare of an older person who has self-harmed
- The outcomes of older people who self-harm and their family carers
- A graphical representation of a conceptual framework for self-harm in late life which demonstrates the importance of relationships, communication and the network surrounding the older person who has self-harmed
- Facilitated case vignette (hospital staff)- key learning points include how to assess immediate aspects of the self-harm, how to explore the patient's present circumstances and needs and other important features of the history, what to look for on mental state

examination, summarising (formulating) the key issues for the patient which underlie the self-harm, responding to the patient's wish to self-discharge (i.e. limits of confidentiality, and evaluating risk and whether involuntary detention and treatment under the Mental Health Act or Guardianship legislation, as appropriate, is relevant), and developing a management plan targeting the patient's individual needs and including involving the family carer and GP.

Appendix 2: Questionnaires

Pre-education Evaluation: Self-harm in Older People

Age: ……. **Gender** (please circle): Male, Female, Non-binary

Profession (circle): GP, doctor, nurse, allied health, residential care staff

Setting of work (circle):

I work in mental health: Yes No

I regularly work with older people: Yes No

I work in: a hospital or hospital outpatients □ I work in the community □

I have had a clinical role in the care of an older person who self-harmed. Yes No

Education: I have received some education on self-harm in general. Yes No

I have received education on self-harm specifically in *older* people. Yes No

1. Which one of the following populations has the highest rate of suicide?

a. Men aged 85-89 □

b. Women aged 25-30 □

c. Women aged 60-64 □

d. Men aged 35-40 □

2. Which one of the following statements is true of ageing?

a. Depression is expected in late life □

b. Quality of life declines □

c. Satisfaction with life increases □

d. Cognitive impairment is expected □

3. People with cognitive impairment are at risk of self-harm.

a. True □

b. False □

4. Compared to younger people, self-harm in older people is associated with

a. Having a personality disorder □

b. Use of lethal means □

c. Less suicidal intent □

d. Absence of a mood disorder □

5. Which of the following is most likely to contribute to self-harm in an older person?

a. Feeling a burden upon relatives □

b. Early life trauma □

c. Needing to move to a nursing home □

d. All of the above □

6. I feel helpless in dealing with self-harm in an older person.

a. True □

b. False □

7. Older people who self-harm are just seeking attention.

a. True □

b. False □

8. Which one of the following is <u>most true</u> for older people?

a. Pharmacological treatments are best for people with dementia and self-harm □

b. There are effective treatments for depression □

c. Cognitive behavioural therapy is not effective □

d. Depression cannot be reliably diagnosed in someone with dementia □

9. Self-harm in an older person can usually be managed by their GP alone.

a. True □

b. False □

10. If an older person who expresses an intent to self-harm does not give consent to contact carers, they should still be contacted despite confidentiality and privacy concerns.

a. True □

b. False □

11. An important consideration in managing self-harm in older people is addressing hopelessness in

a. The general practitioner □

b. The patient □

c. The carer □

d. All of the above □

12. Self-harm is rare in nursing home residents.

a. True □

b. False □

13. Carer burden is one of the primary factors in self-harm in older people.

a. True □

b. False □

14. Which statement is most true regarding carers of older people who have self-harmed?

a. Carers commonly understand why the older person feels this way □

b. Carers usually contact clinicians if concerned about self-harm in their relative □

15. I feel confident assessing self-harm in an older person.

a. True □

b. False □

16. I feel confident talking to families about self-harm in their older relative.

a. True □

b. False □

Post-education Evaluation: Self-harm in Older People

Questions 1-16 from pre-education evaluation were repeated.

Additional questions:

17. This education session will change my clinical practice.

a. True □

b. False □

Do you have any additional comments or feedback on this education session?

.....
.....
.....

Thank you for completing this questionnaire

6.3 Educating primary care: Implementation and evaluation of the educational intervention on self-harm in late life in primary care clinicians

Paper 9 describes the implementation and evaluation of the educational intervention for health care professionals on self-harm in late life. In addition to hospital and community-based staff, primary care practitioners (nurse practitioners, general practice nurses or general practitioners, GPs) were invited to participate in the study. The educational intervention was offered to five area-based Primary Health Network (PHN) education coordinators or consultants, discussed with ten individual Practice Managers of local General Practices, broadly advertised and offered for delivery several times over a year (mid 2018 – mid 2019) (Wand *et al.*, 2020). However, only one PHN accepted the offer of educational intervention.

Subsequent to submission of the education manuscript for publication (Wand *et al*., 2020), one education session for primary care was booked and conducted after business hours in a rural-regional area of New South Wales (NSW), Australia, 31 July 2019. Thirteen attendees comprised 11 primary care practitioners (nine practice nurses and two GPs) and two administrative staff from the PHN. Eight participants completed pre and post-education evaluations; three completed the pre-education evaluation only. The administrative staff attended the session but did not participate in the discussion or complete questionnaires. The content of the educational intervention was identical to that delivered to hospital and community-based health care professionals, except for the case vignettes. The cases for the primary care education session were patients in GP settings (i.e. a nursing home and a general practice), with the facilitated discussion covering the same practice points. The pre- and post-evaluation questionnaires were the same as those presented at the end of Paper 9.

All participants were women, with a mean age of 48.5 (range 28-61). All participants worked with older people in a community setting. Of the five participants who answered the question about whether they had ever had a clinical role with an older person who self-harmed, only one responded in the affirmative. Regarding previous education, six participants had received previous education about self-harm in general and only two had received education about self-harm in older people. One participant did not respond.

Results for the pre/post evaluation in primary care participants are shown in Table 6.6 and Table 6.7.

Table 6.6 Pre-post evaluation of knowledge questions in primary care practitioners.
Participants n=11; (8 complete pre/post; 3 pre-only).

Question number ***Correct answer (multiple choice)***	**Pre Correct N (%)**	**Post Correct N (%)**
Q1. Pick the age bracket with the highest suicide rate. *A. Men aged 85-89*	5 (45)	8 (100)
Q2. Which statement is true for ageing? *C. Satisfaction with life increases with ageing.*	2 (18)	2 (25)
Q3. People with cognitive impairment are at risk of self-harm. *A. True*	8 (73)	6 (75)
Q4. Self-harm in older people is associated with *B. Use of lethal means*	5 (45)	5 (62.5)
Q5. Which items contribute to self-harm (burden, trauma, move to a nursing home, all). *D. All of the above*	9 (82)	8 (100)
Q8. Which is most true for older people? *B. There are effective treatments for depression*	8 (73)	4 (67)*
Q9. Self-harm can usually be managed by GPs alone. *B. False*	11 (100)	7 (87.5)
Q10. Confidentiality in an older person with self-harm. *A. True, carers may be contacted*	6 (55)	7 (87.5)
Q11. Important considerations addressing hopelessness. *D. All of the above*	7 (64)	4 (50)
Q12. Self-harm is rare in nursing homes. *B. False*	9 (82)	8 (100)
Q13. Carer burden is a primary factor in self-harm. *A.True*	11 (100)	6 (75)
Q14. Which is true, A or B? *A. Carers commonly understand why the older person feels this way*	3 (30)**	5 (62.5)

* Pre missing: 1; ** Post missing: 2

Table 6.7 Pre-post evaluation of attitudes/beliefs and confidence items in primary care practitioners.

Participants n=11; (8 complete pre/post; 3 pre-only).

Question number *Desired response designated as correct (true/false)*	Pre Correct N (%)	Post Correct N (%)
Q6. I feel helpless dealing with self-harm in an older person *(false)*	6 (55)	8 (100)
Q7. Older people who self-harm are just seeking attention *(false)*	10 (100)*	8 (100)
Q15. I feel confident assessing self-harm in an older person *(true)*	3 (27)	8 (100)
Q16. I feel confident talking to families about self-harm in their older relative *(true)*	3 (27)	8 (100)
Q17. The education session will change my practice *(true)*	NA	8 (100)

* Pre missing: 1

Two participants responded to the open question at the end of the education session. One participant suggested including voluntary euthanasia in the intervention. A second participant noted that '*Exit*' groups (Exit International is a not-for-profit organisation advocating for the legalisation of voluntary euthanasia and assisted suicide) were being held in the region with a prominent (deregistered) pro-euthanasia medical practitioner, with hundreds of financial members of the groups. The participant had informed the police of this activity. Both participants discussed their concerns with the doctoral candidate after the session. The subject of euthanasia in the very old also arose in the facilitated case-based discussions during the session. There were strongly held views regarding the limits of and difficulty accessing high quality palliative care in the region, whether depression was normal or expected in the context of physical illness and advanced age, and debate over the role of primary care practitioners in decisions to die (including suicide attempts). Lack of access to mental health care and acute home-based geriatric services were discussed, perhaps reflective of the rural/regional setting of the respondents.

Descriptive statistics were used to evaluate the results of the educational intervention delivered to primary care practitioners (see Table 6.6 and Table 6.7). Tests of statistical significance were not appropriate and descriptive only due to small numbers of participants pre- and post-intervention. The questions which showed most striking improvement in responses (i.e. with at least 25% improvement and/or 100% rating the correct answer post intervention) included the prevalence of late life self-harm by age-group (Q1), contributing factors to late life self-harm (Q5), consent and confidentiality (Q10), self-harm in nursing

homes (Q12), and carers understanding why the older person self-harmed (Q14). In a further three knowledge-based questions there was an increase in the proportion of participants with correct answers post-intervention (Q2-4). In four questions the proportion of participants selecting correct responses reduced post-intervention (Q8,9,11,13).

With regards to attitudes and confidence, reassuringly no participant pre- or post-intervention attributed self-harm in an older person to attention seeking. However, marked improvements were observed in practitioners' sense of helplessness in dealing with self-harm in an older person, in their confidence in assessing an older person who has self-harmed, and in their confidence regarding talking to families about self-harm, all of which were endorsed by 100% of participants post intervention. Albeit involving small numbers of engaged practitioners, these knowledge translation outcomes are key to the successful management of late-life suicide.

The impact of the educational intervention was compared between hospital/community and primary care clinicians, using descriptive statistics as the same questionnaire was used to test both groups. The discrepancy in the sample sizes of the two groups (119 vs 8) was too large for meaningful statistical analysis. In both groups of clinicians there was overall improvement in knowledge, attitudes and confidence following the intervention. There were few differences in baseline knowledge of either group as indicated by their pre-intervention responses. For example, similar to the hospital/community group the primary care participants had poor pre-test scores for the epidemiology of suicide, assumptions about ageing (ageist or negative assumptions were more common pre-intervention), differences in self-harm in older and younger people (lethality of means), and about the knowledge and behaviour of carers. Primary care performed better in relation to confidentiality and consent issues pre-intervention. The reasons for this are unknown, perhaps due to the session being run in a rural/regional area; a smaller community with perhaps family members attending the same general practice providing an opportunity for informal GP contact with carers. In general, there was greater knowledge gain in the primary care group. One reason for this may have been that many of the hospital/community clinicians had received prior education on self-harm in general as well as specifically in older people (possible delivered by the doctoral candidate over the last few years), whereas primary care clinicians had not attended such education. Clearly the addition of discussion about how self-harm may relate to requests for voluntary assist dying (VAD) and how to manage such requests were considered relevant for primary care staff, perhaps due to the prominence of active *Exit* groups in the PHN. Similarly, the practical limitations to delivering holistic, responsive individualised specialist services to complex older patients in a regional area were highlighted and warrant inclusion in further local educational interventions on late life self-harm.

6.4 Implications for delivery of the education intervention on self-harm in late life to primary care

Despite concerted efforts in this project to provide education for GPs, the lack of engagement of PHNs precluded any such sessions being run within the timeline of the project. The lack of uptake of the educational sessions by general practice was surprising and disappointing. Similarly a full-day seminar on a variety of topics relevant to mental health in general practice coordinated by the University of NSW in 2019 (in the study catchment area) was also cancelled due to insufficient registrations, despite prominent international speakers and no cost. For the educational intervention, there appeared to be administrative barriers to implementation at the level of the PHNs and practice managers. At a micro level this included difficulty providing basic audio-visual equipment for a *PowerPoint* presentation, lack of space to schedule new talks in PHN education programs planned one year earlier, and reluctance of education coordinators to ask GPs attendees to complete pre/post questionnaires on top of (or in lieu of) other continuing professional development requirements. Practice managers seemed to rely largely on PHNs to run educational programs for their GPs or were unable to coordinate a minimum number of GPs (≥3) to attend single on-site sessions. By contrast, in other international settings practice managers consider it their role to plan and prepare onsite educational sessions for their GPs and nurses (Cunningham *et al.*, 2006). Possible reasons for poor registrations in the PHN scheduled educational sessions are explored in Paper 9 and include time-pressure on GPs, competition with other topics and specifically with suicide-prevention training initiatives (for example, through the concurrent Lifespan project[3]), perceived knowledge and competence regarding the topic, perceived lack of relevance to clinical practice, lack of interest, or a preference for online learning (Yee *et al.*, 2014).

The low number of primary care practitioners precluded drawing conclusions regarding the effectiveness of the educational intervention in this group. However, it was encouraging to see that the intervention was well received, that the confidence and attitudes of all participants improved following the intervention and that knowledge improved on most items. The limitations of the study are similar to those outlined in the companion paper describing the impact of the educational intervention in hospital/community staff (Paper 9, Wand *et al.*, 2020), including questions about the sustainability of the impact, the possibility of socially desirable responses over true attitudes/beliefs, and question marks over actual (as

[3] https://www.blackdoginstitute.org.au/research/lifespan. Accessed 9.10.19

opposed to predicted) effect on practice in late-life self-harm. Notwithstanding these limitations, there appears to be a role for such education with few primary practice clinicians having received any education on this topic despite all of them working routinely with older adult patients.

The overlap between some late life self-harm and VAD was highlighted by two primary care nurses as an important area to be included in future education. Primary care staff expressed discomfort about *Exit International* groups running in the region. The presence of such groups was confirmed by a story in the regional paper in 2018 about a public meeting held by a prominent campaigner for euthanasia (Bennett, 2018[4]). This is complex and important area to be included in clinician education about late-life self-harm. This further illustrates the knowledge translation value of the study in this field as discussed in one of the PhD papers (Wand *et al.*, 2018b).

Finally, the rural/regional setting where this primary care educational intervention was delivered was relevant. Participant discussion and feedback after the session revealed additional considerations for teaching about the assessment and management of late life self-harm. This included, for this area at least, limited local resources, geographically distant and relatively inaccessible specialist teams (e.g. older persons' mental health or acute community-based geriatric response teams), a disproportionate (compared to urban areas) local population of retirees and older people, and a relative lack of choice with few residential aged care facilities compounding hopelessness about the prospect of living in care. Through the lens of clinical staff on the ground it was easy to see how therapeutic nihilism, professional isolation and negative views on ageing developed (Wand *et al.*, 2018a), all of which impact delivery of care to older people who may be at risk of or actually self-harm (Wand *et al.*, 2019a) and may influence support for VAD (Wand *et al.*, 2018b).

[4] available at: https://www.southernhighlandnews.com.au/story/5220540/the-last-exit-dr-philip-nitschke-discusses-assisted-dying-at-public-meeting/ Accessed 26.8.19

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Chapter 7 Synthesis and significance

7.1 Synthesis of study findings

The aims of this thesis were to understand why very old people self-harm, the consequences of their self-harm, their experiences of clinical care (Study 1, Papers 3-6), and their reflections and outcomes one-year later (Study 2, Paper 7). To comprehensively answer these questions the perspectives of the patient themselves, their friends or relatives (hitherto referred to as carers as in the accompanying manuscripts), and their GPs were sought proximal to the self-harm, and the data triangulated using qualitative methodology. This is the first qualitative study to comprehensively triangulate such perspectives regarding self-harm. To reflect the real-world population of older Australians, and to address gaps in the literature, we uniquely used a broad definition of self-harm not defined by intent (Van Orden, 2018), and were deliberately inclusive of older people from culturally and linguistically diverse backgrounds (CALD), the very old (aged 80 or more; with men in this age group having the highest rates of suicide), and those with cognitive disorders, including dementia. The inclusion of older people living in residential aged care facilities, a group whose perspective is rarely sought in self-harm studies (Gleeson *et al.*, 2019), was a further strength. The final aim was to provide translational significance to this project by using the data to inform contemporary initiatives on voluntary assisted dying (VAD) as well as suicide prevention and management. Specifically, with regards to the latter, the qualitative data derived from the three participant groups (i.e. patients, carers and GPs) were used to inform an educational intervention for health care professionals on self-harm in older people, and to evaluate its effects (Study 3, Papers 8-9). Human research ethics committee approval was granted for all studies.

Study 1 recruited 30 patients who had self-harmed within the last month, 32 of their nominated carers, and 13 GPs of the patients. In-depth qualitative interviews with patients and, separately, their carers were conducted and questionnaires were sent to GPs. The patients were from CALD backgrounds (43% did not speak English), the majority were cognitively impaired (90%) and just under half had depression (Wand *et al.*, 2018d). Two-thirds of the patients self-harmed with suicidal intent. Themes from patients regarding the reasons for self-harm were diverse and included loss of raison d'etre, feeling alienated and disconnected, hopelessness and endless suffering and helplessness with rejection (Wand *et al.*, 2018d). The relational context of self-harm in late life was emphasised, with rejection and invalidation

potent antecedents and consequences of the self-harm. Carer themes echoed that of the patients and highlighted communication problems with both clinicians and relatives (Wand *et al.*, 2019c). Carers also described various forms of distress emanating from their relative's self-harm. General practitioners had known their patients for several years and understood the factors contributing to self-harm, but did not see a role for themselves in addressing them (Wand *et al.*, 2018a). Some of their responses reflected a sense of professional isolation, hopelessness and therapeutic nihilism. The triangulated results informed discussion about the overlap between some patients who self-harm and those who might request VAD (Wand *et al.*, 2018b). Specifically, the qualitative data (especially relational factors) generated by Study 1, provided insight into requests for VAD in the context of relational autonomy, i.e. that autonomy occurs within and because of relationships (Nedelsky, 1989). This in turn informed a wider understanding of the role of undue influence and elder abuse in late life suicide and requests for VAD (Wand *et al.*, 2018b).

Study 2 followed-up the original cohort of patients, carers and GPs from the baseline study one year after the self-harm (Wand *et al.*, 2019a). To our knowledge there are no other longitudinal qualitative studies concurrently examining the perspectives of these three groups on self-harm and outcomes over time. Nineteen patients and 29 carers were available for follow-up in-depth interviews and 11 GPs completed the questionnaires. Data on patient outcomes were also derived from medical records where available and for which patients/carers provided consent. The majority of patient participants had dementia (65%), a minority had major depression (14%) and 32% wanted to die at 12 months follow-up. The living circumstances of 12 patients changed following self-harm; 11/30 (37%) moved into a nursing home (in addition to six patients who were already living in a nursing home) and one patient had been transferred to a hospice. Repeated self-harm in the follow-up period occurred in 14% of patients, of whom all were nursing home residents. Seven patients died during the follow-up periods, none by suicide. Patient themes at one-year follow-up reflected those at baseline, namely, endless suffering, hopelessness and further invalidation, denial and secrets. A new theme to emerge was 'miserable in care', especially pertinent given that over half the original cohort were living in a nursing home one year after the initial self-harm.

Carers echoed patient themes including an understanding of the patient's persistent wish to die, perceptions of abandonment by clinicians which were observed in patients and experienced by carers too, and distress regarding placement in a facility as well as unending carer burden. By contrast, the GPs who responded were quite positive and confident in their care provision to the patients who self-harmed; with themes of understanding the issues, the

problem being fixed, and 'the troops having arrived' (i.e. services assisting in management). This was at odds with patient and carer perspectives of clinicians communicating poorly by demonstrating ageism and responding with therapeutic nihilism and/or invalidation.

These incongruent perceptions of GPs compared to patients and their carers may be attributed to a number of biases. Firstly, the overly optimistic GP responses may have been confounded by social desirability biases or denial. Conversely, they may reflect a sense of relief having garnered responses from the wider health system following patient self-harm in an otherwise isolated clinical role. Secondly, the largely positive GP responses may be attributed to sampling bias, with only those GPs who felt confident and well supported participating at follow-up (Wand *et al.*, 2019a). The negative perceptions of clinical care described by patients and carers may equally reflect disappointment in mental health services as well as in primary care.

An empirically derived framework for conceptualising late life self-harm was developed by triangulating themes from the three cohorts at baseline and follow-up, emphasising the relational aspects, positive and negative influences on self-harm, and opportunities to intervene (Wand *et al.*, 2019a).

Taken together these qualitative studies provide important clinical insights, which may guide practice. Firstly, there are a myriad of reasons why very old people self-harm, the majority of whom do so with intent to die in the context of being unable to communicate their needs. Moreover, the pervasive and real hopelessness and helplessness of the whole system (family/friends, GPs, mental health services, wider society) in which the older person is positioned (see conceptual framework in Wand *et al*., 2019a), hitherto relegated to patient cognitive distortion, needs to be addressed. The older person's perceptions of hopelessness and helplessness are not simply a sign of mental illness, but may reflect the dynamics of a system struggling to identify and meet their needs. Therefore, each individual's needs must be heard and understood in order for them to be addressed and in order to empower and give hope. This includes managing both the 'big things'- the Axis I diagnoses- and those that might otherwise be dismissed as 'little things' - such as interpersonal issues, loneliness and unremitting physical symptoms.

Families are an important ally in management and a source of collateral information, but may need help to understand the meaning of the self-harm and how to respond, while being supported in their own right, also to empower and give hope. General practitioners, who know their patients well but may be simultaneously overwhelmed by the patient's

issues and feel unsupported and unequipped to manage them, need to be equally empowered and given hope and support. Aside from a need for more education and training, this suggests that other services should be recruited to assist in management, including mental health services. Clinicians and families should be aware of how their responses to self-harm may inadvertently perpetuate distress by reinforcing invalidation, hopelessness and rejection and that poor communication may reinforce the need for secrets and denial. It is important to improve communication at all levels of the older person's system and to follow-up with older people who have self-harmed.

A proportion of older people who self-harm may do so as an alternative to euthanasia, which is not available in all jurisdictions. The corollary of this is that older people requesting VAD must have a careful assessment of this decision, not only to determine capacity, but to evaluate underlying interpersonal factors and distorted beliefs which may be operating and remediable, and to ensure that there is no undue influence or abuse (Wand *et al.*, 2018b).

In **Study 3** the results of Studies 1 and 2 were combined with existing quantitative data relating to factors associated with self-harm in older people derived from the literature (outlined in Chapter 2) to inform the development of an educational intervention for health care professionals on the assessment and management of late life self-harm (Wand *et al.*, 2019b). The targets for the education were a mixed group (including medical, nursing and allied health) of hospital/community-based and primary care practitioners. Pre/post questionnaires were used to evaluate the educational intervention in terms of change in clinician knowledge, confidence, and attitudes. One hundred and nineteen hospital/community-based clinicians and 11 primary care practitioners (two of whom were GPs) attended an education session. There were significant improvements in knowledge, attitudes and confidence regarding self-harm in late life post-intervention (Wand *et al.*, 2020). The hospital/community-based clinicians had high levels of baseline knowledge, likely due to previous education in this field delivered by the doctoral candidate, potentially underestimating the impact of the intervention. The sustainability of these effects over time, objective evidence of change in clinical practice, and effectiveness of the intervention for GPs warrant further study.

7.2 Translational significance

7.2.1 Significance for understanding voluntary assisted dying and euthanasia

This doctoral thesis started with two case reports (Paper 1) of older adults who for various reasons had desired euthanasia but, as this was illegal in their jurisdiction, they attempted suicide instead (Wand *et al.*, 2016). In these cases the absence of major mental illness, but salience of physical, social and interpersonal factors were highlighted. Through the course of this doctoral study it became apparent that findings such as these had great relevance to current discourse in Australia and internationally on VAD and euthanasia. Specifically, in the Australian context the *Voluntary Assisted Dying Act 2017* (Vic) was passed on the 29 November 2017 and enacted in force on the 19 June 2019, with the first death subsequently occurring under the Act. Similarly, in Western Australia the Voluntary Assisted Dying Bill 2019 has been developed for introduction to Parliament (8 July 2019), having gained recent support in the Lower House.

In Paper 6, the intersection between self-harm in older adults and VAD requests, and the potential for elder abuse and undue influence were discussed (Wand *et al.*, 2018b). This work was directly informed by the qualitative results of Studies 1 (Wand *et al.*, 2018a; Wand *et al.*, 2018d; 2019c) and 2 (Wand *et al.*, 2019a). Key findings were that interpersonal relationships and perceptions of relationships such as dependency and burdensomeness, often echoed by carers and health care professionals alike, are influential in decisions to die, whether by suicide or VAD (Wand *et al.*, 2018b), hence the relevance of the concept of relational autonomy (Nedelsky, 1989). This has implications for understanding the true autonomy of a request for VAD, as well as emphasising that the person must have capacity to request VAD. The *Voluntary Assisted Dying Act 2017* (Vic) specifically highlights the need for the decision to be voluntary and that the doctors making the assessments must safeguard against undue influence in the form of "coercion" (s 20(1)(c), s 29(1)(c)).

The *Voluntary Assisted Dying Act 2017* (Vic) recognised the need for "approved assessment training" and there was provision for the Government to approve training including in relation to assessing a person's eligibility for VAD and "identifying and assessing risk factors for abuse or coercion" (s 114). Findings from this doctoral thesis were used to inform this training conducted by the Voluntary Assisted Dying Training team at the Australian Centre for Health Law Research, Faculty of Law, Queensland University of

Technology. In particular, a significant piece of work (Peisah *et al.*, 2019) referenced two PhD papers (Wand *et al.*, 2018b; d). In this way, this doctoral thesis has already seen important translational impact during a perfect storm of vulnerability for older people.

At an international level, the two case reports and associated paper hitherto referred to (Wand *et al.*, 2016) were cited and discussed in two presentations in a Symposium "Euthanasia and physician-assisted suicide for elderly people with psychiatric disorders or dementia", at the International Psychogeriatric Association Congress in September 2019, in Spain (Goncalves Pereira, 2019; Sánchéz Pérez, 2019). The cases were used to highlight the complexity inherent in assessing requests for euthanasia in older people, related ethical issues and the need for expertise and further discourse on the issue. Dr Sánchéz Pérez also cited the qualitative systematic review from this thesis evaluating why older people self-harm (Wand *et al.*, 2018c), to demonstrate the need to explore the individual reasons for suicide attempts in older people. He emphasised the thesis findings which elucidated older people's perceptions of life as meaninglessness or lacking raison d'etre, their sense of disconnectedness, invisibility, accumulated suffering and painful life, and loss of, and attempt to regain control, as underlying decisions to attempt suicide (Wand *et al.*, 2018c). Dr Sánchéz Pérez (2019) endorsed the recommendations emanating from this thesis (Wand *et al.*, 2018c; d) that physicians should directly ask the older person why they reverted to suicidal behaviour and to actively help him/her regain a sense of control and/or a raison d'etre.

7.2.2 Knowledge translation: Education of clinicians on late life self-harm

A key component of the translational significance of this thesis was knowledge translation of the qualitative findings to inform coal face clinicians. The perceptions and reflections of very old people who had self-harmed, their carers, and GPs, regarding reasons for self-harm, barriers to seeking help, the consequences of self-harm, and experiences of before and aftercare provided rich guidance for the improvement of clinical care. As such, an educational intervention for self-harm prevention and management was derived directly from the qualitative results obtained and complemented by the existing quantitative literature. The first of these papers (Paper 8, (Wand *et al.*, 2019b)) discussed the practical clinical application of the content of the educational intervention for primary care in *Medicine Today*, a journal available to all registered general practitioners (GPs) in Australia with broad potential reach and dissemination. The importance of this topic to the general practice setting was acknowledged by *Medicine Today* who decided to have accompanying Continuing Professional Development (CPD) questions attached to the paper to assess GP learning.

Evidence of knowledge translation is provided in the final paper of this thesis (Paper 9, Wand *et al.*, 2020), the evaluation of the educational intervention for clinicians on late life self-harm. As with the *Medicine Today* paper (Wand *et al.*, 2019b), the content of the educational intervention was informed by the qualitative results from Study 1 and 2 and synthesis of the quantitative literature outlined in Chapter 2. The intervention was delivered to and evaluated with multidisciplinary health care professionals in hospital, community and general practice settings. The intervention was highly valued, low cost and delivered within existing routine educational programs. Results from the evaluation of the intervention in hospital and community-based staff demonstrated significant improvements in knowledge, confidence and attitudes regarding late life self-harm following the intervention (Wand *et al.*, 2020). Further, the intervention format and content were well received by clinicians. Thus, an immediate impact of the evidence-based educational intervention was demonstrated in a real-world target sample of clinicians working with older people.

7.3 Limitations of the thesis

There were some limitations to this study, albeit the first of its kind. The use of clinician researchers, including the doctoral candidate who conducted all the qualitative interviews, was a potential limitation. As the treating psychiatrist for some of the patients it is possible that this professional relationship influenced participant responses where a formulation of the patient's presentation had been shared. It is also possible that this relationship influenced participant responses, inhibiting fully articulated perspectives or offering responses tainted by a social desirability bias. However, many themes derived from the interviews were negative or critical of clinical care, suggesting that this was not the case. Given the negative perceptions of clinical care raised by patients and carers alike, further qualitative studies of the perspectives of GPs and mental health professionals on late life self-harm could elucidate these barriers to care further. The choice of correspondence/questionnaire format to elicit GP responses was purposeful to maximise participation recognising both the time-constraints on GPs and the potentially confronting nature of interview by a psychiatrist after patient self-harm. Focus group interviews may provide a more acceptable alternative to individual qualitative interviews with GPs and mental health care professionals, and still produce rich data. The benefits of a focus group include in-depth discussions, group interactions to produce data and insights that would be less accessible in individual interviews, suitability for examination of sensitive issues, and the exploration of a particular group's experience and knowledge (Liamputtong, 2013).

A full psychiatric assessment was conducted with each patient participant, including some evaluation of personality traits as part of a comprehensive psychiatric interview. More rigorous assessment of personality may have elicited emergent themes with an interpersonal focus, such as invalidation and rejection (Wand *et al.*, 2019a; Wand *et al.*, 2018d; 2019c). Assessment of personality using a validated tool such as the Neuroticism Extraversion Openness (NEO) Personality Inventory (McCrae and Costa, 2010) may have provided greater insight into the significance of emergent interpersonal themes, helping differentiate between pre-existing personality traits and state-specific responses to life stress leading to self-harm. Other work has demonstrated that personality traits such as neuroticism and low openness to experience are associated with suicide (Draper *et al.*, 2014a).

The delivery of the educational intervention (Study 3) was pragmatic, opportunistically capturing multidisciplinary health care professionals in working hours. Although after the intervention there were immediate impacts in knowledge, attitudes and confidence sustainability was not evaluated. Moreover, change in knowledge does not necessarily translate to behavioural change, which is reflected in education theory. For example, the Kirkpatrick model is a commonly used model for evaluating and analysing the effects of training and education programs at four levels; reaction, learning, behaviour and results (Kirkpatrick, 1994). According to the Kirkpatrick model the educational intervention (Study 3) had impact at Levels 1 (feedback and satisfaction with the educational intervention) and 2 (knowledge, skill or attitudinal change) but did not examine impact at Level 3 (changes in healthcare professionals' practice), or improved patient health outcomes, i.e. Kirkpatrick Level 4 (Kirkpatrick, 1994). The study was not designed to test whether the benefits observed after the educational intervention translated to improvements in clinical practice in relation to self-harm in older people. Furthermore, it is well-recognised that the effects of healthcare interventions wane over time (Moore *et al.*, 2011) and we do not know what the optimal interval is between repeating the intervention in order to sustain benefits. Finally, the acceptability of the format and benefits of the educational intervention for GPs (while positive for the few who attended) warrants more examination, as recruitment was difficult.

7.4 Concluding remarks and new avenues for research

This thesis demonstrates the richness of data which may be gathered by using qualitative methods and sampling the systemic context of the particular group of interest, in this case very old people who have self-harmed. It was deliberately broad in scope, inclusive

of any form of self-harm (direct and indirect) and regardless of intent. The participants were very old, mostly cognitively impaired, and included a significant proportion from CALD backgrounds, thus representative of the older population in Australia but hitherto neglected in research per se, let alone in this area. Future research could examine whether intent, underlying reasons and outcomes differ between older people with direct or indirect self-harm from both qualitative and quantitative perspectives. A proportion of very old people in this study had considered euthanasia/VAD an option because they perceived life as not worth living or that their long life had been lived, but as this option was unavailable in their jurisdiction, resorted to self-harm instead. This group deserves particular study as VAD legislation is likely to be expanded across Australian jurisdictions. It would be important to study this group to see how they compare to older people who self-harm for other reasons. The follow-up period for this project was one year, but future studies could extend this time to look at longer-term outcomes, including self-harm although this would need to be balanced against likely higher attrition with time in the very old.

Given the close relationship between self-harm and suicide in older adults, and the disproportionately higher rates of suicide in men compared to women, it would be interesting to qualitatively explore gender differences in older people who self-harm with suicidal intent. Some unanswered questions include whether older men who self-harm with suicidal intent are more vulnerable to feeling burdensome or lacking purpose, are less able to adapt to physical illness or loss of function, or are less resilient or able to cope with interpersonal conflict. Qualitative studies of gender differences in self-harm with suicidal intent have the potential to usefully inform suicide prevention initiatives, which must be specific for older men given the greater prevalence in this group and current lack of targeted effective approaches (Lapierre *et al*., 2011).

Attitudes of clinicians, especially those in acute hospital settings, towards people who self-harm are often negative, consistent with the experiences of the patients they treat (Saunders *et al.*, 2012) and their carers. Formal education programs have been found to improve knowledge and attitudes (Saunders *et al.*, 2012; Wand *et al*., 2020; see Chapter 6). This is especially important for clinicians without mental health expertise and training, who tend to have more negative attitudes which may adversely impact upon patient care (Draper *et al.*, 2014b; Saunders *et al.*, 2012). The need for training in suicide prevention in residential aged care facilities has been highlighted (Couillet *et al.*, 2017), where staff have been found to have limited knowledge of late-life depression and suicide (Walker and

Osgood, 2001). Encouragingly, attitudes towards suicide in late life, including ageism and therapeutic nihilism, improve after training (Ziervogel *et al.*, 2005).

This doctoral thesis demonstrates that some people living in nursing homes, especially those entering as a result of self-harm or reluctantly, must be targeted for support in transitioning to care and for assertive follow-up (Wand *et al.*, 2019a). One way to do this would be to train facility staff to recognise and understand the contributing factors to self-harm in late life and approaches to address them. An online module could be developed to improve access to education for multidisciplinary staff especially hospital shift-workers, nursing home care staff, and GPs, who may prefer online formats (Yee *et al.*, 2014). An extension of the education intervention to crisis supporters (volunteers) is currently being investigated in relation to Lifeline, a charitable organisation that provides free, 24-hour crisis support and suicide prevention services in Australia. In September 2019, the doctoral candidate and Professor Peisah were awarded a grant of $26,000 from the Ageing Futures Institute at the University of New South Wales (UNSW) to collaboratively develop an online tool to train volunteers working for Lifeline. Clinician participant feedback suggested that the content of education sessions should be expanded to include some discussion of the overlap and relevance to VAD. This is a valid suggestion which could be readily accommodated with reference to one of the doctoral papers (Wand *et al.*, 2018b) and other papers which have discussed the project's significance to VAD (Peisah *et al.*, 2019), particularly for jurisdictions where VAD is legalised or pending.

Aside from expanding and developing the educational intervention, the logical next step would be to apply the insights gained in this doctoral work to designing interventions to prevent and manage late life self-harm, including suicide. Interpersonal factors emerged as critical to decisions to self-harm and the responses of the older person's network to the self-harm determined whether his/her distress was amplified or attenuated. The doctoral findings provided further empirical support for the interpersonal theory of suicide (Joiner, 2005), emphasising the relevance of perceived burdensomeness and thwarted belonging (demonstrated here broadly in themes of loneliness, disconnection and alienation). Public health campaigns which promote the fostering and maintenance of social connections (Van Orden *et al.*, 2010) and awareness raising of the impact of loneliness (Cacioppo *et al.*, 2006; Golden *et al.*, 2009) may reduce self-harm in late life.

The study revealed that carers, although often aware of suicidal behaviours and thoughts (Choi *et al.*, 2017; Draper *et al.*, 2018), are often dismissed or excluded by clinicians when the older person self-harms, and bear much distress. Thus, an opportunity is missed to

engage carers as sources of collateral history (identifying underlying contributing factors for self-harm, dissolving secrets and sharing burden) and as allies in implementing management plans. This may be in part due to lack of clinician confidence talking to carers about self-harm (Wand *et al*., 2020). Carers too may struggle to make sense of communications of suicidal ideation or intent and be unsure how to respond or intervene (Owen *et al.*, 2012). Family carers need evidence-based knowledge and skills to understand self-harm in their relative but also to cope with and help manage the patient in the aftermath (Sun *et al.*, 2009) and recruit services if the patient voices thoughts of repeat self-harm (Choi *et al.*, 2019). Programs targeting family carers should be developed and evaluated. Family therapy, as with psychotherapy in general, is underutilised in aged care psychiatry (Ansari and Grossberg, 2016; Peisah, 2006); but maybe especially helpful for late life self-harm where the family milieu is so important. Benefits have been demonstrated in other psychotherapeutic interventions such as using cognitive behavioural approaches for adapting to retirement by finding meaning; this enhances resilience to suicidality in older adults (Lapierre *et al.*, 2007). Additionally, an interpersonal therapy program for older adults at greater risk of suicide which focused upon improving social skills and functioning was found to significantly reduce the severity of depressive symptoms and the score on the Geriatric Suicide Ideation Scale (Heisel *et al.*, 2009). However, these were small studies requiring replication.

This thesis answers many questions about self-harm in the very old from the triangulated perspectives of the older person, their relatives and general practitioner. It also identifies avenues for further study, particularly interventions to prevent self-harm and improve postvention, which must focus on improving communication and understanding. True partnerships between older people and their social and clinical networks are needed to effect positive change.

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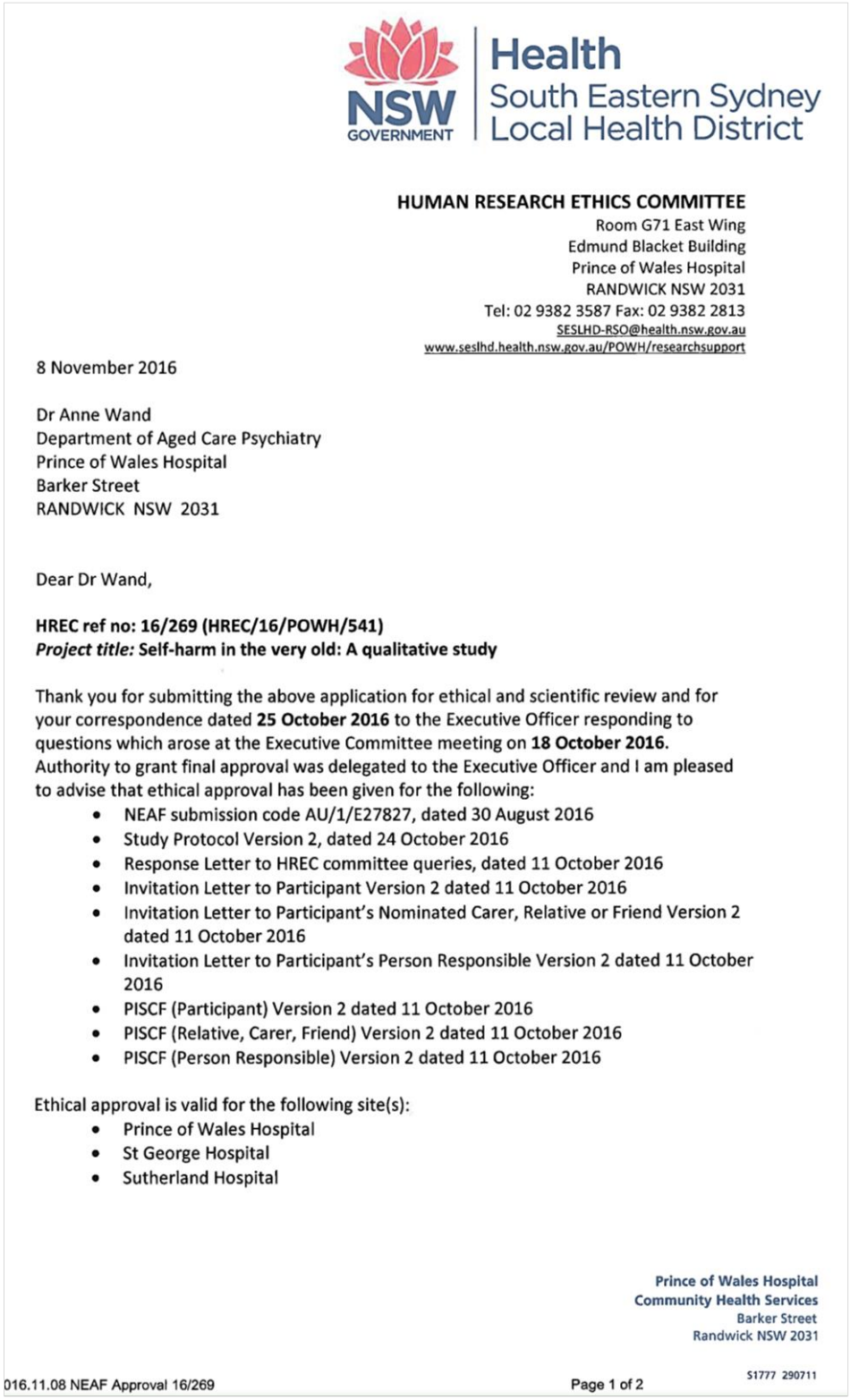
Appendix Letters of ethical approval

This Appendix contains facsimiles of letters of Human Research Ethics Committee Approval for this dissertation.



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8 November 2016

Dr Anne Wand
Department of Aged Care Psychiatry
Prince of Wales Hospital
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RANDWICK NSW 2031

Dear Dr Wand,

HREC ref no: 16/269 (HREC/16/POWH/541)
Project title: **Self-harm in the very old: A qualitative study**

Thank you for submitting the above application for ethical and scientific review and for your correspondence dated **25 October 2016** to the Executive Officer responding to questions which arose at the Executive Committee meeting on **18 October 2016**. Authority to grant final approval was delegated to the Executive Officer and I am pleased to advise that ethical approval has been given for the following:

- NEAF submission code AU/1/E27827, dated 30 August 2016
- Study Protocol Version 2, dated 24 October 2016
- Response Letter to HREC committee queries, dated 11 October 2016
- Invitation Letter to Participant Version 2 dated 11 October 2016
- Invitation Letter to Participant's Nominated Carer, Relative or Friend Version 2 dated 11 October 2016
- Invitation Letter to Participant's Person Responsible Version 2 dated 11 October 2016
- PISCF (Participant) Version 2 dated 11 October 2016
- PISCF (Relative, Carer, Friend) Version 2 dated 11 October 2016
- PISCF (Person Responsible) Version 2 dated 11 October 2016

Ethical approval is valid for the following site(s):

- Prince of Wales Hospital
- St George Hospital
- Sutherland Hospital

Prince of Wales Hospital
Community Health Services
Barker Street
Randwick NSW 2031

016.11.08 NEAF Approval 16/269 Page 1 of 2 S1777 290711

Conditions of approval

1. This approval is valid for 5 years from the date of this letter.
2. Annual reports must be provided on the anniversary of approval.
3. A final report must be provided at the completion of the project.
4. Proposed changes to the research protocol, conduct of the research, or length of approval will be provided to the Committee.
5. The Principal Investigator will immediately report matters which might warrant review of ethical approval, including unforeseen events which might affect the ethical acceptability of the project and any complaints made by study participants.

Optional It is the responsibility of the sponsor or the principal (or co-ordinating) investigator of the project to register this study on a publicly available online registry (eg Australian New Zealand Clinical Trials Registry www.anzctr.org.au).

For NSW Public Health sites only: You are reminded that this letter constitutes ethical approval only. You must not commence this research project until you have submitted your Site Specific Assessment (SSA) to the Research Governance Officer of the appropriate institution and have received a letter of authorisation from the General Manager or Chief Executive of that institution.

Should you have any queries, please contact the Research Support Office on (02) 9382 3587. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office website: http://www.seslhd.health.nsw.gov.au/POWH/researchsupport/default.asp.

Please quote **16/269** in all correspondence.

We wish you every success in your research.

Yours sincerely

Andrew Bohlken
Executive Officer, Human Research Ethics Committee

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Anne Wand

From: humanethics@unsw.edu.au
Sent: Tuesday, 22 November 2016 3:35 PM
To: Anne Wand
Subject: RE: ethics approval for PhD project

Dear Anne,

Thank you for providing copies of your ethics approval for our records. Further review by the UNSW HREC is not required.

Kind regards

Leonne

From: Anne Wand [mailto:Anne.Wand@health.nsw.gov.au]
Sent: Thursday, 17 November 2016 4:52 PM
To: DVCR RECS Human Ethics
Subject: ethics approval for PhD project

Dear UNSW Human Ethics Team,
My name is Anne Wand and I am a PhD candidate with the School of Psychiatry, Faculty of Medicine. My project "Self-harm in the very old: A qualitative study", has recently been granted ethical approval to proceed by the HREC at Prince of Wales Hospital. Please see the attached approval and original NEAF ethics application. Please let me know if you require any additional information.
Thank you for incorporating this approval into my records.
Kind regards,

Dr Anne Wand

Staff Specialist Psychiatrist, Conjoint Senior Lecturer, UNSW

St George Hospital *(Mondays and Thursdays)*
Older Adult Mental Health
7 Chapel St, Kogarah, NSW 2217
T: 02 9113 2035; M: 0409 651 837; F: 02 9113 2098

Prince of Wales Hospital
Aged Care Psychiatry *(Tuesday am)*
Department of Consultation Liaison Psychiatry *(Wednesdays and Fridays)*
Euroa Centre, Barker St, Randwick 2139
T: 02 9382 2796; F: 02 9382 2177

Health
South Eastern Sydney
Local Health District

RESEARCH SUPPORT OFFICE

Room G71, East Wing
Edmund Blacket Bldg
Prince of Wales Hospital
Cnr High & Avoca Streets
RANDWICK NSW 2031
Tel: (02) 9382 3587
Fax: (02) 9382 2813

2 December 2016

Dr Anne Wand
Consultation Liaison Psychiatry
Prince of Wales Hospital
Level 1, Euroa Centre, Barker St
RANDWICK NSW 2031

Dear Dr Wand

SSA Ref: 16/G/360
HREC ref no: 16/269 (HREC/16/POWH/541)
Project title: Self-harm in the very old: A qualitative study.

I refer to your Site Specific Assessment application for the above titled project. I am pleased to advise that on 2 December 2016, the General Manager granted authorisation for the above project to commence at the Prince of Wales Hospital.

The following conditions apply to this research project. These are additional to any conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and are submitted to the lead HREC for review, are copied to the Research Governance Officer.
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the Research Governance Officer.

If you have any queries relating to the above please contact the Research Support Office on (02) 9382 3587.

Yours sincerely

Deborah Adrian
Manager, Research Support Office

Enc.

Prince of Wales Hospital
Community Health Services
Barker Street
Randwick NSW 2031

51777 290711

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RANDWICK NSW 2031
Tel: 02 9382 3587 Fax: 02 9382 2813
SESLHD-RSO@health.nsw.gov.au
www.seslhd.health.nsw.gov.au/POWH/researchsupport

30 January 2017

Dr Anne Wand
Department of Aged Care Psychiatry
Prince of Wales Hospital
RANDWICK NSW 2031

Dear Dr Wand,

HREC ref no: 16/269 (HREC/16/POWH/541)
Project title: **Self-harm in the very old: A qualitative study**

Thank you for your correspondence dated **11 January 2017** to the Human Research Ethics Committee (HREC) requesting an amendment to the above stated ethics approval. Your amendment request was reviewed at the HREC Executive meeting on 24 January 2017.

I am pleased to advise that the following documentation has been approved:

- Amendment Form, dated 10 January 2017
- Protocol Version 3, dated 10 January 2017
- Letter of Invitation to Participant's GP Version 2, dated 10 January 2017
- Consent Form GP Version 1, dated 10 January 2017
- GP Survey – Baseline Version 1, dated 10 January 2017
- GP Survey – Follow Up Version 1, dated 10 January 2017

Ethical approval is valid for the following site(s):

- Prince of Wales Hospital
- St George Hospital
- Sutherland Hospital

This amendment has also been reviewed by the Research Governance Officer at SESLHD. Further authorisation of the above approved documents is not required for any site that has the Research Governance conducted by the SESLHD Research Support Office. Implementation of this amendment can now proceed.

For multi-site projects reviewed by the HREC after 1 January 2011 a copy of this letter must be forwarded to all Principal Investigators at every site approved by the SESLHD

Prince of Wales Hospital
Community Health Services
Barker Street
Randwick NSW 2031

HREC for submission to the relevant Research Governance Officer along with a copy of the approved documents.

Should you have any queries, please contact the Research Support Office on (02) 9382 3587. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office website: http://www.seslhd.health.nsw.gov.au/POWH/researchsupport/default.asp.

Please quote **HREC ref no 16/269** in all correspondence.

We wish you every success in your research.

Yours sincerely

Andrew Bohlken

Executive Officer, Human Research Ethics Committee

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SESLHD-RSO@health.nsw.gov.au
www.seslhd.health.nsw.gov.au/services-clinics/directory/seslhd-research

29 November 2018

Dr Anne Wand
Department of Aged Care Psychiatry
Prince of Wales Hospital
RANDWICK NSW 2031

Dear Dr Wand,

HREC ref no: 16/269 (HREC/16/POWH/541)
Project title: Self-harm in the very old: A qualitative study

Thank you for your amendment request, dated **16 October 2018,** to the above stated ethics approval. Your amendment request was initially reviewed at the Executive Committee meeting on **06 November 2018**.
I am pleased to advise that with your recent correspondence dated **16 November 2018** ethics approval of the amendment has been granted.

The following documentation has been approved:

- Amendment Form, dated 24 October 2018
- Protocol V4 dated 21 October 2018
- PISCF – Clinician (education) V1 dated 24 October 2018
- Letter of Invitation to clinicians (education) V1 dated 22 October 2018
- Pre Evaluation FormV1 dated 22 October 2018
- Post Evaluation Form V1 dated 22 October 2018
- Email response dated 16 November 2018 to EXEC queries

Ethics approval is valid for the following site(s):

- Prince of Wales Hospital
- St George Hospital
- Sutherland Hospital

This amendment has also been reviewed by the Research Governance Officer at SESLHD. Further authorisation of the above approved documents is not required for any site that has the Research Governance conducted by the SESLHD Research Support Office. Implementation of this amendment can now proceed.

For multi-site projects reviewed by the HREC after 1 January 2011 a copy of this letter must be forwarded to all Principal Investigators at every site approved by the SESLHD HREC for submission to the relevant Research Governance Officer along with a copy of the approved documents.

Should you have any queries, please contact the Research Support Office on (02) 9382 3587. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office website: www.seslhd.health.nsw.gov.au/services-clinics/directory/seslhd-research

Please quote **HREC ref no 16/269** in all correspondence. We wish you every success in your research.

Yours sincerely

Andrew Bohlken
Executive Officer, Human Research Ethics Committee

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https://www.seslhd.health.nsw.gov.au/services-clinics/directory/seslhd-research
SESLHD-RSO@health.nsw.gov.au

30 January 2019

Dr Anne Wand
Department of Aged Care Psychiatry
Prince of Wales Hospital
RANDWICK NSW 2031

Dear Dr Wand,

HREC ref no: 16/269 (HREC/16/POWH/541)
Project title: Self-harm in the very old: A qualitative study

Thank you for your correspondence dated **13 December 2018** to the Human Research Ethics Committee (HREC) requesting an amendment to the above stated ethics approval. Your amendment request was reviewed at the Executive Committee meeting on 25 January 2019.

I am pleased to advise that the following documentation has been approved:

- Amendment Form dated 12 December 2018
- Evaluation of education session (post) V2 dated 12 December 2018
- Evaluation of education session (pre) V2 dated 12 December 2018

Ethics approval is valid for the following site(s):

- Prince of Wales Hospital
- St George Hospital
- Sutherland Hospital

This amendment has also been reviewed by the Research Governance Officer at SESLHD. Further authorisation of the above approved documents is not required for any site that has the Research Governance conducted by the SESLHD Research Support Office. Implementation of this amendment can now proceed.

For multi-site projects reviewed by the HREC after 1 January 2011 a copy of this letter must be forwarded to all Principal Investigators at every site approved by the SESLHD HREC for submission to the relevant Research Governance Officer along with a copy of the approved documents.

Should you have any queries, please contact the Research Support Office on (02) 9382 3587. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office website: https://www.seslhd.health.nsw.gov.au/services-clinics/directory/seslhd-research/for-researchers

Please quote **HREC ref no 16/269** in all correspondence.

We wish you every success in your research.

Yours sincerely

Andrew Bohlken
Executive Officer, Human Research Ethics Committee

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