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A scoping review of informal social support in bereavement: Provider and recipient perspectives of helpful and unhelpful interactions

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ADMINISTRATIVE INFORMATION

Support - None to declare.

Review Stage at time of this submission - Preliminary searches.

Conflicts of interest - None declared.

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Amendments - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 16 August 2023 and was last updated on 16 August 2023.

INTRODUCTION

Review question / Objective The aim of the scoping review is to synthesise findings from primary quantitative, qualitative, and mixed-method studies that investigate informal social support provision for bereaved adults in relation to provider and recipient perspectives on helpful and unhelpful interactions.

The scoping review will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines (Tricco et al., 2018). The Sample, Phenomenon of Interest, Design, Evaluation, and Research type (SPIDER; Cooke et al., 2012) framework will be utilised to inform inclusion and exclusion criteria.

The sample will be any adult (18+) who has experienced the bereavement of a family member, friend, or colleague and is sampled from the general community or universities.

The phenomenon of interest will be the features inherent in interactions between informal social

support providers and bereaved adults. Informal social support is defined as the instrumental, emotional, and informational support supplied by an individual's existing social network of family, friends, work colleagues, neighbours, acquaintances, and the community (Aoun et al., 2018; Dyregov & Dyregov, 2008; Wills, 2010). The design and research type will be qualitative, quantitative, and mixed-method primary studies. The evaluations will be helpful or unhelpful interactions between informal social support providers and bereaved adult recipients, considered from the perspective of both providers and recipients.

Background Three factors typically impact the informal social support process in bereavement: norms (rules that govern acceptable behaviour), public stigma (disapproval and discrimination of others based on the dominant norms), and grief literacy (knowledge that facilitates consideration of loss and grief, skills enabling supportive acts, and principles of care and compassion) (Breen, 2021).

To compound the influence of these factors, numerous characteristics of the deceased, bereaved, and potential support provider also influence the informal social support process (Logan et al., 2018). A potential provider must primarily comprehend the support needed for the informal social support process to be beneficial in bereavement (Breen, 2021). Subsequently, the recognised support must be appropriate and proffered by the provider. After that, the recipient must perceive the support provided as helpful (Breen, 2021). This perception is based on the provision's type, source, timeliness (Aoun et al., 2019), and the recipient's responsiveness to social support (Smith et al., 2020). Given the many components involved, it should be no surprise that much can and does go wrong in the informal social support process (Breen, 2021).

In such situations, potential providers can lack compassion, offer mere platitudes, purposely avoid the bereaved, ask damaging questions, and even joke about the loss (Aoun et al., 2018; Breen & O'Connor, 2011). Furthermore, potential providers may not support the bereaved, even when they recognise the need for it (Logan et al., 2018). Grindrod and Rumbold (2018) identified this lack of provision as a result of uncertainty about what support to offer and concern regarding the recipient's privacy. Furthermore, potential providers can face challenges dealing with their own emotions, initiating conversations, communicating about grief, and behaving to comfort themselves rather than supporting the grieving individual (Breen et al., 2017). Moreover, Breen et al. (2017) reported that some bereaved individuals found it difficult to recognise, express, seek, and accept informal social support, further jeopardising the process.

The aforementioned issues place the provision of informal social support for bereaved adults at a juxtaposition: it can be both the key to coping with bereavement and a source of distress. This paradoxical phenomenon has prompted calls for investigating the features inherent in interactions between informal social supporter providers and bereaved adults to understand support attempts that fail (Dyregrov & Dyregrov, 2008; Dyregrov et al., 2018; Lakey & Orehek, 2011; Lehman et al., 1986; Nurullah, 2012). However, simple, standardised psychometric measures seem incapable of capturing the multifaceted interaction between bereaved adults and informal social supporters (Dyregrov et al., 2018). Dyregrov (2002) and Lakey and Orehek (2011) propose that the dynamic processes occurring during these encounters may be more relevant than merely measuring the level of support provided.

Although the extant literature has principally focused on the support needs of bereaved adults (e.g., Schoonover et al. 2022), some investigation of interactions between informal support providers and bereaved adults has been conducted (e.g., Dyregrov, 2006; Dyregrov et al., 2018; Lehman et al., 1986). Notably, Dyregrov et al.'s (2018) work was informed by Lakey and Orehek (2011), who asserted that interactions between social supporters and the bereaved activated a reciprocal emotional regulation process. Utilising their postulated Relational Regulation Theory (RRT), they proposed that interactions instigated by a recipient (e.g., a bereaved parent) impacted the support provider's thoughts, feelings, and behaviours, which, in turn, influenced the recipient (Lakey & Orehek, 2011). They noted how the complexity of this process presents numerous challenges for helpful informal social support provision. In fact, it may be this process that underscores the paradoxical effect of informal social support provision on bereavement.

Rationale Since Freud's first conceptualisation of bereavement, the literature has undergone a transformation from the initial stage models of psychoanalysis, sociology, and anthropology to the current synchronic models of psychology. Research indicates that the biopsychosocial sequela resulting from bereavement is significant, and its severity depends on many bereaved and decedent variables. As bereavement has been deemed one of the most severe stressors an individual can experience, the bereaved typically utilise a variety of coping mechanisms during the bereavement process. Informal social support seeking is one such important means of coping. Despite scant accord regarding its conceptualisation, definition, operationalisation, or measurement, research has consistently identified the beneficial effects of informal social support on bereavement outcomes.

However, while informal social support is favoured over formal social support to ameliorate distress in bereavement, it can also increase psychological distress. This paradox is understandable given the myriad factors idiosyncratic to the social support process in bereavement. Understanding this paradoxical phenomenon requires considering numerous social, individual, and interactive variables. However, to date, social support research has focused on the bereaved's support needs, with scarce attention given to the provider's experiences or the recipient-provider interactive process. In fact, to date, no known scoping review has been conducted that explicitly investigates the perspectives of bereaved adults AND their informal social support providers. As such, this scoping

review aims to increase understanding of the complexities of interactions between informal social support providers and bereaved adults from the perspective of both the provider and recipient. Understanding the processes inherent in informal social support interactions would better clarify how informal social support influences bereavement outcomes. Once identified, features of useful interactions can be fostered, while harmful features can be modified to promote effective informal social support for the bereaved.

METHODS

Strategy of data synthesis A search of several databases will be conducted, including MEDLINE, PsycINFO, CINAHL, ProQuest Central. An additional search for relevant studies in the grey literature by utilising ProQuest Dissertations and Theses will be undertaken. An initial limited search of Google Scholar was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy for the aforementioned databases. The search will consist of the keywords (bereave* or grief or griev* or mourn* or death) (social support* or social network* or social relationship* or peer support* or family support*) (provider* or recipient* or interaction* or perspective*) with slight variations depending on the database. A citation search and reference list search will identify any further articles. Each database will be searched by title and abstract only, with two limiters applied: peer-reviewed and English language.

Data will be synthesised narratively and grouped according to primary outcomes (helpful and unhelpful interactions), identifying the number of studies assessing each of the outcomes, the range of effect sizes (low to high), and grouping together closely those studies that utilised similar measures of informal social support or outcome assessment. This scoping review will consider both experimental and quasi-experimental study designs including randomized controlled trials, non-randomized controlled trials, before and after studies and interrupted time-series studies. In addition, analytical observational studies including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies will be considered for inclusion. This review will also consider descriptive observational study designs including case series, individual case reports and descriptive cross-sectional studies for inclusion. Qualitative studies will also be considered that focus on qualitative data including, but not limited to, designs such as

phenomenology, grounded theory, ethnography, qualitative description, action research and feminist research.

Following the search, all identified citations will be collated and uploaded into EndNote 20 (Clarivate Analytics, PA, USA) and duplicates removed. The titles and abstracts will then be screened by one independent reviewer for assessment against the inclusion criteria for the review. A second reviewer will screen 10% of the articles. A third reviewer will be utilised to arrive at consensus in the case of disagreements. Potentially relevant sources will be retrieved in full and their citation details imported into Endnote 20. The full text of selected citations will be assessed in detail against the inclusion criteria by one independent reviewer, with a second reviewer assessing 10% of the articles. Reasons for exclusion of sources of evidence at full text that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, or with an additional reviewer. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram (Tricco et al., 2018). Records will be imported into the EndNote reference management system for Stage 1 and Stage 2 article selection. Articles will be screened independently by one reviewer, with a second reviewer screening 10% of the articles. A third reviewer will be utilised to arrive at consensus in the case of disagreements. Data extraction will be performed by one reviewer to a standardised data extraction template and independently checked by a second reviewer. Data extracted will include specific details about the participants, concept, context, study methods, and key findings relevant to the review question. The data extraction tool will be modified and revised as necessary during the process of extracting data from each included evidence source. Modifications will be detailed in the scoping review. Any disagreements that arise between the reviewers will be resolved through discussion or by a third reviewer. If appropriate, authors of papers will be contacted to request missing or additional data, where required. Once approved, the information will be entered into Microsoft Excel and Word templates for data synthesis.

Study quality will be assessed with The Johanna Briggs Institute assessment measures as appropriate for the study designs (e.g. cross-sectional analytical, cohort/longitudinal studies). One reviewer will independently rate study quality

and a second reviewer will be utilised to arrive at consensus of study quality. Quality assessment of the chosen studies will be conducted via the Johanna Briggs Institute of critical appraisal tools (JBI; <https://jbi.global/critical-appraisal-tools>).

Eligibility criteria Inclusion criteria:

Empirical primary research.

Adults over the age of 18 from the general population.

Quantitative, observational (including prospective and retrospective cohort studies), qualitative, mixed methods, cross-sectional studies, theses, randomised and non-randomised control trials.

Study considers intended, perceived, and/or received informal social support behaviour towards a bereaved adult, from the perspective of the informal social support provider (real or hypothesised) AND bereaved (real or hypothesised).

Any publication date.

English language.

Full text available.

Bereaved of a deceased human

Exclusion Criteria:

Conference abstracts or proceedings, commentaries, articles in media, editorials, op-eds, opinion articles, letters to the editor, replies from author, periodicals, news items, erratum.

Children and adolescents (below age 18).

Protocols/frameworks, book chapters or reviews, textbooks, narrative papers, calls for research, case studies, systematic reviews, trade publications, discussion and perspective papers.

Study does not consider intended, perceived, and/or received informal social support behaviours towards a bereaved adult from the perspective of the informal social support provider (real or hypothesised) AND bereaved (real or hypothesised).

Non-English language.

No full text available

Bereaved of a deceased non-human (e.g., pet).

Source of evidence screening and selection

Following the search, all identified citations will be collated and uploaded into EndNote 20 (Clarivate Analytics, PA, USA) and duplicates removed. The titles and abstracts will then be screened by one independent reviewer for assessment against the inclusion criteria for the review. A second reviewer will screen 10% of the articles. A third reviewer will be utilised to arrive at a consensus in the case of disagreements. Potentially relevant sources will be retrieved in full and their citation details imported into Endnote 20. The full text of selected citations will be assessed in detail against the inclusion criteria by one independent reviewer, with a

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Reporting results / Analysis of the evidence

Study quality will be assessed with The Johanna Briggs Institute assessment measures as appropriate for the study designs (e.g. cross-sectional analytical, cohort/longitudinal studies). One reviewer will independently rate study quality and a second reviewer will be utilised to arrive at consensus of study quality.

Presentation of the results The findings of this review will be presented at scientific and academic congresses and distributed to community and government stakeholders. A manuscript summarising the scoping review findings will be submitted for publication in a peer-reviewed journal.

Proposed title: A scoping review of informal social support in bereavement: Provider and Recipient perspectives of helpful and unhelpful interactions.
Authors: Tognela, J. A., Breen, L. J., Rudaizky, D., Robinson, K. T.

Primary journal: Death Studies Impact Factor: 4.34
Secondary journal: Omega: Journal of Death and Dying ImpactFactor: 2.85.

Language restriction English or availability of translation into English.

Country(ies) involved Australia.

Keywords Informal social support; Bereavement; Interactions; Helpful and unhelpful informal social support.

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Contributions of each author

Author 1 - Josephine Tognela - Author 1 conducted finalising inclusion and exclusion criteria, initial and final screening, data extraction, quality assessment, and manuscript drafting.

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Author 2 - Breen Lauren - Author 2 provided expertise on conceptual, methodological, article selection, quality analysis, and resolving disputes between Reviewer 1 and Reviewer 2. The author read, provided feedback and approved the final manuscript.

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Author 3 - Daniel Rudaizky - Author 3 provided statistical expertise.

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Author 4 - Kylie Robinson - The author assisted with screening, full text, and data quality assessment by assessing 10% of the articles against the inclusion criteria for the review.

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