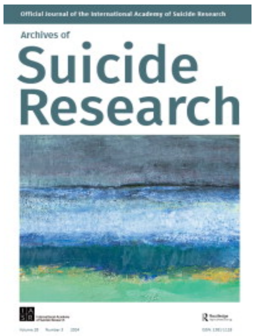

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ABSTRACT

Objective: There is a growing body of evidence on suicide risk in family carers, but minimal research on parents caring for children with disabilities and long-term illnesses. The aim of this study was to conduct the first dedicated research on suicide risk in parent carers and identify: (1) the number of parent carers experiencing suicidal thoughts and behaviors, and (2) the risk and protective factors for suicidality in this population.
Method: A cross-sectional survey of parent carers in England ($n = 750$), co-produced with parent carers. Suicidal thoughts and behaviors were measured with questions from the Adult Psychiatric Morbidity Survey. Frequencies summarized the proportion of carers experiencing suicidal thoughts and behaviors. Logistic regressions identified risk and protective factors.
Results: 42% of parents had experienced suicidal thoughts and behaviors while caring for a disabled or chronically ill child. Only half had sought help for these experiences. Depression, entrapment, dysfunctional coping, and having a mental health diagnosis prior to caring, were significant risk factors.
Conclusion: Parent carers contemplate suicide at levels that exceed those of other family carers and the general public. There is an urgent need, in policy and practice, to recognize parent carers as a priority group for prevention and intervention.

HIGHLIGHTS

- This is the first dedicated study of suicide risk in parent carers.
- More than 40% of parents had considered suicide while caring for a disabled or chronically ill child.
- The risk factors for suicidal ideation in parent carers were depression, entrapment, dysfunctional coping strategies, and having a mental health diagnosis prior to becoming a carer.
- Parent carers may be a high-risk group for suicide and need urgent support.

KEYWORDS
Caregivers; disabled children; parent carer; patient and public involvement; suicidal ideation

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Supplemental data for this article can be accessed online at https://doi.org/10.1080/13811118.2024.2363230230.

INTRODUCTION

More than 800,000 children in the UK have disabilities or long-term illnesses and the majority are cared for by their parents (UK Government, 2018). Although caring for a child with a disability or long-term illness can be extremely rewarding (Hastings & Taunt, 2002), it can also take a significant toll. Parent carers experience high rates of physical and mental illness, social isolation, relationship breakdown, and financial strain (Lee et al., 2017; Murphy et al., 2007).

Illness, isolation, relationship problems, and financial distress are all risk factors for suicide in the general population (O'Connor & Nock, 2014). There is also emerging evidence of suicide risk in family carers, with a recent review identifying evidence of suicidal thoughts and behaviors in people providing care for family members with a wide variety of illnesses or disabilities and across a range of low-, middle-, and high-income countries (O'Dwyer et al., 2021). Despite this growing body of evidence, only three studies have reported on suicide risk in parent carers specifically (Lucas et al., 2015; Nakigudde et al., 2016; Skeen et al., 2014).

These studies suggest a serious issue—with as many as 12% of parent carers in one study reporting suicidal thoughts in the previous two weeks (Skeen et al., 2014)—but much remains to be understood. Only one of the previous studies (Lucas et al., 2015) focused on suicide risk as a primary aim, with the other two reporting suicidal thoughts and behaviors as secondary or even incidental findings (Nakigudde et al, 2016; Skeen et al., 2014). As a result, there is a lack of knowledge on risk and protective factors for parent carers. Furthermore, the previous studies were all specific to a particular illness or disability. An understanding of suicidal thoughts and behaviors in parent carers more generally may help to inform the changes in policy and practice necessary to identify and support at-risk parents.

The aim of this study was to conduct the first dedicated study of suicide risk in parents caring for children with a range of different illnesses and disabilities. The objectives were to identify: (1) the number of parent carers who experienced suicidal thoughts and behaviors, and (2) the risk and protective factors for suicidality in this population. To achieve these objectives, a cross-sectional survey of parent carers in England was conducted and an exploratory approach to data analysis was taken.

MATERIALS AND METHODS

Co-Production

There has been a noticeable lack of co-production (also known as Patient and Public Involvement) in previous studies of suicide risk in carers. To address this and ensure the research was informed by carers' needs and experiences, the study was co-produced with four parent carers. They attended research training before the study began (Staley et al., 2019) and then collaborated, as equal members of the research team, on every aspect of the research (including design, funding application and ethical approval, recruitment, analysis, interpretation, and manuscript preparation). Academic ways of working were adapted to facilitate the involvement of the carers, who were also paid for their time and supported practically and emotionally throughout the project. An advisory group—including researchers, parent carers, experts in disability education, carer charities, and health and social care professionals—provided additional feedback and support as needed.

Recruitment

The study was promoted as research on the wellbeing of parent carers, to minimize bias created by carers self-selecting into, or out of, a study about suicide (O'Dwyer et al., 2016). Convenience sampling was used, with prospective participants recruited via schools, charities, carer support groups, hospice services, National Health Service (NHS) Trusts, social media, and word of mouth. People were eligible to participate if they: lived in England; were the parent, step-parent, foster parent, kinship carer or legal guardian for a child with a long-term illness or disability; and, the child (or, if caring for multiple children, at least one of the children) was under 18. The Equality Act 2010 considers a disability to be a physical or mental impairment that has a substantial and long-term negative effect on a person's ability to do everyday activities, with long-term considered to be 12 months or more. To encourage the recruitment of a diverse sample, no specific illnesses or disabilities were mentioned in the recruitment materials. [Note: Because there is considerable tension around the language of disability (see Andrews et al. 2019), we have used both "disabilities" and "long-term illnesses" (and their variants) throughout the research and this paper]. Recruitment was conducted between October 2021 and March 2022.

The study was approved by the West Midlands—Coventry and Warwickshire Research Ethics Committee and the NHS Health Research Authority (21/WM/0190). All participants were fully informed about the purpose of the study prior to participation (including the presence of questions about suicide) and the information specified that completion of the survey would be taken as consent. Contact information for support and crisis services was provided at the start and end of the survey, and at points where questions about suicide appeared. The survey was available for completion online and in hard copy. To encourage participation, surveys were completed anonymously. To further ensure anonymity, only truncated IP addresses were retained by the online survey, reply-paid envelopes were provided with the hard copy surveys, and no data were collected on how participants had heard about the study.

Measures

Given the absence of previous research on parent carers, the survey was designed to capture a wide range of factors that might contribute to, or protect against, suicidality in this population. The choice of measures was informed by existing theories of suicide (Durkheim, 2006; O'Connor & Kirtley, 2018; Shneidman, 1993; Van Orden et al., 2010), the risk and protective factors identified in studies of suicide risk in other groups of carers, and feedback from parent carers and the charities who support them. The survey was divided into sections on carer demographics, the caring role, physical health, emotional wellbeing, suicidal thoughts and behaviors, the experience of caring, and relationships. Fourteen validated scales were included, as well as standard measures for demographic characteristics and bespoke items related to the caring role. The complete list of items and scales is provided in Supplementary Table 1.

Where participants had more than one child with a long-term illness or disability, relevant questions in the caring role section were answered first for the oldest child and then again for each subsequent child (see Supplementary Table 1). To avoid violating independence of data assumptions, only the responses for the oldest child were included in the current analysis.

The suicidal thoughts and behaviors section included an adapted version of the Adult Psychiatric Morbidity Survey questions (McManus et al., 2016). The adaptations allowed us to: (1) distinguish between lifetime experiences and experiences while caring; (2) capture experiences in timeframes suitable for comparison with other studies of suicide risk in carers; and (3) address a lack of clarity in nomenclature that has been criticized in previous research on suicide risk in carers (O'Dwyer et al, 2021). The adapted questions are listed in Table 2. Questions on non-suicidal self-harm were also included, but not reported here.

Data Management

All data were entered into SPSS Version 28 and screened for eligibility and missing or implausible values. Cases that were ineligible or had an excess of missing data (defined as not having completed any of the suicide questions or having more than three of the validated scales completely missing) were removed. After removal of these cases, there were no implausible values and no more than 5% with missing items on the validated scales. Where scales had instructions for the management of missing data, these were followed. For the remaining scales, expectation maximization (EM) imputation was used to replace missing items, with imputed values rounded to the nearest legitimate value before the calculation of scale scores. Scores for validated scales were then calculated in accordance with the instructions for each scale. Missing data were not imputed for demographic variables, caring variables, or other bespoke items.

Analysis

Given the dearth of previous research on parent carers, and suggestions in the broader literature that existing theories of suicide may not adequately reflect the experiences of family carers (O'Dwyer et al., 2016), the analysis was not limited to testing a particular theoretical model. Instead, an exploratory, data-driven approach was taken.

Frequencies and descriptive analyses were run on all measures

For univariate and multivariable analysis, the dependent variable was "Suicidal Thoughts and Behaviors While Caring." Participants were classified as having suicidal thoughts and behaviors while caring if they: (a) answered "*Yes*" to having thought about killing themselves, having made a plan to kill themselves, or having made an attempt to kill themselves, and (b) indicated that this was either "*Only After*" or "*Both Before and After*" becoming a carer.

A series of logistic regressions were conducted to identify univariate associations between measures in each section of the survey and the dependent variable. Variables for which the confidence intervals did not include 1 were then included in a multivariable, forced entry, logistic regression.

Diagnostic tests were conducted as part of the multivariable analysis and no concerns were identified

Variables that were associated with increased odds of experiencing suicidal thoughts and behaviors in the multivariable model were considered risk factors, while variables associated with decreased odds were considered protective factors.

RESULTS

Sample Demographics

Seven hundred and eighty-seven surveys were completed. After screening for eligibility and missing data, $n = 750$ parent carers were included in the analysis. A full breakdown of participant demographics is reported in Table 1. The majority were white, heterosexual, women who were born in the UK or Ireland and identified themselves as a mother or step-mother. Participants were currently living across all regions of England, the majority were in long-term relationships, and just over half had been educated to degree level or higher. Approximately half were not in paid employment and two-thirds reported having given up work to care for their child. More than one-third were not formally registered as a carer with their general practitioner or local authority[b]. Twenty-five percent were caring for more than one child with a long-term illness or disability and 30% were caring for another family member or friend. Sixty percent had other children *without* long-term illnesses or disabilities. The age of the oldest child receiving care ranged from less than 1 year to 33 years old, with an average age of 11 years. A wide range of illnesses and disabilities were represented (see Supplementary Table 2). Most children had multiple illnesses or disabilities, with approximately one in five considered life-limiting or terminal.

Suicidality

More than half the sample (55%) had felt life was “not worth living” and half (50%) had wished they were “dead and away from it all”. The majority of those parent carers (91% of those who felt life was not worth living and 90% of those who wished they were dead) had felt this way while caring.

Just under half the sample (47%) had thought of killing themselves, with the majority of those (89%, or 41% of the total sample) experiencing suicidal thoughts while caring. One in eight parent carers (12%) had made a plan to kill themselves, with two-thirds of those (67%, or 8% of the total sample) having made a plan while caring. One in ten parent carers (10%) had attempted to kill themselves, with 25% of those (2.5% of the total sample) having made an attempt while caring.

The majority (62%) of parent carers reporting suicidal thoughts had experienced these thoughts in the last twelve months, with approximately one-third (36%) of those who reported plans having made a plan in the last twelve months. One participant reported making a suicide attempt in the two weeks before the survey, with the remainder of those who reported suicide attempts saying these had occurred more than a year

TABLE 1. Participant demographics.

Variable	M (SD) or *N* (%)
Age (years)	44.31 (7.33)
Gender	
Female	716 (95.5)
Male	26 (3.5)
Non-binary or other	6 (0.8)
Missing	2 (0.3)
Sexuality	
Heterosexual	677 (90.3)
Gay, Lesbian, Bisexual or Other	67 (8.9)
Missing	6 (0.8)
Currently in a long-term relationship	
No	170 (22.7)
Yes	578 (77.1)
Missing	2 (0.3)
Education	
GCSEs or lower[c]	165 (22)
A Levels[d]	142 (18.9)
Degree or higher	442 (58.9)
Missing	1 (0.1)
Employment	
Full-time	112 (14.9)
Part-time or casual	283 (37.7)
On leave or unemployed	353 (47.1)
Missing	2 (0.3)
Given up work to care	
No	281 (37.5)
Yes	466 (62.1)
Missing	3 (0.4)
Managing on current income[e]	
Impossible	20 (2.7)
Difficult all the time	198 (26.4)
Difficult some of the time	296 (39.5)
Not too bad	195 (26)
Easy	39 (5.2)
Missing	2 (0.3)
Regular volunteering	
No	533 (71.1)
Yes	214 (28.5)
Missing	3 (0.4)
Born in the UK or Ireland	
No	66 (8.8)
Yes	683 (91.1)
Missing	1 (0.1)
Ethnicity[e]	
White	709 (94.5)
Mixed or from multiple ethnic groups	14 (1.9)
Asian (including Indian, Pakistani, Bangladeshi, Chinese or other Asian background)	12 (1.6)
Black (including Caribbean, African, or other black background)	7 (0.9)
Gypsy, Traveler, or Roma	0
Other	4 (0.5)
Missing	4 (0.5)
Current region of England	
North East	49 (6.5)
North West	76 (10.1)
Yorkshire and The Humber	59 (7.9)
West Midlands	78 (10.4)
East Midlands	43 (5.7)
East of England	55 (7.3)
London	61 (8.1)
South East	153 (20.4)
South West	169 (22.5)
Missing	7 (0.9)

(*continued*)

TABLE 1. Continued.

Variable	M (SD) or *N* (%)
Registered as a carer with general practitioner or local authority[b]	
No or not sure	281 (37.5)
Yes	467 (62.3)
Missing	2 (0.3)
Relationship to child[a]	
Mother or step-mother	695 (92.7)
Father or step-father	22 (2.9)
Other	29 (3.9)
Missing	4 (0.5)
Age of the child requiring care[a] (Years)	11.40 (4.46)
Age at which child's illness or disability became apparent[a]	
Before birth	30 (4)
At birth	118 (15.7)
At another age	599 (79.9)
Missing	3 (0.4)
Severity of child's illness or disability[a]	
Mild or moderate	257 (34.3)
Severe	356 (47.5)
Profound	108 (14.4)
Missing	29 (3.9)
Child's illness or disability is life-limiting or terminal[a]	
No	610 (81.3)
Yes	134 (17.9)
Missing	6 (0.8)
Child has multiple illnesses or disabilities[a]	
No	174 (23.2)
Yes	570 (76)
Missing	6 (0.8)
Living situation[a]	
Living with the child all of the time	730 (97.3)
Not living with the child all of the time	18 (2.4)
Missing	2 (0.3)
Caring for more than one child with a long-term illness or disability	
No	558 (74.4)
Yes	191 (25.5)
Missing	1 (0.1)
Caring for another family member or friend with a long-term illness or disability	
No	519 (69.2)
Yes	228 (30.4)
Missing	3 (0.4)
Other children without long-term illnesses or disabilities	
No	293 (39.1)
Yes	454 (60.5)
Missing	3 (0.4)

Notes: [a]Oldest child if the participant had multiple children with disabilities or illnesses; [b]Known as local government, city council, municipality or prefecture outside the UK. [c]General Certificate of Secondary Education, typically completed by age 16. [d]Advanced Level Qualifications, typically completed by age 18 and a standard requirement for attending university in the UK. [e]Categories collapsed prior to regression analyses.

before the survey. A detailed breakdown of the frequencies for suicidality is reported in Table 2.

When responses were combined to create the dependent variable, 42% of participants ($n = 318$) were classified as having experienced suicidal thoughts and behaviors while caring. Just over half of those carers (53%) had never disclosed these thoughts or experiences to anyone.

Risk and Protective Factors

In the univariate analyses, 22 variables (spanning demographics, physical and emotional wellbeing, caring role, caring experience, and relationships) were associated with suicidal thoughts and behaviors while caring (see Supplementary Table 3). Because this did not exceed the rule of thumb that recommends no more than one predictor for every 10 cases in the smaller category in a logistic regression (in this study 22 predictors and $n = 308$ participants classified as having suicidal thoughts and behaviors while caring), all 22 variables were included in the multivariable regression.

The multivariable model was significant, $\chi^2(22) = 168.58$, $p < .001$, with an overall correct classification percentage of 79% (see Table 3). Having a mental health diagnosis prior to becoming a carer, depression, entrapment, and dysfunctional coping were significant predictors. Parent carers who had received a mental health diagnosis prior to becoming a carer were more likely to have experienced suicidal thoughts and behaviors while caring than those who had not received a diagnosis (OR = 1.56, 95% CI = 1.09, 2.24). As symptoms of depression (OR per 1 unit increase = 1.04, 95% CI = 1.02, 1.07), feelings of entrapment (OR per 1 unit increase = 1.10, 95% CI = 1.04, 1.16), and use of dysfunctional coping strategies (OR per 1 unit increase = 1.05, 95% CI = 1.01, 1.09) increased, so did the odds of having suicidal thoughts and behaviors while caring.

DISCUSSION

In this study, 42% of parent carers had experienced suicidal thoughts and behaviors while caring. Only half of those had ever disclosed, or sought help for, these experiences. One-third of the total sample reported having suicidal thoughts in the 12 months before the survey. A few carers (2.5% of the total sample) had attempted suicide while caring, including one carer in the two weeks before the survey.

This level of suicidal thinking exceeds that reported by the general UK population, where only 5% of British adults reported having suicidal thoughts in the previous year (McManus et al., 2016). It also exceeds rates reported for other groups of carers, where 16% of people caring for a family member with dementia in Australia and 18% of people caring for a family member with cancer in Korea report suicidal thoughts in the previous year (O'Dwyer et al., 2016; Park et al., 2013).

There are a few possible explanations for the high rate of suicidal thoughts in our sample. First, caring for a disabled or chronically ill child is often a long-term or even lifetime role, unlike caring for a person with cancer or dementia where the progress and treatment of the condition means the role is usually time-limited (Barrett et al., 2014; Luppa et al., 2008). There are also few (and highly stigmatised) opportunities for relinquishing the care of a disabled child, unlike the care of a person with dementia where residential options, such as care homes, are not only available but actively encouraged (at least in high-income countries) (Ellem et al., 2016; Luppa et al., 2008; Morris et al., 2002). This chronic exposure to the stress of caring may underlie the elevated rates of suicidal thinking in parent carers.

Second, the UK has experienced more than a decade of austerity which, combined with the COVID-19 pandemic, has led to the closure of some social care services, underfunding of the National Health Service (NHS), and reduced access to specialist education,

TABLE 2. Proportion of parent carers reporting suicidality.

Questions	*N*	Percent (95% CI)
Have you ever felt life was not worth living?		% of total sample
Yes	411	54.8 (51, 58)
No	338	45.1 (42, 49)
Missing	1	0.1
Was this before or after you became a carer? ($n = 411$)		% of sub-sample
Only before	35	8.5 (6, 11)
Only after	185	45 (40, 50)
Both before and after	190	46.2 (41, 51)
Missing	1	0.2
When did you last feel this way? ($n = 411$)		
In the last two weeks	119	29 (25, 33)
More than two weeks ago, but in the last twelve months	168	40.9 (36, 46)
More than a year ago	124	30.2 (26, 35)
Have you ever found yourself wishing you were dead and away from it all?		% of total sample
Yes	379	50.5 (47, 54)
No	369	49.2 (46, 53)
Missing	2	0.3
Was this before or after you became a carer? ($n = 379$)		% of sub-sample
Only before	38	10 (7, 13)
Only after	185	48.8 (44, 54)
Both before and after	155	40.9 (36, 46)
Missing	1	0.3
When did you last feel this way? ($n = 379$)		
In the last two weeks	106	28 (23, 32)
More than two weeks ago, but in the last twelve months	149	39.3 (35, 44)
More than a year ago	123	32.5 (28, 37)
Missing	1	0.3
Have you ever thought of killing yourself, even though you would not actually do it?		% of total sample
Yes	351	46.8 (43, 50)
No	397	52.9 (49, 57)
Missing	2	0.3
Did these thoughts occur before or after you became a carer? ($n = 351$)		% of sub-sample
Only before	40	11.40 (8, 15)
Only after	166	47.3 (42, 53)
Both before and after	145	41.3 (36, 46)
When did you last have these thoughts? ($n = 351$)		
In the last two weeks	86	24.5 (20, 29)
More than two weeks ago, but in the last twelve months	131	37.3 (32, 42)
More than a year ago	134	38.2 (33, 43)
Have you ever made a plan to kill yourself?		% of total sample
Yes	90	12 (10,14)
No	658	87.7 (85, 90)
Missing	2	0.3
Was this before or after you became a carer? ($n = 90$)		% of sub-sample
Only before	29	32.2 (23, 42)
Only after	27	30 (21, 39
Both before and after	33	36.7 (27, 47)
Missing	1	1.1
When did you last make a plan to kill yourself? ($n = 90$)		
In the last two weeks	12	13.3 (6, 20)
More than two weeks ago, but in the last twelve months	21	23.3 (15, 32)
More than a year ago	57	63.3 (53, 73)
Have you ever made an attempt to kill yourself, by taking an overdose of tablets or in some other way?		% of total sample
Yes	76	10.1 (8, 12)
No	670	89.3 (87, 92)
Missing	4	0.5
Was this before or after you became a carer? ($n = 76$)		% of sub-sample
Only before	56	73.7 (64, 84)
Only after	13	17.1 (9, 26)

(*continued*)

TABLE 2. Continued.

Questions	*N*	Percent (95% CI)
Both before and after	6	7.9 (2, 14)
Missing	1	1.3
When did you last attempt to kill yourself? ($n = 76$)		
In the last two weeks	1	1.3 (0, 4)
More than two weeks ago, but in the last twelve months	0	0
More than a year ago	74	97.4 (94, 100)
Missing	1	1.3

TABLE 3. Results of a multivariable logistic regression with "suicidal thoughts and behaviors while caring" as the dependent variable ($n = 728$).

Predictors	B (SE)	df	exp b	95% CI
Carer demographics				
Given up work to care				
No[a]				
Yes	0.05 (0.18)	1	1.05	0.74, 1.51
Managing on current income				
Impossible or difficult[a]				
Not too bad or easy	−0.11 (0.20)	1	0.90	0.60, 1.33
Volunteering				
No[a]				
Yes	−0.13 (0.19)	1	0.88	0.60, 1.28
Currently in long-term relationship				
No[a]				
Yes	−0.31 (0.21)	1	0.74	0.48, 1.12
Caring role				
Age of child	0.03 (0.02)	1	1.03	0.99, 1.07
Living situation				
Living with the child all the time[a]				
Not living with the child all the time	0.81 (0.59)	1	2.24	0.71, 7.05
Positive aspects of caring	−0.01 (0.01)	1	0.99	0.97, 1.01
Physical health				
Misuse of prescription or over-the-counter medication in the past year	0.09 (0.11)	1	1.10	0.89, 1.36
Physical activity	−0.01 (0.04)	1	0.99	0.91, 1.08
Emotional wellbeing				
Mental health diagnosis prior to becoming a carer				
No[a]				
Yes	0.45 (0.18)	1	1.56	**1.09, 2.24**
Current long-term physical or mental illness or disability				
No[a]				
Yes	0.16 (0.19)	1	1.17	0.82, 1.68
Depression	0.04 (0.01)	1	1.04	**1.02, 1.07**
Hopelessness	0.01 (0.02)	1	1.01	0.96, 1.05
Anxiety	−0.03 (0.02)	1	0.97	0.93, 1.02
Experience of caring				
Stigma	−0.02 (0.02)	1	0.99	0.95, 1.02
Self-efficacy	0.03 (0.07)	1	1.03	0.90, 1.17
Burnout	0.05 (0.20)	1	1.05	0.72, 1.55
Entrapment	0.10 (0.03)	1	1.10	**1.04, 1.16**
Dysfunctional coping	0.05 (0.02)	1	1.05	**1.01, 1.09**
Relationships				
Services meeting needs	0.05 (0.13)	1	1.05	0.82, 1.35
Conflict	−0.09 (0.13)	1	0.91	0.71, 1.17
Social support	−0.04 (0.02)	1	0.97	0.92, 1.01

[a] Reference category in the analysis.

The bolded CIs are the statistically significant ones.

all of which have increased the burden on parent carers (Canning & Robinson, 2021; Macdonald & Morgan, 2021). This may, in part, explain why the rate of suicidal thinking in our sample is higher than that reported in studies of carers conducted before the COVID-19 pandemic or in other countries. The context within which the research was undertaken should not, however, be used to dismiss the findings. The fact that more than 40% of parent carers have experienced suicidal thoughts and behaviors while caring (with even more, 56%, feeling life was not worth living) is a serious cause for concern and warrants urgent attention in policy and practice (which we address further below).

Although 2.5% of parent carers reported attempting suicide while caring, only one participant (0.13%) had attempted suicide in the previous year. This is lower than the general population (where 0.7% of British adults had attempted suicide in the previous year; McManus et al., 2016) and may be an artifact of the limited demographic diversity of our sample or simply that those with more recent suicide attempts were unwilling or unable to participate in the study. It may also be that factors specific to the caring role serve as a barrier to suicide attempts. In a qualitative study of people caring for family members with dementia (O'Dwyer et al., 2013), carers said the knowledge that no-one else would care for the person with dementia after their death stopped them from acting on suicidal thoughts. While this may seem positive (in so much as it prevented deaths by suicide), those carers also said this knowledge in no way alleviated the suicidal thoughts, which persisted and were a source of considerable distress (O'Dwyer et al., 2013). An inability to act on suicidal thoughts can also trigger thoughts of homicide-suicide, in which carers consider ending their own life and the life of the care recipient (Bourget et al., 2010; Karch & Nunn, 2011; Nakigudde et al., 2016; O'Dwyer et al., 2016). Unfortunately, the legal and ethical framework for the current study prohibited asking about homicide in an anonymous survey, so it is unclear if parent carers in our sample also experienced thoughts of homicide or attempted homicide-suicide. Given the large number of parent carers contemplating suicide and evidence of homicidal thoughts in other groups of carers, there is an urgent imperative for the development of research frameworks that can enable the measurement of homicidal thoughts and behaviors in future studies. The low level of missing data in the current study clearly shows that carers are willing to disclose difficult experiences if the research is carefully designed and sensitively conducted. Qualitative research—to understand why more parent carers are not acting on their suicidal thoughts or reporting more recent suicide attempts—would also be valuable.

In the multivariable model, depression, entrapment, dysfunctional coping, and a mental health diagnosis prior to becoming a parent carer, were identified as risk factors for suicidal thoughts and behaviors while caring. These are all known risk factors for suicide in the general population (Nock et al., 2008; O'Connor & Nock, 2014; O'Connor & Portzky, 2018), and depression and dysfunctional coping have also been identified as risk factors in other groups of carers (Huang et al., 2018; Joling et al., 2019; O'Dwyer et al., 2014; 2016). To our knowledge, entrapment has not been included as a variable in any of the previous quantitative studies of suicide risk in carers, but it is reflected in the qualitative literature where carers (including parent carers) have attributed their suicidal thoughts to feeling trapped or wanting a reprieve from the caring role (Lewis, 2015; Lucas et al., 2015, Nakigudde et al, 2016; O'Dwyer et al., 2013).

Depression, entrapment, and dysfunctional coping are also amenable to intervention. It is important, however, that interventions take a holistic approach. While individual approaches, such as anti-depressants or psychological therapies, can offer relief from symptoms or model healthier coping strategies (Han et al., 2021; Mikkola et al., 2021), they do not address the wider social, economic, and political circumstances that contribute to carers' feelings of depression and entrapment or force them to rely on dysfunctional coping strategies (Brimblecombe et al., 2018; Larkin & Milne, 2013). It is possible that some of the variables associated with suicidal thoughts and behaviors at the univariate level (such as services not meeting needs, stigma, difficulty managing on income, and giving up work to care) have an indirect relationship with suicidal thoughts and behaviors via their contribution to depression, entrapment, or dysfunctional coping. Addressing those factors at a more systemic level—through improved policy, better funding, or more proactive service provision for children with disabilities and their families—could offer a more sustainable means of preventing suicidal thoughts and behaviors in parent carers than medication or psychological therapies. Given the cross-sectional nature of our study, however, it was not possible to explore this. Longitudinal research is required to identify any mediating or moderating relationships between risk factors.

Studies of other groups of carers have identified volunteering (Rosato et al., 2019), remaining in paid employment (Park et al., 2013), and social support (O'Dwyer et al., 2014) as protective factors, but in the current study no variables were associated with reduced odds of suicidal thoughts and behaviors in the multivariable model. This could be an artifact of our statistical definition of a protective factor (as a main effect rather than an interaction) or simply that we did not measure the factors that are protective for parent carers. Qualitative research—examining the lived experience of parent carers and exploring how risk and protective factors manifest and interact to trigger suicidal thoughts and behaviors—could be helpful in informing the choice of measures and statistical approach in future studies.

Thirty-seven percent of parent carers in our sample reported a mental health diagnosis prior to becoming a carer and this was a risk factor for suicidal thoughts and behaviors while caring. Screening parents for preexisting mental health problems at the onset of the caring role could enable proactive provision of support, potentially preventing the caring role from exacerbating these conditions to the point of suicide risk. It is important to note, however, that not all parent carers who experience suicidal thoughts and behaviors have a history of mental health problems. In fact, in the current study, 54% of parent carers who experienced suicidal thoughts and behaviors while caring had not received a mental health diagnosis prior to becoming a carer, and 31% did not report a current long-term physical or mental illness. Some previous studies have only considered suicide risk in carers who screen positive for mental health problems (e.g., Joling et al., 2018) and, in health and social care settings, suicide risk is often only assessed in people presenting with symptoms of depression (Diamond et al., 2017; Horowitz et al., 2013). It is vital that in both future research, and frontline health and social care settings, all parent carers are assessed for suicidality.

The importance of asking all parent carers about suicidal thoughts and behaviors is also highlighted by the fact that 53% had not previously disclosed, or sought help for, these experiences. This is consistent with previous studies of carers (including parent carers) and the general population (McManus et al., 2016; O'Dwyer et al., 2016; Skeen et al., 2014). In the general population, non-disclosure has been linked to a lack of social connections and a fear of shame, rejection, or hospitalization (Fulginiti & Frey, 2019; Husky et al., 2016; Mérelle et al., 2018). It is unclear from previous research why carers are reluctant to disclose or seek help, but the same factors may apply. In the case of parent carers, the threat of safeguarding or child removal may also be pertinent (Taylor et al., 2019). Qualitative research could be helpful in further understanding why some parent carers in England have not disclosed and what (if any) support was received by those who did.

This study is the first of its kind and provides unequivocal evidence of suicidality in parent carers. It has several strengths, including: a large sample that spans every region of England and a wide range of illnesses and disabilities; a comprehensive suite of measures; low levels of missing data; and, genuine co-production. The findings should, however, be interpreted in light of some limitations. Despite considerable efforts to reach a diverse range of parent carers, the sample consists predominantly of white, well-educated mothers. Consequently, the findings may not extrapolate to fathers or parent carers from more socially or ethnically diverse groups. Eligibility was also limited to parent carers living in England and so the findings may not reflect the experiences of parent carers in other parts of the UK or internationally. Although the exploratory approach was appropriate for the state of the evidence on suicidality in parent carers, the large number of univariate analyses may have increased the Type 1 error rate. For the multivariable analysis, suicidal thoughts and behaviors were merged into one outcome variable. It is possible that the risk factors for suicide plans and suicide attempts differ from those for suicidal thoughts (Klonsky et al., 2017; May & Klonsky, 2016). Given the relatively small number of plans and attempts in our sample, however, it was not appropriate to run models with these as separate outcomes. The cross-sectional design meant it was not possible to determine any causal link between caring and suicidal thoughts, nor how rates and risk factors vary across the caregiving trajectory. Finally, the study used convenience sampling and did not include a comparison group of parents caring for children without disabilities or long-term illnesses.

Despite these limitations, the findings have immediate implications for policy and practice in England. Carers are not currently recognized as a priority group in the national mental health and suicide prevention strategies, and suicide risk is not addressed in the national carer strategy. Furthermore, although the Care Act 2014 entitles all carers in England to an assessment of their needs, Carer Assessments do not consider suicide risk and many carers have never received an assessment (Bennett, 2016). There is an urgent need for parent carers to be acknowledged as a potentially high-risk group for suicide and identified as a priority in national policy. There is also a clear need, in health and social care, for routine assessment of suicide risk in parent carers, as well as dedicated support for parent carers experiencing suicidal thoughts. More generally, there is an overwhelming need for all parent carers in England to receive better and more proactive support (House of Lords, 2022), which could help to prevent suicidal thoughts and behaviors.

Further research is also required. First, although some parents of older children were included in the sample, the majority were caring for a child aged under 18. The experience of caring for an adult child can be complicated by the parent's own aging (Seltzer et al., 2011; Song et al., 2016) and dedicated research on suicide risk in older parent carers is warranted. Second, although risk factors such as depression and entrapment align with some existing theoretical models of suicide (e.g., O'Connor & Kirtley, 2018), more work is required to understand the extent to which these theories explain suicide risk in carers. Third, longitudinal research is required to consider how suicide risk in parent carers changes across the life course of the child. Finally, although the current study provides clear evidence of suicidal thoughts and behaviors, it is unclear how many parent carers die by suicide. To our knowledge there is currently no systematically collected data on deaths by suicide in carers, information which would help to inform more targeted prevention and intervention efforts.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

REFERENCES

Andrews, E., Mona, L. R., Pilarski, C. R., Forber-Pratt, A. J., Lund, E. M., & Balter, R. (2019). #SayTheWord: A disability culture commentary on the erasure of 'disability'. *Rehabilitation Psychology*, *64*(2), 111–118. https://doi.org/10.1037/rep0000258

Barrett, P., Hale, B., & Butler, M. (2014). *Caring for a family member with a lifelong disability*. In *Family carer and social capital: Transitions in informal care* (pp. 75–90). Springer.

Bennett, L. (2016). *Care Act for carers: One year on. Carers Trust, UK*. https://carers.org/resources/all-resources/81-care-act-for-carers-one-year-on

Bourget, D., Gagne, P., & Whitehurst, L. (2010). Domestic homicide and homicide-suicide: The older offender. *Journal of the American Academy of Psychiatry and the Law*, *38*, 305–311.

Brimblecombe, N., Jose-Luis, F., Knapp, M., Rehill, A., & Wittenberg, R. (2018). Review of the international evidence on support for unpaid carers. *Journal of Long-Term Care*, *0*(0), 25–40. September, https://doi.org/10.31389/jltc.3

Canning, N., & Robinson, B. (2021). Blurring boundaries: The invasion of home as a safe space for families and children with SEND during COVID-19 lockdown in England. *European Journal of Special Needs Education*, *36*(1), 65–79. https://doi.org/10.1080/08856257.2021.1872846

Diamond, G. S., Herres, J. L., Ewing, E. S. K., Atte, T. O., Scott, S. W., Wintersteen, M. B., & Gallop, R. J. (2017). Comprehensive screening for suicide risk in primary care. *American Journal of Preventive Medicine*, *53*(1), 48–54. https://doi.org/10.1016/j.amepre.2017.02.020

Durkheim, E. (2006). *On suicide* (R. Buss, Trans.). Penguin Classics.

Ellem, K., Wilson, J., & Chenoweth, L. (2016). When families relinquish care of a child with a disability: Perceptions from birthmothers. *Australian Social Work*, *69*(1), 39–50. https://doi.org/10.1080/0312407X.2015.1015039

Fulginiti, A., & Frey, L. M. (2019). Exploring suicide-related disclosure motivation and the impact on mechanisms linked to suicide. *Death Studies*, *43*(9), 562–569. https://doi.org/10.1080/07481187.2018.1504349

Han, A., Yuen, H. K., & Jenkins, J. (2021). Acceptance and commitment therapy for family caregivers: A systematic review and meta-analysis. *Journal of Health Psychology*, *26*(1), 82–102. https://doi.org/10.1177/1359105320941217

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal of Intellectual and Developmental Disabilities*, *107*(2), 116–127.

Horowitz, L. M., Snyder, D., Ludi, E., Rosenstein, M. D., Kohn-Godbout, J., Lee, L., Cartledge, T., Farrar, A., & Pao, M. (2013). Ask suicide-screening questions to everyone in medical settings: The asQ-em quality improvement project. *Psychosomatics*, *54*(3), 239–247. https://doi.org/10.1016/j.psym.2013.01.002

House of Lords. (2022). *A gloriously ordinary life: Spotlight on social care*. Adult Social Care Committee Report, HL Paper 99. https://committees.parliament.uk/publications/31917/documents/181472/default/

Huang, Y.-C., Hsu, S.-T., Hung, C.-F., Wang, L.-J., & Chong, M.-Y. (2018). Mental health of caregivers of individuals with disabilities: Relation to suicidal ideation. *Comprehensive Psychiatry*, *81*, 22–27. https://doi.org/10.1016/j.comppsych.2017.11.003

Husky, M. M., Zablith, I., Fernandez, V. A., & Kovess-Masfety, V. (2016). Factors associated with suicidal ideation disclosure: Results from a large population-based study. *Journal of Affective Disorders*, *205*, 36–43. https://doi.org/10.1016/j.jad.2016.06.054

Joling, K. J., O'Dwyer, S. T., Hertogh, C. M. P. M., & van Hout, H. P. J. (2018). 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*, *33*(2), 263–270. https://doi.org/10.1002/gps.4708

Joling, K. J., Ten Have, M., de Graaf, R., & O'Dwyer, S. T. (2019). 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*, *19*(1), 320. https://doi.org/10.1186/s12888-019-2317-y

Karch, D., & Nunn, K. C. (2010). Characteristics of elderly and other vulnerable adult victims of homicide by a caregiver: National Violent Death Reporting System – 17 US States, 2003-2007. *Journal of Interpersonal Violence*, *26*(1), 137–157. https://doi.org/10.1177/0886260510362890

Klonsky, E. D., Qiu, T., & Saffer, B. Y. (2017). Recent advances in differentiating suicide attempters from suicide ideators. *Current Opinion in Psychiatry*, *30*(1), 15–20. https://doi.org/10.1097/YCO.0000000000000294

Larkin, M., & Milne, A. (2013). Carers and empowerment in the UK: A critical reflection. *Social Policy and Society*, *13*(1), 25–38. https://doi.org/10.1017/S1474746413000262

Lee, M. H., Park, C., Matthews, A. K., & Hsieh, K. (2017). Differences in physical health and health behaviors between family caregivers of children with and without disabilities. *Disability and Health Journal*, *10*(4), 565–570. https://doi.org/10.1016/j.dhjo.2017.03.007

Lewis, L. F. (2015). 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*, *30*(5), 488–406. https://doi.org/10.1177/1533317514559829

Lucas, M. S., Brawner, B. M., Hardie, T. L., Beacham, B., Paidipati, C., Diaz, M., Lauer, A., Hobbie, W. L., & Deatrick, J. A. (2015). Assessing suicidal ideation and behaviors among survivors of childhood brain tumors and their mothers during sociobehavioral research. *Oncology Nursing Forum*, *42*(5), E319–E329. https://doi.org/10.1188/15.ONF.42-05AP

Luppa, M., Luck, T., Brähler, E., König, H.-H., & Riedel-Heller, S. G. (2008). Prediction of institutionalisation in dementia: A systematic review. *Dementia and Geriatric Cognitive Disorders*, *26*(1), 65–78. https://doi.org/10.1159/000144027

Macdonald, K., & Morgan, H. M. (2021). The impact of austerity on disabled, elderly and immigrants in the United Kingdom: A literature review. *Disability & Society*, *36*(7), 1125–1147. https://doi.org/10.1080/09687599.2020.1779036

May, A. M., & Klonsky, E. D. (2016). What distinguishes suicide attempters from suicide ideators? A meta-analysis of potential factors. *Clinical Psychology: Science and Practice*, *23*(1), 5–20. https://doi.org/10.1111/cpsp.12136

McManus, S., Hassiotis, A., Jenkins, R., Dennis, M., Anzar, C., Appleby, L. (2016). Chapter 12: Suicidal thoughts, suicide attempts, and self-harm. In S. McManus, P. Bebbington, R. Jenkins & T. Brugha (Eds.), *Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014*. NHS Digital. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/556596/apms-2014-full-rpt.pdf

Mérelle, S., Foppen, E., Gilissen, R., Mokkenstorm, J., Cluitmans, R., & Van Ballegooijen, W. (2018). Characteristics associated with non-disclosure of suicidal ideation in adults. *International Journal of Environmental Research and Public Health*, *15*(5), 943. https://doi.org/10.3390/ijerph15050943

Mikkola, T. M., Kautiainen, H., Mänty, M., von Bonsdorff, M. B., Koponen, H., Kröger, T., & Eriksson, J. G. (2021). Use of antidepressants among Finnish family caregivers: A nationwide register-based study. *Social Psychiatry and Psychiatric Epidemiology*, *56*(12), 2209–2216. https://doi.org/10.1007/s00127-021-02049-1

Morris, J., Abbott, D., & Ward, L. (2002). Residential school placements and disabled children: The contrasting views of local education authorities and of parents. *Journal of Research in Special Educational Needs*, *2*(1). https://doi.org/10.1111/j.1471-3802.2002.00158.x

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development*, *33*(2), 180–187. https://doi.org/10.1111/j.1365-2214.2006.00644.x

Nakigudde, J., Mutamba, B. B., Bazeyo, W., Musisi, S., & James, O. (2016). An exploration of caregiver burden for children with nodding syndrome (lucluc) in Northern Uganda. *BMC Psychiatry*, *16*(1), 255. https://doi.org/10.1186/s12888-016-0955-x

Nock, M. K., Borges, G., Bromet, E. J., Alonso, J., Angermeyer, M., Beautrais, A., Bruffaerts, R., Chiu, W. T., de Girolamo, G., Gluzman, S., de Graaf, R., Gureje, O., Haro, J. M., Huang, Y., Karam, E., Kessler, R. C., Lepine, J. P., Levinson, D., Medina-Mora, M. E., … Williams, D. (2008). Cross-national prevalence and risk factors for suicidal ideation, plans and attempts. *The British Journal of Psychiatry: The Journal of Mental Science*, *192*(2), 98–105. https://doi.org/10.1192/bjp.bp.107.040113

O'Connor, R. C., & Kirtley, O. J. (2018). The integrated motivational-volitional model of suicidal behaviour. *Philosophical Transactions of the Royal Society of London. Series B, Biological Sciences*, *373*(1754), 20170268. https://doi.org/10.1098/rstb.2017.0268

O'Connor, R. C., & Nock, M. K. (2014). The psychology of suicidal behaviour. *The Lancet. Psychiatry*, *1*(1), 73–85. https://doi.org/10.1016/S2215-0366(14)70222-6

O'Connor, R. C., & Portzky, G. (2018). The relationship between entrapment and suicidal behavior through the lens of the integrated motivational-volitional model of suicidal behavior. *Current Opinion in Psychology*, *22*, 12–17. https://doi.org/10.1016/j.copsyc.2017.07.021

O'Dwyer, S. T., Janssens, A., Sansom, A., Biddle, L., Mars, B., Slater, T., Moran, P., Stallard, P., Melluish, J., Reakes, L., Walker, A., Andrewartha, C., & Hastings, R. P. (2021). Suicidality in family caregivers of people with long-term illness and disabilities: A scoping review. *Comprehensive Psychiatry*, *110*, 152261. https://doi.org/10.1016/j.comppsych.2021.152261

O'Dwyer, S. T., Moyle, W., Taylor, T., Creese, J., & Zimmer-Gembeck, M. J. (2016). Homicidal ideation in family carers of people with dementia. *Aging & Mental Health*, *20*(11), 1174–1181. https://doi.org/10.1080/13607863.2015.1065793

O'Dwyer, S. T., Moyle, W., Pachana, N. A., Sung, B., & Barrett, S. (2014). Feeling that life is not worth living (death thoughts) among middle-aged, Australian women providing unpaid care. *Maturitas*, *77*(4), 375–379. https://doi.org/10.1016/j.maturitas.2014.01.013

O'Dwyer, S., Moyle, W., & van Wyk, S. (2013). Suicidal ideation and resilience in family carers of people with dementia: A pilot qualitative study. *Aging & Mental Health*, *17*(6), 753–760. https://doi.org/10.1080/13607863.2013.789001

O'Dwyer, S. T., Moyle, W., Zimmer-Gembeck, M., & De Leo, D. (2016). Suicidal ideation in family carers of people with dementia. *Aging & Mental Health*, *20*(2), 222–230. https://doi.org/10.1080/13607863.2015.1063109

Park, B., Kim, S. Y., Shin, J.-Y., Sanson-Fisher, R. W., Shin, D. W., Cho, J., & Park, J. H. (2013). Suicidal ideation and suicide attempts in anxious or depression family caregivers of patients with cancer: A nationwide survey in Korea. *PloS One*, *8*(4), e60230. https://doi.org/10.1371/journal.pone.0060230

Rosato, M., Tseliou, F., Wright, D. M., Maguire, A., & O'Reilly, D. (2019). Are volunteering and caregiving associated with suicide risk? A census-based longitudinal study. *BMC Psychiatry*, *19*(1), 296. https://doi.org/10.1186/s12888-019-2255-8

Seltzer, M. M., Floyd, F., Song, J., Greenberg, J., & Hong, J. (2011). Midlife and aging parents of adults with intellectual and development disabilities: Impact of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities*, *116*(6), 479–499. https://doi.org/10.1352/1944-7558-116.6.479

Shneidman, E. S. (1993). Suicide as psychache. *The Journal of Nervous and Mental Disease*, *181*(3), 145–147. https://doi.org/10.1097/00005053-199303000-00001

Skeen, S., Tomlinson, M., Macedo, A., Croome, N., & Sherr, L. (2014). Mental health of carers of children affected by HIV attending community-based programmes in South Africa and Malawi. *AIDS Care*, *26* (1), S11–S20. https://doi.org/10.1080/09540121.2014.906559

Song, J., Mailick, M. R., Greenberg, J. S., Ryff, C. D., & Lachman, M. E. (2016). Cognitive aging in parents of children with disabilities. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *71*(5), 821–830. https://doi.org/10.1093/geronb/gbv015

Staley, K., Cockcroft, E., Shelly, A., & Liabo, K. (2019). 'What can I do that will most help researchers?' A different approach to training the public at the start of their involvement in research. *Research Involvement and Engagement*, *5*(1), 10. https://doi.org/10.1186/s40900-019-0144-4

Taylor, B. L., Mosse, L., & Stanley, N. (2019). Experiences of social work intervention among mothers with perinatal mental health needs. *Health & Social Care in the Community*, *27*(6), 1586–1596. https://doi.org/10.1111/hsc.12832

Van Orden, K. A., Witte, T. K., Cukrowicz, K. C., Braithwaite, S., Selby, E. A., & Joiner, T. E. (2010). The interpersonal theory of suicide. *Psychological Review*, *117*(2), 575–600. https://doi.org/10.1037/a0018697

UK Government. (2018). *Family resources survey: Financial year 2016/2017*. https://www.gov.uk/government/statistics/family-resources-survey-financial-year-201617