

## **Suicidality in family caregivers of people with long-term illnesses and disabilities: A scoping review.**

### **Authors**

Siobhan T. O'Dwyer, PhD<sup>1,2</sup>

Astrid Janssens, PhD<sup>3,4</sup>

Anna Sansom, PhD<sup>1</sup>

Lucy Biddle, PhD<sup>5,6</sup>

Becky Mars, PhD<sup>5,12</sup>

Thomas Slater, PhD<sup>9</sup>

Paul Moran, MD<sup>5,6</sup>

Paul Stallard, PhD<sup>14</sup>

Julia Melluish<sup>14</sup>

Lisa Reakes<sup>14</sup>

Anna Walker<sup>14</sup>

Charmaine Andrewartha<sup>14</sup>

Richard P. Hastings, PhD<sup>10,11</sup>

### **Affiliations**

<sup>1</sup>University of Exeter Medical School, College of Medicine and Health, University of Exeter

<sup>2</sup>National Institute for Health Research Applied Research Collaboration South West Peninsula (NIHR PenARC)

<sup>3</sup>User Perspectives and Community-based Interventions, Department of Public Health, University of Southern Denmark

<sup>4</sup>Centre for Innovative Medical Technology, Odense University Hospital

<sup>5</sup>Population Health Sciences, Bristol Medical School, University of Bristol

<sup>6</sup>The National Institute for Health Research Applied Research Collaboration West (NIHR ARC West) at University Hospitals Bristol and Weston NHS Research Foundation, UK

<sup>9</sup>School of Social Sciences, Cardiff University

<sup>10</sup>Centre for Educational Development, Appraisal and Research (CEDAR), University of Warwick

<sup>11</sup>Centre for Developmental Psychiatry and Psychology, Monash University

<sup>12</sup>National Institute for Health Research (NIHR) Biomedical Research Centre, University Hospitals Bristol NHS Foundation Trust

<sup>13</sup>Department of Health, University of Bath

<sup>14</sup>Family caregiver

### **Addresses**

Dr Siobhan O'Dwyer, University of Exeter Medical School, Heavitree Rd, Exeter EX1 2LU, United Kingdom.

Associate Professor Astrid Janssens, Unit for User Perspectives, Department of Public Health, University of Southern Denmark, J.B. Winslows Vej 9B, 1<sup>st</sup> Floor, 5000 Odense C, Denmark.

Dr Anna Sansom, University of Exeter Medical School, Heavitree Rd, Exeter EX1 2LU, United Kingdom.

Dr Lucy Biddle, Bristol Medical School, University of Bristol, Canynge Hall, 39 Whatley Road, Bristol BS8 2PS, United Kingdom

Dr Tom Slater, School of Social Sciences, Cardiff University, 2.14B Glamorgan Building, King Edward VII Avenue, Cardiff CF10 3WT, United Kingdom

Professor Richard P. Hastings, CEDAR, University of Warwick, Coventry CV4 7AL, United Kingdom

Dr Becky Mars, Bristol Medical School, University of Bristol, Oakfield House, Bristol BS8 2BN, United Kingdom

Professor Paul Moran, Bristol Medical School, University of Bristol, Oakfield House, Bristol BS8 2BN, United Kingdom

Professor Paul Stallard, Department of Health, University of Bath, Bath BA2 7AY, United Kingdom

Julia Melluish, c/- Dr Siobhan O'Dwyer, University of Exeter Medical School, Heavitree Rd, Exeter EX1 2LU, United Kingdom

Lisa Reakes, c/- Dr Siobhan O'Dwyer, University of Exeter Medical School, Heavitree Rd, Exeter EX1 2LU, United Kingdom

Anna Walker, c/- Dr Siobhan O'Dwyer, University of Exeter Medical School, Heavitree Rd, Exeter EX1 2LU, United Kingdom

Charmaine Andrewartha, c/- Dr Siobhan O'Dwyer, University of Exeter Medical School, Heavitree Rd, Exeter EX1 2LU, United Kingdom

**Corresponding Author**

Dr Siobhan O'Dwyer  
[s.odwyer@exeter.ac.uk](mailto:s.odwyer@exeter.ac.uk)  
+44 01392 722402

## **Suicidality in family caregivers of people with long-term illnesses and disabilities: A scoping review.**

### **Summary**

An emerging body of international research suggests family caregivers may be a high-risk group for suicide, but the evidence has not been synthesised. Forty-eight peer-reviewed journal articles were included in this review, spanning low-, middle-, and high-income countries and a variety of illnesses and disabilities. The proportion of caregivers experiencing suicidal ideation ranged from 2.7% to 71%, with evidence of suicide attempts, deaths by suicide, and deaths by homicide-suicide also reported. Risk and protective factors varied across studies and there was little consideration of differences by caregiving relationship, type of illness/disability, or country. There is sufficient evidence to warrant concern for caregivers around the world and prompt action in policy and practice, but more rigorous research is required to draw clear, nuanced conclusions about risk and inform evidence-based prevention and intervention.

### **Introduction**

Worldwide more than 1000 million people are living with disabilities and long-term illnesses<sup>1</sup>, and the majority are cared for by family and friends. In the UK for example, there are nine million family caregivers and their unpaid labour saves the UK government £132 billion per year<sup>2</sup>, while in the USA the unpaid labour of 41 million caregivers is estimated to be worth \$470 billion<sup>3</sup>. In low- and middle-income countries, the prevalence of disability is higher and caregiving frequently occurs in the context of war, poverty, forced migration, food insecurity, and/or HIV<sup>4</sup>.

Despite their substantial social, economic, and personal contribution, caregivers face significant physical, psychological, and financial demands and, as a result, experience high rates of physical and mental illness, social isolation, and financial distress<sup>5,6</sup>. It has also been suggested that caregivers might be a high-risk group for suicide. Rosengard and Folkman<sup>7</sup> were the first to explore this and found that 34% (n=85) of men caring for male partners with AIDS reported experiencing suicidal ideation during the two-year study. Suicidal ideation and deaths by suicide have since been reported in studies of caregivers from Australia, Malawi, the Netherlands, India, Japan, and the USA<sup>8-13</sup>, including people caring for family members with dementia, schizophrenia, and cancer<sup>14-16</sup>. Given their sizeable contribution to health and social care, suicidality in caregivers is a significant public health issue<sup>17</sup>, but it has been paid little attention in policy and practice, at least in part due to the absence of a comprehensive review of the evidence.

Given the relative infancy of the field and absence of previous synthesis, a scoping review, rather than a systematic review, was conducted<sup>18-20</sup>. Unlike systematic reviews, which seek to answer narrow questions and include evidence from a limited range of study designs, scoping reviews seek to answer broad questions and incorporate a range of study designs<sup>18</sup>. They are most appropriate when a topic is complex and has not been previously reviewed, and there is a need to identify gaps in the evidence base<sup>18</sup>. The aim of this study was to undertake a comprehensive review of the evidence on suicidality in family caregivers. Our objectives were to: (1) identify peer-reviewed journal articles that have reported on suicidal ideation, suicide attempts, or deaths by suicide in family caregivers; (2) synthesise the findings of those articles; (3) identify gaps in the extant literature; and (4) provide recommendations for future research, policy, and practice.

### **Methods**

The review was conducted in accordance with Arskey and O'Malley's<sup>18</sup> five-stage framework, and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Scoping Review reporting guidelines and checklist have been followed in the reporting of methods and results<sup>21</sup>. Caregivers (JM, LR, AW, CA) were involved in Stages 1 and 5, drawing on their lived experience to refine the research questions and critically review the literature.

In Stage 1, the following research questions were identified: (1) What are the rates (either prevalence or incidence) of suicidal ideation, suicide attempt, and death by suicide in adult family caregivers? (2) What are the risk and protective factors for suicidal ideation, suicide attempt, and death by suicide in adult family caregivers? (3) Do rates and risk/protective factors vary based on the relationship between caregiver and care recipient or the type of illness/disability? (4) Do any interventions exist for adult family caregivers who contemplate or attempt suicide? (5) What are the lived experiences of adult family caregivers who have suicidal thoughts and/or behaviours?

In Stage 2, the search strategy was developed, piloted, refined, and executed. Key words and related Medical Subject Headings (MeSH) terms were identified.

The search strategy initially included a detailed list of search terms related to suicide, caregivers, and long-term illness or disability. Alternative terms for caregivers/carers were included to capture studies that, for example, referred to a mother or grandparent caring for a disabled child, but did not explicitly refer to that person as a caregiver or carer. We also included a comprehensive list of chronic illnesses and disabilities to identify articles that focused on specific conditions but did not use a generic expression of illness or disability. This approach, however, produced an excessive number of search results, the vast majority of which were not relevant to the review. It also failed to capture key studies known to the research team.

An information specialist advised us to simplify the search strategy to focus only on the main themes of suicide and caregivers (with the term 'carer' used as a synonym to capture the mixed usage endemic to the family care literature). Consequently, the final search terms used were: (carer\* OR caregiver\*) AND suicid\*. Carer/caregiver were searched in title and/or abstract, suicid\* was searched in any field. Searches were conducted on 10th June 2019 using the online search databases MEDLINE – Medical Literature (OvidSP), PsycINFO – Behavioral Sciences and Mental Health (OvidSP), and CINAHL – Cumulative Index to Nursing and Allied Health Literature (EBSCO). Due to the practical and conceptual differences in the roles, experiences of, and pathways to support for young caregivers<sup>22</sup>, we limited our focus to caregivers aged over 18. Only peer-reviewed academic journal articles, published in English, were considered (see Panel).

Reference lists of included full-text articles were searched to identify additional articles for screening, and a cited reference search was conducted on 23<sup>rd</sup> September 2019. Results were reviewed to check that no articles known to the team were missing, with one additional article subsequently included<sup>23</sup>. Results were also examined to confirm that no previous reviews had been conducted. Searches were updated on 31<sup>st</sup> March 2020 and three additional articles included<sup>24-26</sup>. Cited reference searches were also conducted for these articles, but no additional articles were found.

In Stage 3, search results were uploaded to EndNote and duplicates removed. SOD, AJ, and AS screened the title and abstract of each article using pre-determined inclusion and exclusion criteria (see Table 1). The first 20% were triple screened and decisions compared and discussed before screening the remainder (divided among SOD (25%), AJ (25%) and AS (50%)). Discrepancies and uncertainties were discussed and resolved by consensus. Full text copies of included articles were then screened by SOD, AJ, and SA, with resolution of uncertainties as before. Reasons for exclusion at full-text screening were recorded.

In Stage 4, included full-text articles were divided between the three reviewers for data extraction. Data were extracted using a bespoke template in Excel, including author, year, title, aim, study design, term used for caregiver, term used for suicidality, measure of suicidality, country of study, condition of care recipient, relationship between caregiver and care recipient, main findings, and recommendations. Consistent with scoping review methodology<sup>18</sup>, quality appraisals were not conducted.

In Stage 5, the extracted data were collated, summarised, critically reviewed, and reported. Each article was categorised by SOD and AJ as quantitative, qualitative, mixed methods, or other, and then further categorised according to whether an understanding of suicidality was the primary aim or a secondary aim/incidental finding. Using the extracted data from Stage 4, a brief narrative summary of the articles in each category was prepared. All members of the research team critically reviewed these summaries, highlighting consistencies and inconsistencies across articles, and gaps in the literature. This information was then prepared into a narrative account of the evidence base. Consistent with our aims and objectives, and informed by the available evidence, this account was structured according to the headings: Article Types and Samples; Nomenclature and Measurement; Suicidal Thoughts and Behaviors; Risk and Protective Factors; Interventions; Lived Experience and Professional Reflections; and, Recommendations.

#### *Role of the Funder*

This review was funded by an Initiator Grant from GW4. GW4 had no role in the design or conduct of the review, preparation of the manuscript, or decision to publish.

#### **Results**

A flow diagram of the search process is provided in Figure 1. The most common reason for exclusion was that caregiver suicide/ideation was not measured or reported. Other reasons included: suicide/ideation was reported for the person receiving care, not the caregiver; there was no long-term illness/disability/condition in the person receiving care; protocol only; or the focus was on assisted suicide/euthanasia.

#### *Article Types and Samples*

Forty-eight peer-reviewed journal articles were included. The methods and findings of each article are provided in Table 2. Twenty-eight articles were quantitative studies (including three longitudinal studies<sup>7,11,24</sup> and one intervention study<sup>27-29</sup>), 10 were qualitative studies, two were mixed-method studies, and eight articles were ‘other’ (including case reports and the reflections of health and allied health professionals). Only 17 articles had the study of suicidality in caregivers as the primary aim; the remainder had suicidality as a secondary aim or incidental finding. One ‘other’ article – co-authored by caregivers – provided a “roadmap” for future research, practice, and policy<sup>30</sup>. None of the included articles drew on existing theories of suicide (or homicide-suicide) to justify their approach or interpret their findings.

A wide range of countries, including low-, middle-, and high-income countries, were represented. A wide range of conditions were also represented, including dementia, HIV/AIDS, Down’s syndrome, schizophrenia, quadriplegia, and cancer. Some articles did not identify specific illnesses or disabilities, describing their samples more broadly in terms of physical and mental disabilities, chronic or terminal illnesses, or cancer. In the majority of articles, caregivers were the parent, spouse, or adult child of the care recipient. In studies that directly assessed caregivers, seven did not detail the relationship. Sample sizes varied widely, ranging from n=1 case reports<sup>31</sup> to large national datasets<sup>8,26,32</sup>.

### *Nomenclature and Measurement*

In studies that directly assessed caregivers (n=21), a variety of terms for suicidal ideation were used, including: thoughts of suicide, death wishes, wanting to die, thinking that life is not worth living, and thinking they would be better off dead. None of the qualitative studies that directly assessed caregivers specified the question used to elicit responses about suicidality, and so the remainder of this paragraph refers to quantitative and mixed-method studies. In some studies, suicidal ideation, self-harm, and/or suicide attempts were assessed within a single question or merged to create a composite item<sup>8,10,11,33</sup>, so it was not possible to determine discrete estimates of prevalence or incidence for each phenomenon. Five studies did not provide any detail on the measure used to assess suicidality<sup>12,16,34-36</sup> and others provided insufficient detail<sup>25,27,28,37,38</sup>. Some studies only assessed suicidal ideation in caregivers who met criteria for depression or prolonged grief<sup>11,33</sup>, but other studies identified suicidal ideation in caregivers without depression, anxiety, or other mental illness<sup>10,37</sup>. In some studies, suicidal ideation was also evident in caregivers whose care recipient had been admitted to residential care or had died<sup>7,11,14,33,39</sup>. The timeframes for questions about suicidal ideation and attempts varied widely, ranging from *in the last week* to *ever*. Several studies did not report the timeframe for their measure of suicidality<sup>16,25,27-29,33-36,40-42</sup>. One study assessed suicidal ideation at multiple timepoints over several years<sup>11</sup> and another merged data from two timepoints<sup>24</sup>. Some did not report estimates of prevalence or incidence, but instead provided the mean on a scale score or used the data to compare between groups<sup>27-29,32,34,38,41</sup>.

### *Suicidal Thoughts and Behaviors*

In quantitative studies that directly assessed caregivers, the proportion of caregivers reporting suicidal ideation ranged from 2.7%<sup>9</sup> to 71%<sup>33</sup>. Suicide attempts were measured discretely in only one study, which found that 2.8% of the total sample of caregivers of people with cancer in Korea (11.5% of those with suicidal ideation) had attempted suicide in the previous year<sup>37</sup>. In a study of dementia caregivers in Australia<sup>14</sup>, 18.7% of caregivers with suicidal ideation reported being likely to attempt suicide in the future.

In a US study that asked hospice and palliative social workers to identify patients and caregivers at risk in the previous year<sup>43</sup>, 55.4% reported one or more caregivers who exhibited warning signs of suicide (see Table 2 for definitions of warning signs), 6.8% reported one caregiver who had attempted suicide, and 4.1% reported one caregiver who died by suicide.

Only one study, from Northern Ireland, focused specifically on suicide deaths<sup>26</sup>. It found no association between caregiving and suicide in fully adjusted statistical models, but caregivers who were also volunteers had a significantly reduced risk of suicide.

Only four studies compared suicidal ideation between caregivers and non-caregivers. Two of those found caregivers had higher levels of suicidal ideation<sup>8,32</sup>, while the other two found no significant difference<sup>12,24</sup>. Two studies provided narrative comparisons with population levels of suicidal ideation and both noted higher levels of suicidal ideation in caregivers than in the general population<sup>14,17</sup>.

One study reported suicidal ideation combined with homicidal ideation (i.e. thoughts of killing the care recipient)<sup>15</sup>. In that Japanese study of people caring for family members with schizophrenia *and* experiencing violence perpetrated by the care recipient, 15.7% had suicidal thoughts and 26.7% had thoughts of “murder-suicide”.

Although not the primary focus of the review, several of the included studies also identified homicidal behaviors in caregivers. No attempted homicide-suicides were reported, but homicide deaths followed by attempted suicides were reported in an article on English caregivers<sup>44</sup> and three articles reported deaths by homicide-suicide, whereby a caregiver killed the care recipient and then themselves<sup>44-46</sup>. In an American study of 68 cases of homicides perpetrated by caregivers<sup>45</sup>, 30 cases were classified as homicide-suicides. These were further classified into three categories of motivation: (1) “a desire on the part of the caregiver to stop the suffering of the victim and end their own lives despite not having any notable illness themselves”; (2) “the inability of the caregiver to continue to meet the needs of an ill spouse or child due to either a recent diagnosis of their own or an ongoing chronic illness that had progressed”; and, (3) “an impending crisis for the perpetrator unrelated to the illness of the victim”<sup>45</sup>. Two of the articles on homicide-suicide deaths noted that in the majority of cases there was no history of family or spousal violence<sup>45,46</sup>.

A variety of methods for plans, attempts, and deaths by suicide and homicide-suicide were noted in case reports and the qualitative literature<sup>13,20,44,48,50</sup>, including violent and high-lethality methods.

### *Risk and Protective Factors*

Fourteen quantitative studies reported statistical analyses of factors associated with suicidality<sup>7,8,10,11,14,17,24,26,35,37-39,47,57</sup>. A lack of consistency in the variables measured and analysed makes it difficult to synthesise the findings. Some commonly identified risk factors, however, included depression, anxiety, dysfunctional coping strategies, dissatisfaction with the caring role, and lack of support. Commonly identified protective factors included older caregiver, reasons for living, optimism, older care recipient, employment while caring, and volunteering. There were conflicting findings on the association between suicidal ideation and the relationship between caregiver and care recipient, the duration of caregiving, and caregiver gender<sup>17,24,34,37,39,47</sup>. In a Dutch study<sup>24</sup> the significant risk factors for suicidal ideation in dementia caregivers were also significant for non-caregivers.

Three quantitative studies considered differences between illnesses/disabilities<sup>24,41,47</sup>, with two of the three noting significantly higher levels of suicidal ideation in caregivers of people with more severe mental illnesses and disabilities<sup>41,47</sup>. Two studies of HIV considered the caregiver’s own HIV status, but found no significant association with suicidal ideation<sup>7,10</sup>. One study considered differences between countries and found that caregivers in Malawi were significantly less likely to report suicidal ideation than caregivers in South Africa.

### *Interventions*

One intervention study was identified, a psychoeducational group intervention for family caregivers of people with dementia in Japan that was reported in three articles<sup>27-29</sup>. Although the aim of the research was not to address suicidality, there was a significant improvement on a measure of “suicidal depression” at post-test that was maintained at 2-month follow-up.

### *Lived Experience and Professional Reflections*

Lived experience was captured predominantly through qualitative studies using interviews<sup>13,42,48-51</sup>, focus groups<sup>23,52</sup> and caregivers’ blogs<sup>53</sup>.

Qualitative studies provided evidence of suicidal ideation in a range of caregiving contexts, as well as plans for suicide, attempted suicide, and at least one death by suicide<sup>13</sup>. Most qualitative studies provided little in-depth context for these experiences or events, but some common themes were clear: the desire for an escape or reprieve from the caring role, depression, isolation, a lack of support or resources, and conflict with other family members or professional caregivers. Some protective factors were also identified, including determination, non-caring roles, positive coping strategies, social support, and faith.

Four qualitative studies also reported thoughts of homicide-suicide, one in people caring for children with nodding syndrome in Uganda<sup>23</sup>, and three in people caring for family members with dementia<sup>48,54,55</sup>. It was not clear whether thoughts of suicide came before or after thoughts of homicide, but a wish to relieve the care recipient’s suffering and a desire for the caring role to end were common themes.

One ‘other’ article comprised a social worker’s reflections on a career spent supporting family caregivers of people with dementia<sup>56</sup>, while another described the methods used by community nurses in the UK to support an older male caregiver through a suicidal crisis<sup>31</sup>.

### *Recommendations*

One article, co-authored by caregivers, focused entirely on recommendations<sup>30</sup>, while 29 studies included recommendations for future research and practice (see Table 3 for summary). The article co-authored by caregivers also noted that none of the existing research had been co-produced with caregivers.

## Discussion

This scoping review identified a small but meaningful body of evidence on suicidality in family caregivers. The findings provide consistent evidence of suicidal ideation, suicide attempts, and deaths by suicide across a diverse range of caregivers. Much of the existing research has focused on suicidal ideation, however, with little consideration of suicide attempts or deaths by suicide. Across quantitative studies there is also considerable diversity in nomenclature and measurement, making it difficult to synthesise findings and draw clear conclusions about incidence and prevalence, risk and protective factors, or variations according to caregiving relationship and type of illness/disability. We found no interventions specifically designed to address suicidality in family caregivers, although at least two articles clearly showed that suicidal thoughts in caregivers were amenable to intervention<sup>27,31</sup>. Qualitative studies, mixed-method studies, case reports, and professional reflections provided further evidence of suicidality in family caregivers, but lacked the depth required for a nuanced understanding of the phenomenon (largely because suicidality was an incidental finding, rather than a primary aim). What is clear, however, is that family caregivers are an at-risk group for suicide and suicidal experiences are present across a range of countries, caregiving relationships, and illnesses/disabilities. With levels as high as 71% in some samples and likely to be an underestimate in others<sup>15,32,57</sup> (not least because carers may fear the consequences of reporting<sup>30</sup>, particularly in qualitative research<sup>54</sup>), there is a clear imperative for dedicated research and evidence-based policy and practice to understand and address suicidality in family caregivers.

Some of the risk factors for suicidal ideation identified in this review are consistent with those seen in the general population – including depression, anxiety, and dysfunctional coping strategies – but others (such as dissatisfaction with the caring role and conflict over care provision) are unique to caregivers. This has implications for the use of existing risk assessments for suicide (already questionable in their diagnostic accuracy<sup>58</sup>), which do not capture the risk factors specific to the caring role and are not designed for the dyadic nature of caregiving (particularly the potential need to safeguard a vulnerable care recipient if a caregiver is suicidal and/or homicidal). Some studies also identified suicidal ideation in caregivers *without* mental illness. This has implications for both research and practice, highlighting the importance of assessing suicidal ideation in *all* caregivers, not just those with depression or anxiety. Very few studies considered protective factors, but in those that did some modifiable factors (such as positive coping strategies and having non-caring roles) were identified and may provide a useful foundation for strengths-based approaches to suicide prevention<sup>59,60</sup> in this population.

Although suicide risk may vary according to the caregiving relationship and the nature of the illness/disability, there is insufficient evidence to determine which relationships or conditions confer greater (or lesser) risk. It is reasonable to assume that risk may be higher in conditions that require longer or more complex care, that are subject to greater social stigma, or are afforded less publicly funded treatment and support, but further research is required. Similarly, there is insufficient evidence to determine whether risk varies by other caregiver or care recipient characteristics (including gender, sexuality, ethnicity, religion, or socioeconomic status) or across countries, cultures, and different healthcare systems. An understanding of how risk varies between different groups of caregivers will be the key to identifying at-risk caregivers in practice and developing targeted intervention and prevention programs.

Despite a lack of consistency in some findings, the evidence clearly shows that clinicians are encountering at-risk caregivers<sup>31,43,56</sup>. Suicide prevention training programs for health and social care professionals and other community gatekeepers are well established and generally effective at improving knowledge, reducing stigma, and enhancing confidence to intervene e.g. <sup>61-65</sup>, but to our knowledge none address the risks associated with family caregiving (including the potential for suicide-homicide) or provide guidance on safeguarding vulnerable care recipients. Further research on suicidality in caregivers would provide a strong foundation for the development of tailored suicide prevention training for the professionals and communities who support them. In the meantime, policy makers and clinicians should be made aware of the evidence and encouraged to make use of existing suicide prevention and intervention programs to identify and support at-risk caregivers.

The existing evidence also shows that suicidal ideation is not limited to periods of active caregiving, but can manifest after institutionalisation and bereavement<sup>7,11,14,33,39</sup>. This is consistent with research on caregivers' experiences of these transitions more generally<sup>66,67</sup> and highlights the need for policy makers and clinicians to recognise caregiving as a trajectory and provide support for caregivers (and assess for suicide risk) at every

stage of the caregiving journey<sup>11</sup>. Also, although the focus of this review was on suicide, several articles provided evidence of homicidal ideation and deaths by homicide or homicide-suicide. As Brown<sup>44</sup> notes, caregivers are “no ordinary perpetrators” and the death of a chronically ill or disabled person at the hands of their caregiver is a “double-edged tragedy” that challenges our understanding of care and vulnerability, and highlights significant gaps in our health and social care systems. These experiences – and most notably the fact that they do not appear to be associated with pre-existing domestic violence – warrant urgent consideration in both research and practice<sup>44</sup>.

Consistent with the emerging nature of the field, many articles made recommendations for research and practice, and highlighted the urgent need for researchers, clinicians, and policy makers to consider and address suicidality in family caregivers. Several articles, however, did not give any consideration to their findings of suicidality<sup>12,27,28,36,50-52</sup>, with one Brazilian study<sup>25</sup> dismissing as “inconsequential” a finding of suicidal ideation in 10% of caregivers of children with cerebral palsy. This may, in part, stem from a misconception that the altruistic nature of caregivers means they are unlikely to act on suicidal thoughts<sup>13</sup>. But the evidence on deaths by suicide and homicide-suicide<sup>44,46</sup>, including the use of violent or highly lethal methods<sup>68,69</sup>, should firmly dispel this.

Considerably more research is required to understand suicidal ideation, suicide attempts, and deaths by suicide in family caregivers. In particular there is a need for: (1) suicide risk in family caregivers to be a primary aim of research; (2) stronger research designs (including the use of non-caregiving controls, adjustment for pre-caregiving suicidality, longitudinal studies, and international comparative studies); (3) more robust samples; and, (4) clear, comprehensive, and consistent nomenclature and measurement. There is also a need for research to be co-produced with caregivers and care recipients. In other areas of health research, patients and caregivers have been recognised as ‘experts by experience’ and their involvement in research has been shown to empower them, enhance the quality of the research, and strengthen impact on policy and practice<sup>70,71</sup>. In suicide research more specifically, there is also growing recognition of the importance of user involvement<sup>72,73</sup>. The fact that the only caregiver co-authored article included in this review was authored anonymously due to fear and stigma<sup>30</sup>, however, highlights the importance of ensuring that caregivers and care recipients who collaborate on research are supported and safeguarded throughout the process. Finally, as research in this field progresses, it may be pertinent to consider how the emerging evidence on suicidality in caregivers aligns with existing theories of suicide (and homicide-suicide) and whether the development of caregiver-specific theory is warranted<sup>14</sup>.

Although this review has highlighted an important new area of research, it has a number of limitations. First, it focused only on adult caregivers. Young caregivers – for whom the challenges of caregiving are complicated by their own developmental and educational needs – may also be at risk<sup>74</sup>. Second, for logistical reasons we only included studies published in English. Studies published in other languages may hold valuable information about suicide risk in family caregivers and could inform research, practice, and policy. Third, we conducted a scoping review rather than a systematic review. Although a systematic review may have been more rigorous, a scoping review was appropriate for the state of the field<sup>75</sup>, allowing us to identify the extent, range, and nature of the existing evidence<sup>18,20</sup> and highlight clear gaps<sup>18,20</sup> that need to be addressed before meaningful systematic reviews can be conducted. Fourth, the review was limited to peer-reviewed academic journal articles. Grey literature, mainstream media, and lay reports<sup>e.g.76</sup> may contain useful information on suicide (and homicide-suicide) attempts and deaths, and offer insights into community perceptions of, and responses to, suicidality in caregivers. Finally, our search strategy may have excluded relevant studies that did not use the term carer or caregiver.

Before concluding, it is important to note that this review was conducted prior to the COVID-19 pandemic. The pandemic and associated lockdowns have increased pressure on family caregivers<sup>77</sup>, reduced the availability of both formal and informal support for caregivers (including respite)<sup>78,79</sup>, and seen millions take on new caregiving responsibilities<sup>80</sup>. The need for dedicated research on, and widespread awareness of, the potential for suicidality in caregivers may now be more urgent than ever before.

## Conclusions

To our knowledge, this is the first review of suicidality in family caregivers. The extant literature is sufficient to warrant concern for caregivers around the world and provides an urgent imperative for immediate action to identify and support at-risk caregivers. The majority of research on this topic has been published in the last 10 years and there is a lack of consistency across studies. To ensure this rapidly expanding field can inform evidence-based policy and practice going forward, more research is required and it must draw on rigorous methods and robust samples.

### **Panel: Search Strategy and Selection Criteria**

Articles for this review were identified through searches of MEDLINE, PsycINFO, and CINAHL for articles published before 31<sup>st</sup> March 2020, with the terms (carer\* OR caregiver\*) AND (suici\*). Articles included from those searches were subject to a cited reference search and their reference lists were manually searched. One article known to the authors, but not identified in any searches was also included. Articles published in English were included. Articles were excluded if: suicide/ideation was not measured or reported; suicide/ideation was reported in relation to the person receiving care, not the caregiver; no illness, disability, or medical condition was given for the person receiving care; article was a protocol for future research; or, the focus was on assisted suicide or euthanasia.

### **Panel: Research in Context**

#### *Evidence before this study*

Family caregivers provide the majority of care for people with long-term illnesses and disabilities. As a result of their significant social, economic, and personal contribution, caregivers experience high rates of physical and mental illness, social isolation, and financial distress. They may also be a high-risk group for suicide. Suicidal ideation and deaths by suicide have been reported in studies of caregivers from Australia, Malawi, the Netherlands, India, Japan, and the USA, including people caring for family members with dementia, schizophrenia, and cancer. Despite this, there has been no previous review of the evidence.

#### *Added value of this study*

This is the first time the evidence on suicidality in family caregivers has been synthesised. Drawing together a seemingly disparate literature, the review highlights suicidal thoughts and behaviors in caregivers from around the world and across a range of illnesses and disabilities. The review also highlights a lack of evidence-based methods for identifying and supporting at-risk caregivers who – due to the dyadic nature of their caregiving role, and the social and cultural dynamics of care – may require more comprehensive screening and support than non-caregivers. Finally, the review identifies evidence of homicidal thoughts and behaviours that adds complexity to the concept of suicide risk in caregivers and challenges existing views of caregivers' capacity for lethal behavior.

#### *Implications of the available evidence*

Although much remains to be understood, there is sufficient evidence to warrant serious concern for caregivers around the world and prompt immediate action in research, policy, and practice. In particular, there is a need for more rigorous research with robust samples, and the development of evidence-based methods for identifying and supporting at-risk caregivers and their care recipients. Moving forward, it will also be essential to include caregivers in the co-production of research and the development and evaluation of new policies and practices. They are experts by experience, but their voices are noticeably absent from much of the existing literature.

### **References**

1. World Health Organisation Global Disability Action Plan 2014-2021: Better health for all people with disability. Available at: [https://apps.who.int/iris/bitstream/handle/10665/199544/9789241509619\\_eng.pdf;jsessionid=B091752FE8908D95175E4D1D71EFCAD7?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/199544/9789241509619_eng.pdf;jsessionid=B091752FE8908D95175E4D1D71EFCAD7?sequence=1) (Accessed 10<sup>th</sup> August 2020).
2. Carers UK: Facts and Figures. Available at <https://www.carersuk.org/news-and-campaigns/press-releases/facts-and-figures> (Accessed 10th August 2020).
3. Reinhard S, Feinberg LF, Houser A, Chouler R, Evans M. *Valuing the invaluable: 2019 Update – Charting a path forward*. AARP Public Policy Institute: Washington, DC; 2019.
4. Thrush A, Hyder A. The neglected burden of caregiving in low and middle-income countries. *Disabil Health J* 2014; **7(3)**: 262–72.
5. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: A clinical review. *JAMA* 2014; **311(10)**: 1052–60.
6. Pinquart M, Sorensen S. Differences between caregivers and non-caregivers in psychological health and physical health: A meta-analysis. *Psychol Aging* 2003; **18(2)**: 250–67.
7. Rosengard C, Folkman S. Suicidal ideation, bereavement, HIV serostatus and psychosocial variables in partners of men with AIDS. *AIDS Care* 1997; **9(4)**: 373–84.
8. O'Dwyer ST, Moyle W, Pachana NA, Sung B, Barrett S. Feeling that life is not worth living (death thoughts) among middle-aged, Australian women providing unpaid care. *Maturitas* 2014; **77(4)**: 375–9.

9. Lucas MS, Brawner BM, Hardie TL et al. Assessing suicidal ideation and behaviors among survivors of childhood brain tumors and their mothers during sociobehavioral research. *Oncol Nurs Forum* 2015; **42(5)**: E319–29.
10. Skeen S, Tomlinson M, Macedo A, Croome N, Sherr L. Mental health of carers of children affected by HIV attending community-based programmes in South Africa and Malawi. *AIDS Care* 2014; **26(Suppl 1)**: S11–20.
11. Joling KJ, O'Dwyer ST, Hertogh CMPM, van Hout HPJ. The occurrence and persistence of thoughts of suicide, self-harm and death in family caregivers of people with dementia: a longitudinal data analysis over 2 years. *International Journal of Geriatric Psychiatry* 2018; **33(2)**: 263–70.
12. Koyama A, Matsushita M, Hashimoto M et al. Mental health among younger and older caregivers of dementia patients. *Psychogeriatrics* 2017; **17(2)**: 108–14.
13. Shaji KS, Smitha K, Lal KP, Prince MJ. Caregivers of people with Alzheimer's disease: a qualitative study from the Indian 10/66 Dementia Research Network. *International Journal of Geriatric Psychiatry* 2003; **18(1)**: 1–6.
14. O'Dwyer ST, Moyle W, Zimmer-Gembeck M, De Leo D. Suicidal ideation in family carers of people with dementia. *Aging & Mental Health* 2016; **20(2)**: 222–30.
15. Kageyama M, Solomon P, Yokoyama K, Nakamura Y, Kobayashi S, Fujii C. Violence Towards Family Caregivers by Their Relative with Schizophrenia in Japan. *Psychiatr Q* 2018; **89(2)**: 329–40.
16. Meyer F, Zhang B, Gao X, Prigerson HG. Associations between cognitive impairment in advanced cancer patients and psychiatric disorders in their caregivers. *Psycho-Oncology* 2013; **22(4)**: 952–55.
17. dos Santos Treichel C, Jardim V, Kantorski LP, Guimaraes Lima M. Prevalence and factors associated with suicidal ideation among family caregivers of people with mental disorders. *Journal of Clinical Nursing* 2019; **28(19-20)**: 3470–77.
18. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* 2005; **8(1)**: 19–32.
19. Mays N, Roberts E, Popay J. Synthesising research evidence. In N. Fullop, P. Allen, A. Clarke, N. Black, ed. *Studying the organisation and delivery of health services: Research methods*. Routledge: London; 2001.
20. Levac C, Colquhoun H, O'Brien KK. Scoping studies: Advancing the methodology. *Implement Sci* 2010; **5(1)**: 69.
21. Tricco A, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRSIMAScR): Checklist and Explanation. *Ann Intern Med* 2018; **169**: 467–73.
22. Aldridge, J. Where are we now? Twenty-five years of research, policy and practice on young carers. *Crit Soc Policy* 2018; **38(1)**: 155-165.
23. Nakigudde J, Mutamba BB, Bazeyo W, Musisi S, James O. An exploration of caregiver burden for children with nodding syndrome (lucluc) in Northern Uganda. *BMC Psychiatry* 2016; **16**: 255.
24. Joling KJ, Ten Have M, de Graaf R, O'Dwyer ST. Risk factors for suicidal thoughts in informal caregivers: results from the population-based Netherlands mental health survey and incidence Study-2 (NEMESIS-2). *BMC Psychiatry* 2019; **19(1)**: 320.
25. Figueiredo AA, Lomazi EA, Montenegro MA, Bellomo-Brandao MA. Quality of Life in Caregivers of Pediatric Patients with Cerebral Palsy and Gastrostomy Tube Feeding. *Arq Gastroenterol* 2020; **10**: 10.
26. Rosato M, Tseliou F, Wright DM, Maguire A, O'Reilly D. Are volunteering and caregiving associated with suicide risk? A Census-based longitudinal study. *BMC Psychiatry* 2019; **19(1)**: 296.
27. Hosaka T, Sugiyama Y. Structured intervention in family caregivers of the demented elderly and changes in their immune function. *Psychiatry and Clinical Neurosciences* 2003; **57(2)**: 147–51.
28. Hosaka T, Sugiyama Y. A structured intervention for family caregivers of dementia patients: a pilot study. *Tokai J Exp Clin Med* 1999; **24(1)**: 35–9.
29. Mizuno E, Hosak T, Ogihara R, Higano H, Mano Y. Effectiveness of a stress management program for family caregivers of the elderly at home. *J Med Dent Sci* 1999; **46(4)**: 145–53.
30. Anonymous Members of the Peninsula Public Involvement G, Liabo K, O'Dwyer S. Research Commentary: A Carer's Roadmap for Research, Practice, and Policy on Suicide, Homicide, and Self-Harm. *Behav Sci* 2019; **9(5)**: 01.
31. Chamberlain L, Anderson C, Knifton C, Madden G. Suicide risk in informal carers of people living with dementia. *Nurs Older People* 2018; **30(5)**: 20–25.

32. Stansfeld S, Smuk M, Onwumere J et al. Stressors and common mental disorder in informal carers-An analysis of the English Adult Psychiatric Morbidity Survey 2007. *Social Science & Medicine* 2014; **120**: 190–8.
33. Lichtenthal WG, Nilsson M, Kissane DW et al. Underutilization of mental health services among bereaved caregivers with prolonged grief disorder. *Psychiatric Services* 2011; **62(10)**: 1225–9.
34. Chiu Y-W, Yin S-M, Hsieh H-Y, Wu W-C, Chuang H-Y, Huang C-T. Bereaved females are more likely to suffer from mood problems even if they do not meet the criteria for prolonged grief. *Psycho-Oncology* 2011; **20(10)**: 1061–8.
35. Del Grande da Silva G, Jansen K, Barbosa LP et al. Burden and related factors in caregivers of young adults presenting bipolar and unipolar mood disorder. *International Journal of Social Psychiatry* 2014; **60(4)**: 396–402.
36. Valente LE, Truzzi A, Souza WF, et al. Health self-perception by dementia family caregivers: Sociodemographic and clinical factors. 2011; **69(5)**: 73944.
37. Park B, Kim SY, Shin JY et al. Suicidal ideation and suicide attempts in anxious or depressed family caregivers of patients with cancer: a nationwide survey in Korea. *PLoS ONE* 2013; **8(4)**: e60230.
38. Aloba O, Ajao O, Alimi T, Esan O. Psychometric Properties and Correlates of the Beck Hopelessness Scale in Family Caregivers of Nigerian Patients with Psychiatric Disorders in Southwestern Nigeria. *J Neurosci Rural Pract* 2016; **7(Suppl 1)**: S18–25.
39. Abbott CH, Prigerson HG, Maciejewski PK. The influence of patients' quality of life at the end of life on bereaved caregivers' suicidal ideation. *J Pain Symptom Manage* 2014; **48(3)**: 459–64.
40. Abasiubong F, Bassey EA, Ogunsemi OO, Udobang JA. Assessing the psychological well-being of caregivers of people living with HIV/AIDS in Niger Delta Region, Nigeria. *AIDS Care* 2011; **23(4)**: 494–500.
41. Oza H, Parikh MN, Vankar GK. Comparison of caregiver burden in schizophrenia and obsessive-compulsive disorder. *Archives of Psychiatry and Psychotherapy* 2017; **19(2)**: 32–41.
42. England M. Planning and Emotional Health of Abused Adult Children Caregivers. *Can J Nurs Res* 2005; **37(3)**: 10–33.
43. Washington KT, Albright DL, Parker OD, Gage LA, Lewis A, Mooney MJ. Hospice and palliative social workers' experiences with clients at risk of suicide. *Palliative & Supportive Care* 2016; **14(6)**: 664–71.
44. Brown H. Not only a crime but a tragedy [...] exploring the murder of adults with disabilities by their parents. *Journal of Adult Protection* 2012; **14(1)**: 6–21.
45. Karch D, Nunn KC. Characteristics of elderly and other vulnerable adult victims of homicide by a caregiver: National Violent Death Reporting System-17 U.S. States, 2003–2007. *Journal of Interpersonal Violence* 2011; **26(1)**: 137–57.
46. Bourget D, Gagne P, Whitehurst L. Domestic homicide and homicide-suicide: The older offender. *Journal of the American Academy of Psychiatry and the Law* 2010; **38(3)**: 305–11.
47. Huang Y-C, Hsu S-T, Hung C-F, Wang L-J, Chong M-Y. Mental health of caregivers of individuals with disabilities: Relation to suicidal ideation. *Comprehensive Psychiatry* 2018; **81**: 22–7.
48. Kim HJ, Kehoe P, Gibbs LM, Lee JA. Caregiving Experience of Dementia among Korean American Family Caregivers. *Issues in Mental Health Nursing* 2019; **40(2)**: 158–65.
49. O'Dwyer S, Moyle W, van Wyk S. Suicidal ideation and resilience in family carers of people with dementia: A pilot qualitative study. *Aging Ment Health* 2013; **17(6)**: 753–60.
50. Riley J, Fenton G. A terminal diagnosis: The carers' perspective. *Couns Psychother Res* 2007; **7(2)**: 86–91.
51. Sanderson C, Lobb EA, Mowll J, Butow PN, McGowan N, Price MA. Signs of post-traumatic stress disorder in caregivers following an expected death: A qualitative study. *Palliat Med* 2013; **27(7)**: 625–31.
52. Marimbe BD, Cowan F, Kajawu L, Muchirahondo F, Lund C. Perceived burden of care and reported coping strategies and needs for family caregivers of people with mental disorders in Zimbabwe. *Afr J Disabil* 2016; **5(1)**: 209.
53. Anderson JG, Eppes A, O'Dwyer ST. "Like Death is Near": Expressions of Suicidal and Homicidal Ideation in the Blog Posts of Family Caregivers of People with Dementia. *Behav Sci* 2019; **9(3)**: 03.
54. O'Dwyer ST, Moyle W, Taylor T, Creese J, Zimmer-Gembeck MJ. Homicidal ideation in family carers of people with dementia. *Aging & Mental Health* 2016; **20(11)**: 1174–81.

55. Lewis LF. Caregiving for a loved one with dementia at the end of life: An emergent theory of rediscovering. *American Journal of Alzheimer's Disease and Other Dementias* 2015; **30(5)**: 488–96.
56. Silverberg E. Applying the 3-A grief intervention approach to nursing home placement: acknowledge, assess and assist. *Canadian Nursing Home* 2011; **22(2)**: 22–5.
57. O'Dwyer ST, Moyle W, Zimmer-Gembeck M, De Leo D. Suicidal ideation in family carers of people with dementia: A pilot study. *Int J Geriatr Psychiatry* 2013; **28(11)**: 1182–88.
58. Runeson B, Odeberg J, Pettersson A, Edbom T, Adamsson IJ, Waern M. Instruments for the assessment of suicide risk: A systematic review evaluating the certainty of the evidence. *PLoS ONE* 2017; **12(7)**: e0180292.
59. Hirsch JK, Rabon JK, Chang EC. Applied resiliency and suicide prevention: A strengths-based, risk-reduction framework. In JK. Hirsch, EC. Chang, JK. Rabon, ed. *A positive psychological approach to suicide: Theory, research, and prevention*. Springer: Switzerland; 2019.
60. Page AC, Stritzke WGK. *Alternatives to Suicide: Beyond risk and toward a life worth living*. Academic Press, Elsevier: London; 2020.
61. Arensman E, Coffey C, Griffin E, et al. Effectiveness of depression-suicidal behaviour gatekeeper training among police officers in three European regions: Outcomes of the Optimising Suicide Prevention Programmes and Their Implementation in Europe (OSPI-Europe) study. *Int J Soc Psychiatry* 2016; **62**: 651–60.
62. Chauliac N. How does gatekeeper training improve suicide prevention for elderly people in nursing homes? A controlled study in 24 centres. *Eur Psychiatry* 2016; **37**: 56–62.
63. Terpstra S, Beekman A, Abbing J, Jaken S, Steendam M, Gilissen R. Suicide prevention gatekeeper training in the Netherlands improves gatekeepers' knowledge of suicide, prevention and their confidence to discuss suicidality, an observational study. *BMC Public Health* 2018; **18**: 637.
64. Jacobson JM, Osteen P, Jones A, Berman A. Evaluation of the Recognizing and Responding to Suicide Risk training. *Suicide Life Threat Behav* 2012; **42(5)**: 471–85.
65. Litteken C, Sale E. Long-term effectiveness of the Question, Persuade, Refer (QPR) suicide prevention gatekeeper training program: Lessons from Missouri. *Community Ment Health J* 2018; **54**: 282–92.
66. Strang VR, Koop PM, Dupuis-Blanchard S, Nordstrom M, Thompson B. Family caregivers and transition to long-term care. *Clin Nurs Res* 2006, **15(1)**: 27–45.
67. Li, LW. From caregiving to bereavement: Trajectories of depressive symptoms among wife and daughter caregivers. *J Gerontol B Psychol Sci Soc Sci* 2005; **60(4)**: 190–98.
68. Runeson B, Tidemalm D, Dahlin M, Lichtenstein P, Langstrom N. Method of attempted suicide as a predictor of subsequent successful suicide: National long-term cohort study. *BMJ* 2010; **341**: c3222.
69. Shenassa ED, Catlin SN, Buke SL. Lethality of firearms relative to other suicide methods: A population based study. *J Epidemiology Community Health* 2003; **57(2)**: 120–24.
70. Brett J, Staniszewska S, Mockford C. Mapping the impact of Patient and Public Involvement on health and social care research: A systematic review. *Health Expect* 2012; **17(5)**: 637–50.
71. Brett J, Staniszewska S, Mockford C. A systematic review of the impact of patient and public involvement on service users, researchers, and communities. *Patient* 2014; **7(4)**: 387–95.
72. Wadman R, Williams AJ, Brown K, Nielsen E. Supported and valued? A survey of early career researchers' experiences and perceptions of youth and adult involvement in mental health, self-harm and suicide research. *Res Involve Engagem* 2019; **5**: 16.
73. Littlewood DL, Quinlivan L, Steeg S, et al. Evaluating the impact of patient and carer involvement in suicide and self-harm research: A mixed-methods, longitudinal study protocol. *Health Expect* 2019; Epub ahead of print.
74. Thomas N, Stainton T, Jackson S, Cheung WY, Doubtfire S, Webb A. Your friends don't understand: Invisibility and unmet needs in the lives of 'young carers'. *Child and Family Social Work* 2003; **8(1)**: 35–46.
75. Pham MT, Rajic A, Greig JD, Sargeant JM, Papadopoulous A, McEwen SA. A scoping review of scoping reviews: Advancing the approach and enhancing consistency. *Res Synth Methods* 2014; **5(4)**: 371–85.
76. Disability Day of Mourning. Available at <https://disability-memorial.org/> (Accessed 19<sup>th</sup> August 2020).
77. Phillips D, Paul G, Fahy M, et al. The invisible workforce during the COVID-19 pandemic: Family carers at the frontline. *HRB Open Research*; Available at <https://hrbopenresearch.org/articles/3-24> (Accessed 10<sup>th</sup> August 2020).

78. Lightfoot E, Moone RP. Caregiving in times of uncertainty: Helping adult children of aging parents find support during the COVID-19 Outbreak. *J Gerontol Soc Work* 2020; Epub ahead of print.
79. Coronavirus Act 2020. Available at <https://www.legislation.gov.uk/ukpga/2020/7/contents/enacted> (Accessed 10<sup>th</sup> August 2020).
80. Carers Week 2020 Research Report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak. Available at <https://www.carersweek.org/images/CW%202020%20Research%20Report%20WEB.pdf> (Accessed 10<sup>th</sup> August 2020).
81. Webb-Robbins LM, Wilson Z. Analysis of HIV caregivers in South Africa: A South African depression and anxiety group. *J Hum Behav Soc Environ* 2008; **17(3-4)**: 281-292.

### **Acknowledgements**

Dr Siobhan O'Dwyer is supported by the National Institute for Health Research Applied Research Collaboration South West Peninsula. Paul Moran and Becky Mars are part-funded by the National Institute for Health Research Biomedical Research Centre at University Hospitals Bristol and Weston NHS Foundation Trust and the University of Bristol. The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research or the Department of Health and Social Care.

This review was funded by an Initiator Grant from GW4. GW4 had no role in the study design, the synthesis and interpretation, the writing of the manuscript, or the decision to submit the manuscript for publication. SOD confirms that she had full access to all the articles included in this review and had final responsibility for the decision to submit the manuscript for publication.

The authors would like to thank Dr Katie Maras for her contributions to the early development of this work.

**Table 1.** Inclusion and exclusion criteria.

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Informal, unpaid, or family caregivers aged over 18 years (including bereaved caregivers)	Caregivers aged under 18 years. Formal, paid, or professional caregivers.
Caring for a person with a long-term illness, condition, or disability (including persistent or chronic mental illness)	Care recipients with: <ul style="list-style-type: none"> <li>• Acute illnesses or conditions (including present to acute hospital with suicidal thoughts or self-harm)</li> <li>• Munchausen’s by proxy</li> <li>• Malnutrition</li> <li>• Ageing (without a specified illness or disability)</li> </ul>
Reporting on suicidal ideation, suicide attempt, or death by suicide.	Reporting on euthanasia, physician-assisted suicide, assisted dying
Article types: <ul style="list-style-type: none"> <li>• Original research</li> <li>• Secondary analysis</li> <li>• Review with case study</li> <li>• Case study</li> <li>• Professional reflection</li> <li>• Commentary</li> </ul>	Articles types: <ul style="list-style-type: none"> <li>• Protocol</li> <li>• Review without case study</li> <li>• PhD thesis</li> <li>• Book chapter</li> </ul>
Published in English between 1989 and 2019 (extended to 2020)	Published prior to 1989 or in a language other than English

**Table 2.** Summary of included articles.

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
Abasiubong <sup>40</sup>	2011	Quantitative: n=312 caregivers	Secondary/Incidental	Nigeria	HIV	Relatives (not further specified)	One item from the Self-Rating Depression Scale and one item from the Self-Report Questionnaire (SRQ-20) were taken together to indicate “suicidal tendencies”. No further information on measurement provided.  3.7% (n=11) of caregivers had suicidal tendencies.
Abbott <sup>39</sup>	2014	Quantitative: n=127 caregivers	Primary	USA	Cancer	Spouse, adult child, sibling, parent, other relative, friend, other	Four screening items from the Yale Evaluation of Suicidality scale were used to assess suicidality, including “In light of your circumstances how strong has your wish to die been?” and “In light of your current circumstances, have you ever had thoughts of killing yourself?”. The other two screening items were not specified. Authors note that response options were No, Possible and Yes, and these were “regrouped” to create a binary variable for suicidal ideation with Yes and Possibly responses classified as Yes and No as No.  Suicidal ideation reported in 12% (n=15) of caregivers pre-bereavement, and in 17% (n=21) of caregivers post-bereavement.  In a multivariate model, significant predictors of suicidal ideation post-bereavement were caregivers’ perceptions of care-recipients’ quality of life at end of life (OR 0.79), spousal relationship to care recipient (OR 5.30), and baseline suicidal ideation (OR 4.13).  <i>Interpret with Caution: One of three publications (see also Lichtenthal et al. (2011) and Meyer et al. (2013)) from the ‘Coping with Cancer’ study.</i>
Adelman <sup>5</sup>	2014	Other	Secondary/Incidental	USA	"Functionally Impaired"	Spouse	Case study of an attempted suicide, attributed to “overwhelming caregiver burden”.
Aloba <sup>38</sup>	2016	Quantitative: n=264 caregivers	Secondary/Incidental	Nigeria	Schizophrenia, bipolar, depression	Parent, spouse, sibling, adult child, grandparent	Mean score for suicidality on the Mini International Neuropsychiatric Interview of 1.05 (SD=1.79).  Significant positive correlation between suicidality and hopelessness.
Anderson <sup>53</sup>	2019	Qualitative: n=9 caregiver blogs	Primary	UK and USA	Alzheimer’s disease and related dementias	Daughter, heterosexual spouses	In blogs authored by caregivers, implicit expressions of suicidal and homicidal thoughts were identified. No suicidal acts or behaviours reported.

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
							Thoughts were linked to an end to the caregiving role, not wanting to go through the same experience as the care recipient, and the care recipient's desire for death.
Anonymous <sup>30</sup>	2019	Other	Primary	UK	N/A	N/A	Commentary co-authored by caregivers, making recommendations for future research on suicide risk in caregivers.
Bourget <sup>46</sup>	2010	Other	Secondary/Incidental	Canada	Alzheimer's disease; "physically and psychologically handicapped"	Spouse, parent, adult child	Retrospective analysis of coroners' files on domestic homicides and homicide-suicides perpetrated by older people between 1992 and 2007 (n=27), including three case studies of homicide-suicides perpetrated by a caregiver.  Attributed to caregiver(s) mental and physical health problems, care recipient(s) wish to die, desire to relieve suffering of care recipient, impending institutionalisation of care recipient, and isolation of caregiver.
Brown <sup>44</sup>	2012	Other	Secondary/Incidental	UK	Downs syndrome, genetic disorder, learning disabilities	Parent	Case studies of n=6 homicides, perpetrated by parent caregivers between 1999 and 2009.  Two cases included the suicide of the caregiver and one included the attempted suicide of the caregiver. Attributed to caregiver burden and depression.
Chamberlain <sup>31</sup>	2018	Other	Primary	UK	Dementia	Spouse	Professional reflection of nurses' management of suicidal ideation in a family caregiver.  Suicidal thoughts attributed to care recipient's challenging behaviour, failed institutionalisation of care recipient, caregiver's emotional exhaustion, and conflict between caregiver and professional care workers.  Evidence of dysfunctional coping, disturbed sleep, and symptoms of depression in caregiver.
Chiu <sup>34</sup>	2011	Quantitative: n=432 caregivers	Secondary/Incidental	Taiwan	Cancer (deceased)	Spouse, adult child, adult child-in-law, sibling	Measure not specified in Methods and no data in Results, but authors comment in the Discussion that "no suicide (behavior) was noted in our study" and "there was no gender difference in suicidal ideation".
Del Grande da Silva <sup>35</sup>	2014	Quantitative: n=113 caregivers	Secondary/Incidental	Brazil	Bipolar, depression	Parent, spouse	25.7% (n=29) of caregivers had "suicide risk/ideation". Assessment of risk/ideation not specified.  In a multivariate analysis, suicide risk was not a significant predictor of caregiver burden.

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
England <sup>42</sup>	2005	Qualitative: n=50 caregivers.	Secondary/Incidental	USA	Cognitive impairment	Adult children (with a history of experiencing abuse)	In interviews n=43 (86%) caregivers reported suicidal ideation and n=13 (26%) reported “parasuicide”. Of those reporting parasuicide, n=4 had attempted suicide in the previous year.  Evidence of dysfunctional coping in suicidal caregivers.  No definition of parasuicide provided. Unclear if thoughts of suicide were experienced as a caregiver or previously.
Figueiredo <sup>25</sup>	2020	Quantitative; n=30 caregivers	Secondary/Incidental	Brazil	Tetraparetic cerebral palsy with gastrostomy tube feeding	Mother, grandmother	Suicidal ideation was assessed with the Beck Scale for Suicide Ideation, but no additional information on this measure was provided.  10% (n=3) of caregivers “presented positive response to suicidal ideation.”
Hosaka <sup>27</sup>	2003	Quantitative: n=20 female caregivers	Secondary/Incidental	Japan	Dementia	Adult child, adult child-in-law, spouse	Significant pre-post improvement on the General Health Questionnaire sub-scale for suicidal depression after a 5-session psychoeducational intervention (Pre: $M=1.10$ ; $SD=1.48$ ; Post: $M=0.85$ , $SD=2.85$ )
Hosaka <sup>28</sup>	1999	Quantitative: n=20 female caregivers	Secondary/Incidental	Japan	Dementia	Adult child, adult child-in-law, spouse	Significant pre-post improvement on the General Health Questionnaire sub-scale for suicidal depression after a 5-session psychoeducational intervention. Data presented in a figure, so exact means and standard deviations not available.  <i>Interpret with Caution: Published as a ‘pilot study’, but sample size and participant demographics are identical to Hosaka et al. (2003).</i>
Huang <sup>47</sup>	2018	Quantitative: n=255 caregivers	Primary	Taiwan	Mental disability, physical disability	Parent, adult child, spouse, sibling, friend, other	18.8% (n=48) of caregivers endorsed the suicidal ideation item on the Taiwanese Depression Questionnaire (“I have been feeling miserable and have even wanted to die”; in the previous two weeks).  Compared with caregivers without suicidal ideation, a significantly higher proportion of caregivers with suicidal ideation were primary caregivers, received no support from co-caregivers, cared for younger care recipients, cared for people with mental disability, and cared for people with catastrophic diseases. No significant difference between suicidal and non-suicidal caregiver age, caregiver gender, marital status, years of education, employment status, duration of care, living with care recipient, care recipient gender, relationship to caregiver, duration of illness, or care recipient receiving social welfare.

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
							In a multivariate model, age of care recipient (OR 0.98), care recipient with catastrophic disease (OR 3.15), probable depression (OR 3.90), and probable mental disorder (OR 9.40) were significant predictors of suicidal ideation.
Joling <sup>11</sup>	2018	Quantitative; n=192 caregivers	Primary	Netherlands	Dementia	Spouse or other relative	<p>Caregivers who screened positive for major depression on the Mini International Neuropsychiatric Interview were asked “Over the past two weeks, did you repeatedly consider hurting yourself, feel suicidal, or wish that you were dead?”. Caregivers were assessed every 3 months for 24 months.</p> <p>Of the n=76 caregivers who reported symptoms of major depression, n=9 (11.8% of those with symptoms of depression; 4.7% of the total sample) reported suicidal ideation. N=3 reported suicidal ideation at multiple timepoints. N=1 reported suicidal ideation after institutionalisation of care recipient, and N=1 after death of care recipient.</p> <p>Compared with caregivers without depression and caregivers with symptoms of depression only, caregivers with symptoms of depression and suicidal ideation had significantly more depressive symptoms, lower sense of competency and mastery, more health problems, less happiness, less family support, and more feelings of loneliness.</p>
Joling <sup>24</sup>	2019	Quantitative; n=1582 caregivers	Primary	Netherlands	Physical problems, mental problems, ageing, dementia	Spouse, first-degree family, other family, friend	<p>Suicidal ideation assessed with the Suicidality Module of the Composite International Diagnostic Interview version 3.0. It was assessed at baseline (T1) and three years later (T2). At T1 caregivers were asked “Have you seriously thought about committing suicide?” and the timeframe was the previous 12 months. At T2 caregivers were asked the same question and the timeframe was the previous 3 years. Caregivers were considered to have suicidal thoughts if they were reported at any point in the 4-year period.</p> <p>2.9% (weighted percentage, adjusted for age and gender) (n=36) of caregivers reported suicidal thoughts. N=15 caregivers at T1, n=21 caregivers at T2, and n=6 caregivers at both timepoints.</p> <p>There was no significant difference in suicidal thoughts between caregivers and non-caregivers.</p> <p>In a multivariate analysis, unemployment (OR 2.34), living without a partner (OR 2.39), social support (OR 0.5), chronic illness (OR 3.75), mood disorder (OR 12.32), anxiety disorder</p>

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
							<p>(OR 5.23), impaired social functioning (OR 4.34), impaired physical functioning (OR 4.73) and impaired emotional functioning (OR 3.58) were significant predictors of suicidal thoughts in caregivers. No caregiving characteristics (e.g. reason for care, type of care, amount of care, duration of care) were significant predictors of suicidal thoughts.</p> <p>The same variables were significant predictors of suicidal thoughts in non-caregivers, with low education and a negative life event in the past 12 months also significant predictors of suicidal thoughts in non-caregivers.</p>
Kageyama <sup>15</sup>	2018	Quantitative: n=277 caregivers	Secondary/Incidental	Japan	Schizophrenia	Parent, spouse, sibling, other	<p>Three bespoke items were used: “Have you had suicidal thoughts due to violence by the patient?”; “Have you had thoughts of murder-suicide with the patient due to his/her violence?”; and, “Have you wished for the patient’s death due to his/her violence?”.</p> <p>Among the n=210 caregivers who had experienced physical violence perpetrated by the care recipient, 15.7% (n=33) had experienced suicidal thoughts, 26.7% (n=56) had thoughts of murder-suicide, and 31% (n=65) had wished for the care recipient’s death.</p> <p>Among the n=41 caregivers who had experienced psychological violence only (perpetrated by the care recipient), none reported suicidal ideation, 4.9% (n=2) had thoughts of murder-suicide, and 4.9% (n=2) had wished for the care recipient’s death.</p>

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
Karch <sup>45</sup>	2011	Other	Secondary/Incidental	USA	Not specified  (N.B. This sample included some elderly and vulnerable adults)	Spouse, adult child, parent, sibling, adult child-in-law, adult step-child, friend, other  (N.B. This sample included some paid care workers and health professionals)	<p>Analysis of caregiver-perpetrated homicides, identified in the National Violent Death Reporting System for 17 US States between 2003 and 2007.</p> <p>Of the 68 caregiver perpetrated homicides identified, 44% (n=30) were homicide-suicides.</p> <p>Three main motivations for homicide-suicide were identified: (1) “Desire on the part of the caregiver to stop the suffering of the victim and end their own lives despite not having any notable illness themselves”; (2) “The inability of the caregiver to continue to meet the needs of an ill spouse or child due to either a recent diagnosis of their own or an ongoing chronic illness that had progressed”; (3) “An impending crisis for the perpetrator unrelated to the illness of the victim” (including but not limited to a caregiver wanting to die by suicide but not wanting to leave care recipient without care).</p>
Kim <sup>48</sup>	2019	Qualitative: n=18 Korean-American caregivers	Secondary/Incidental	USA	Dementia	Spouse, adult child	<p>In interviews, n=4 caregivers (22%) reported thoughts of suicide, thoughts of homicide-suicide, and wishing for the death of the care recipient. One caregiver specified methods.</p> <p>Thoughts attributed to the care recipient’s symptoms, the burden of caregiving, and a lack of support. Caregivers also considered suicide and homicide-suicide as a solution to the problems of caregiving and the burden of illness, and as a good death that would remove burden and suffering from other family members.</p>
Koyama <sup>12</sup>	2017	Quantitative: n=104 caregivers (n=46 caregivers aged under 65 years; n=58 caregivers aged over 65 years)	Secondary/Incidental	Japan	Dementia	Spouse, adult child, daughter-in-law, other	<p>10.9% (n=5) of younger caregivers and 10.3% (n=6) older caregivers reported suicidal ideation in the previous two weeks.</p> <p>Question not specified, but responses classified as present (composite of response options “sometimes”, “often”, or “always”) and absent.</p> <p>No significant difference in suicidal ideation between caregivers and age- and gender-matched controls.</p>
Lewis <sup>55</sup>	2014	Qualitative: n=101 caregivers	Secondary/Incidental	USA	Dementia	Adult child, adult child-in-law, friend, adult grandchild, adult grandchild-in-law, spouse	<p>Variety of data sources, including interviews, memoirs, blogs, observation of caregiving, observation of support group.</p> <p>“Several caregivers considered assisting a loved one in suicide or ending their own lives as a potential way out of their own suffering”.</p>

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
							Thoughts attributed to sleep deprivation, emotional exhaustion, lack of reprieve/support, desire for escape.
Lichtenthal <sup>33</sup>	2011	Quantitative: n=86 bereaved caregivers	Secondary/Incidental	USA	Cancer (deceased)	Spouse, adult child	<p>The Yale Evaluation of Suicidality was used. Scores range from 0 to 16 and a dichotomous variable was created based on median split, so that caregivers with a score greater than 1 were considered to have "suicidal thoughts or gestures".</p> <p>16% (n=14) met the criteria for prolonged grief disorder.</p> <p>Prolonged grief disorder was significantly associated with suicidality. 71% (n=10) of those with prolonged grief disorder reported suicidal thoughts or gestures. 50% (n=5) of them accessed services.</p> <p>In a multivariate analysis, suicidality was not a significant predictor of mental health service use.</p> <p><i>Interpret with Caution: One of three publications (see also Meyer et al. (2013) and Abbott et al. (2014)) from the 'Coping with Cancer' study.</i></p>
Lucas <sup>9</sup>	2015	Quantitative: n=186 caregivers	Primary	USA	Survivors of childhood brain tumors	Mother	<p>Testing the feasibility of a protocol for the assessment of suicidal ideation in caregivers by non-specialist research staff.</p> <p>The Brief Symptom Inventory (Thoughts of ending life in the past seven days: A little bit; moderately; quite a bit; extremely often) and the Columbia Suicide Severity Rating Scale (Ideation Severity: None; wish to be dead; nonspecific active suicidal thoughts; active suicidal ideation without intent to act; active suicidal ideation with some intent to act but no specific plan; active suicidal ideation with specific plan and intent) were used.</p> <p>2.68% (n=5) of caregivers endorsed suicidal ideation (n=3 a little bit, n=1 moderately, n=1 extremely often).</p> <p>No caregivers endorsed having a plan or specific intent to act (n=1 none, n=3 wish to be dead, n=1 non-specific active suicidal thoughts).</p> <p>Process notes indicated that when asked about suicidal ideation caregivers spoke of anger, sadness, feeling overwhelmed, feeling trapped, and financial burdens.</p>

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
							The protocol was deemed feasible, with research staff able to refer participants to specialist support as needed and caregivers open and cooperative.
Marimbe <sup>52</sup>	2016	Mixed-method: n=31 caregivers	Secondary/Incidental	Zimbabwe	Schizophrenia, bipolar disorder	Parent, sibling, aunt, spouse, adult child	Caregivers participated in in-depth interviews and focus groups. The Shona Symptom Questionnaire was self-administered after the interview, and included assessment of suicidal ideation.  9.7% (n=3) of caregivers had suicidal ideation (timeframe not specified). Two were the mother of the care recipient, one was a sister.
Meyer <sup>16</sup>	2013	Quantitative: n=356 bereaved caregivers	Secondary/Incidental	USA	Cancer	Not specified	No information provided on measurement of suicidality. Suicidality only reported in a regression model: “after adjustment for the identified confounders of white race and patient self-efficacy, patient cognitive impairment was significantly associated with caregiver pre-loss MDD [major depressive disorder]... without associated increases in suicidality (and in fact a trend toward reduced suicidality)”.  <i>Interpret with Caution: One of three publications (see also Lichtenthal et al. (2011) and Abbott et al. (2014)) from the ‘Coping with Cancer’ study.</i>
Mizuno <sup>29</sup>	1999	Quantitative: n=56 caregivers	Secondary/Incidental	Japan	Dementia, frailty resulting from vascular events or physical disability	Daughter-in-law, daughter, spouse	Significant pre-post improvement on the General Health Questionnaire sub-scale for suicidal depression after a 5-session psychoeducational intervention. Significant difference maintained at 2-month follow-up.  Data presented in a figure, so exact means and standard deviations not available.  <i>Interpret with Caution: Appears to be the same intervention as Hosaka et al. (2003) and Hosaka et al. (1999), with expanded sample.</i>
Nakigudde <sup>23</sup>	2016	Qualitative: n=54 caregivers	Secondary/Incidental	Uganda	Nodding syndrome	Parent, other relative	“Homicidal and suicidal ideation” was identified as a theme in the analysis of interviews and focus groups. The authors noted that homicidal ideation was “commonly discussed” and that suicidal thoughts were implied through statements such as “I was thinking I would be better off dead” and “I didn’t want to live”. One participant was quoted as explicitly contemplating suicide.  Thoughts attributed to sadness, not wanting to see care recipient suffer, stigma, concern for other family members, and desire for reprieve from the difficulties of the caring role.

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
O'Dwyer <sup>34</sup>	2016	Qualitative: n=21 caregivers	Secondary/Incidental	Australia	Dementia	Spouse, sibling, adult child, adult child-in-law	<p>In interviews about homicidal ideation, n=1 caregiver expressed thoughts of homicide-suicide. Authors note that the caregiver's "statements on which came first – thoughts of homicide or thoughts of suicide – were conflicting". The caregiver specified a method, based on the homicide-suicide deaths of friends.</p> <p>Reasons for not acting on the thoughts included "personal determination, the absence of additional stressors such as physical health problems, and a commitment to, and involvement in, activities outside caring". The threat of jail was cited as the rationale for thoughts of homicide-suicide rather than thoughts of homicide alone.</p>
O'Dwyer <sup>14</sup>	2016	Quantitative: n=566 caregivers	Primary	Australia, North America, United Kingdom, Other	Dementia	Spouse, adult child, adult child-in-law, other	<p>Three of the four items from Suicidal Behavior Questionnaire-Revised were used to assess suicidality, with response options merged to create dichotomous measures. Item 2 (How often have you thought about killing yourself in the past year?) with the responses of Never or Rarely classified as 'non-suicidal' and responses of Sometimes, Often or Very Often classified as 'suicidal'. Item 3 (Have you ever told someone that you were going to commit suicide or that you might do it?) with any Yes responses classified as having disclosed suicidal ideation. Item 4 (How likely is it that you will attempt suicide some day?) with responses of Likely, Rather Likely or Very Likely classified as 'likely to attempt' and responses of Never, No Chance At All, Rather Unlikely, or Unlikely classified as 'unlikely to attempt'.</p> <p>16% (n=91) of caregivers were classified as suicidal. Of these, 50.5% (n= 46) had disclosed suicidal intentions and 18.7% (n = 17) were likely to attempt suicide in the future.</p> <p>No significant difference in proportion classified as suicidal between caregivers with a care recipient at home, caregivers with a care recipient in an institution, and bereaved caregivers.</p> <p>In a multivariate analysis, age (Exp B 0.96), depression (Exp B 1.06), and reasons for living (Exp B 0.48) were significant predictors of suicidal ideation. In a mediational model, greater dysfunctional coping and less satisfaction with social support had significant indirect effects on suicidal ideation via increased depression.</p>
O'Dwyer <sup>8</sup>	2014	Quantitative: n=3077 female caregivers	Primary	Australia	Long-term illness, disability, frailty	Not specified	<p>Comparison between female caregivers (n=3077) and female non-caregivers (n=7451).</p>

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
		(n=2005 included in multivariate analysis)					<p>“Death thoughts” assessed with a single item: In the past week, have you been feeling that life isn’t worth living? (Yes/No). Self-harm and suicide attempt assessed with a single item: In the past six months, have you deliberately hurt yourself or done anything that you knew might have harmed or even killed you? (Yes/No).</p> <p>7.1% (n=218) of caregivers had felt life was not worth living in the previous week. This was significantly more than 5.7% of non-caregivers.</p> <p>No significant difference between caregivers and non-caregivers for self-harm and suicide attempts (less than 1% in both groups).</p> <p>In a multivariate model, social support (Exp B 0.74), mental health (Exp B 0.97), caregiver satisfaction (Exp B 0.56), and depression (Exp B 3.95) were significant predictors of death thoughts.</p>
O'Dwyer <sup>57</sup>	2013	Quantitative: n=120 caregivers	Primary	Australia, Canada, USA, Other	Dementia	Spouse, adult child, adult child-in-law, other	<p>Three of the four items from Suicidal Behavior Questionnaire-Revised were used to assess suicidality, with response options merged to create dichotomous measures. Item 2 (How often have you thought about killing yourself in the past year?) with the responses of Never or Rarely classified as ‘non-suicidal’ and responses of Sometimes, Often or Very Often classified as ‘suicidal’. Item 3 (Have you ever told someone that you were going to commit suicide or that you might do it?) with any Yes responses classified as having disclosed suicidal thoughts or intentions. Item 4 (How likely is it that you will attempt suicide some day?) with responses of Likely, Rather Likely or Very Likely classified as ‘likely to attempt’ and responses of Never, No Chance At All, Rather Unlikely, or Unlikely classified as ‘unlikely to attempt’.</p> <p>26% (n=32) of caregivers were classified as suicidal. Of these, 50% (n=16) had disclosed suicidal thoughts or intentions and n=9 were classified as likely to attempt suicide in the future.</p> <p>In a multivariate model, depression (Exp B 1.12) was a significant predictor of suicidal ideation.</p> <p><i>Interpret with Caution: Data from this study included in O’Dwyer (2016).</i></p>

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
O'Dwyer <sup>49</sup>	2013	Qualitative: n=9 caregivers.	Primary	Australia	Dementia	Spouse, adult child, adult child-in-law, adult grandchild	<p>In interviews, n=9 caregivers (44%) reported experiencing suicidal ideation while caring. None had attempted suicide whilst caring, but n=9 had made preparations for a suicidal act. N=2 caregivers reported having suicidal thoughts on multiple occasions during the caregiving trajectory.</p> <p>Thoughts attributed to the need for reprieve from the caregiving role, financial imperatives, emotional distress, and poor physical health. A sense of responsibility for the care recipient and other family members, and faith were cited as reasons for not acting on thoughts. Some caregivers anticipated contemplating or attempting suicide after the institutionalisation or death of the care recipient.</p> <p>Authors identified three main factors distinguishing caregivers who had experienced suicidal thoughts from those who had not: mental health problems prior to caregiving; physical health problems while caring; conflict with family or service providers.</p> <p>Compared with caregivers who did not report suicidal ideation, the authors also noted that those who did report suicidal ideation engaged in information seeking and self-care less frequently, had fewer opportunities for engaging in social activities, had poorer knowledge of available support services, had less involvement with family, and had more difficulty accessing services.</p>
Oza <sup>41</sup>	2017	Quantitative: n=100 caregivers	Secondary/Incidental	India	Schizophrenia, Obsessive Compulsive Disorder	Spouse, parent, sibling, adult child	<p>No information provided in Methods or Results, but in the Discussion the authors note that “The GHQ-28 suicidal subscale shows a significantly stronger death wish in caregivers of patients with schizophrenia and the overall score for the suicidal subscale is also significantly higher in the schizophrenia group”.</p>
Park <sup>37</sup>	2013	Quantitative: n=897 caregivers	Primary	Korea	Cancer	Spouse, adult child, parent, sibling	<p>Caregivers were “asked about suicidal ideation and suicide attempts during the previous year”. No other information provided on measurement of suicidality.</p> <p>17.7% (n=159) of caregivers reported suicidal ideation, 2.8% (n=25) had attempted suicide during the previous year. Levels of suicidal ideation and suicide attempt were significantly higher in caregivers with anxiety or depression than in caregivers without anxiety and depression.</p> <p>In a multivariate analysis for caregivers with anxiety, being female (OR 1.96), not being married (OR 2.26), becoming unemployed while caring (OR 1.97), and low quality of life</p>

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
							<p>(positive adaptation) (OR 1.67) were significant predictors of suicidal ideation.</p> <p>In a multivariate analysis for caregivers with depression, being female (OR 2.08), not being married (OR 1.97), becoming unemployed while caring (OR 1.76), and low quality of life (burden, disturbance, positive adaptation) (OR 2.29; OR 2.13; OR 2.05) were significant predictors of suicidal ideation. Staying employed while caregiving (OR 0.56) and caring for an older person (OR 0.60) were also significant predictors.</p> <p>In a multivariate model for caregivers with anxiety, becoming unemployed while caring (OR 3.27) was a significant predictor of suicide attempts. In caregivers with depression, not being married (OR 3.59) and low quality of life (financial) (OR 2.73) were significant predictors of suicide attempts.</p>
Riley <sup>50</sup>	2007	Qualitative: n=9 caregivers	Secondary/Incidental	UK	Chronic or terminal illness	Spouse	In interviews one caregiver reported wanting to “end it all” and specified a method.
Rosato <sup>26</sup>	2019	Quantitative; n=130,816 caregivers	Primary	UK	Long-term physical or mental ill-health/disability, problems related to old age	Family member, friend, neighbour, other	<p>Using mortality data, ICD codes for definite suicides and deaths of undetermined intent (ICD-10: X60-X84, Y10-Y34, Y87.0, Y87.2) were “combined to define suicide”.</p> <p>Of the n=17,708 deaths in the 45 month follow-up period, n=528 were classified as suicide. Of these, 17% (n=90) were in people “engaged in prosocial activities” (i.e. caregiving and/or volunteering). The authors note that “a more disaggregated breakdown was not possible due to disclosure rules associated with use of the data”.</p> <p>In age- and sex-adjusted models, being a caregiver only and being a caregiver <i>and</i> a volunteer significantly reduced the risk of mortality by suicide, compared with those who did neither. The effect for caregivers only was not maintained in models also adjusted for religion, marital status, single person household, socioeconomic status, economic activity, and self-reported health status, but it was maintained in these models for those who were caregivers <i>and</i> volunteers.</p> <p>In analyses stratified by mental health status, “volunteers and caregivers with better mental health tend to have a lower risk of suicide but those with poor mental health tend to exhibit the same risk as those not engaging in either activity”.</p>

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
Rosengard <sup>7</sup>	1997	Quantitative: n=253 male caregivers	Primary	USA	Men with AIDS	Spouse	<p>As part of the Structured Clinical Interview for DSM-III-R, caregivers were asked “Has there ever been a time when you thought you would be better off dead”. For follow-up assessments, the timeframe was limited to the previous six months. Aggregate scores based on responses at 5 time-points over two years were used to create four categories: Never (“participants who reported never having suicidal thoughts either in their lifetime or during the study”); Lifetime (“participants who reported that they had suicidal thoughts in their lifetime, but not during the course of the study”); Lower Ideation (“participants who reported suicidal ideation during the study whose aggregate scores fell below the mean”); Higher ideation (“participants who reported suicidal ideation during the study whose aggregate scores fell above the mean”).</p> <p>N=29 caregivers were classified as Higher Ideation, n=56 as Lower Ideation, n=38 as Lifetime, and n=126 as Never.</p> <p>Age, race, and level of employment were not significantly associated with suicidal ideation. Education and income were significantly negatively associated with suicidal ideation.</p> <p>There was a significant association between bereavement and suicidal ideation, with a higher proportion of those in the High Ideation group being bereaved than in the other groups.</p> <p>There was no significant association between caregivers’ own HIV status and suicidal ideation.</p> <p>In a multivariate analysis of psychosocial variables with all caregivers, variables that significantly distinguished the Higher Ideation group from the other groups were: (lack of) perceived social support, use of behaviour escape-avoidance coping strategies, (less) subjective integration, and (more) caregiver burdens. Optimism significantly distinguished the Never group from the other groups.</p> <p>Additional multivariate analyses were run for bereaved caregivers, non-bereaved caregivers, HIV+ caregivers, and HIV- caregivers.</p> <p>In bereaved caregivers, caregiver burden, perceived social support, and behavioural escape-avoidance coping significantly</p>

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
							<p>distinguished the Higher Ideation group from the other groups. No variables significantly distinguished the Never group from the other groups.</p> <p>In non-bereaved caregivers, perceive social support and subjective integration significantly distinguished the Higher Ideation group from the other groups. No variables significantly distinguished the Never group from the other groups.</p> <p>In HIV+ caregivers, no variables significantly distinguished the Higher Ideation group from the other groups, or the Never group from the other groups.</p> <p>In HIV- caregivers, subjective integration and behavioural escape-avoidance coping significantly distinguished the Higher Ideation group from the other groups. Optimism significantly distinguished the Never group from the other groups.</p>
Sanderson <sup>51</sup>	2013	Qualitative: n=32 bereaved caregivers	Secondary/Incidental	Australia	Ovarian cancer (deceased)	Spouse, adult child, sibling	In interviews six-months post-bereavement, one caregiver reported understanding how other caregivers could become suicidal. The thoughts were attributed to a lack of meaning or purpose.
Shaji <sup>13</sup>	2003	Qualitative: n=17 caregivers	Secondary/Incidental	India	Alzheimer's disease	Not specified, majority daughters-in-law	<p>In interviews, n=5 caregivers (29%) "had suicidal ideation" and n=1 "had made an attempt". Timeframe not specified.</p> <p>Authors also note that "a few months" after the interviews, one caregiver died by suicide. The suicide was attributed to a lack of support from, and conflict with, other family members. The caregiver had also been diagnosed with major depressive disorder and prescribed anti-depressants, but was "irregular with follow-up and had discontinued medication".</p>
Silverberg <sup>56</sup>	2011	Other	Secondary/Incidental	Canada	Alzheimer's disease or related dementia	Family (not further specified)	In reflecting on ten years as a social worker and personal experience as a caregiver, and making recommendations for how professional care staff can support families, the author notes that family caregivers navigating nursing home placement and "experiencing high levels of distress and loneliness may have suicidal ideation and be at risk of hurting themselves".
Skeen <sup>10</sup>	2014	Quantitative: n=952 caregivers	Secondary/Incidental.	South Africa, Malawi	HIV	Not specified	<p>Suicidal ideation was assessed with one item from the Patient Health Questionnaire: Over the past two weeks, how often have you had thoughts that you would be better off dead or of hurting yourself?</p> <p>12.2% (n=116) of caregivers reported suicidal ideation in the past two weeks. 8.5% (n=81) "met the threshold for both mental</p>

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
							<p>health disorders and suicidal ideation”, 19.5% (n=185) met the threshold for mental health disorders but did not report suicidal ideation, and 3.7% (n=35) reported suicidal ideation only.</p> <p>No significant difference in suicidal ideation between HIV positive caregivers, caregivers living with someone with HIV, and caregivers living in HIV-free households.</p> <p>In a multivariate analysis of caregivers who met the threshold for mental disorder and had suicidal ideation, living in Malawi (compared with living in South Africa) (OR 0.41), living in a household where no-one was employed (OR 2.26), living with a sick family member (OR 1.71), low perceived community support for HIV (OR 1.64), and living in poor housing conditions (OR 1.55) were significant predictors of suicidal ideation.</p> <p>68.1% (n=79) of caregivers with suicidal ideation had sought care.</p>
Stansfeld <sup>32</sup>	2014	Quantitative: n=1367 caregivers	Secondary/Incidental	UK	Long-term physical or mental ill health or disability	Family, friends, neighbours, other	<p>Questions from the Revised Clinical Interview Schedule were used to assess suicidal ideation: “whether respondents, in the last week or year, or at any other time, had wished they were dead, had thoughts about suicide without intentions to act, or had attempted to take their life”.</p> <p>Compared with non-caregivers (number unclear), caregivers were “twice as likely to report thinking about suicide in the last week... and more likely to report wishing they were dead in the last week”.</p> <p>No other data reported in Results, but in the Discussion authors note that “approximately 4% of the current sample acknowledged suicidal thoughts in the preceding year”. It is unclear if this is the whole sample, or just the caregivers.</p>
dos Santos Treichel <sup>17</sup>	2019	Quantitative: n=537 caregivers	Primary	Brazil	Mental disorders	Relatives (not further specified)	<p>Suicidal ideation was assessed with a single item from the “SRQ-20”, that “asked if, in the past 30 days, the individual ‘have ever thought about ending their life’”.</p> <p>12.5% (n=67) of caregivers reported suicidal ideation.</p> <p>In a multivariate analysis of “sociodemographic variables”, age (51-60 years, OR 0.38; 61 years and over; OR 0.27) and schooling (5-8 years, OR 2.56; 0-4 years, OR 3.44) were significant predictors of suicidal ideation.</p>

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
							In a multivariate analysis of “variables related to care” (adjusted for age, sex and schooling), feelings of overload (light overload, OR 3.51; moderate/heavy overload, OR 2.73), stress problems and ownership (but not use of) psychotropic drugs (OR 5.22), stress problems and use of psychotropic drugs (OR 4.28), and dissatisfaction with family relationships (OR 2.03) were significant predictors of suicidal ideation.
Valente <sup>36</sup>	2011	Quantitative: n=137 caregivers	Secondary/Incidental	Brazil	Dementia	Adult child, spouse, sibling, other	8.8% (n=12) of caregivers had “death wish”. No other information reported.
Washington <sup>43</sup>	2016	Other	Primary	USA	Hospice and palliative patients	Family member or friend	<p>N=74 hospice and palliative social workers surveyed about their encounters with patients, family caregivers, and other clients who had exhibited warning signs of suicide, attempted suicide, or died by suicide. Warning signs were defined as “suicidal communications, threats or behaviours that are not reasonably explained by other factors in the individual’s life”, with an example noting that “A warning sign could include statements such as ‘I can’t stand the pain any longer. I just want to end it.’ Or, ‘I’d be better off dead’. Or, ‘I think I’m going to kill myself.’” Warning signs for a “pending suicide attempt” were listed as “a previous suicide, complaints of serious depression and thoughts of death, giving away prized possessions, preparing a will, putting financial affairs in order, stockpiling pills, purchasing a firearm, saying goodbye, and any other word or deed that suggests the person may be planning to die by suicide”.</p> <p>55.4% (n=41) of social workers reported that one or more primary caregivers exhibited warning signs for suicide; 6.8% (n=5) reported one primary caregiver attempted suicide (none reported more than one); 4.1% (n=3) reported one primary caregiver died by suicide (none reported more than one).</p> <p>Of those who intervened with a caregiver exhibiting warning signs of suicide (number not provided), 89.6% agreed they had sufficient knowledge of suicide to intervene and 83.7% agreed they had sufficient clinical skills related to suicide to intervene.</p> <p>87.7% said suicide was included in their degree programme; 21.3% said it had sufficiently prepared them. 69.9% had received some continuing professional education on suicide; 55.5% received at least one hour of continuing professional education on suicide in the previous year. 93.5% agreed that learning more about suicide would be valuable for their work.</p>

First Author	Year	Article Classification & Sample Size	Focus on Suicidality	Country	Care Recipient Illness/Disability	Caregiver Relationship to Care Recipient	Key Findings
Webb-Robins <sup>81</sup>	2008	Mixed-method: n=71 caregivers	Secondary/Incidental	South Africa	HIV, AIDS	Not specified	<p>Past suicidal ideation was assessed with a stressful life events scale. Caregivers were classified as rural (n=46), semi-rural (n=11), and urban (n=14).</p> <p>37.5% of rural caregivers, 63.6% of semi-rural caregivers, and 21.4% of urban caregivers had “ever had thoughts of suicide”.</p> <p>There was no significant difference in thoughts of suicide between groups. No caregivers reported current thoughts of suicide.</p> <p>Qualitative explanations for suicidal ideation in the past included: “stigmatization for HIV diagnosis, unemployment/lack of financial resources, despair due to loss of loved ones to HIV, and a general loss of hope”.</p>

**Table 3.** Summary of recommendations for research, policy, and practice.

In policy:

- Recognise the significance of the caregiving role for public health and the economy, not just for individuals.
- Develop and fund evidence-based policies and programmes that support caregivers.

In clinical and community practice:

- Train health professionals and other relevant workers to identify at-risk caregivers and intervene appropriately.
- Screen for pre-existing mental illness and suicidal ideation at the onset of the caregiving role.
- Assess caregivers for suicide risk, not just mental illness.
- Assess caregivers for suicide risk *and* homicide risk.
- Consider cultural traditions and family dynamics related to caregiving that might heighten or mask suicide risk.
- Create safe spaces for caregivers to discuss thoughts of suicide (and homicide) without fear of repercussions such as criminal prosecution or removal of the care recipient.
- Avoid the assumption that contact with generic caregiver support services will be sufficient to mitigate suicide risk.
- Refer at-risk caregivers to appropriate suicide prevention, support, and treatment.
- Balance support for caregivers with safeguarding of care recipients.

In research:

- Include caregivers in the prioritisation of research questions, the development of research methods, and the interpretation of research findings.
- Conduct comparative studies to identify how suicide risk in caregivers varies across countries, cultures, and illnesses/disabilities.
- Examine, via longitudinal studies, how suicide risk changes across the caregiving trajectory.
- Examine, via qualitative studies, the lived experience of caregivers who have contemplated and/or attempted suicide (and homicide).
- Collect quantitative data on suicide attempts, deaths by suicide, homicidal ideation, and deaths by homicide-suicide.
- Examine the impact of social, cultural, and political risk and protective factors (not just individual and/or psychological ones).
- Develop evidence-based, culturally appropriate intervention and prevention strategies for suicide risk in caregivers, and evaluate these using feasibility studies and randomised controlled trials.