## REVIEW





# Experiences and needs of adult informal carers of adults at risk of suicide: A systematic review with mixed methods analysis

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## Abstract

Aim: To systematically review and synthesize primary research on experiences and needs of adult informal caregivers of adults at risk of suicide.

**Design:** Systematic review with a data-based convergent synthesis.

Data Sources: MEDLINE, PsychINFO and CINAHL were searched in April 2022 and February 2023. English language research focusing on experiences of adult carers of adults was included.

Methods: Articles were screened by title (n=9077) and abstract (n=132) with additional articles (n=6) obtained via citation and hand searching. Thirty-one included studies were quality assessed using the Mixed Methods Appraisal Tool and study data were systematically extracted prior to thematic synthesis.

Results: Five interconnected themes resulted: transitions; living with fear and uncertainty; changing relationships; interface with healthcare professionals and services; what carers need and want. Caring impacts mental, physical and social wellbeing. Relationships are affected in ways which might not be evident when caring for a minor. Repeated suicidal behaviour is particularly challenging with ongoing hypervigilance contributing to burden, burnout and interpersonal strain. Poor carer support exacerbates negative effects; carers need to feel informed, educated, involved and holistically supported.

Conclusion: Timely support for carers is essential. Interventions should address emotional responses, relational changes and effective care recipient support. Longitudinal research is required to understand effects of ongoing caring where there are multiple suicide attempts.

Implications: Nurses can provide carers with early support and information and longer term psychosocial interventions. If carers are adequately equipped and supported patient safety and wellbeing will be improved.

Impact: Findings of this systematic review include relational changes due to carer hypervigilance reducing autonomy and living with the possibility of suicide. Clinician awareness of the potential for relational shifts will help them prepare and support carers.

Patient or Public Contribution: There was no patient or public contribution.

## KEYWORDS

caregiving, carers, mental health, suicide risk

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## INTRODUCTION

Worldwide, suicide accounts for over 800,000 deaths each year, with 20 suicide attempts for every completed suicide (World Health Organization, 2014). Still more people experience suicide ideation (House et al., 2020) and a proportion of these will engage in suicidal behaviour, such as planning and rehearsing, with some coming very close to acting on their thoughts. Determining who is at risk of suicide, however, is complex. Whilst there is a plethora of evidence on suicide risk factors, such as mental illness, previous self-harm, childhood adversity and unemployment, it is virtually impossible to predict who will or will not die by suicide (Hawton et al., 2022). Most people who think about suicide do not end their lives, some because of an absence or cessation of intent and others due to preventative intervention and care. Therefore, there are many more people who could be considered at risk of suicide than will actually attempt or complete the act.

A proportion of those who die by suicide are in touch with mental health services at the time of their death and many have contact with primary or secondary health care in the year prior to their death (Knipe et al., 2022). These services are often heavily reliant on informal carers (family members, partners, friends) to support vulnerable individuals at home, including when they are actively struggling with suicidal thoughts and behaviours (Grant et al., 2015). Many people will be supporting someone at risk of suicide without any professional support. It has been estimated that in the UK there are over a million informal carers supporting a person with a mental health condition (Rethink, 2021), but globally there is no posited figure.

Recognition of this informal caregiver population in policy and strategy is inadequate. The World Health Organization advocates carer involvement in mental health care design and delivery, but their suicide prevention emphasis is on people who attempt or are bereaved by suicide, with carers receiving minimal attention (World Health Organization, 2014). The UK Suicide Prevention Strategy for England (Department of Health and Social Care, 2023) has a key objective pertaining to people bereaved by suicide and includes mention of attending to carers of those at risk, which is positive. However, support needs of carers are not prioritised in the strategy or linked to any specific action. Some tailored interventions for families and carers of people at risk of suicide exist, but they primarily target carers of adolescents, with interventions for adult carers of adults being few (Krysinska et al., 2021). Various non statutory support agencies provide information for family and friends but, with some exceptions, this is largely focused on what they can do to support the suicidal individual rather than support for carers themselves (Maple et al., 2021), despite the fact that research suggests considerable trauma and stress to carers (Buus et al., 2014).

Nurses encounter informal caregivers supporting adults at risk of suicide in mental health, primary and acute care (Clua-García et al., 2021; Ling, 2020). These contacts are an opportunity to engage carers and provide or direct them to supportive interventions (Vatne et al., 2021). To achieve this, it is important to understand

caregivers' experiences and establish what exactly their needs are in order to inform practice and influence policy and strategy.

Previous systematic reviews of research in this area have been undertaken (Juel et al., 2021; Lavers et al., 2022). However, because almost half of the studies in the Juel et al. (2021) systematic review and nearly a third in that by Lavers et al. (2022) involved participants who predominantly or exclusively cared for under 18 year olds, issues especially salient for adults caring for adults may not have been elucidated. Furthermore, despite the relative recency of both reviews, the mounting interest in this field has resulted in publication of new studies. The current systematic review provides a contemporaneous understanding of the experiences of adult caregivers of adults at risk of suicide to inform and advance future research, policy and interventions.

### 1.1 Aim

The aim of this systematic review was to understand what is known about the experiences and needs of adults who care for another adult they consider to be at risk of suicide.

## **METHODS**

## Design

A data-based convergent synthesis design (Hong et al., 2017) was adopted. This involves data transformation and combined analysis of quantitative and qualitative data using a single approach. Thematic synthesis (Thomas & Harden, 2008) was used for data transformation of the relevant textual quantitative data (numerical results of quantitative studies are not included in the analysis) and for analysis and synthesis of transformed quantitative data and qualitative data. Thematic synthesis involves both the aggregation of descriptive themes and the development of analytical themes within a framework that encompasses three stages to synthesis: line by line coding of individual study findings; organizing codes into descriptive themes; and developing analytical themes.

This systematic review is adherent to relevant EQUATOR guidance and PRISMA reporting (Page et al., 2021). It is not registered on Prospero.

### Search strategy 2.2

Search terms were established using the PICo (population, phenomenon of interest, context) framework (Lockwood et al., 2015), with the assistance of a specialist health librarian. Main key words were 'informal caregivers', 'experience' and 'suicide'. Because the focus is on risk of suicide, self-harm was not included as a key word because it would have highlighted studies including non-suicidal self-harm. Search terms are shown in Table 1.



TABLE 1 Search terms and inclusion/exclusion criteria.

TABLE I Search	erms and inclusion/exci	usion criteria.
Population: Adult carers of adults at risk of suicide	Phenomenon of interest	Context
"Informal caregiver*(s)"	Experience* (s)	Suicid* (suicide, suicidality, suicided, suicidal, suicide attempt, suicidal behaviour)
"Informal carer*(s)"	Feeling* (s)	
"Significant other* (s)"	Perspective* (s)	
Famil*	View* (s)	
"Next of kin"	Support	
Relative*(s)	Need* (s)	
Partner* (s)		
Spouse		
Wife		
Husband		
Daughter*		
Son*		
Parent*		
Mother		
Father		

## **Boolean operators**

("informal caregiver" OR "informal carer" OR "significant other" OR famil\* OR "next of kin" OR relative\* OR partner\* OR spouse OR wife OR husband OR daughter\* OR son\* OR parent\* Or mother OR father) AND (feeling\* OR perspective\* OR view\* OR support OR need\*) AND suicid\* NOT (assisted suicide or euthanasia or right to die or death with dignity) NOT (children or adolescents or youth or child) NOT suicide bereavement

## Inclusion and exclusion criteria

Inclusion criteria: Peer reviewed empirical qualitative, quantitative or mixed methods studies that included a focus on the experiences and needs of adult informal caregivers of adults at risk of suicide. Reports from the same research study were included if they reported new or additional findings.

Exclusion criteria: Non empirical papers, literature reviews and grey literature, research exclusively studying paid carers, young carers, carers of children and adolescents, and people bereaved by suicide. Studies investigating experiences around euthanasia or assisted dying.

## 2.3 | Information sources

The data bases MEDLINE, PsychINFO and CINAHL were searched on 19 April 2022 with a repeat search on 28 February 2023 to identify any relevant new articles (none were identified). Database limits were English language, adult (age 18 years and over) and date of publication from 1990 onwards. Citation and hand searching were carried out to retrieve additional studies.

## 2.4 | Eligibility criteria

Inclusion and exclusion criteria are listed in Table 1. Where studies involved adult carers of mixed age groups or populations (i.e. children/adolescents and adults; carers and people bereaved), they were excluded if it was clear that over half of care recipients were under the age of 18 years or over half of participants were bereaved. In the few cases where ages of care recipients were not reported, the study team discussed the likelihood of half or more being adult based on the relationships with the caregiver participant (e.g. if the carer was an adult partner or friend it was assumed the carer recipient would also be adult).

Studies were identified, screened and selected or otherwise by the first author. Selection decisions were reviewed with the other authors and disagreements resolved through discussion. Citations of papers that were excluded after full assessment for eligibility are provided in the Supplementary file \$1.

## 2.5 | Quality appraisal

The Mixed Methods Appraisal Tool MMAT (Hong et al., 2018) was used to assess the quality of included studies. The MMAT consists of tools to assess quantitative, qualitative and mixed methods studies, including quantitative non-randomized and descriptive studies. The current version has resulted from comprehensive testing and evaluation of previous versions (Pace et al., 2012; Souto et al., 2015). As most of the quantitative studies in this review were descriptive, the MMAT was considered to be an appropriate tool. Scoring of quality appraisal is not supported by MMAT and responses to appraisal questions are 'yes/not clear/no', with descriptions to defend decisions. In this review, 'not clear' was also used to denote 'somewhat'. Quality appraisal was conducted to determine strengths and weaknesses of studies rather than for exclusion purposes. Assessment was carried out by the first author and discussed with the other authors to achieve consensus.

## 2.6 | Extraction of data items

Data relevant to the review question were extracted in line with Aveyard et al. (2021) guidance to develop data extraction tables unique to individual reviews. Data extracted included study characteristics of location, research aim and design, sample size, basic demographics, relationship of caregivers to care recipients, validated measures used, and key themes and results (see Tables 2 and 3). Data not relevant to the review question were not extracted, for example, where studies investigated both carer and care recipient experiences, only data specific to carers were included.

## 2.7 | Data synthesis

Line by line coding was carried out in relevant sections of all selected papers to develop descriptive themes as the first phase of

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		_ u_	Leading Global Naming Research
	Summary of findings related to carers	70% of sample exhibited depressive symptoms with 30% severe symptoms Anxiety symptoms present in 30% of sample Resilience reduced in 40% sample. Scores indicated helplessness and a decrease in the ability to influence one's life. Emotional distress negatively associated with use of coping strategies for positive redefinition and personal growth.  Depressive symptoms lowest in relatives of individuals with a single suicide attempt.  Lowest involvement and resilience with relatives of individuals with multiple attempts Avoidance used as a strategy with relatives of people with repeated behaviours	73.9% of sample who answered relevant question reported being treated with respect, 57.1% felt listened to, 53.8% were given information about treatments, 28.8% felt punished or stigmatized, 28.6% felt injury was not taken seriously by ED staff 31.4% of sample who answered relevant question were not seen in a timely fashion, 28.9% did not feel cultural considerations were addressed, 14.5% thought staff used jargon, 37.6% reported that ED staff did not want to communicate with them about the patient. Positive experiences related to good experiences with staff and being provided with information Negative experiences included perceived unprofessional behaviour by staff, perceiving that suicide attempt was not taken seriously, feeling that waiting time was too long, a need for better communication of discharge plans or instructions
Caregiver relationship to care	recipient	Carers Parent = 20 (77.0%) Spouse = 6 (23.0%) Bereaved Parent = 8 (57.1%) Spouse = 4 (28.6%) Daughter = 2 (14.3%)	Included parents, partners, friends and 'other'
Demographics: Carers (age/sex/	ethnicity) care recipients (age)	Carers (n = 26) 19 female (73.0%) 7 male (27.0%) Mean age 44 years (range 28-60 years) Bereaved (n = 14) Mean age 40 years (range 18-50 years) 14 female (100%) Ethnicity not reported Care recipients (n = 26) Mean age 25 (range 16-51 years) Decedents (n = 14) Mean age 35 years (range 18-50 years)	*Demographic information not available for all participants.  Carers 156 female (61.4%) 32 male (12.6%) 66 not known (26.0%) Age (years) 25-34=21 (8.3%) 35-44=40 (15.7%) 45-54=71 (28%) 55+=46 (18.1%) Not known = 187 (26.4%) Ethnicity—173 White non Hispanic (68.1%) 12 hispanic, black or 'other' 12 (4.7%) 69 not known (27.2%) Care recipients All over 18 years
Sample size (only including	carers or bereaved participants)	pa	N=254 carers
Characteristics of included quantitative studies.	Research aim and design	N=40  To study the psychological consequences 26 carers of suicidal behaviour for relatives of 14 bereav the suicidal person, as well as factors affecting the severity of depressive and anxiety symptoms.  Design Pilot cross sectional study Validated measures Adapted Beck depression and anxiety scales Adapted COPE questionnaire Adapted resilience test Adapted Family Environment scale	Aim  To explore the experiences of psychiatric consumers and family members in the ED following a suicide attempt Design Online survey 49 questions One open ended question Validated measures None used
TABLE 2 Characteristics	Author/year/location	Borisonik and Kholmogorova (2018) Russia	Cerel et al. (2006) USA

Author/year/location	Research aim and design	Sample size (only including carers or bereaved participants)	Demographics: Carers (age/sex/ethnicity) care recipients (age)	Caregiver relationship to care recipient	Summary of findings related to carers
Chiang et al. (2015) Taiwan	Aim  To examine the relationship between caring stress, suicidal attitude and suicide care ability among family carers of suicidal individuals  Design  Cross sectional correlational study with path analysis techniques.  Validated measures  Caring Stress Scale  Suicidal Caring Ability Scale	164 carers	Carers  101 female (61.6%) 63 male (38.4%) Mean age 43.92 years (5D 13.84) Ethnicity not reported Care recipients Not reported, author gave confirmation that at least half were 18 years or over	59 parent (36.0%) 33 spouse (20.1%) 28 child (17.0%) 44 other (26.9%)	Caring Stress Scale mean score 80.73 (SD 16.11) indicating mild level.  Suicidal Attitudes Scale mean score 75.21 (SD 7.20) indicating relatively positive attitude.  Suicidal Caring Ability Scale mean score 104.79 (SD 13.31) indicating high score in suicidal caring ability.  Older caregivers had less positive attitudes. Female caregivers had a higher level of stress.  Caring stress had direct effect on suicidal attitude (b=0.27, p=.01) indicating higher caring stress was associated with a more positive attitude towards suicidal individuals.  Caring stress did not have a significant effect on suicide care ability (b=0.15, p=.11).  Higher holistic caring burden associated with less care ability.  Association between suicidal attitude and care ability was significant (r=.65, p<.01) indicating that positive attitudes were associated with better care ability.
Chessick et al. (2007) USA	Aim  To examine whether caregivers of bipolar patients reporting current suicidal ideation (SI) and/or a history of a suicide attempt (SA) reported higher levels of burden and/or poorer health compared to caregivers of patients without these suicidality indices  Design  Cross sectional design—validated questionnaires. Part of a larger RCT. Validated measures  The Social Behaviour Assessment Scale (SBAS)  Centre for Epidemiological Studies of Depression Scale (CES-D) The General Health Scale from the Medical Outcomes Survey (MOS)  36-item Short-Form Health Survey	500 carers	Carers 345 females (65.3%) 155 males 34.7% Mean age 50.2 years (5D 13.1) 439 Caucasian (87.8%) Black, Hispanic, Asian or other 12.2% Care recipients Mean age 39.9 years (5D 13.5)	Parent 188 (37.6%) Spouse 182 (36.4%) Child 22 (4.4%) Sibling 28 (5.6%) Other 80 (16%)	Significant main effects of positive current SI (F = 4.64, df = 1, p = .03) and positive SA history (F = 7.16, df = 1, 456, p < .01) on caregiver self-reported general health, that is, relatives of patients with current SI and those of patients with lifetime history of SA reported lower general health status. No interactions between SI and SA history were found in predicting caregiver general health status, depression or burden.  Parents of patients with positive lifetime SA history had more burden on the role dysfunction scale than spouses of patients with a negative SA history reported more burden on the role dysfunction scale than parents of patients with negative SA history reported more burden on the role dysfunction scale than parents of patients with negative Elifetime SA.  Parents reported higher levels of depressive symptoms than spouses if patient had lifetime SA and current SI. Spouses reported higher levels of depression than parents if patient had negative lifetime SA but current SI.

Caregivers reported lower caregiving demand when veteran had high perceived burdensomenesss

> Black/African American 19 (44.0%) Native American, multi-racial or

65+=4(9.0%)

planning between Veterans and their

Part of a RCT studying joint safety

White 7 (16.0%)

All over 18 years

Problem solving module of the Family

Validated measures

Caregiver Burden Inventory (CBI) Assessment Device (FAD)

reporting greater family problem

Included Hypothesis 1B-caregivers

caregivers.

solving will report lower burden.

other (39%) Care recipients

Veteran social coping was associated with higher associated with caregiver negative feelings fewer negative feelings towards Veterans Relationships with lower mutual coping were

towards veterans

Close non family supports 12 Family members 15 (35.0%)

(28%)

18-34=12 (28.0%) 45-64=20 (47.0%)35-44=7 (16.0%)

28 female (65.0%)

15 male (35.0%)

interpersonal perceptions related to

To examine the association between

USA

suicide and social coping efforts.

Age (years)

time demands on caregiver

Author/year/location	Research aim and design	Sample size (only including carers or bereaved participants)	e size (only including Demographics: Carers (age/sex/orbereaved participants) ethnicity) care recipients (age)	Caregiver relationship to care recipient	Summary of findings related to carers
Chessick et al. (2009) USA	Aim To evaluate whether caregivers' health and depression varied over time in relation to changes in patients' suicide ideation (SI) and depressive symptoms  Design Longitudinal naturalistic observational study  Validated measures Centre for Epidemiological Studies of Depression Scale (CES-D) The General Health Scale from the Medical Outcomes Survey (MOS)  36-item Short-Form Health Survey	500 carers	As above—same sample	As above	Caregivers general health status was poorer when the care recipient had higher SI at baseline, 6 and 12 months compared to those caring for people with lower SI at each time point [F(1,764)= 5.28, p=.02] even after controlling for patient history of SA, education and patient global functioning. This was evident among parent and spousal caregivers.  Caregivers of patients whose SI increased from baseline at 6 and/or 12 months also reported poorer health at 6 and 12 months compared to those caring for patients with ho increase in SI.  Caregiver self-reported health was consistently correlated with patients SI over time.  Patient depression scores were not related to caregiver health. SI contributed to caregiver health status, but depression did not.  Patients with higher baseline, 6 and 12 month SI were associated with higher depression scores in caregivers [F(1,722)=4.91, p=.03]  Increase in patients SI from baseline was not significantly associated with caregiver CES-D depression scores at 6 and 12 months [F(1,301)=1.35, p=.25]
Crasta et al. (2021)	Aim	43 carers	Carers	Partner 16 (37.0%)	Caregivers who reported social coping experienced

health status in both measures used—SF-6D (0.57 vs

(difference=3.0). CAUD-SI had significantly poorer

0.60, p > .01) and EQ-5D-5L (0.58 vs 0.66, p < .001).

marginal mean differences between groups included

pain (difference=2.4), physical role functioning

physical component score (42.7 vs 45.0, p < .001).

Specific domains with statistically significant physical functioning (difference = 3.5), bodily (difference=3.0), emotional role functioning (difference=4.0), and social role functioning

Component Score (37.5 vs 38.9, p = .007) and

CAUD-SI had lower adjusted means for Mental

Adjusted comparison of outcomes for CAUD-SI & CAUD

(0.83 vs 0.32, p < .001).

visits (1.45 vs 0.59, p < 0.001) and hospitalization

productivity loss (54.7 vs 39.6, p < .001), and activity

impairment (49.0 vs 39.5, p < .001).

presenteeism (48.4 vs 34.7, p < .001), overall work

(12.3% vs 8.5%, p = .021), although no difference traditional provider visits (7.9 vs 6.5, p = .005), ER

for visit to psychiatrist. CAUD-SI had higher

a psychologist or therapist in the last 6 months A higher percentage of CAUD-SI reported visits to

# TABLE 2 (Continued)

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	Summary of findings related to carers	Carers of people with unipolar depression and SI (CAUD-SI) respondents reported higher mental health burden than carers of people with unipolar depression and no SI (CAUD) in terms of self-reported medical diagnosis of depression (47.8% vs 37.5%, overall distribution p < .001) and sleep problems (14.8% vs 10.9%, overall distribution p < .05). PHQ-9 scores indicated significant difference between groups (p < .001) with more CAUD-SI reporting moderate, moderately severe and severe depression Unadjusted comparison of outcome for CAUD-SI & CAUD—CAUD-SI reported significantly lower scores for physical functioning (44.9 vs 48.7, p < .001), physical role functioning (40.4 vs 43.7, p < .001), physical role functioning (38.1 vs 41.5, p < .001), and social role functioning (38.1 vs 41.5, p < .001), and social role functioning (38.1 vs 41.5, p < .001), and social role functioning (38.1 vs 41.5, p < .001) and lower PCS (46.2 vs 48.5, p < .001) and Mental Component Scale (38.4 vs 40.3, p < .001) ascores.  CAUS-SI reported lower EQ-5D-5L measured health status (0.63 vs 0.73, p < .001).
	Caregiver relationship to care recipient	Not reported
	Demographics: Carers (age/sex/ethnicity) care recipients (age)	Carers CAUD-SI Female 298 (53.8%) Male 256 (46.2%) Mean age 40.7 years (5D 15.2) Ethnicity not reported CAUD Female 487 (58.2%) Male 350 (41.8%) Mean age 43.5 (5D 15.2) Ethnicity not reported Care recipients All over 18 years
	Sample size (only including Demographics: Carers (age/se) carers or bereaved participants) ethnicity) care recipients (age)	554 carers depression and suicide ideation (CAUD-SI) F 837 carers dep only (CAUD)
	Research aim and design	Aim  To assess the additional humanistic and economic burden experienced by persons caring for patients with depression and suicidal ideation in five major European countries  Design  Retrospective observational study Validated measures used Demographic Health characteristics—self reported BMI, exercise, alcohol consumption, smoking status. Charlson Cormobidity Index (CCI) Patient Health Questionnaire (PHQ-9) Medical Outcomes Study 12-Item Short-Form Health Survey version 2 (SF-12v2) Mental Component Summary (MCS) Physical Component Summary (PCS) Short-Form 6 Dimension (SF-6D) derived from SFv2 (prior 4 weeks) EuroQol 5-Dimension 5-Level version Eq.55D-5L
ABEE 2 (Collellaeu)	Author/year/location	Jaffe et al. (2021) Europe

care and support from services (74% vs 42%; chi-squared = 9.087, df = 1, p = 0.0003)

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TABLE 2 (Continued)

Author/year/location	Research aim and design	Sample size (only including carers or bereaved participants)	Demographics: Carers (age/sex/ethnicity) care recipients (age)	Caregiver relationship to care recipient	Summary of findings related to carers
Katz et al. (2015) USA	Aim  To examine the relationship between the perception of risk of harm and family distress, burden, empowerment, coping, physical and mental health, appraisal of the caregiving experience, family communication and family functioning  Design  Secondary analysis of baseline data from RCT of the family to family peer driven education programme  Validated measures  FEIS worry and displeasure scale Family Empowerment Scale (FES)  Coping Inventory (COPE)  Brief Symptom Inventory (BSI-18)  Centre for Epidemiological Studies  Depression Scale (CES-D)  SF-12 measure of health Family Assessment Device (FAD) Family problem Solving Communication (FPSC)  Experience of Caregiving Inventory (ECI)	434 carers in total 104 (24.0%) noted perceived risk of harm. 28 (26.7% of carers noting perceived risk of harm and 6.5% of total sample) reported risk of harm to self (5H) only and the same number Reported risk of SH and harm to others In total 56 carers of pts at risk of harm to self (5H)	N = 56 carers  14 male (25%)  Other genders not reported  Mean age harm to self carers  49.8 years (5D 9.5)  Mean age harm to self and harm to others carers age 50.2 years (5D 6.7)  Ethnicity—40 (71.42%) white  Care recipients  Mean age 30.8 years (5D 15.1)	Not reported	Participants who perceived risk of harm were more likely to report that their ill family member had a hospitalization for mental health reasons in the previous 6 months and had a greater number of hospitalisations in the previous 6 months than those without a perceived recent risk of harm. Subjective burden was significantly greater in the harm to self and others (BOTH) and harm to others (OTHERS) groups compared with the no perceived recent risk of harm group (NONE) as measured by the FEIS worry and displeasure scales. All perceived recent risk of harm groups (harm to SELF, OTHERS and BOTH) reported greater objective burden compared with the NONE group as measured by the FEIS daily living assistance and supervision subscales Psychological distress was greater in all perceived risk of harm groups (OTHERS, SELF and BOTH) compared with the NONE group as measured by the CESD, the BSI, and the SF12 mental health scale. No differences were observed across groups in physical health.  OTHERS, SELF and BOTH groups had more overall negative appraisal of the caregiving experience compared with the NONE group  Participants in the SELF group thought more often about the good aspects of their relationship with the ill relative compared with participants in the NONE group.
Kjellin and Östman (2005) Sweden	Aim  To investigate family burden and relatives participation in care in relation to (1) physical violence towards others by psychiatric before	155 carers 27 (17.4%) carers of patients who had attempted suicide prior to admission according to patient notes	Carers 79 female (51%) Other genders not reported 48% aged 40–49 years Ethnicity not reported	Spouses 29% Parents 27% Siblings or other relatives 27% Children 12% Close friends 5%	Of all carers of patients who had exhibited harm to self and/or harm to others (N=155): 28% reported they had to give up leisure time 16% reported they had to give up work 33% reported they were prevented from having

Of all carers of patients who had exhibited harm to	self and/or harm to others ( $N=155$ ):	28% reported they had to give up leisure time	16% reported they had to give up work	33% reported they were prevented from having	their own company	31% feared patient might attempt suicide	39% experienced mental health problems	25% reported negative effects on relationship with	patient	Relatives of patients with suicide attempts more often	stated they were prevented from having own	company (52% vs 29%; chi-squared = $5.317$ , df = $1$ ,	- T
		elatives 27%											

Mean age 43 years (SD 13)

been physically violent prior

patient notes

structured interviews (95 questions)

Validated measures None used

researcher administered semi Cross sectional study involving

Care recipients

2 (1.3%) carers of patients who had attempted suicide and to admission according to

attempts of psychiatric patients

before admission

Design

or at admission, and (2) suicide

53% expressed a desire for counselling together

with patient

37% desires individual counselling themselves 73% reported they had someone else to turn to when difficulties occurred

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Author/year/location	Research aim and design	Sample size (only including Demographics: Carers (age/se, carers or bereaved participants) ethnicity) care recipients (age)	Demographics: Carers (age/sex/ ethnicity) care recipients (age)	Caregiver relationship to care recipient	Summary of findings related to carers
Australia	Aim  To explore experiences of carers of a person diagnosed with BPD (including questions on suicide/self-harm from perspectives of carer)  Design  Cross sectional study—online survey involving 60 multiple choice, 15 open ended and 9 Likert rated questions  Validated measures  None used	121 carers 64 with experience of patient suicidal behaviour	Carers 78/102 female (76.5%) 24/102 male (25.5%) Age (years) <18=1/119 (0.84%) 18-64=110/119 (92.46%) 5-65=8/119 (6.7%) Ethnicity not reported Care recipients All over 18 years	Parent 31/103 (30%) Partner/sibling/child 49/103 (47.6%) Other 23/103 (24.3%)	64/121 participants completed questions relating to suicidal behaviour but response rates across questions was low 45/60 (75%) said the person they cared for had tried to end their life, 9/60 (15%) said they had not made an attempt 5/60 (8.3% did not know)* (NB numbers reported do not add up to 60/100%) Concerns expressed included:  • Lack of explanation/information • Lack of choice of support services • Difficulty accessing crisis support/responsiveness of support • Not being taken seriously • Need for individualized carer support (group and 1–1)
Magne-Ingvar and Öjehagen (1999a) Sweden	Aim  To investigate (1) the significant other's (SO) view on problems and reasons for the suicide attempt and on the patients need for help as well as their ability to perceive suicidal communication, (2) whether information from SOs was helpful in the assessment of the patient and (3) the wellbeing of the SOs and their need for support  Design  Cross sectional study with interview questionnaire Validated measures  None used	81 carers	Carers 49 female (60%) Other genders not reported Age—all over 18 years Ethnicity not reported Care recipients Mean age 39 years (range 18–92 years)	Partners 31 (38.3%) Parents 30 (37.0%) Adult children 12 (14.8%) Friends 6 (7.4%) Siblings 2 (2.5%)	30% of SOs said SA was not unexpected Over 50% SOs perceived themselves to have provided psychological support to the patient 1/3 SOs reported that they had provided help with practical matters 53% reported that the patient did not turn to them with their difficulties 75% SOs said they were upset, worried or shocked after SA 16% reported they felt physically unwell 25% reported sleep, mood and/or appetite problems problems problems problems and significant of the giving psychological and/or instrumental support was a burden to them Most SOs found it helpful to talk to a professional after patient's SA and felt relieved after giving their view on the attempt.

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Author/year/location	Research aim and design	Sample size (only including carers or bereaved participants)	Demographics: Carers (age/sex/ethnicity) care recipients (age)	Caregiver relationship to care recipient	Summary of findings related to carers
Magne-ingvar and Öjehagen (1999b) Sweden	Aim  To investigate the views of SOs concerning the situation of the patients, their involvement in the patients' treatment and their own wellbeing and need of support 1 year after patient's SA  Design  Cross sectional study with interview questionnaire (68 questions)  Validated measures  None used	84 carers (above sample + 13 participants not reported on in previous study, with 10 dropouts, that is, 81+13-10=84)	Carers 50 female (59.5%) 34 men (40.5%) Age not reported but all over 18 Ethnicity not reported Care recipients All over 18 years	Parents 37 (44,0%) Partners 28 (33.3%) Adult children 10 (12.0%) Friends 7 (8.3%) Siblings 2 (2.4%)	11 (14%) participants reported repeated SA of care recipient 20% reported perceiving suicidal signals 70% were worried about repeat attempt, more so when patient had history of repeat attempts Worrying about patient was considered stressful Parents worried more often Nearly half of participants had not talked to patient about SA Partners especially still had questions about suicidal behaviour 80% participants had someone to turn to—(parents more than partners) Nearly half would like professional counselling with patient apartners 45% thought patient treatment was insufficient, 53% wanted more treatment. Higher satisfaction was associated with inpatient care 22% carers thought they had not been treated well by staff 2/3 carers had not received enough information about the patients situation Involvement in care was considered insufficient—carers wanted more 83% thought their general wellbeing was satisfactory—less often with partners 2/3 reported one or more symptoms of worry, tiredness, headache, irritability, downheartedness, epigastric pain, impaired sleep, tension, hopelessness, anxiety. 1/3 reported 40 more symptoms. 32% had professional support, another 16% felt they needed it 547% SOs had other worries, for example, financial Poor wellbeing was associated with questions about suicide attempt, less access to social support, desiring better support

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Author/year/location	Research aim and design	Sample size (only including Demographics: Carers (age/secarers or bereaved participants) ethnicity) care recipients (age)	Demographics: Carers (age/sex/ethnicity) care recipients (age)	Caregiver relationship to care recipient	Summary of findings related to carers
Maple et al. (2021) Australia	Aim  To identify predictors of caregiver burden identified as a result of caring Design  Cross sectional study Online survey Validated measures Stigma of Suicide Scale Suicidal Ideation Attributes Scale Kessler-10 psychological distress scale Caregiver Burden Scale	carers	Carers 390 Women 89.7% 38 Men 8.7% 7 Other 1.6% Mean age 47.91 years (5D12.03) Ethnicity not reported Care recipients Not reported but carer relationships to care recipient indicate that most were over 18 years	Not available for final sample but of overall sample of 666 (before exclusion of ineligible participants or incomplete data): Child 168 (25.2%) Friend 156 (23.4%) Partner Parntner Parntner Parntner (9.2%) Other 58 (8.7% Family relation 42 (6.3%) Sibling 39 (5.9%) Colleague 8 (1.2%) Missing 63 (9.5%)	Being female (B=0.11, $p$ <.05, $sr^2$ = 1%), reported doseness with the supported person (B=0.11, $p$ <.05, $sr^2$ = 1%), high impact of the SA (B=0.17, $p$ <.001, $sr^2$ = 2%), high frequency of contact 6 months prior to SA (B=0.12, $p$ <.01, 1%), and high psychological distress (B=0.32, $p$ <.001, $sr^2$ = 5%) contributed significantly to high caregiver burden.  Most care recipients had multiple SAs. Participants who had confidence in supporting the person (B=-0.14, $p$ <.01, $sr^2$ = 1%), perceived adequate level of healthcare for patient (B=-0.09, $p$ <.05, $sr^2$ = 1%), and adequate support the care received (B=-0.20, $p$ <.001, $sr^2$ = 3%, and had higher SI themselves (B=-0.11, $p$ <.05, $sr^2$ = 1%) experienced significantly less caregiver burden. Participants who did not feel well supported reported higher scores on SI, psychological distress and caregiver burden compared to participants who were supported
McDonell et al. (2003) USA	Aim  To investigate the relationship between burden, its previously established patient and caregiver correlates and other possible correlates such as substance abuse, depressive symptoms and suicidality in outpatients with schizophrenia.  Design Part of a RCT investigating efficacy of a multiple family group treatment programme  Validated measures  Revised Ways of Coping Checklist Social Support Questionnaire Family Burden Interview Schedule	84 carers	Garers 65 Male 77.4% 19 Female 22.6% Mean age 51.0 (5D 12.8) European-American 90.5% Non-European-American 9.5% Gare recipients Mean age 33.2 years (5D 9.4)	Parent 71.4% Sibling 11.9% Partner 9.5% Other 7.2%	Family awareness of patient SI was significantly correlated to family burden r= (82) 0.49, p <.01 (as are patient age, illness duration and family resource).  Young patient age, low family resources and family awareness of suicide all found to be significant predictors of family burden.  There was a discrepancy between patient reported and family awareness of SI-60% patients reported SI but only 17% carers were aware of SI.  Awareness of SI appears to have a significant effect on caregiver burden when controlling for other significant variables therefore is an independent risk factor for burden.

Abbreviations: SA, suicide attempt; SI, suicide ideation.

thematic synthesis (Thomas & Harden, 2008). NVIVO version 12 (QRS International, 2018) was used to assist with data storage and coding in the development of the descriptive themes. Analytical themes were then developed from the descriptive themes to answer the review question. Synthesis was carried out by the first author and themes developed in discussion with the other authors.

## 3 | RESULTS

The outcome of the systematic search and screening is shown in Figure 1.

## 3.1 | Study characteristics

## 3.1.1 | Quantitative papers

Fourteen quantitative studies involving 12 cohorts were included (Borisonik & Kholmogorova, 2018; Cerel et al., 2006; Chessick et al., 2007, 2009; Chiang et al., 2015; Crasta et al., 2021; Jaffe et al., 2021; Katz et al., 2015; Kjellin & Östman, 2005; Lawn & McMahon, 2015; Magne-Ingvar & Öjehagen, 1999a, 1999b; Maple et al., 2021; McDonell et al., 2003). Study designs included descriptive and analytical cross-sectional studies with samples totalling 3705 carer participants (14 were bereaved by suicide). Areas

examined related to caregiver or family burden, health outcomes of carers and coping ability. Various validated measures were used in nine studies (see Table 2) and five studies devised questionnaires based on clinical experience and relevant literature. Characteristics of quantitative studies are presented in Table 2.

## 3.1.2 | Qualitative papers

Seventeen qualitative papers reporting 16 studies comprising 282 carer participants (14 bereaved by suicide) were included (Asare-Doku et al., 2017; Castelli Dransart & Guerry, 2017; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; McLaughlin et al., 2014, 2016; Nosek, 2008; Nygaard et al., 2019; Rheinberger et al., 2021; Sellin et al., 2017; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021). Studies investigated experiences and perspectives related to caring for a suicidal individual, and experiences of help seeking and service provision. One study used focus groups and the remaining used interviews. Qualitative study characteristics are presented in Table 3.

## 3.2 | Quality appraisal

Quality appraisal is outlined in Supplementary file S1. Of the quantitative papers 9/14 were assessed to be of moderate or

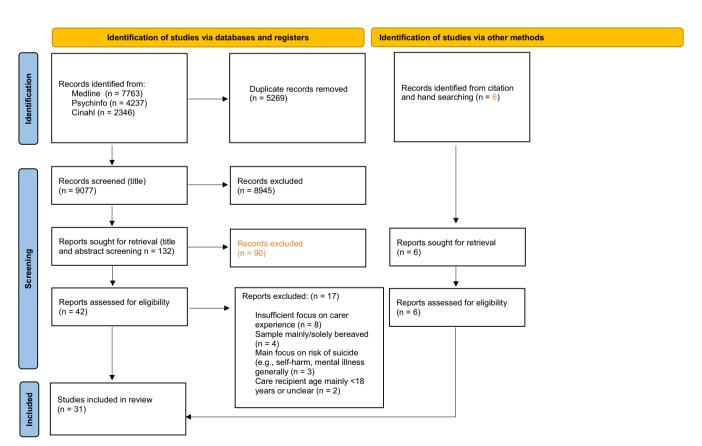


FIGURE 1 Process of study selection (Page et al., 2021).

TABLE 3 Characteristics of included qualitative studies.

Author/year/location	Research aim and design	Sample size (only including carers or bereaved participants)	Caregiver Demographics: Carers (age/sex/ relationship to care ethnicity) care recipients (age) recipient	Caregiver relationship to care recipient	Summary of key themes/findings
Asare-Doku et al. (2017) Ghana	Aim  To understand the experiences of suicide attempt survivors and how they cope with the aftermath Design Interpretative Phenomenological Analysis	10 carers	6 males 4 females Mean age 41 years (range 25-62 years) Ethnicity not reported Care recipients All over 18 years	4 fathers 2 mothers 1 brother 1 husband 1 sister 1 aunt	Experiencing shame and stigma—intra and extra family stigma, not talking about it, gender dynamics in management of shame, isolation Reactive affect—shock, surprise, shock but not surprise (ongoing suicidality), anger, shattered myth Surviving the stress of attempt—spiritual coping, social support, avoidance
Castelli Dransart and Guerry (2017) Switzerland	Aim  To understand the help-seeking experiences of significant others and their perception of the care their loved one received including carer interactions and collaboration with healthcare providers  Design  Qualitative interview study	18 carers	16 women 2 men Mean age 44 years (range 23-61 years) Ethnicity not reported Care recipients All over 18 years	7 partners 3 Child 3 Mothers 3 Sisters 2 friends	Help seeking process—Considerable time and energy providing support/ preventing acting out suicide ideation/getting help from third party. Suicidal person refusing care versus need for professional care. The help-seeking road was tortuous and difficult—helpless, disillusioned, desperate, angry, not listened to, not understood not helped by those they contacted. Multiple attempts experienced.  Perceptions of patient care for suicidal person—% expressed dissatisfaction with care, a recurring complaint was the quality of patient care; access to means not restricted, inadequate assessment of suicide risk, inadequate risk management plan, poor information sharing, needing to take on 'care manager' role. Feelings of exhaustion and hopelessness amplified.  Perception of collaboration with professionals—Nearly half of participants reported positive experiences while the care recipient was an inpatient. More than 1/3 not able to get information on patient's health due to adulthood/confidentiality. Professionals not taking account of information from caregivers, not seen as a valid representative. Leading to anger, having to be persistent, amplification of anxiety, helplessness, contradictory messages from professionals. Lack of empathy from professionals. Needing support and education.

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Author/year/location	Research aim and design	Sample size (only including carers or bereaved participants)	Caregiver Demographics: Carers (age/sex/ relationship to care ethnicity) care recipients (age) recipient	Caregiver relationship to care recipient	Summary of key themes/findings
Dempsey et al. (2019) Australia	Aim  To explore clinician and caregiver perspectives on service provision for family members of young people (15-25 years, av. 20.5 years) attending a specialist clinic for moderate-severe mood disorder.  Design  Qualitative interview study with thematic analysis	8 carers	7 female 1 male Mean age 52.50 years (\$D 3.78) Ethnicity not reported Care recipients Mean age 20.5 years (\$D 3.01)	Parents	Initial Needs: information—needing contact numbers for general and crisis situations; confusion over what to use when; differences in what clinicians believed they provided and what caregivers perceived they had been given; barriers due to wishes of patient; need for shared understanding between caregivers.  Support—reassurance and emotional support, gaining hope from referral to service, feeling safe due to contact with service, reduced anxiety, value of peer support, want for mentoring  Crisis Needs: information—needing to know how to get help, initial information 'goes out of the window' in crisis; caregivers' perception of a crisis not necessarily viewed in the same way by clinicians.  Support—heightened distress, 'roller-coaster' of emotions means need for more intensive support  Concern about patients' treatment and future in general; needing more information on options available; concerned about difficulties re-referring; feeling unready for discharge  Support—concerns about how they would cope  Carer Challenges: Own emotions—anxiety, distress, shock/surprise, shame, isolation with burden of care, bewilderment, importance of accessing own support  Family and life—struggling to balance other responsibilities and leisure time with caring, developing own mental health problems, struggling to take time out of work, concerns about degradation of family relationships  Managing suicide risk—feeling unskilled, not knowing how to speak to patient, what restrictions to place on patient, needing specific information, feeling as though they were not doing enough, appreciative of help they did get, wanting more time with treating team to help manage time between visits, wanting group information sessions

Fogarty et al. (2018)	Aim	47 family and friends Carers	Carers	Not reported	PHQ-9 scores fell within mild depression range
Australia	To examine the complexities of and		26 female (55%)		GAD scores fell within minimal to normal range
	tensions within suicide prevention		21 males (45%)		Tension 1: respect for privacy vs vigilant risk monitoring.
	approaches for at-risk males,		Median age 47 years (range		Tension 2: differentiating normal vs risky behavioural change.
	and how suicide prevention and		19-65 years)		Tension 3: familiarity vs anonymity in risk monitoring.
	interventions for men may be		Ethnicity not reported		Tension 4: respecting autonomy vs imposing restraints.
	improved.		Care recipients		Tension 5: dependence on vs perceived failures of community services.
	Design		All over 18 years		
	Secondary analysis of qualitative data				
	from focus groups				
	This is the only qualitative study to				
	include validated measures				
	Patient Health Questionnaire PHQ-9				
	General Anxiety Disorder Scale (GAD)				

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Author/year/location	Author/year/location Research aim and design	Sample size (only including carers or bereaved participants)	Caregiver Demographics: Carers (age/sex/relationship to care ethnicity) care recipients (age) recipient	Caregiver relationship to care recipient	Summary of key themes/findings
Girfin (2008) Australia	Aim  To hear the voice of a small sample of family members who have an adult daughter or sister receiving treatment for severe personality disorder featuring a chronic pattern of self-harm and suicidality  Design Qualitative interview study	4 carers	Carers 3 female 1 male Age all over 18 years Ethnicity not reported Care recipients All over 18 years	Parents	Chronic and traumatic stress: due to ongoing worry and repeated witnessing of self-harm and near death; fearful responses to the phone ringing at night; emotional strain and exhaustion through lack of sleep, concerns about their own physical health; finding treatment approaches that discourage hospital admission unhelpful and increasing burden of care.  The responsibility and support dilemma: Torn between wanting to care for/support and thinking they should step back but fearing the consequences; intensified by mixed messages from professionals; importance of support from professionals and family and friends

Trying to make sense of it all: Reflecting on own lives and parenting; looking

in context of active caring; mixed feelings of love and anger; strain/

distance on couple and other adult children relationships; differing

Impact of BPD on the broader family: Intensified mother-daughter bond

for explanations

Mental health system and the family: health professionals providing little

views among family members leading to tension and division

support to, but relying on, family; not understanding relationships

inconsistency/contradictory advice; disliking lack of professional between multiple services involved in patient's care; faced with

recognition of the carer burden; wanting respite; feeling like health services regarded them as 'over-anxious'; not feeling listened to so approaching higher authorities

knowledge/understanding/support for caring; uncomfortable clinical

BPD, the family and the broader system: becoming advocates; wanting

contacts; lack of collaboration from professionals

in treatment and discharge planning; needing dialogue to provide empathy but relating to clinician experience; lack of involvement

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Summary of key themes/findings	Family burden: taking responsibility for the safe care of the family member; the potential for actual suicide took over and affected the whole family across a period of time; impact on activities of living and leisure activities for prolonged periods; unrelenting burden of worry and psychological stress; negative effect on physical and emotional health of family members; ongoing hypervigilance.  Competing pressures: usual daily stressful life issues carry on; fear of what will be found on arrival home; anxieties over and above daily chores; effect on personal life, family life, working life; balancing family and work responsibilities  Secrecy and shame: pressure from family member not to speak to others; perceived stigma; feelings of shame—concerned about what others thought; feigning normality; feeling prevented from obtaining emotional and psychological support  Helplessness and guilt: helplessness, powerless and alienation; guilt due to feeling unable to help.	Carers unmet needs: Having practical support, respite and advice Feeling acknowledged and included Having someone to turn to consistency of support	Mood down due to loved one's situation, constant worry, not thinking about the future because it is too sad.  Theory: From not knowing to identifying (seeking information and learning) to gaining awareness (piecing together the information, recognizing patterns, seeking to understand triggers, increased vigilance) to knowing and understanding (knowing the signs, knowing the seriousness, how to manage the illness, being able to cope with the behaviour) to taking action (taking steps to respond to the depressed and suicidal loved one, repeated attempts to find what works, close	monitoring) to watching and waiting (always on their minds, checking effectiveness of actions, waiting for signs of improvement) to reaching limit (running out of sympathy, being pulled back into the cycle) to in cases Not wanting to know (not talking about it, extended family members not talking about it, becoming less involved)
Caregiver relationship to care recipient	Not reported	Not reported	Partner 7 Parent 8 Sibling 1 Adult daughter 1	
Caregiver Demographics: Carers (age/sex/relationship to care ethnicity) care recipients (age) recipient	Carers  14 female  4 male  Age range 25–78 years  Ethnicity not reported  Care recipients  All not reported but where relationships are mentioned in the text and from correspondence with one author it was agreed that half or more were likely to have been 18 years or over	Same sample as above	Carers Sex not reported Age not reported—all over 18 years Ethnicity not reported Care recipients All over 18 years	
Sample size (only including carers or bereaved participants)	11 carers 7 bereaved	11 carers 7 bereaved 1s	17 carers a	
Research aim and design	Aim  To investigate the experiences of carers and the impact that the suicidal behaviour of a family member has on them  Design  Qualitative interviews	Aim To explore the support needs of voluntary family carers of persons at risk of suicide  Design Qualitative interviews	Aim  To investigate the experiences of families who manage the care of depressed and suicidal individual at home  Design  Grounded theory	
Author/year/location	McLaughlin et al. (2014) Ireland	McLaughlin et al. (2016) Ireland	Nosek (2008) USA	

TABLE 3 (Continued)

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care Summary of key themes/findings	Sense of solidarity: minimized the feelings of isolation, communication and acknowledgement of each other's feelings and ways of coping Challenges to the relationship: very stressful, work out, all other issues and plans of less importance than child's situation, more time at home for vigilance, all energy on caring whilst trying to hold on to everyday life, little or no time for each other as a couple, time together not comforting or rewarding, different reactions, doubt about how to support their offspring, not always perceiving offspring's need for support the same way.  Responding to different reactions and coping strategies: ways of coping based on traditional stereotypical gender roles—mothers had in depth conversations with offspring and contact with professionals, fathers did practical things, mothers needed to talk extensively about SA, fathers tried to unwind by doing things on their own, frustration about partner's coping strategies, one partner being the stronger, stronger partner alternating, conflict meaning finding new ways of managing the situation	Interpersonal: Roadblocks—negative interactions with ED staff, reliance on carers initiative to ensure care, patient obstruction of care, discharge when out of crisis, no support for support person Pathways—positive interactions with ED staff, support person involved in assessments, presence of support person in ED Systemic: Roadblocks—chaotic ED environment, prioritization of physical presentation, long waiting times, understaffing in ED, poor access to mental health staff in ED, transactional mental health assessments, inadequate discharge plans Pathways—detailed mental health assessments, access to mental health staff, involvement in discharge decisions
Caregiver ' relationship to recipient	Parents	Parent 10 Partner 4 Friend 1 Other 1
Caregiver Demographics: Carers (age/sex/relationship to care ethnicity) care recipients (age)recipient	Carers 12 female 7 male Age range 42-81 years Ethnicity not reported Care recipients At least half were 18 years or over (range 14-54 years)	Carers 11 female 5 male Age—all over 16 years Ethnicity not reported Care recipients All over 16 years
Sample size (only including carers or bereaved participants)	19 parents	16 carers
Research aim and design	Aim  To explore how the parents and their relationship with their partner or ex-partner were affected following their son or daughter's suicide attempt or serious suicide threats.  Design  Qualitative interviews	Aim  To understand the experiences of help seekers and support persons during a suicide related ED presentation to identify from their perspectives what works, what does not work and areas for improvement in the delivery of crisis care for suicide in Australia Design  Qualitative interviews with grounded theory approach
Author/year/location	Nygaard et al. (2019) Denmark	Rheinberger et al. (2021) Australia

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e Summary of key themes/findings	Participation as experienced by relatives of persons who are subject to inpatient care due to a risk of suicide means 'being actively involved in the process in which the person regains their desire to live' Struggling for being able to be present for the person at risk of suicide: being present as a helpful resource; creating a space for connectedness; risk of losing the person can involve doubt about ones' ability to contribute in a meaningful way; lacking knowledge about the situation; facilitated when professional caregivers invite relatives to be included; doubt and questioning are balanced by experiences of connectedness  Being able to share everyday life: relatives search for contact with the person at risk of suicide as a way of being able to participant in what is going on; includes a need for reciprocal communication with professional caregivers; participation is rather about supporting your family member rather than joining forces with the professional caregivers; dealing with uncertainty concerning what the persons wishes and needs are; holding back one's own needs and adjusting to the other; maintaining contact when the person is emotionally distant.  Nurturing sources for vitality: dealing with one's awareness of the risk of losing the loved person; holding on to possibilities of life while simultaneously agonizing over the risk of losing the loved person; nurturing and caring presence	On guard day and night—observation and safety Maintaining activities of daily living—physical care, providing treatment, arranging activities Creating a nurturing environment—caring and support, fostering tranquillity, re-awakening hope Effects of caring—support systems, families coping strategies Barriers to caring—lack of support systems, caring difficulties, families caring ability problems Family environment and Chinese culture—the family setting, relationship and mood, stigma, folk therapy Impending burnout—recurrent suicidal thoughts and attempts
Caregiver relationship to care recipient	Close relatives	Partner 6 Parent 4 Siblings 3 Adult children 2
Demographics: Carers (age/sex/ethnicity) care recipients (age)	Carers 5 female 3 male Age range 30–80 years Ethnicity not reported Care recipients All over 18 years	Carers 9 men 6 women Mean age 50 years Ethnicity not reported Care recipients Mean age 40 years
Sample size (only including carers or bereaved participants)	8 carers	15 carers
Research aim and design	Aim  To describe the phenomenon of participation as experienced by relatives of persons who are subject to inpatient psychiatric care due to a risk of suicide.  Design  Reflective lifeworld.	Aim  To explore family carers and suicidal ex-patients perspectives of caring for someone after a suicide attempt  Design  Grounded theory
Author/year/location	Sweden	Sun and Long (2008) Taiwan

Author/year/location	Research aim and design	Sample size (only including carers or bereaved participants)	Demographics: Carers (age/sex/ethnicity) care recipients (age)	Caregiver relationship to care recipient	Summary of key themes/findings
Spillane et al. (2020) Ireland	Aim  To explore the overall impact of a family member's high risk selfham, in terms of psychological, physical and psychosomatic consequences.  Design Interpretative Phenomenological Analysis	9 carers	Carers 6 female 8 Sibling 3 male Mean age 44 years (range 33-61) Flend 1 Ethnicity not reported Care recipients Age not reported but carer relationships to care recipient suggest at least half are 18 years or over	Partner 3 Sibling 3 Parent 2 Fiend 1	Implications for health and wellbeing:  Physical and psychosomatic responses—shock, breathing, heart rate, nausea. Susceptibility to physical illness. Worse for those who had experienced multiple high-risk self-harm acts. Changes in lifestyle behaviours. Sleep.  Psychological responses—panic, shock, numbness, disbelief, fear, anxiety. Autopilot, controlled panic, shutdown mode, state of high alert. Low self-esteem, depression, panic attacks in longer term. More pronounced psychological impact among participants responding to multiple acts of high-risk self-harm—reduced confidence, self-esteem, shame, rejection, isolation.  Process of meaning making—increased understanding of mental illness, gaining control of the uncontrollable Feelings of responsibility—Caring for the self-harm patient, care for self Caring for self to care for others Challenges with support network—Formal aftercare following self-harm, informal aftercare following self-harm
Talseth et al. (2001) Norway	Aim  To illuminate the meaning of relatives lived experiences of being met by mental health care personnel during the care of their family member at risk of suicide  Design  Phenomenological Hermeneutic method, Narrative inquiry	15 relatives	Carers 8 Female 7 male Age—all over 18 years Ethnicity not reported Care recipients All over 18 years	Not reported	Helpless and powerless:  Not knowing what to do to meet the needs of a person at risk of suicide In response to personnel and the healthcare system—not being listened to, connected with or supported, dealing with ongoing suicidality Being met (Norwegian context—commonly used phrase referring to acknowledging and noticing another human being while engaging in dialogue that is, being aware of the needs of the other):  Being seen as a human being  Participating in I-Thou relationship with personnel  Trusting personnel, treatment and care, feeling trusted by personnel, being consoled, entering into hope
Vandewalle et al. (2021) Belguim	Aim  To develop an understanding of family members expectations of care and treatment for their relative  Design  Qualitative study based on grounded theory	14 carers	Carers 10 female 4 male Mean age 42 years (range 23-66) Ethnicity not reported Care recipients All over 18 years	Partner 5 Parent 3 Adult child 3 Sibling 3	Struggling to remain hopeful while looking through the lens of uncertainty: Assuming safety as a priority Looking for a healing approach and environment Counting on continuity of care Wanting to be loved and supported

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to care Summary of key themes/findings	Reasons for self-harm They cannot communicate (communication difficulties and difficulty expressing emotion) 5.6%) Suicide and secrets 6) Invalidation by carers Experiences Anger Guilt and self-blame It made us ill Ignoring self-harm Shared shame and stigma Clinicians dismissing the carer Relief and support when patient received good care Solutions More practical support and structure Improving communication Removing means of self-harm Advanced care directives	Living experiences:  Practical roles—Dseudo care management, financial support travel/ transport assistance, keeping them safe, emotional support transport assistance, keeping them safe, emotional support  Lack of agreed role—lack of specific conversations, assumptions about stepping into caring role, lack of requisite skills  Hypervigilance—post discharge suicide watch, most participants reported multiple attempts of care recipient, managing hypervigilance without impacting relationship, strain of ongoing hypervigilance, morphing into the role of advocate  The delicate balancing of the relationship—emotional implications of making practical decisions about how to respond to personal safety, reframing relationships, no safety net for carers  The human approach to supportive intervention: navigating the health system, little preparation for the emotional state that accompanies the responsibility  Post discharge as a touchpoint for carer distress—not being involved in discharge decision making, lack of collaboration in discussions regarding risk, uncertainty in time between discharge and follow	up appointments, risk assessment tools in hospitals did not provide accurate reflection on risk at home, need for information, fighting the system in advocating  What helped and what did not help—kindness, wanting to be asked if they were equipped to manage suicide watch, not to be viewed as a side—line act but a main event, seeking own therapeutic support, having a collaborative relationship with services, role being recognized
Caregiver relationship to care recipient	Adult child 24 (75%) Spouse 5 (15.6%) Sibling 1 (3%) Grandchild 1 (3%) Friend 1 (3%)	13 Child (41%) 6 Partner (19%) 4 Friend (12%) 4 Parent (12%) 4 extended family (12%) 1 sibling (4%)	
Demographics: Carers (age/sex/ethnicity) care recipients (age)	Carers  17 female (53.1%)  15 male (46.9%)  Age—all over 18 years Ethnicity not reported  Care recipients  Mean age 86.5 years (range  80-102 years)	Carers Female 24 (75%) Male 8 (25%) Age—all over 18 years 2 Aboriginal Torres Strait Islander (6%) Care recipients Age not reported but carer relationships to care recipient suggest at least half are 18 years or over	
Sample size (only including carers or bereaved participants)	32 carers	25 carers 7 bereaved	
Research aim and design	Aim  To explore the perspectives of relatives/friends of older people who had self-harmed regarding the reasons for and potential interventions, and the effects on the relatives/friends of the self-harm  Design  Qualitative interviews	Aim  To understand how carers explain their experiences of caring roles and responsibilities and how they navigate health systems while undertaking these roles  Design  Narrative inquiry	
Author/year/location	Wand et al. (2018) Australia	Wayland et al. (2021) Australia	

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moderate to low quality, two were high quality and three were judged to be of low quality. Stronger studies were those which used validated measures and used probability sampling, and weaker studies were those which involved self-selected samples, used non validated questionnaires and/or had not addressed non-response bias.

Qualitative studies were mainly moderate (15/17) with two being assessed as high quality. Some studies gave limited detail of the sample. High quality papers reported coherent methodologies, attended to researcher reflexivity and presented robust ethical procedures.

## 3.3 | Themes

Five key themes and 20 subthemes reflecting carers experiences and needs were derived from the thematic synthesis (Figure 2): transitions; living with fear and uncertainty; changing relationships; interface with healthcare professionals and services; and what carers need

and want. The themes are interrelated, as depicted by the black arrows in Figure 2, reflecting the simultaneous intrapersonal, interpersonal, external and systemic factors that influence the caregiver experience. For example, the transition into the caregiver role was both influenced by and influenced interface with healthcare services, and led on to living with fear and uncertainty and changing relationships with care recipients, all of which shaped carers wants and needs. Articles linked to the themes and subthemes are presented in Table 4.

## 3.3.1 | Theme 1: Transitions

Transitions associated with caring and the consequences of these transitions were described in 23 studies. The length of time participants had been in a caring role varied between studies; some had a more acute recollection of onset, such as 'being thrown into it' (Vandewalle et al., 2021, p. 1143), others talked in the context of longevity, for example, 'he's been like that for 27 years' (McLaughlin

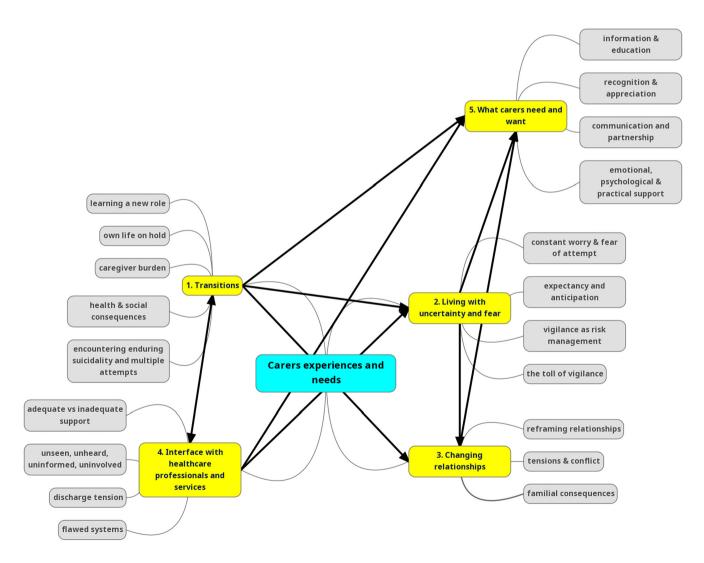


FIGURE 2 Five themes and 20 subthemes reflecting carers experiences and carers needs. The black arrows denote the interconnected nature of the themes to illustrate the transition into caring, which influences and is influenced by interface with healthcare professionals and services and leads on to living with fear and uncertainty and changing relationships, all of which shape what carers need and want.

TABLE 4 Articles linked to themes and sub themes.

Theme	Subtheme	Articles including theme/subtheme
1. Transitions		Asare-Doku et al., 2017; Castelli Dransart & Guerry, 2017; Chessick et al., 2007, 2009; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Jaffe et al., 2021; Katz et al., 2015; Kjellin & Östman, 2005; Magne-Ingvar & Öjehagen, 1999b; Maple et al., 2021; McLaughlin et al., 2014, 2016; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2017; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Learning a new role	Asare-Doku et al., 2017; Castelli Dransart & Guerry, 2017; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Magne-Ingvar & Öjehagen, 1999b; Nosek, 2008; Sellin et al., 2017; Spillane et al., 2020; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Own life on hold	Asare-Doku et al., 2017; Castelli Dransart & Guerry, 2017; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2005, 2008; Magne-Ingvar & Öjehagen, 1999b; McLaughlin et al., 2014, 2016; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2017; Spillane et al., 2020; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Caregiver burden	Chessick et al., 2007; Chiang et al., 2015; Crasta et al., 2021; Katz et al., 2015; Kjellin & Östman, 2005; Maple et al., 2021; McDonell et al., 2003; McLaughlin et al., 2014; Wayland et al., 2021
	Health and social consequences	Borisonik & Kholmogorova, 2018; Chessick et al., 2007, 2009; Chiang et al., 2015; Crasta et al., 2021; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Jaffe et al., 2021; Katz et al., 2015; Magne-Ingvar & Öjehagen, 1999a, 1999b; Maple et al., 2021; McLaughlin et al., 2014; Nygaard et al., 2019; Spillane et al., 2020
	Encountering enduring suicidality and multiple attempts	Asare-Doku et al., 2017; Borisonik & Kholmogorova, 2018; Castelli Dransart & Guerry, 2017; Chessick et al., 2007, 2009; Giffin, 2008; Magne-Ingvar & Öjehagen, 1999b; Maple et al., 2021; McLaughlin et al., 2014, 2016; Nosek, 2008; Sellin et al., 2017; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wayland et al., 2021
2. Living with fear and uncertainty		Asare-Doku et al., 2017; Borisonik & Kholmogorova, 2018; Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Fogarty et al., 2018; Giffin, 2008; Kjellin & Östman, 2005; Magne-Ingvar & Öjehagen, 1999a, 1999b; McLaughlin et al., 2014, 2016; Nosek, 2008; Nygaard et al., 2019; Sellin et al 2018; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Constant worry and fear	Cerel et al., 2006; Giffin, 2008; Kjellin & Östman, 2005; Magne-Ingvar & Öjehagen, 1999a, 1999b; McLaughlin et al., 2014, 2016; Nosek, 2008; Nygaard et al., 2019; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wayland et al., 2021
	Expectancy and anticipation	Asare-Duko et al., 2017; Giffin, 2008; McLaughlin et al., 2014; Nosek, 2008; Sellin et al., 2018; Spillane et al., 2020; Sun & Long, 2008, 2019; Wayland et al., 2021
	Vigilance as risk management	Castelli Dransart & Guerry, 2017; Fogarty et al., 2018; Giffin, 2008; McLaughlin et al., 2014, 2016; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2018; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	The toll of vigilance	Borisonik & Kholmogorova, 2018; Giffin, 2008; Kjellin & Östman, 2005; McLaughlin et al., 2014; Nosek, 2008; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Wand et al., 2019; Wayland et al., 2021
3. Changing relationships		Asare-Doku et al., 2017; Borisonik & Kholmogorova, 2018; Castelli Dransart & Guerry, 2017; Chessick et al., 2007; Chiang et al., 2015; Crasta et al., 2021; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Katz et al., 2015; Kjellin & Östman, 2005; Magne-Ingvar & Öjehagen, 1999b; McLaughlin et al., 2014, 2016; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2017; Spillane et al., 2020; Sun & Long, 2008; Wand et al., 2019; Wayland et al., 2021
	Reframing relationships	Asare-Doku et al., 2017; Castelli Dransart & Guerry, 2017; Chessick et al., 2007; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Katz et al., 2015; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2017; Spillane et al., 2020; Wayland et al., 2021
	Tensions and conflicts	Asare-Doku et al., 2017; Chiang et al., 2015; Fogarty et al., 2018; Giffin, 2008; Kjellin & Östman, 2005; McLaughlin et al., 2016; Nosek, 2008; Wand et al., 2019; Wayland et al., 2021



TABLE 4 (Continued)

Theme	Subtheme	Articles including theme/subtheme
	Familial effects	Asare-Doku et al., 2017; Borisonik & Kholmogorova, 2018; Chessick et al., 2007; Chiang et al., 2015; Crasta et al., 2021; Dempsey et al., 2019; Giffin, 2008; Magne-Ingvar & Öjehagen, 1999b; McLaughlin et al., 2014, 2016; Nygaard et al., 2019; Spillane et al., 2020; Sun & Long, 2008; Wand et al., 2019
4. Interface with healthcare professionals and services		Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Kjellin & Östman, 2005; Lawn & McMahon, 2015; Magne-Ingvar & Öjehagen, 1999a, 1999b; Maple et al., 2021; McLaughlin et al., 2014, 2016; Rheinberger et al., 2021; Sellin et al., 2017; Spillane et al., 2020; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Unseen, unheard, uninformed uninvolved	Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Dempsey et al., 2019; Giffin, 2008; Lawn & McMahon, 2015; Magne-Ingvar & Öjehagen, 1999b; McLaughlin et al., 2016; Nosek, 2008; Rheinberger et al., 2021; Spillane et al., 2020; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Discharge tension	Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Dempsey et al., 2019; Giffin, 2008; Lawn & McMahon, 2015; Nosek, 2008; Rheinberger et al., 2021; Spillane et al., 2020; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Flawed systems	Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Dempsey et al., 2019; Giffin, 2008; Lawn & McMahon, 2015; McLaughlin et al., 2016; Rheinberger et al., 2021; Talseth et al., 2001; Vandewalle et al., 2021; Wayland et al., 2021
5. What carers want and need		Asare-Doku et al., 2017; Borisonik & Kholmogorova, 2018; Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Chessick et al., 2007, 2009; Chiang et al., 2015; Crasta et al., 2021; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Katz et al., 2015; Kjellin & Östman, 2005; Lawn & McMahon, 2015; Magne-Ingvar & Öjehagen, 1999a, 1999b; McDonell et al., 2003; McLaughlin et al., 2014, 2016; Nosek, 2008; Nygaard et al., 2019; Rheinberger et al., 2021; Sellin et al., 2017; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Information and education	Asare-Doku et al., 2017; Castelli Dransart & Guerry, 2017; Crasta et al., 2021; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Katz et al., 2015; McDonell et al., 2003; McLaughlin et al., 2016; Nosek, 2008; Rheinberger et al., 2021; Sun & Long, 2008; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Recognition and appreciation	Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Giffin, 2008; McLaughlin et al., 2014, 2016; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Communication and partnership	Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Giffin, 2008; McLaughlin et al., 2014, 2016; Rheinberger et al., 2021; Sellin et al., 2017; Spillane et al., 2020; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Emotional, psychological and practical support	Asare-Doku et al., 2017; Borisonik & Kholmogorova, 2018; Castelli Dransart & Guerry, 2017; Chessick et al., 2007, 2009; Chiang et al., 2015; Dempsey et al., 2019; Giffin, 2008; Katz et al., 2015; Kjellin & Östman, 2005; Magne-Ingvar & Öjehagen, 1999a, 1999b; McLaughlin et al., 2014, 2016; Nygaard et al., 2019; Sun & Long, 2008; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021

et al., 2014, p. 3). Initial emotional responses such as shock, guilt and anger were cited along with helplessness and powerlessness, quickly followed by a realization that there was a need to take on a carer role to support the individual and keep them safe. For some, this occurred alongside sensemaking, which involved revisiting belief systems and reflecting on lives before suicidality:

It made me question more about my parenting than anything else ... it really made me sit down and go through the way I brought him up

(Spillane et al., 2020, p. 293)

Participants reported feeling ill equipped for this new role:

Well, I think I still feel like I-a little bit all at sea ... I'm not really sure I would know what to do, to be honest (Dempsey et al., 2019, p. 107)

although over time some carers had worked things out for themselves:

OK, let's not try that again, let's try this approach... and a lot of it was hit and miss.

(Nosek, 2008, p. 40)

Common caregiver tasks included providing or practical support. This involved talking, being available and conveying love, advocacy and general support such as organizing appointments. Taking on the caring

role and learning to meet care recipients' needs along with balancing other family and work demands, meant that carers often had to put their own life on hold:

The first thing I said is forget about myself (Wand et al., 2019, p. 597)

Caregiver burden was measured in seven studies. Two of these (Katz et al., 2015; McDonell et al., 2003) suggested that perceived presence of suicide ideation increased burden even if actual ideation wasn't always present. Chiang et al. (2015) and Maple et al. (2021) found burden to be higher in females and suggested that relational closeness could result in higher burden due to the level of emotional investment. Related, Crasta et al. (2021) proposed that caregiver burden reduced when the care recipient's perceived burdensomeness was higher because individuals asked for less support when they felt a burden on people they loved. Subjective reports of caregiver burden were either in response to direct questions, through quotes, for example, 'the burden for the carer support person is heavy' (Wayland et al., 2021, p. 669) or through interpretation and analysis such as the theme of 'family burden' derived by McLaughlin et al. (2014).

All studies referred to the caring experience being stressful, and 16 indicated physical, and/or psychological consequences, such as psychological distress, including carers feeling traumatized; deteriorating general and mental health; and poor wellbeing. Participant narratives gave reports of feeing generally run down, exhausted, anxious and low in mood.

I'm a bit run down at the moment, I have a cold and an enormous cold sore

(Spillane et al., 2020, p. 293),

You can't believe how tired, you know, how tired you feel

(Giffin, 2008, p. 134)

Are you kidding? Of course I am depressed.' You know, 'What kind of parent wouldn't be, if they had been living with what I have been living with for two years?

(Dempsey et al., 2019, p. 107)

One study examined suicide ideation in carers (Maple et al., 2021) and found evidence in participants who had high psychological distress, particularly when carer support was perceived as inadequate. However, these authors also found a negative association between suicide ideation and caregiver burden and postulated that this may be due to them seeking professional help, informed by their awareness of the need for support and how to access such.

Social consequences of caring for someone at risk of suicide largely arose from shame, stigma, and living with the ongoing threat of suicide, which led to avoidance and withdrawal:

I was ashamed, when it happened. ... I have never ever told any of my family people

(Asare-Doku et al., 2017, p. 3)

I've just no desire for actual social interaction...like if the person that you think loves you, tries to kill herself, like so many times, it does have an effect on your opinion of yourself

(Spillane et al., 2020, p. 288)

McLaughlin et al. (2014) noted that perceived stigma could be a barrier to help seeking:

She (the nurse) was very nice and I know she would have felt like talking to me but I didn't want to tell people

(McLaughlin et al., 2014, p. 4)

Participants experiences with healthcare services (see theme 4) influenced transitions within the caring role. For example, when carers felt they were not recognized as being instrumental to the support of the care recipient, were not informed about what was going on and how they could help, were not advised regarding crisis contacts, and were not offered kindness or support for themselves, feelings of frustration, despair, helplessness and powerlessness appeared to be even more overwhelming.

Borisonik and Kholmogorova (2018) examined differences between carers of people who had made a single suicide attempt verses multiple attempts, and another 16 studies referred to carers encountering enduring suicidality and/or multiple attempts. Suicide attempts were not always considered to be undertaken with high intent:

She has been pumped a few times because she took an overdose of medicine. I've felt she has never tried 100% to take her own life. Because every time she has taken an overdose she has phoned and told me. It is a way of asking for help, I feel

(Talseth et al., 2001)

There was consistent indication that negative effects of caring increased with persistent suicidal behaviour. Sun and Long (2008) and Nosek (2008) presented theories illustrating the cyclical nature of suicidal crises and caregiver responses, with each model highlighting caregiver burnout as a result of responding to repeated episodes. Some studies indicated a transition towards a sense of reluctant acceptance of living with the ongoing possibility of suicide (Asare-Doku et al., 2017; Giffin, 2008; Nosek, 2008; Sellin et al., 2017; Spillane et al., 2020) although reflecting on this acceptance could be painful for carers and did not necessarily reduce emotional turmoil:

I imagine that I've come to terms with the fact that if anything, now, did happen to her, we've done all we can, but we haven't lived through it, have we ... but have I really [come to terms with it], while there's a little nagging doubt in my mind?

(Giffin, 2008)

## 3.3.2 | Theme 2: Living with fear and uncertainty

This theme was highlighted in 20 papers. Fear of suicide attempt was common, resulting in constant worry and rumination about care recipients' safety:

I'm always thinking is she safe today? Will she cut her wrist? Does she want to die?

(Sun & Long, 2008, p. 1946)

Constant worry could become an 'unrelenting burden' (McLaughlin et al., 2014, p. 3) and for carers in some studies, this led to expectancy of suicide attempts or completed suicide: 'when's it gonna happen' (Nosek, 2008, p. 40); 'is this another suicide attempt' (Giffin, 2008, p. 134). Worry and anticipation frequently resulted in hypervigilant behaviour in an attempt to maintain care recipients' safety and manage carers' fear and uncertainty. Hypervigilance was underpinned by fear and a sense of responsibility, for example, 'my only responsibility was to keep him alive' (Vandewalle et al., 2021, p. 1140), and feelings of helplessness and powerlessness. Vigilance ranged from regular telephone calls and check-ins: "and then I'll send a text 'all ok?'" (Spillane et al., 2020, p. 290) to reducing access to means: 'I'm not gonna leave tablets for her like that' (Wand et al., 2019, p. 598), and being 'on guard day and night' (Sun & Long, 2008, p. 1943). Carers who lived with care recipients often did not leave the house in case of a suicide attempt or, if they did, they experienced anticipatory fear about what they might find when they arrived back home.

You feel guilty almost about going out of the house, you feel frightened about coming home again because you think what are you going to come home to?

(McLaughlin et al., 2014, p. 3)

'Suicide watch' was a term used by participants in several studies (Castelli Dransart & Guerry, 2017; McLaughlin et al., 2014; Nosek, 2008; Spillane et al., 2020; Sun & Long, 2008; Wayland et al., 2021) who had either been advised it by healthcare providers or self-prescribed it to try and achieve a semblance of control.

They (the hospital) actually said take her home, you're on suicide watch. I had her actually sleep in my bed that night, I just couldn't even leave her in her own bedroom

(Wayland et al., 2021, p. 666)

Carers in some studies expressed experiences of, or concerns about, relational tension when they tried to balance care recipient safety and autonomy (Fogarty et al., 2018; Giffin, 2008; Vandewalle et al., 2021; Wayland et al., 2021). Some studies showed that carers often existed within a stasis of 24-h high alert, with the ongoing vigilance taking a toll on sleep, for example, 'I lay the whole time with one eye open' (Talseth et al., 2001, p. 253). This contributed to burnout, which was identified by McLaughlin et al. (2014), Nosek (2008) and Sun and Long (2008). Linked to burnout, some narratives or outcomes were interpreted to indicate detachment and avoidance, either as a coping strategy (Borisonik & Kholmogorova, 2018; Sun & Long, 2008; Wand et al., 2019) or a way of self-preservation (Fogarty et al., 2018; Nosek, 2008).

## 3.3.3 | Theme 3: Changing relationships

Effects on individual or familial relationships were identified in 21 papers.

Relationships were often reframed as a result of suicide attempts; the very fact that a suicide attempt had occurred meant that the relationship could not go back to how it was before the attempt (Nosek, 2008; Sellin et al., 2017; Wayland et al., 2021). This was illustrated by participants who articulated a sense of living with the possibility of eventual suicide (Asare-Doku et al., 2017; Giffin, 2008; Nosek, 2008; Sellin et al., 2017; Spillane et al., 2020). Becoming a sort of 'case manager' (Castelli Dransart & Guerry, 2017; Wayland et al., 2021) whereby carers sorted things out for and took care of the person's mental health and safety, meant that the emphasis of some relationships shifted from 'equal to advocate' (Wayland et al., 2021, p. 670). Some parents of adult children found that their parental roles were forced to revert backward from an adult-adult dynamic to adultchild relationship (Spillane et al., 2020; Wayland et al., 2021) and some partners experienced a need to become somewhat parental in order to maintain safety (Fogarty et al., 2018; Spillane et al., 2020).

Kjellin and Östman (2005) found that many relationships between their caregiver participants and suicidal individuals deteriorated, and negative feelings towards the care recipient, or their suicidal behaviour, were evident in other studies, which in certain cases resulted in invalidating exchanges or tensions (Asare-Doku et al., 2017; Fogarty et al., 2018; Nosek, 2008; Wand et al., 2019). Participants in a few studies reported difficult feelings associated with 'treading on eggshells' (e.g. Wayland et al., 2021, p. 667) and feeling controlled by the care recipient's state of mind (McLaughlin et al., 2016; Nosek, 2008). Chiang et al. (2015) found that older caregivers held more negative attitudes and suggested that this may be due to stigma or long-term caring. However, they also found that caring ability was high in older carers and surmised that long-term caring made them adept. Conflicting positive and negative emotions experienced by carers such as love or sympathy alongside anger were noted (Asare-Doku et al., 2017; Giffin, 2008), while Sellin et al. (2017) highlighted the increased intimacy experienced within the relationship, and carers' realization of their importance to the care recipient, suggesting that not all relationship changes were negative. Similarly, while Katz et al. (2015) found negative appraisals of the effects on family, they also noted a focus on good aspects of relationships with care recipients, which they linked to fear of loss.

The deleterious impact on the family was shown in several studies, particularly when suicidality was ongoing. This was due to strained relationships with the care recipient or the family having to reconcile themselves with their own sense of stigma:

> ... they are ruining the family from within the family (Dempsey et al., 2019, p. 107)

> ... the incident has put us in a very difficult situation in the vicinity where we live and we have still not recovered much yet. It has changed our family course and I know that it will take us several years to recover very little

> > (Asare-Doku et al., 2017, p. 5)

Crasta et al. (2021) suggested that good social coping was associated with less negative appraisals of the relationship with the care recipient and Sun and Long (2008) noted that families with strong coping strategies were more able to provide effective care. Chessick et al. (2007) indicated differences in the effects of caring for a person at risk of suicide on parental and partner relationships, with the former experiencing higher levels of burden and depression when there was a history of suicide attempt but not necessarily current ideation, and the latter when there was no history, but suicide ideation was present. These authors suggested that this might be to do with parents not being able to relinquish parental tasks as anticipated and partners' expectations of their partner's role in the relationship being somewhat thwarted. Giffin (2008) and Nygaard et al. (2019) identified that tension within parental partnerships could occur, and two studies noted differences in responses and coping between male and female parents (Asare-Doku et al., 2017; Nygaard et al., 2019) although Nygaard et al. (2019) also found that the experience could bring the parent partnerships together in a sense of solidarity. Magne-Ingvar and Öjehagen (1999b) found that parents had worried about the patient more frequently than partners, but partners less often had a confidant(e). This study also found that nearly half of participants had not talked to care recipients about the suicide attempt, suggesting possible relational tensions or communication difficulties. There was minimal attention to the experiences of siblings and effects of this on carers, but Giffin (2008) and Spillane et al. (2020) noted the anger of siblings due to the focus of attention on the care recipient and Spillane et al. (2020) described the isolation of the sibling caregivers in their study.

## 3.3.4 | Theme 4: Interface with healthcare professionals and services

Nineteen papers included information about carers experiences and perspectives of healthcare systems and professionals. Carer satisfaction was largely dependent on perceptions of the mental health care the care

recipient received. Participants perceived both adequate and inadequate care, but the latter was more common. Care was considered adequate when the care recipient was safe, supported, treated with kindness, had time with staff and received psychological interventions. Continuity of care and good communication between professionals were also important factors for participants. Maple et al. (2021) found that caregiver burden was lower when care was experienced as adequate.

Care was viewed as inadequate when the aforementioned features of adequate care were lacking. In addition, superficial, brief, insensitive and impersonal care was considered to be poor.

Participants in 14 studies reported a lack of support for themselves as carers. Unsupported carers reported being unseen, unheard and uninformed.

> I said to the doctors 'but me, I need help, I need help', and I was crying and I didn't have any tissues and nobody offered me any, and then, everybody was watching me cry, nobody said anything

> > (Castelli Dransart & Guerry, 2017, p. 8)

One doctor I spoke to ... he was really dismissive ... dismissing with a wave of the hand the observation of someone who'd known him [patient] for a long time

(Wand et al., 2019, p. 598)

I got a bunch of photocopied brochures that's it (Wayland et al., 2021, p. 668)

Uppermost for many participants in these studies was the experience of being uninvolved in the patients care, be that when they sought information or tried to provide it, with some studies identifying confidentiality as a barrier. Participants stressed that they could not be expected to safely manage the care recipient at home without an understanding of their needs and some preparation to help meet these needs.

'We [as parents] do not always understand what is happening. But all they do is give vague answers and refer to confidentially boundaries. That is very confronting, because we are the ones who are stuck in this situation'. Participant 12, mother (Vandewalle et al., 2021, p. 1143).

Good carer support described involved practical and educational support and information, being listened to, treated with kindness and respect, and not made to feel blamed.

... she gave us coping skills

(McLaughlin et al., 2016, p. 2);

We were informed about what has been happening the whole time

(Talseth et al., 2001, p. 251)

... the mental health person ... he had a chat with me as well for about half an hour, to get a read on the situation (Rheinberger et al., 2021, p. 6) Maple et al. (2021) found that caregivers who felt adequately supported experienced less psychological distress, suicide ideation and caregiver burden. Good support could have a profound positive effect in understanding a loved one's presentation:

Now it is easier for me to understand and empathize with her situation because I know why she has suicidal thoughts. I used to have no context, so her expressions were just, yeah, "really crazy". I used to say that I was married to "a psychiatric patient". Now I am able to see it in a much more positive way.

(Vandewalle et al., 2021, p. 1143)

There was discontent with healthcare services overreliance on carers to support the person at home. Discharge tension was expressed in 12 studies, with carers being of the view that risk would intensify once the individual was back at home and away from hospital support. Participants reported a lack of involvement in discharge planning despite being key to supporting this plan at home. Some felt they had no choice with regard to taking the care recipient back into their care, even if they had reservations about the individual's safety:

The real disappointment for me was when her suicide attempt led her to the hospital, but after three days, they just released her and that was it. Yet I told them 'but listen, she is not ready to get out, we've been dealing with this for ten years, you can be sure that she will try again (Castelli Dransart & Guerry, 2017, p. 6)

Difficulties experienced by participants in 10 studies were perpetuated by healthcare systems that were experienced as flawed and complex, meaning that carers did not always know how or where to access support. Common problems were long waiting times (e.g. in the emergency department, a psychiatric bed or for psychological therapy) and insufficient resources (e.g. staff, psychological interventions, carer support). Problems with services were considered by some participants to contribute to poorer outcomes:

There's nothing there for us, do you understand, there's been nothing there over the years, as a carer there's nothing there for you but had there been at the start I reckon, some sort of support for us, we could have had a better life as a family

(McLaughlin et al., 2016, p. 2)

## 3.4 | Theme 5: What carers need and want

Needs of caregivers were identified either by study participants themselves or by the authors from their data analyses in 29 papers. Sixteen studies noted that carers need practical information and education, including about mental health problems and suicide;

strategies to help manage the person at home; how to seek help during a crisis; and how mental healthcare systems function.

Which solution? How to react? This is how I feel that relatives, they need help in these situations.

(Castelli Dransart & Guerry, 2017, p. 9)

 $\dots$  more information about what mom is going through and what I could do about it

(Vandewalle et al., 2021, p. 1143)

Eight studies identified that carers wanted to be appreciated as fundamental providers of care for the person at risk of suicide, and recognized as people in their own right, with their own needs. They wanted to be valued as possessors of salient and crucial information:

Family member(s) must be taken seriously. They need to be listened to. They are the ones who live with the individual on a daily basis and they are more aware of what is going on with the individual than any other person

(Cerel et al., 2006, p. 346)

Related, twelve studies found participants wanted healthcare providers to communicate and work in partnership with them to meet care recipients needs and keep them safe:

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

(Wand et al., 2019, p. 597)

Support for carers was identified in 19 studies which endorsed psychological interventions to address the emotional, relational and mental health impact of caring, interventions to help develop coping strategies, and the need for couple or family therapy to help reconcile with the relational changes associated with caring. The importance of having the opportunity to talk about what was happening for them was clear across all of these studies.

Families need a place to talk and acknowledge the impact that it has on the family. The offer to speak to someone would have been appreciated. It has had a devastating effect on my family

(McLaughlin et al., 2016, p. 3)

In addition to emotional and psychological support, practical support such as respite was considered as a need in a minority of studies, and Asare-Doku et al. (2017) and Sun and Long (2008) highlighted the importance of acknowledging cultural needs when considering support for carers, particularly due to the stigma that may be attached to suicide in certain cultures.

## **DISCUSSION**

In this systematic review we identified 31 primary research papers investigating experiences and needs of adult informal caregivers of adults at risk of suicide. Five interrelated themes related to caregiver experiences were identified: transitions; living with fear and uncertainty; changing relationships; interface with healthcare professionals and services; and what carers want and need.

Transitions spanned the experience of being thrown into or gradually entering the caregiver role through to long term caring. Studies consistently identified negative emotional and health related consequences of caring for suicidal individuals, with positive associations being few. Problematic encounters with healthcare services increased caregiver stress, with discharge being a time of particular tension due to the lack of involvement or opportunity to express concerns. Communication with healthcare professionals was obstructed when clinicians displayed concrete interpretation of confidentiality boundaries, which tested relationships with professionals.

These insights largely reflect previous systematic reviews (Juel et al., 2021; Lavers et al., 2022) although the current review suggests that negative consequences of caring are experienced as increasingly severe with ongoing suicidality and multiple suicide attempts. This appears to be mediated somewhat by persistent and repeated cycles of hypervigilant behaviour acted out in the context of fear and uncertainty. Hypervigilance was demonstrated through strategies such as suicide watch, constant alert, and persistent checking. Fear and associated hypervigilance resulted in disturbed sleep, which in turn had a detrimental impact on mental and physical wellbeing. In some cases impaired wellbeing led to caregiver burden and burnout, which are known to be associated with poor health and social outcomes (Gérain & Zech, 2019).

Hypervigilance is an understandable response to fear and uncertainty because it enables carers to feel a semblance of control in their endeavour to preserve safety. Indeed, it mirrors the nursing practice of constant observation (Reen et al., 2020), which Veale et al. (2023) argue objectifies individuals as 'risks' and prioritizes physical safety at the expense of emotional safety. This might suggest that if carers focus solely on behavioural vigilance, open communication between them and care recipients may be stymied and the validating ambiance of loving presence, compromised. Moreover, constant vigilance may be a lonely and draining experience, potentially leading to interpersonal conflict between caregivers and care recipients: relational tension as a result of restricting care recipients' autonomy was described in some of the studies reviewed. Such tension is likely to be particularly challenging when care recipients are adults, as parents of adolescents may manage suicidal behaviour through compassionate exertion of parental authority (Omer & Dolberger, 2015), which parents of adults may struggle to implement, and partners or friends more so. Mechanisms of relational tension related to hypervigilant behaviour included carers feeling a sense of expectancy of suicide. Expectancy might involve anticipating the loss of the person by suicide (Lascelles, 2021), despite active and supportive endeavours to

prevent such an outcome. Expectancy and anticipatory loss may stimulate the strong emotions experienced by carers such as grief, guilt and anger. Relational tension could also be underpinned by care recipients' own guilt or anger: guilt for putting carers through such a gruelling ordeal or in response to sensing caregiver burnout, and anger at being stripped of their autonomy. Guilt and anger are known to intensify feelings of burdensomeness and increase suicidal desire (Hawkins et al., 2014; van Orden et al., 2010). Excessively vigilant behaviour, therefore, may not only negatively affect carer wellbeing and relationships with care recipients but elevate rather than mitigate care recipients suicide risk. Given these potential adverse effects, nurses and other clinicians should take care to understand the familial context and social support available to caregivers before prescribing or endorsing frenetic physical observation, and families should be helped to facilitate a more emotionally supportive and hopeful presence. Safety planning, which is considered an important intervention in reducing suicidal behaviour (Nuij et al., 2021), and should ideally involve families or carers to promote helpful communication (Mughal et al., 2023), can help with this aim. Findings from this systematic review indicate a need for safety planning to address relational tension, facilitate validation, and include strategies to reduce both care recipient and caregiver helplessness. This stance supports the call for a shift towards a 'safety' emphasis rather than a 'risk' emphasis (Mughal et al., 2023). To support this aim, research investigating dyadic experiences of hypervigilant behaviour is required to help increase understanding of whether or not this strategy is helpful and how collaborative safety planning can best be implemented.

Caregiver exposure to suicide attempts (or the threat thereof) and their aftermath might be an explanatory factor for the more severe consequences associated with caring for adults with enduring suicidality. Exposure to suicide attempts is associated with reduced wellbeing and suicide attempt in the exposed, particularly close relations (Hvidkjær et al., 2020). Therefore, it may be that carers of people who repeat suicide attempts become vulnerable to suicidal behaviours themselves, especially if they experience their own mental health problems. The informal caregiver population is known to have an increased risk of suicide (O'Dwyer et al., 2021) and risk indicators such as poor mental and physical health, sleep disturbance and helplessness were highlighted in this systematic review. Surprisingly only one study investigated suicide ideation of carers of people at risk of suicide (Maple et al., 2021), finding it to be positively associated with psychological distress and low carer support but negatively associated with caregiver burden, possibly because carers sought professional help. Risk factors associated with carers of suicidal individuals may be offset by protective factors of help-seeking, problem-solving ability, sense of purpose, and connection to the care recipient. Furthermore, these carers might carry an intrinsic prevention bias due to their caring role. More research, including longitudinal inquiry, is needed to understand how carers of individuals who repeat suicidal behaviour are affected over time, in order to inform tailored interventions for both carers and carer/care recipient dyads. This might include

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quantitative and qualitative investigation of health outcomes and suicide ideation to help understand if relationships between exposure to suicidal behaviour and carer mental health and/or suicide ideation exist. With regard to clinical practice, nurses and other clinicians should be aware of the detrimental effects of repeated suicidal episodes on carers. They should assess impacts, including mental health and suicide ideation and ensure provision of, or signposting to, appropriate support.

Interventions for carers must address thoughts and feelings as well as physical safety strategies and should attend to the emotions that underly hypervigilant behaviour, such as fear, uncertainty and anticipatory loss. Tackling these aspects may help carers coexist with the disturbing possibility of suicide without needing to remain in a detrimental state of constant high alert. Grant et al. (2015) advise that to assist caregiver empowerment carers need to accept their limitations in the prevention of suicide due to its inherent unpredictability. It is feasible that if carers are less immobilized by fear and uncertainty, they may be able to offer a calm and containing presence and engage in more helpful dialogue with the care recipient, which might be protective.

The majority of participants in the studies reviewed were parents, followed by partners. Relational changes included parents having to take back a level of parental control which had previously been relinquished. Some studies proposed that partners may experience caregiving differently to parents, particularly interpersonal aspects such as shifting from equal to advocate, adopting an authoritarian role and reconciling with the fact that a partner's wish to die may at times surpass their wish for the relationship. This reflects broader research, for example, Lewis (2015) noted distinctive characteristics in partners of people with mental illness in relation to loss; loss of the true partnership; loss of the anticipated future of the partnership; loss of a sexual relationship. However, living with the knowledge that the relationship may not be, or was not, sufficient to prevent a suicide attempt is an experience unique to a caring context which involves suicidality. McGivern (2021) suggests that partners can experience ambiguous loss following their partner's suicide attempt, whereby they exist in the aftermath with a partner who is physically present but psychologically absent. The psychological absence is related to the suicidal decision making which involved exiting the partnership.

Just two studies in the current review referred to siblings and this was mainly in the context of family dynamics as opposed to a specific caregiving role. However, both studies elicited sibling anger, which may fuel wider familial tension, lead to emotional difficulties and amplify carer stress. Siblings are often neglected at times of familial stress related to mental ill health or suicide (Bowman et al., 2014; Dyregrov, 2005; Karlstad et al., 2021) and they are barely mentioned in relation to a sibling's suicidal behaviour, although Shivers et al. (2022) found that adult siblings who have siblings with mental illness and suicide ideation can experience carer burden.

Interventions focusing on the practical, relational and emotional effects of living with a family member at risk of suicide are clearly required. The current systematic review has identified a need for

psychological interventions targeting the carer/family and care recipient together, such as couple or family therapy. These interventions should be tailored to context and needs, with family interventions being flexible enough to attend to the various roles within the family, the adult-adult dynamic, and differing experiences and perspectives. Research aiming to develop effective couple interventions which incorporate these elements is beginning to emerge (Khalifian et al., 2022), however current family-based interventions are predominantly tailored to families where the suicidal individual is an adolescent (Ougrin et al., 2015).

Additional carer needs identified in this systematic review included information and education, collaboration and various forms of carer support. These findings are not novel; most have been identified by previous reviews of carers of people with mental illness and/or who are at risk of suicide (Doody et al., 2017; Juel et al., 2021; Lavers et al., 2022). This replication underlines the need for policy makers, commissioners, managers and clinical leaders to review systems and practice to improve the caregiver experience. There is a strong need for improved interventions involving education and skills training specifically for adult carers of adults (Krysinska et al., 2021).

Nurses are frequently involved with patients and families in the immediate aftermath of a suicide attempt and in ongoing safety planning and treatment. As such they can deliver early information, support and education to carers as well as longer term psychosocial interventions. However, training is essential. Training should incorporate dissemination of evidence from systematic reviews, skills development, and lived experience from carers themselves as part of coproduced education packages, delivery of which should be prioritized for front line staff.

## Strengths and limitations

Strengths of this systematic review include the mixed method approach and the relatively large number of studies compared to previous reviews. In addition, the focus on adult carers of adults brings additional insights to the experiences of carers which will be of benefit to clinical practice.

A primary limitation is the screening, selection, appraisal and synthesis of studies being carried out by the first author only, although oversight through discussion was provided by the other authors. Most of the quantitative studies were cross sectional and involved online or interview based questionnaires meaning there were no comparison groups, not all used validated measures and there was some risk of non-response bias. However, the questionnaires were all relevant to the research question.

A small number of the studies reviewed included a minority of bereaved individuals or carers of young people, however the vast majority of study participants were adult carers of over 18-year olds. Most studies were conducted in western countries with participants predominantly white, female and middle aged. This highlights a need for research that adequately targets global majority populations and

a wider adult age range. This may require revisiting normative western definitions of caring and considering novel recruitment and data collection strategies.

## CONCLUSIONS 5

Healthcare services are reliant on informal caregivers to support individuals at risk of suicide in their home environments and it is likely that many carers support family members without any health or social care support. This systematic review provides insights into the challenging and frightening experiences encountered by this population and highlights support and involvement needs. There is a requirement for timely interventions that involve early support and information to help caregivers understand what has happened, what they can do to help, how to navigate the healthcare system and how they can take care of themselves. In addition, longer term interventions are required to aid processing of emotional responses and adjustment to living with the possibility of suicide. Psychosocial interventions should include development of coping and communication strategies. As well as carer specific programmes, couple and family therapy interventions should be developed to address relational issues raised by the care recipient's suicidality, and transitions into and consequences of a caring role. Support for carers is not just a healthcare issue. Policy makers have a responsibility to ensure cares are properly recognized in suicide prevention strategy and policy, including securing investment to support this important population.

## **AUTHOR CONTRIBUTIONS**

KL was responsible for study conception. KL, ZD, DJ, HA contributed to study design and interpretation of results. KL conducted searches, assessed studies for eligibility and quality, and extracted and synthesised data with support from the other authors. KL drafted the manuscript and ZD, DJ, HA reviewed it critically for intellectual content. All authors approved the final report and are accountable for all aspects of the work.

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The authors have no conflict of interest to declare.

## PEER REVIEW

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## DATA AVAILABILITY STATEMENT

Data available from corresponding author on request.

## **IMPACT STATEMENT**

Nurses and clinicians working in all specialities will encounter informal carers during and following patients' suicidal crises and are in a prime position to provide information, education and support. We think that the findings of this review will raise clinicians' awareness of the impact caring can have, both in the short and longer term, and how the relationship between the carer and care recipient can be affected. These understandings will enable clinicians to adapt and enhance their practice, helping carers to feel recognized and supported, which will go some way to assisting them in their role.

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