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Addressing Existential Distress in Family Caregivers: A Scoping Review of Meaning-Making Interventions

Natalie S. McAndrew, PhD, RN, ACNS-BC, CCRN-K^{1,2} [Associate Professor] [Nurse Scientist], Tamryn F. Gray, PhD, RN, MPH³ [Instructor in Medicine], Lyndsey Wallace, PsyD, ABPP⁴ [Clinical Health Psychologist and Associate Professor], Kelly Calkins, PhD, RN⁵ [Assistant Professor], Jill Guttormson, PhD, RN⁵ [Professor and Dean], Eric Harding, MLS⁶ [Clinical Services Librarian], Allison J. Applebaum, PhD^{7,8} [Associate Attending Psychologist] [Associate Professor of Psychology in Psychiatry]

¹University of Wisconsin-Milwaukee, School of Nursing, College of Health Professions & Sciences, 1921 East Hartford Avenue, Milwaukee, WI 53211

²Froedtert & the Medical College of Wisconsin Froedtert Hospital, 9200 West Wisconsin Avenue, Milwaukee, WI 53226

³Dana-Farber Cancer Institute, Brigham and Women's Hospital, Harvard Medical School

⁴Department of Psychiatry and Behavioral Medicine, Medical College of Wisconsin, Medical College of Wisconsin, 9200 W. Wisconsin Ave., Milwaukee, WI 53226, USA

⁵Marquette University, College of Nursing, P.O. Box 1881, Milwaukee, WI 53201

⁶Medical College of Wisconsin Libraries, 8701 Watertown Plank Road, Milwaukee, WI 53226

⁷Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, Memorial Hospital for Cancer and Allied Diseases, 641 Lexington Avenue, 7th Floor, New York, NY 10022

⁸Weill Cornell Medicine, Department of Psychiatry, 525 East 68th Street, New York, NY 10065

Abstract

Objectives: Family and friend caregivers often feel overwhelmed by and ill-prepared for their responsibilities. Many feel helpless living with uncertainty about the outcome of the patient's illness, which leads to existential distress. Supportive care interventions that address existential distress by promoting meaning and purpose buffer the negative effects of caregiver burden and promote resilience and growth. The purpose of this scoping review is to describe the depth and breadth of available interventions targeting caregiver existential distress.

Methods: We followed the Joanna Briggs Institute's scoping review methods and applied the PRISMA Extension checklist. SCOPUS, Ovid MEDLINE, and PsycINFO databases were

Corresponding Author: Natalie McAndrew, University of Wisconsin-Milwaukee, School of Nursing, College of Health Professions & Sciences, 1921 East Hartford Avenue, Milwaukee, WI 53211, mcandre3@uwm.edu.

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searched for interventions that targeted existential distress by promoting meaning-making, spiritual well-being, post-traumatic growth, and/or benefit finding for caregivers of seriously ill adult patients.

Results: We screened 1,377 titles/abstracts and 42 full-text articles. Thirty-one articles (28 unique studies) met inclusion criteria. Most interventions were designed for caregivers supporting patients with cancer (n = 14) or patients receiving palliative care (n = 9). Promising interventions included Meaning-Centered Psychotherapy for Cancer Caregivers, Meaning-Based Intervention for Patients and their Partners, Legacy Intervention for Family Enactment, Family Participatory Dignity Therapy, and Existential Behavioral Therapy. More than half of the studies (n = 20, 64%) were in the feasibility/acceptability/pilot stage of intervention testing.

Conclusion: Large RCTs with more diverse samples of caregivers are needed. Future research should explore the impact of delivering meaning-making interventions to caregivers throughout the illness trajectory. Developing strategies for scaling up and conducting cost analyses will narrow the research and practice gap for meaning-making interventions.

Keywords

Cancer; psychological care; spiritual care; supportive care; quality of life; bereavement; Existential distress; meaning-making; family caregivers; spiritual well-being; interventional research

Introduction

Family caregivers (defined as relatives, chosen families, and friends) are instrumental to the delivery of high-quality patient care. Despite their expanding role as collaborators in patient care, family caregivers receive limited acknowledgement and support within healthcare systems. Caregiving for a seriously ill person is a daunting responsibility, and yet, family caregivers often receive little preparation, resources, and support for their important caregiving role [1]. The majority of caregivers experience caregiver burden, which occurs when caregiving requirements exceed one's capacity, threaten caregiver well-being, and compromise their ability to care for the person living with serious illness [2].

For many, caregiver burden contributes to symptoms of anxiety, depression, and isolation [3]. The uncertainty inherent in serious illness contributes to spiritual and existential distress, understudied aspects of caregiver burden [4]. Further, caregivers are expected to provide emotional support to the patient while confronting their own fears that the person they are supporting could die [5]. Existential distress, a major challenge for caregivers, is also caused by the extensive demands of the caregiving role, guilt associated with prioritizing their own needs, and changes to one's sense of identity, all of which can lead to a loss of meaning and purpose. [4]

Despite these negative outcomes, positive changes can also result from caregiving. Documented benefits of caregiving include personal growth, deepened relationships, and an increased sense of meaning and purpose [3]. Interventions that address existential distress can promote these positive outcomes and buffer caregiver burden [4]. Meaning-making, a cognitive and emotional process in which an individual searches for connection and purpose to make sense of their situation, is a way of coping with existential issues during

stressful and traumatic events [4]. Meaning-making interventions incorporate the strategies of cognitive reappraisal, cognitive-emotional processing, and meaning-focused coping [6]. Meaning-making interventions have been used successfully with diverse patient populations; however, little is known about meaning-making interventions designed for family caregivers. An earlier review of psychosocial interventions for cancer caregivers suggested interventions that target existential distress for this population are limited [7]. Our scoping review is the first to describe the range of available interventions that target existential distress for family caregivers supporting patients with serious illness.

Methods

Guided by the Joanna Briggs Manual for Evidence Synthesis [8] and the PRISMA-ScR checklist [9] we began the review process by determining the population of interest: adult family caregivers of seriously ill adult patients. The concept of interest was interventions that promote meaning making, target existential distress, and/or aim to enhance meaning and purpose, spiritual well-being, post-traumatic growth, or benefit finding. We defined meaning-making interventions as those that aim to help an individual(s) make sense of their experience or find meaning and/or benefits during times of distress or suffering [4]. The context was inpatient, outpatient, or community settings.

The objectives of this scoping review were to:

1. Describe theoretical foundations of family caregiver interventions focused on meaning-making and mechanisms of action,
2. Determine the family caregiver populations in which meaning-making interventions have been tested,
3. Provide a rich description of the breadth and depth of interventions that aim to enhance meaning and purpose for family caregivers, including recipients of interventions (caregiver only or caregiver and patient), components, dosage, delivery, platform, and setting in which the intervention is delivered, and
4. Describe the efficacy of meaning-making interventions based on changes in outcome measures and effect sizes.

Studies were included in the review if they met the following criteria: (1) Participants were adult family caregivers (≥ 18 years of age) caring for seriously ill adults; (2) the intervention included at least one component that addressed meaning-making in caregivers; and (3) the intervention targeted the outcomes of meaning, existential distress, spirituality, benefit finding, or post-traumatic growth. All phases of intervention development were included. We excluded publications that were: not research, non-interventional studies, protocols, dissertations, case studies, pediatric population studies, review articles, and conference abstracts.

To create the search, a medical sciences librarian built a foundation search of meaning-making and caregiver terms, and then combined the Cochrane Highly Sensitive Search and Waffenschmidt's NRS hedge. Databases searched included SCOPUS, Ovid MEDLINE, and PsycINFO. The complete search from Ovid MEDLINE is found in Figure 1. The

search captured literature published through March 9, 2021 and was managed in Zotero and uploaded to Rayyan [10] for article screening and selection. The review protocol was not registered in PROSPERO as they do not accept scoping reviews.

Five team members independently screened titles and abstracts in Rayyan with an a priori criterion that at least 3 team members screen each abstract. Any disagreements were discussed as a team until agreement was reached. Two team members reviewed each full text article, and after the final selection of articles, two extracted data to ensure accuracy.

We created a Qualtrics form that captured the elements needed to achieve the goals of this review. Data were downloaded from Qualtrics for descriptive analysis in SPSS and text-based responses were downloaded to Microsoft Word for analysis. The first author created an evidence table to display data in a synthesized format to guide further analysis.

Results

Search results are described in the PRISMA diagram (Figure 2). We screened 1,377 article titles and abstracts, and 42 full-text articles. Three articles were identified manually after search completion because they were follow-up studies from two of the included studies identified in the original search. The search was updated from 3/9/2021 to 3/9/2023 and 8 additional articles were found. A total of 31 articles were included in the review representing 28 unique studies. Of these 31 articles, two were secondary analyses from RCTs that provided more information about the intervention mechanisms of action. One study reported qualitative data (exit interviews) from a mixed-method RCT.

Study country, design, patient population supported by caregivers

Studies took place in the United States (n = 13); China (n = 5); Germany (n = 4), Australia (n = 3); Canada (n = 1); England, (n = 1); Japan (n = 2); Iran (n = 1), and Switzerland (n = 1) (Supplemental Table 1). Most studies were single site, with seven multi-site studies. More than half (n = 20, 64%) were feasibility/acceptability or pilot studies. Slightly more than half (n = 18, 58%) either used a dyadic approach that included both the patient and family caregiver, or the intervention was designed for the patient, and the family caregiver was included as part of intervention delivery. The remaining 13 studies focused on the caregiver as the sole intervention recipient. Most caregivers were supporting patients with cancer (n = 14) or those in receipt of palliative care (n = 9). While most of the palliative care patients had advanced cancer, some had advanced neurological, cardiac, or renal disease. Patient populations also included Alzheimer's Disease (n = 3), motor neuron disease (n = 2), and multiple sclerosis, (n = 1). Two studies included bereaved caregivers (n = 2). Seven studies included patients with early-stage disease or initiated the intervention early in the treatment process.

Caregiver samples

This scoping review represents a total of 1,599 family caregivers (range: 5 to 354). The mean reported age was 56.55 years (range: 38 to 70). Of the studies that reported sex, almost all samples were at least 50% female, with many samples comprised of 70% or higher female participants. Although multiple studies did not report race, of those reporting

race, many samples were 80% White or higher. Two samples were more racially diverse with 44% [11] and 69% [12] African American family caregivers. In terms of relationship to the patient, the percentage of caregivers who were spouses ranged from 32% to 100% across studies (all studies represented some percentage of caregivers who were spouses/partners), with many samples including higher than 50% spouses/partners. Thirteen studies identified adult children (range: 3% to 55% of the caregiver sample) [11,13–24]. Nine studies identified parents (range: 9.7% to 52% of the caregiver sample) [5,13,15,17,19,21–23,25]. Five studies identified siblings (range: 1.9% to 11% of the caregiver sample) [13–15,18,25]. Two studies identified friends as representing 1% and 5.7% of caregiver samples [5,25].

Content of Interventions, delivery, and dosage

Intervention components and mechanisms of action are listed in Supplemental Table 2. Most interventions were delivered in person (n = 18); some were delivered virtually or by phone (n=3) or hybrid (n = 3). The interventions took place in the outpatient (n = 11) inpatient setting (n = 13), and community settings (n = 7). Interventionists were primarily clinical psychologists or psychology graduate students, although chaplains, advanced practice nurses and senior volunteers also served as interventionists. Two interventions were self-directed [13,20]. Intervention length across studies ranged from one session [26,27] to eight sessions [14,28] with individual sessions ranging from 20 minutes [29] to four hours [19].

Expressive Writing, Peer Helping, and Spiritual Education Interventions (n = 3)—Meaning-based coping strategies included engaging in expressive writing about caregiving experiences [29] or peer helping behaviors [30] and teaching caregivers about spiritual well-being [31]. In the expressive writing intervention, caregivers wrote freely without interruption or editing about their deepest emotional thoughts and feelings about caring for the person they were supporting. In a peer helping intervention, patients and caregivers created an informational resource for other families coping with cancer [30]. Topics for the spiritual education sessions included hope, inner strength, uncertainty, meaning and purpose in life, positive changes, redefining self and priorities, and spirituality/religiosity.

Meaning-, Hope-, and Existential-Focused Interventions (n = 8)—In the Meaning-based Intervention for Patients and their Partners, couples learned to face death within the safety of their relationship and develop a sense of control surrounding the circumstances of death [32]. Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C) [5,13,18] helped caregivers connect to meaning and purpose despite challenges they may encounter in their caregiving role. In addition to in-person delivery, MCP-C has also been provided in a self-paced format that included webcasts and a discussion board with caregivers could interact with one another [13]. Hope Therapy employs a strengths-based approach to help caregivers develop goals and agency to improve quality of life and meaning in life [28]. Hope therapy is delivered in a group format and addresses goal regulation, negative self-talk, and overcoming obstacles.

Existential Behavioral Therapy (EBT) for caregivers addresses death anxiety and bereavement, as well as the skills of mindfulness, self-care, and stress management [19,25,33]. Traditional EBT is delivered in a group format using cognitive behavioral therapy with mindfulness exercises [19]. An abbreviated version of EBT was also developed for caregivers [25]. Cognitive Existential Couple Therapy (CECT) [33] focuses on the existential concerns of patient and caregiver dyads, how they communicate these concerns, and tailors the intervention to the couple's needs [33].

Dignity and Legacy Interventions (n = 13)—In the dignity therapy (DT) studies that included caregivers, the interventionist invited caregivers to join the patient as they discussed what was most important in the patient's life [34–36]. These sessions were transcribed to create a generativity document. Legacy Intervention Family Enactment (LIFE) [11,12], Family Participatory Dignity Therapy (FPDT) [15,23], and Family Dignity Therapy (FDT) [16,24,37] are based on DT. The LIFE intervention teaches the patient and caregiver problem solving skills while engaging them in reminiscence as part of developing a legacy project. In FPDT the dyad is fully engaged in the interview process with the interventionist who collects photos from the family to create a colorful legacy electronic “e-product”. In FDT, the major components are reminiscence and a spiritual diary to promote engagement in meaning-based coping. Other researchers have applied DT theoretical concepts to guide development of shorter interventions for caregiver and patient dyads [20,26]. Dignity Talk [20] was created by adapting the original DT prompts to promote meaningful conversations between patients and family members about their feelings and needs. There is no interventionist for Dignity Talk, rather the patient and family caregiver work collaboratively to enact this intervention. The Caregiver Outlook Intervention [21] was developed from emotional self-disclosure literature and DT concepts. Participants respond to open-ended questions about their life, caregiving, relationships, and life goals; the interventionist does not provide interpretation, but only elicits additional details.

Pre-loss and Bereavement Interventions (n = 4)—Pre-Loss Group Therapy is guided by the process of meaning reconstruction and concepts from Shear's complicated grief therapy to help caregivers work through anticipated losses [14]. Also intended to support family caregivers through anticipated losses, the Family-Focused Support Conversation [27] helps families make meaning of end-of-life care transitions through structured conversation with healthcare professionals. To support bereavement, Meaning-Centered Psychotherapy (MCP) was adapted to address grief among Japanese caregivers [38]. Similarly, in Bereavement Life Review [17] the caregiver is interviewed about their memories of the patient. The interventionist then creates an album for the caregiver with the key words they shared and adds photos and drawings.

Theoretical underpinnings—Twenty-seven articles provided some description of the theory or theories that guided the development of the intervention, including stress and coping, the dignity model, existential theory and conceptual underpinnings of logotherapy, caregiving stress process model, supportive expressive model, social cognitive theory, hope theory, theory of family sense of coherence, and Rogerian theory. The most common theory applied was the dignity model. Mechanisms of action included meaning-making

or coping [5,13,26,29,33]; meaning reconstruction [11,12]; meaning created through the mechanism of helping others in similar circumstances (helper therapy principle) [30]; life review [17,34] through the process of discussing and confronting death [25,33,39]; and mindfulness-based stress reduction [19,39]. DT is thought to increase meaning, purpose, and dignity through the dignity conversing repertoire (dignity conserving perspectives and practices) and decrease distress through moderation of the bereavement experience [26,34]. Meaning-based interventions are thought to mediate the relationship between caregiver distress and caregiver outcomes through meaning-based coping [5].

Intervention Fidelity—Adherence to the intervention manual or protocol was high across the five studies reporting this information, ranging from 91.55% to 99% [5,12,14,19,30]. One study reported a process evaluation of intervention fidelity [37].

Timing of measures and outcomes studied

Twelve studies included pre-post measurement [12,14,17,23,28,31–36,38], while six studies evaluated three data collection points [5,11,13,19,21,29] and four studies examined four data collection points [15,22,25,30]. Follow-up measures occurred from 2 to 12 months post-intervention. Almost all studies measured anxiety, depression, burden, and overall distress. Other outcomes measured included personal meaning, meaning in life, meaning in caregiving, spiritual well-being, hope, posttraumatic stress disorder symptoms, coping, religious coping, quality of life, changes in affect, mindfulness, transcendence, appraisal of health, life satisfaction, social functioning, and prolonged grief. One study examined the family-focused outcome of family adaptability and cohesion [15].

Findings and Intervention Effects

There were significant findings in 74% (n = 23) of the studies (Supplemental Table 3). Six studies provided effect sizes [5,11–13,19,32]. These effect sizes ranged from small to large, with most reporting medium effect sizes. Improved outcomes included meaning in life [11,28,39], quality of life [19,28], benefit finding [5,13], personal meaning [5,29], meaning/peace [32], hope [23] spiritual well-being [5,17,21,23] and increased quality of life [19]. Caregivers also experienced decreased stress, [12] anxiety [15,19,32], depression [5,12,15,17,32,38], and post-traumatic stress symptoms, [33] as well as improved symptoms of complicated grief, post-traumatic growth [14,38] and increased family adaptability [15].

Feasibility and acceptability findings—Enrollment rates ranged from 18% [19] to 89% [12] with an average of 51.8%. Intervention completion rates ranged from 53% [5] to 100% [22,32] with an average completion rate of 91%. Reported study attrition rates were 0% [35] to 49% [5], with an average rate of 25.2%. Reasons family caregivers did not enroll or dropped out of the study included: no caregiver identified, inadequate time to participate; decline in the patient's condition, or the patient died before study completion; believing additional support was either unnecessary or already being provided by family and friends; their own health concerns; and lack of interest [5,11,25,30,34,35].

Qualitative Summary—Overall, the reviewed interventions were feasible and acceptable to caregivers. Qualitative data suggested benefits, such as: better connection and

communication with family members [11]; rediscovery of identity and roles, and new motivation for personal and social activities [38]; strengthened family relationships [23]; increased caregiver agency [18], and better preparation for end of life [27,34]. Some caregivers expressed that DT was more beneficial for the patient [35]. Caregivers receiving MCP-C recommended that the intervention be delivered earlier [18].

Discussion

This scoping review describes a range of meaning-focused interventions that family caregivers found to be acceptable and feasible. Caregiver outcomes (e.g., distress, meaning, and quality of life) improved with many of the reviewed interventions. The relatively high rates of caregiver enrollment and intervention completion may signify that these highly burdened caregivers are deeply in need of interventions that target existential distress and appreciate opportunities to participate in trials that focus – at least in part – on their unique needs. The full version of EBT and MCP-C were the most promising interventions solely targeted to caregivers.

More than half of all reviewed interventions targeted both the caregiver and the patient. We included dyadic studies in our review if they measured quantitative and/or qualitative caregiver responses to the meaning-making intervention. Some interventions used a dyadic approach throughout; other studies, such as DT or those using a DT adaptation, invited the caregiver to support the patient in activities related to the legacy project. It was noted by some caregivers that DT was more beneficial to the patient than the caregiver. LIFE, FPDT, and the Meaning-based Intervention for Patients and their Partners were dyadic interventions that demonstrated greater improvement in caregiver outcomes than other reviewed dyadic interventions, a difference which could be attributed to the degree to which the caregiver was engaged in the intervention. Ensuring that dyadic interventions address the unique needs of both the caregiver and the patient is an important consideration for future intervention development.

Theories

Most studies included only limited detail regarding a theoretical basis for the intervention and few included a conceptual model. Without a narrative describing the intervention's mechanism of action or a visual representation, the intended and expected effects of the intervention were unclear. However, it should be noted that many interventions were developed or adapted from interventions with a strong theoretical foundation.

Caregiving Populations

Most studies enrolled caregivers supporting oncology or palliative care patients with a variety of diseases in later stages; the interventions in these studies included preparation for death and dying. Our review highlights a gap in supportive meaning-focused interventions specifically tailored for caregivers supporting patients in cancer survivorship. Additionally, only one study tested an intervention for caregivers supporting a patient in early stages of disease [33]. Delivering meaning-making interventions earlier in a serious illness may better prepare and support caregivers throughout their caregiving experience. However, Applebaum

and colleagues caution that immediately after diagnosis may not be an ideal point for intervention delivery, as caregivers need time to adjust to their caregiving role [18]. There is also a need to develop and test caregiver meaning-making interventions with other serious illness populations, such as patients with solid organ failure, chronic obstructive pulmonary disease (COPD), interstitial lung disease, and survivors of critical illness. Further, the optimal timing of meaning-making interventions for caregivers may differ depending on the specific patient population the caregiver is supporting. For example, adjustment to the caregiving role may differ depending on the disease, treatment, and caregiving requirements.

Only two reviewed studies addressed bereavement in family caregivers [17,38]. Of these studies, one was an adaptation of MCP in the Japanese cultural context [38]. Bereavement is a critical time in which family caregivers require supportive meaning-focused interventions; however, after the death of the patient the healthcare system typically disconnects from the family caregiver, decreasing their access to resources and support. The limited number of bereavement meaning-focused interventions for family caregivers of adults suggests the need for further intervention development, adaptation and testing in this area. The focus of this review was studies of adult caregivers supporting adult patients with serious illness. Although another study that adapted MCP to the grief context did not meet our inclusion criteria for this review due to its pediatric patient population, Meaning-Centered Grief Therapy is a promising 16-session bereavement intervention for parents who have lost a child (less than 25 years of age) to cancer [40]. This intervention demonstrated preliminary evidence of improvements in prolonged grief, meaning, depression, hopelessness, posttraumatic growth, positive affect and health-related quality of life [40]. Given these positive results it may be appropriate to adapt and test this intervention for caregivers in a nonparental relationship with adult patients who died. Additional research is needed to examine the effect of meaning-making interventions for family caregivers across the illness trajectory and during bereavement.

To determine how to best meet the needs of all family caregivers, it is necessary for diverse caregiver participants to be enrolled in clinical trials. We found most caregivers enrolled in the reviewed studies were White, middle-aged women who were a spouse or partner of the patient. Caregivers in rural areas; male caregivers; young adult caregivers; non-spousal caregivers; and caregivers who identify as lesbian, gay, bisexual, transgender, and queer (LGBTQ+), and/or Black, Indigenous, and People of Color (BIPOC) were either not well represented or not represented at all in the included studies. In a sub-analysis from the 2015 Caregiving Report [41], 5% of caregivers identify as LGBTQ+, 42% are male, 15% are from rural areas, 26% still have children living in the home, and 50% are employed. Across the reviewed studies, there was a lack of standardization in reporting caregiver characteristics, such as gender, race, ethnicity, and relationship to the patient. Standardizing the reporting of this information will enable researchers to understand whether certain interventions are more or less effective for different groups of caregivers. We found that other potentially relevant caregiver characteristics, such as LGBTQ+ identity, were not reported in any of the studies reviewed. It is critical that we fully capture caregiver characteristics that may affect the efficacy of interventions. Future research should focus on developing caregiver inclusive and culturally relevant adaptations to meaning-making interventions to better meet the needs of underserved caregiver populations.

Interventionists and Intervention Delivery

Most interventionists were clinical psychologists, psychiatrists, or psychology graduate students. While these mental health professionals are well-suited to deliver meaning-focused interventions, the existing shortage of mental health professionals [42] poses a challenge to scaling these types of interventions for delivery in routine clinical practice.

Scalability was considered in the LIFE intervention in which senior volunteers from the community were trained as interventionists and successfully delivered this intervention to palliative care patients and their caregivers in the community [11,43]. An important direction for future research is the development of interventions that are tailored to other caregiver populations and could be delivered by caregivers, as this approach holds high yield for reach and scalability within communities. As experts in caregiving, former family caregivers may be well suited to deliver supportive interventions to promote meaning in caregiving. It also may provide both participants and caregiver interventionists with a unique connection that they may not have with healthcare professionals who do not share their same experience. Supporting other caregivers may also help former caregivers make sense of their own caregiving experiences. More research is needed to examine the feasibility of volunteer interventionists delivering interventions within the community.

Developing strategies to enlist healthcare professionals to integrate meaning-making interventions for caregivers within healthcare systems is another important consideration. For example, nurses, social workers, and chaplains who regularly interact with patients and their caregivers could be trained to deliver promising caregiver interventions. A successful model of interprofessional meaning-making interventionist training is the Meaning Centered Psychotherapy Training Program for Cancer Care Providers, which is offered to all healthcare professionals caring for patients with serious illness [44]. Attending an interactive learning program such as this can serve as the first step in preparing interprofessional teams to train others within their healthcare organization to deliver meaning-making interventions and to integrate aspects of these interventions into routine clinical care.

At the start of intervention development it is critical to determine how caregiver interventions could be integrated into routine clinical practice and to estimate the associated cost [45]. This information is vital to making the business case for establishing programs and funding interventionist roles in order to expand supportive meaning-focused interventions for caregivers.

Most of the reviewed interventions were delivered in-person; only a few were delivered via phone or videoconferencing. Delivering interventions remotely can increase the reach of meaning-focused interventions to underserved caregivers (e.g. rural caregivers). Flexible delivery models, including remote delivery, may be more likely to achieve desired effects through increased caregiver access and engagement in the intervention [18].

Intervention fidelity strategies were not reported in some of the reviewed studies. Of those reported, most fidelity checks involved direct supervision and recording sessions to measure compliance with the treatment manual. Attention to intervention fidelity is critical

to determining whether the intervention is delivered as intended. Transparency in reporting intervention fidelity is necessary to advance the science in this area.

Fit with prior reviews

Caregivers need support to address existential distress, anxiety, depression, burden and guilt, and changes to their role identity; they also desire strategies to support their self-care [46]. While there are interventions that address aspects of caregiver burden [45,47], previous reviews pointed to a gap in interventions that target existential issues [7,48,49]. Our review aimed to describe the range of available interventions for caregivers that target existential distress, an understudied aspect of caregiver burden. We found some promising interventions that address caregiver existential distress through meaning-focused strategies; however, most of the interventions reviewed require further development and testing.

More than half of the interventions were dyadic. While dyadic interventions can address existential distress for the patient and the caregiver, some intervention content is best delivered individually given that caregivers may not be comfortable sharing all aspects of their caregiving experience with the patient. Interventions that combine both individual and dyadic sessions may have greater impact on existential distress within the family system; however, we found no interventions that took that approach.

When examining the outcomes across the reviewed studies, we found the majority focused on psychological and spiritual well-being. However, a biobehavioral model [50] could provide a roadmap for examining how meaning-making interventions could impact other physical caregiver outcomes such as sleep and fatigue, and broaden our view of existential distress and associated interventions.

Clinical Practice Considerations

A recent review of caregiver interventions noted that the design of most caregiver studies did not address future implementation [45]. Cost analyses and scalability must be considered early on in intervention development in order to determine how to translate and fund caregiver support interventions. None of the reviewed studies included a cost analysis and only one addressed scalability. This omission is partially explained by the early phases of intervention testing. Developing scalable, cost-effective interventions is key to expanding the reach and accessibility of caregiver support.

Limitations

We focused our scoping review on an important, yet understudied, aspect of caregiver burden: existential distress. We further narrowed this review to interventions designed for caregivers of adult patients; therefore, there may be efficacious meaning-making interventions for caregivers of children not captured by this review. Additionally, caregiver demographics and characteristics were not reported consistently across studies, which limited our ability to understand the effect of interventions on specific caregiver groups. The wide range of outcomes studied further limited possible comparisons between interventions. We included all phases of intervention development; therefore, effect sizes were only

reported in a small number of studies. Finally, as this was a scoping review, the quality of studies was not appraised.

Conclusion

Meaning-making interventions may be valuable to caregivers throughout the illness experience. This scoping review highlights a range of promising meaning-making interventions that address existential distress; however, further intervention development and testing is needed to demonstrate efficacy in large randomized controlled trials. As these interventions demonstrate benefit, implementation research is needed to translate them into clinical care. Importantly, there is a need for studies of the effect of meaning-making interventions for family caregiver populations who were underrepresented or not represented in this review.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Declaration of conflicting interests:

We have no conflicts of interest to report related to the completion of this project.

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Key Messages

What is already known on this topic?

- Existential distress is a common source of caregiver burden.
- There is a need to explore the depth and breadth of available interventions targeting existential distress for caregivers.

What this review study adds

- Interventions were acceptable and feasible.
- 74% had significant results.

Significance of findings for research and clinical practice

- Large randomized controlled trials, diverse caregiver samples, and translation to practice strategies are needed.

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APA PsycInfo <1806 to March Week 1 2021>

1 (Meaning making or Meaning centered).mp. 6330
 2 (Meaning making or Meaning centered).ti,ab. 5943
 3 Existentialism.mp. or exp Existentialism/ 5764
 4 (Existential therapy or Existential psychotherapy or Existential behavi* therapy).mp. 1530
 5 Meaning centered group psychotherapy.mp. 35
 6 (Palliative care.mp. or exp Palliative Care/) and Meaning.mp.1620
 7 Meaning in life.ti,ab. 2840
 8 dignity therapy.ti,ab. 152
 9 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 17162
 10 exp FAMILY/ or exp NUCLEAR FAMILY/ or exp FAMILY RELATIONS/ or family.mp. 1708172
 11 (informal caregiver or family caregiver).mp. or exp Caregivers/69977
 12 partner*.mp. 303357
 13 significant other.mp. 3114
 14 relative*.mp. 1756678
 15 exp Parents/ or exp PARENT-CHILD RELATIONS/ or parent*.mp. 889756
 16 family member*.mp. 141964
 17 10 or 11 or 12 or 13 or 14 or 15 or 16 4003146
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 19 randomized controlled trial.pt. 524786
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 30 comment/ or editorial/ or exp review/ or meta analysis/ or consensus/ or exp guideline/ 4165647
 31 hi.fs. or case report.mp. 674068
 32 or/30-31 4765203
 33 29 not 32 10191889
 34 26 or 33 10668183
 35 18 and 34 946
 36 limit 35 to English language 909

Figure 1.
Full Search from Ovid MEDLINE

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only

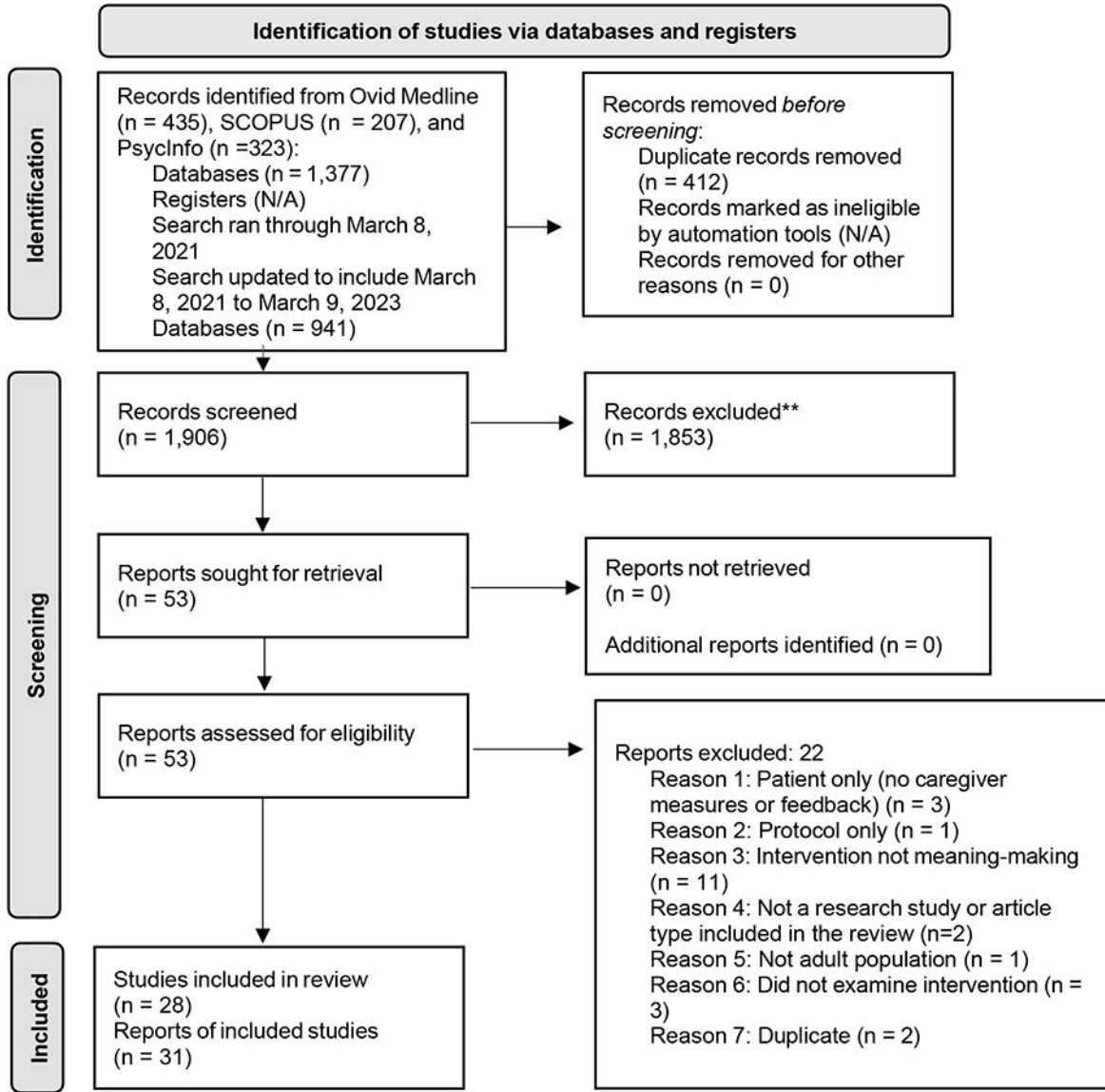


Figure 2. PRISMA Diagram