Comparative Effectiveness Review
Number xxx

Interventions to Improve Care of Bereaved Persons

Executive Summary

Main Points

- Only a small body of evidence has addressed screening approaches. There was insufficient evidence for evidence statements regarding patient experience, validity and diagnostic accuracy of the screening tool or approach, or adverse events associated with the screening process.
- A small body of evidence has addressed the identification of bereaved people at risk or with grief disorder; and reports positive diagnostic accuracy of the Inventory of Complicated Grief (ICG). However, none of the identified studies used a DSM or ICD grief disorder diagnosis as the reference standard.
- A substantial body of evidence addressed psychotherapy, pharmacotherapy, expert-facilitated support groups, peer support, self-help approaches, and other interventions (writing and music, comprehensive support, integrative medicine and CAM) but the strength of evidence (SoE) was limited for many interventions. No study evaluated spiritual counselling.
- We found moderate SoE for the beneficial effect of psychotherapy on severity of grief disorder, grief symptoms, and depression symptoms and expert-facilitated support groups on grief symptoms and depression symptoms.
- There is a small body of evidence reporting on patients diagnosed with grief disorders; with low SoE for the beneficial effect of psychotherapy on grief disorder and grief symptoms.

Background and Purpose

Bereavement – the state of having lost someone – and grief – the emotional response to the loss - are fundamental aspects of the life course and most individuals will experience the loss of someone during their lifetime.[1] Most individuals experience acute grief without formal intervention, yet a small subset of individuals develop complicated grief or grief with a high level of distress that extends 6 to 12 months following the

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death.[2] This type of grief was named prolonged grief disorder by the WHO and included in the ICD-11 in 2018[3] and classified as a formal disorder in the DSM-V TR in 2022.[4] There are a range of decisional dilemmas related to the screening, intervention, and follow-up of bereaved individuals for grief and grief-related needs over time. First, there are important questions related to the appropriate screening of bereaved individuals, or those who may become bereaved, to identify and intervene on maladaptive grief responses, such as prolonged grief disorder. There are also several decisional dilemmas pertaining to appropriate interventions for grief. Given the cyclical and non-linear trajectory of grief, identifying the optimal time for intervention is a persistent challenge for the field. There are also outstanding questions regarding the effectiveness of treatment for bereaved individuals who have been identified as having a grief disorder. Finally, questions remain regarding feasible and appropriate follow-up of bereaved individuals identified as grieving and with grief-related needs.

In 2023, Congress directed The Agency for Healthcare Research and Quality (AHRQ) to establish an evidence base for what constitutes high-quality bereavement and grief care. This systematic review will inform an independent subject matter expert panel which will assess the feasibility of developing consensus-based quality standards for high quality bereavement and grief care. That panel will be convened by the Substance Abuse and Mental Health Services Administration (SAMHSA).

Methods

The systematic review was guided by a systematic review protocol[5] registered in PROSPERO (CRD42023466057). Key informants supporting the protocol development and a multidisciplinary technical expert panel the report.

We searched PubMed, EMBASE, CINAHL, PsycINFO, Social Work Abstracts, and Dimensions, clinicaltrials.gov, ICTRP, Cochrane Database of Systematic Reviews, PROSPERO, and four clinical practice guideline databases from inception to September 8, 2023. We set up a submission of Supplemental Evidence And Data for Systematic Reviews (SEADS), reference-mined pertinent reviews, and contacted experts in the field. The search will be updated during public review of the report.

We included evaluations of screening approaches, diagnostic accuracy studies, grief interventions, and treatment of grief disorder studies reporting on an intervention and concurrent control group or comparator intervention.

We assessed the risk of bias, evaluated the applicability of studies, and determined the strength of evidence following AHRQ EPC methods.

Results

The literature searches identified 8,301 citations, we obtained 3,497 as full text, and 166 met eligibility criteria.

Screening

We identified 5 studies evaluating screening approaches. No study evaluated the clinical impact of the screening process and none of the studies reported on administrative time of the screening process or rater-reliability of the screening tool. There was insufficient evidence to address best timing of screening as well as whether the effects of screening vary by patient characteristics or settings.

Diagnosing

We identified 11 studies evaluating diagnostic tools. This small body of evidence addressed the identification of bereaved people at risk for or with a grief disorder; the Inventory of Complicated Grief (ICG) was the only tool evaluated in more than one study and showed positive diagnostic accuracy. However, none of the identified studies used a gold standard references of either the DSM or ICD grief disorder diagnosis. Instead, diagnostic accuracy was based on health outcomes measured over time or a diagnostic interview assessing grief disorder symptoms. None of the studies reported on the test-retest reliability or the clinical impact of a correct or incorrect diagnosis. The evidence was also insufficient for concrete evidence statements on patient experience.

Grief interventions

We identified 172 studies evaluating interventions to address bereavement. A substantial body of evidence addressed psychotherapy, pharmacotherapy, expert-facilitated focus

groups, peer support, self-help approaches, and other interventions (writing and music, comprehensive support, integrative medicine, and CAM). We found moderate strength of evidence for the beneficial effect of psychotherapy, expert-facilitated support groups, and writing and music therapy on severity of grief disorder, grief symptoms, and depression symptoms. There was insufficient evidence for the effect of peer support or self-help approaches.

Table: Summary of findings and strength of evidence Key Question 3

Intervention and Comparison	Key Outcome	Findings	Strength of Evidence
Psychotherapy	Incidence of grief disorder	N/A	Insufficient
Psychotherapy	Severity of grief disorder	Favors intervention (SMD - SMD -0.73; CI -1.00, -0.45; RR 0.49; CI 0.26, 0.92)	Moderate for benefit
Psychotherapy	Grief symptoms	Favors intervention (SMD -0.49; CI -0.84, 0.14; 18)	Moderate for benefit
Psychotherapy	Quality of life	No systematic effect (SMD 0.30; CI -0.19, 0.80)	Low for no effect
Psychotherapy	Loneliness	N/A	Insufficient
Psychotherapy	Suicidal ideation, attempted suicide, suicide completion	Conflicting results (SMD -0.22; CI -0.55, 0.12; RR 1.06; CI 0.48, 2.33)	Insufficient
Psychotherapy	Adverse health behaviors	No systematic effect (SMD 0.32; -0.29, 0.93)	Insufficient
Psychotherapy	Depression symptoms	Favors intervention (SMD ¬0.41; CI -0.55 0.55; RR 1.05; CI 0.11, 9.93)	Moderate for benefit
Psychotherapy	Unintended consequences of the intervention	N/A	Insufficient
Pharmacotherapy	Incidence of grief disorder; Severity of grief disorder	N/A	Insufficient
Pharmacotherapy (citalopram)	Grief disorder symptoms	Favors intervention (RR 0.65; CI 0.53, 0.79; 1 study, n=198).	Low for benefit
Pharmacotherapy (citalopram)	Grief symptoms	No systematic effect (SMD -0.07; -0.78, 0.65; 1 study, n=30)	Insufficient
Pharmacotherapy	Quality of life	N/A	Insufficient
Pharmacotherapy (nortriptyline)	Depression symptoms	N/A	Insufficient
Pharmacotherapy	Loneliness; Suicide outcomes; Adverse health behaviors	N/A	Insufficient
Pharmacotherapy	Suicidal ideation	Favors intervention (RR 0.21; CI 0.07, 0.60; 1 study, n=198)	Low for benefit
Pharmacotherapy	Unintended consequences of the intervention	N/A	Insufficient
Expert-facilitated Support Group	Incidence of grief disorder	N/A	Insufficient

Expert-facilitated Support Group	Severity of grief disorder	No systematic effect (SMD -0.16; CI -0.51, 0.19)	Insufficient
Expert-facilitated Support Group	Grief symptoms	Favors intervention (SMD -0.34; CI -0.62, -0.06; RR 1.19; CI 0.57, 2.45)	Moderate for benefit
Expert-facilitated Support Group	Quality of life	No systematic effect (SMD 0.33; CI -1.18, 2.46)	Insufficient
Expert-facilitated Support Group	Loneliness	N/A	Insufficient
Expert-facilitated Support Group	Adverse health behaviors	No systematic effect (SMD -0.15; CI -0.50, 0.20)	Insufficient
Expert-facilitated Support Group	Depression symptoms	Favors intervention (SMD -0.40; CI -0.75, -0.06)	Moderate for benefit
Expert-facilitated Support Group	Suicidal ideation, attempted suicide, suicide completion	Favors intervention (RR 0.19; CI 0.02, 2.04)	Low for benefit
Expert-facilitated Support Group	Unintended consequences of the intervention	N/A	Insufficient
Peer Support	Incidence of grief disorder; Severity of grief disorder	N/A	Insufficient
Peer Support	Grief symptoms	No systematic effect (estimate N/A)	Insufficient
Peer Support	Quality of life	No systematic effect (RR 0.63; CI 0.22, 1.79)	Insufficient
Peer Support	Depression; Loneliness; suicide outcomes; adverse health behaviors	N/A	Insufficient
Peer Support	Unintended consequences of the intervention	No systematic effect (estimate N/A}	Insufficient
Self-help intervention	Incidence of grief disorder	N/A	Insufficient
Self-help intervention	Severity of grief disorder	No systematic effect (SMD -0.47; CI -0.96, 0.03)	Insufficient
Self-help intervention	Grief symptoms	No systematic effect (SMD 0.40; CI -0.23, 1.04)	Insufficient
Self-help intervention	Quality of life	Both studies reported positive effects, but the estimates varied and no meaningful summary could be derived (SMD 0.21; CI -1.09, 1.51)	Insufficient
Self-help intervention	Loneliness; Suicide outcomes; Adverse health behaviors	N/A	Insufficient
Self-help intervention	Depression symptoms	No systematic effect (SMD -0.21; CI -0.98, 0.56)	Low for no effect
Self-help Intervention	Unintended consequences of the intervention	N/A	Insufficient
Other: Writing and Music	Grief disorder symptoms	No systematic effect (SMD -0.22; CI 1.06, 0.63)	Low for no effect
Other: Writing and Music	Grief symptoms	Both studies reported positive effects, but the estimates varied and no meaningful summary could be derived (SMD 0.22; CI -1.55, 1.99)	Insufficient

Other: Writing and Music	Depression symptoms	No systematic effect (SMD 0.21; CI -0.88, 1.30)	Low for no effect
Other: Comprehensive Provider Support	Grief disorder symptoms	No systematic effect (RR 0.49; CI -2.40, 1.43	Low for no effect
Other: Comprehensive Provider Support	Grief symptoms	No systematic effect (SMD -1.18; CI -3.30, 0.94; RR 0.32; CI 0.14, 0.76)	Low for no effect
Other: Comprehensive Provider Support	Quality of life	Favors intervention (SMD 0.37; CI 0.23, 0.51)	Low for benefit
Other: Comprehensive Provider Support	Loneliness	Favors intervention (SMD -0.42; CI -0.82, -0.01)	Low for benefit
Other: Comprehensive Provider Support	Suicide ideation	Favors intervention (SMD -0.52; CI -0.92, -0.11)	Low for benefit
Other: Comprehensive Provider Support	Depression symptoms	No systematic effect (SMD -0.30; CI -0.85, 0.24; RR 0.54; CI 0.11, 2.53)	Low for no effect
Other: Integrative Medicine	Grief disorder symptoms	Both studies reported positive effects, but the estimates varied and no meaningful summary could be derived (SMD -0.94; CI -1.68, -0.21)	Insufficient
Other: Integrative Medicine	Grief disorder symptoms	Both studies reported positive effects, but the estimates varied and no meaningful summary could be derived (SMD -1.37; CI -8.73, 5.99)	Insufficient
Other: Integrative Medicine	Depression symptoms	No systematic effect (SMD -0.79; CI -2.28, 0.71)	Low for no effect
KQ3a: Effect of intervention timing	All key outcomes	We did not detect systematic effects, but analyses were limited	Insufficient
KQ3b: Effect of Gender	Grief symptoms	The proportion of women in the study was associated with the effect of the intervention on grief symptoms indicating that men and women may respond differently to the intervention, but few studies contributed to the analysis	Low for potentially differential effect
KQ3b: Effect of Grief Severity	Depression symptoms	Grief severity was associated with the effect of the intervention on depressive symptoms and suggested that participants with more complicated grief benefit more from interventions, but analysis were limited	Low for potentially differential effect
KQ3b: Effect of Patient Characteristics	All key outcomes	No systematic effect of relationship to deceased, age of deceased, expected (vs unexpected) death, violent death, adults (vs pediatric sample)	Low for potentially no effect
KQ3b: Effect of Setting	All key outcomes	No systematic effect detected for US (vs non-US) or setting of the death of the loved one	Low for potentially no effect

Notes: N/A no studies

Grief disorder treatment

We identified 3 studies evaluating treatment for patients diagnosed with grief disorder. All studies evaluated psychotherapy. There was low strength of evidence for the beneficial effect of psychotherapy on grief disorder and grief symptoms. None of the studies reported on outcomes including continued meeting grief disorder criteria, quality of life, loneliness, suicide outcomes, substance use, or unintended consequences.

Limitations

We identified a large body of evidence documenting intervention evaluations for bereaved persons. However, the evidence for diagnosing and treating grief disorders is limited given that grief has only been introduced as a clinical diagnosis in the ICD-11 in 2018 and the DSM-IV TR in 2022.

Implications and Conclusions

Despite the large body of evidence identified in the report, more research is needed on identifying effective screening approaches. Furthermore, a clinical diagnosis specific to grief has only been introduced recently and more diagnostic accuracy studies are needed using the established diagnoses. While a substantial body of evidence demonstrates positive effects of grief interventions on grief and depression symptoms, more evidence is needed to quantify the presence and absence of unintended consequences, harms, and adverse events associated with interventions. In addition, future research should assess the effects of treatment for individuals with a clinically diagnosed grief disorder.

A clinical diagnosis specific to grief has only recently been introduced and more research is needed on identifying effective screening approaches and we need more diagnostic accuracy data on existing grief disorder assessment tools. A substantial body of evidence demonstrates positive effects of grief interventions on grief and depression symptoms, but more data are needed on the presence or absence of adverse events. Future research needs to assess the effects of treatment for people with a clinically diagnosed grief disorder.

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