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Qualitative evaluation of a problem-solving intervention for informal hospice caregivers

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Abstract

Background—Informal hospice caregivers may experience compromised well-being as a result of significant stress. Although quite limited, problem-solving interventions with this population have garnered empirical support for improved caregiver well-being.

Aim—Researchers sought to answer the following question: which specific intervention processes impacted informal hospice caregivers who participated in a problem-solving intervention?

Design—Researchers conducted a thematic analysis of open-ended exit interviews with informal hospice caregivers who had participated in a structured problem-solving intervention.

Setting/participants—Participants were friends and family members who provided unpaid care for a home hospice patient receiving services from one of two hospice agencies located in the Pacific Northwest region of the United States.

Results—During their participation in the problem-solving intervention, caregivers actively reflected on caregiving, structured problem-solving efforts, partnered with interventionists, resolved problems, and gained confidence and control.

Conclusions—The study findings provide much needed depth to the field's understanding of problem-solving interventions for informal hospice caregivers and can be used to enhance existing support services.

Keywords

caregivers; hospices; intervention studies; problem solving; qualitative research

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Conflict of interest statement

None declared.

Introduction

Inspired by the work of Dame Cicely Saunders and other palliative care pioneers in the United Kingdom in the 1960s, the modern hospice movement has spread across the globe. As of 2006, there were over 8000 hospices in more than 110 countries world-wide.¹ After adapting the English hospice philosophy and modifying some elements of care delivery, hospices in the United States now support over one million terminally ill patients and their families each year.²

In the United States, hospice eligibility is primarily defined by reimbursement practices. The Medicare Hospice Benefit, which covers the cost of care for over 83% of all US hospice patients,² requires that individuals have a prognosis of six months of survival or less if their illness runs its normal course. In addition, patients must elect hospice care for their terminal illness rather than choosing approaches aimed at curing disease or prolonging life.³ Finally, unlike many countries, most hospice patients in the United States (68.6%) receive care in their place of residence.²

Consistent with its English roots, hospice care in the United States is designed to maximize the quality of life of patients and ensure that they ultimately experience a death that is as natural and comfortable as they choose. Services are provided not only to patients, but also to their family members and friends, many of whom serve as informal caregivers, commonly referred to as *informal carers* or *family carers* in many English-speaking countries outside of the United States. Informal caregivers engage in a range of tasks including personal care, service coordination, pain and symptom management, and provision of emotional or spiritual support.⁴⁻⁶

Given caregivers' myriad responsibilities and the highly emotional context in which dying often occurs, it is not surprising that problems arise in caregiving at end of life. Problems commonly facing informal hospice caregivers include challenges associated with witnessing and responding to the patient's decline, managing pain and other symptoms, and handling unsolicited critiques of care by family members and friends.⁷ Successful resolution of such problems has both a direct and indirect effect on psychological functioning of caregivers. Psychological distress is ameliorated when the problem is resolved and adaptive coping and general competence are enhanced, resulting in improved self-esteem, a sense of mastery and control, and elevated perceptions of overall quality of life.⁸

Although few standardized interventions exist to facilitate informal hospice caregiving,⁵ early research suggests that problem-solving interventions may benefit individuals caring for a dying loved one. For example, one randomized controlled trial (RCT) of a coping intervention involving problem-solving training for informal hospice caregivers found that participation in the intervention was associated with significant improvement in quality of life and reduction of symptom- and task-related burden.⁹ Although such interventions have demonstrated promise, continued evaluation is critical.

RCTs are commonly regarded as the gold standard in intervention evaluation.¹⁰ A limitation of RCTs, and all designs relying exclusively on pre-test/post-test measures, is that little is learned about what occurs between pre- and post-testing, leading some to illustratively refer to actual intervention processes as taking place in a 'black box.' Qualitative evaluation research seeks to peer into the black box, to describe how the intervention worked, and to understand the mechanisms that brought about change.¹¹

The study described herein represents part of a larger, mixed methods evaluation of a problem-solving intervention for informal hospice caregivers. As part of the larger study, researchers administered measures pre- and post-intervention. Results indicated that

caregivers experienced significantly decreased levels of anxiety and significantly increased quality of life following participation in the intervention.^{12,13} To support these findings and assess process elements of the intervention, this study explored participants' post-intervention interviews. By employing qualitative evaluation techniques, researchers sought to more fully understand caregiver experiences and the processes by which the changes identified in the larger study were effected. Specifically, researchers sought to answer the following question: which specific intervention processes impacted informal hospice caregivers who participated in a problem-solving intervention?

Methods

In partnership with two hospice agencies located in the Pacific Northwest region of the United States, researchers recruited informal caregivers to participate in a standardized problem-solving intervention. Inclusion criteria required that participants be providing unpaid care to a patient receiving home hospice services, be age 18 or older, have completed at least a sixth-grade education, have no or only mild cognitive impairment, be able to speak and read English, and be without functional hearing loss or have a hearing aid allowing them to participate in the intervention. A member of the hospice admissions staff presented the research opportunity to caregivers upon admission, asking if they would agree to be contacted to learn more about the study. Contact information for willing caregivers was then forwarded to the research office. An interventionist then called potential participants to determine their eligibility and schedule an initial visit, during which the project was discussed and informed consent was obtained.

A total of 138 caregivers were referred to the research team. Eight chose not to participate, citing lack of time, interest, and/or anticipated travel. Four were not eligible to participate (one was a paid/professional caregiver, and three were no longer actively caregiving due to their loved one's death). The remaining 126 caregivers were enrolled in the study. Participants' average age was 59, and over half had earned a bachelor's degree or greater. Table 1 lists additional demographic characteristics of participants at the time of enrollment in the study.

Of the original 126 participants, 89 (71%) completed the full study protocol and participated in an exit interview. Qualitative data generated during these interviews formed the basis of the present study. When establishing the final data set, researchers excluded data from the first 10% of the sample ($n = 8$) to ensure that caregivers' comments reflected feedback on the intervention after fidelity among the interventionists had been firmly established. In addition, five interviews were unusable due to technical difficulties related to audio-recording. Consequently, 76 caregiver interviews were analyzed. Prior to the start of the study, researchers were granted approval from the Institutional Review Board of the Principal Investigator's university.

The problem-solving intervention

Participants took part in a psycho-educational intervention, during which they learned Nezu et al.'s¹⁴ ADAPT problem-solving method and implemented it to address a specific challenge they encountered when caring for a dying family member or friend. This particular intervention was selected due to the extensive body of literature supporting its efficacy with diverse populations⁸ and the availability of an existing manual written for the general public rather than a professionally trained audience.¹⁴ ADAPT is an acronym representing five key steps: (1) adopting a positive, optimistic attitude to problem solving; (2) clearly defining the problem; (3) generating a list of alternative approaches to solving the problem; (4) predicting consequences of each possible approach and selecting the one

judged most likely to be effective; and (5) trying the selected approach and monitoring its effects.

The intervention was delivered face-to-face or by videophone during three individual sessions. Two additional visits were required to administer measures and conduct exit interviews. Interventionists were masters-prepared health professionals (two nurses, two social workers) who had received additional training in preparation for working with informal hospice caregivers and teaching the ADAPT method. The full study protocol was typically executed over the course of 21–30 days, although the timing of sessions was adjusted to accommodate caregivers' needs. If a caregiver's loved one died before the intervention was completed, the intervention ended unless the participant indicated a desire to continue. All participants received a \$50 gift card, regardless of whether they completed the full study protocol.

Data collection

Qualitative data were collected during semi-structured interviews of participants during their fifth and final visit with the interventionist. Broad, open-ended questions and prompts were used to encourage participants to reflect on all stages of the intervention and to provide insight into the benefits and challenges associated with their involvement in the project: *What were your general impressions of the intervention? Thinking back over the entire intervention, were there specific aspects you found beneficial? If so, which ones and how did you find them beneficial? Were there specific aspects you found unhelpful or problematic? If so, which ones and how were they unhelpful or problematic? What suggestions would you provide for future application of this intervention with hospice caregivers?* All interviews were digitally audio-recorded and later transcribed prior to analysis.

Data analysis

Researchers employed techniques outlined by Braun and Clarke¹⁵ to conduct thematic analysis of the data. An inductive approach was used to guide this process, resulting in the development of themes that were closely linked to the data. Braun and Clarke describe inductive analysis as 'a process of coding the data without trying to fit it into a preexisting coding frame, or the researcher's analytic preconceptions' (p.83). Researchers sought to code extracts primarily at the semantic rather than latent level, meaning that themes were largely identified within the overt meanings of the data.

Firstly, transcribed data were imported into *NVivo 8* qualitative research software. Then, two researchers independently generated a list of initial codes based on the inductive analysis of approximately 10% of the interviews included in the sample. Peer debriefing allowed the researchers to develop and refine a coding framework that was modified through an ongoing discussion of differences. Codes were then sorted into themes with a goal of achieving both internal homogeneity (i.e. themes held together in a meaningful way) and external homogeneity (i.e. clear differences were evident among themes).¹⁶ Use of multiple coders and peer debriefing strategies contributed to the trustworthiness of the study, the standard by which rigor of qualitative research is measured.¹⁷ To further enhance trustworthiness, researchers employed prolonged engagement, the practice of spending extended periods of time with research participants to develop trust and better understand the context of the phenomenon under investigation. Because researchers delivered the intervention to each caregiver during multiple visits over a period of at least three weeks, they had sufficient time to observe and work to understand how participants experienced the problem-solving intervention.

Results

Data analysis resulted in the identification of five themes, summarized in Table 2, describing processes deemed by study participants to be central to their experience of the problem-solving intervention: reflecting on caregiving, structuring problem-solving efforts, partnering with an interventionist, resolving problems, and gaining confidence and control. To varying degrees, the processes described within each theme explained the changes caregivers underwent while participating in the problem-solving intervention. Each of the themes is described in detail below. Where direct quotations are used, caregivers are identified by study number rather than name to ensure participant confidentiality.

Reflecting on caregiving

Data comprising the theme *reflecting on caregiving* described or made reference to the reality that participating in the problem-solving intervention forced caregivers to make space in their lives to reflect on challenges they were facing. For many participants, the day-to-day realities of caregiving had become routine and automatic. For others, the demands on their time and energy typically left little room for introspection. Consequently, caregivers appreciated the opportunity to think through things. This process manifested itself in different ways for different individuals. For some caregivers, examining problematic situations was helpful. One man (#115) explained: 'It forces you to articulate specific issues and gets you thinking about them. It becomes kind of a genesis to ... deeper thinking.' For other participants, the problem-solving intervention caused them to examine areas of their lives they had been avoiding. One such participant (#153) stated, 'It got me thinking about some things that I was not dealing with and thinking about a lot of things I haven't dealt with.' Another woman (#923) echoed the sentiment of many participants who had sacrificed their own emotional needs during the caregiving process: 'It made me think more about things that I really didn't think about: how I feel, how I'm handling things.' Many caregivers discussed the benefits associated with engaging in a process that required careful reflection and thought although, as illustrated by the examples above, the reasons participants valued this aspect of the intervention were varied. This reflection set the stage for engaging in structured problem-solving efforts.

Structuring problem-solving efforts

The theme *structuring problem-solving efforts* emerged from data provided by caregivers, who repeatedly cited the structured format of the problem-solving intervention as helpful. Segments of data comprising this theme were initially labeled with codes denoting the 'focused,' 'logical,' 'rational,' and 'systematic' quality of the intervention. This theme was particularly apparent among caregivers who found themselves overwhelmed by the realities of caring for a dying loved one. For them, walking through a logical, rational problem-solving process brought focus to their efforts. One participant (#921) explained:

It helped me think logically as opposed to just feeling everything It's nice to have some concrete steps to follow ... I can figure out a way to break [a problem] down, divide it into manageable pieces.

The idea of 'manageable pieces' recurred throughout the data set. In a similar vein, one caregiver (#127) spoke about the clarity she gained after 'dissecting' a problem and the steps required to gain control over it. Another (#916) commented that in the absence of a structured process, 'everything ... felt huge.'

Participants reported that the intervention workbook was particularly useful in helping them focus their problem-solving efforts. Each participant was provided with a copy of *Solving life's problems*,¹⁴ which presented the structured ADAPT method in detail. While

caregivers were not required to read the entire workbook, interventionists referred to specific pages when teaching the ADAPT model. Several caregivers mentioned voluntarily reading the workbook between intervention sessions and provided positive feedback. One caregiver (#927) consulted the workbook frequently during the intervention. She stated, '[The book] had some really great practical advice.' Another (#158) stated, 'I'm going to keep studying that book, and I'm going to keep going through this stuff over and over. It's definitely been a lot of help.' Many caregivers cited the structured, focused nature of the intervention as beneficial. Helping keep the process focused were the study interventionists.

Partnering with an interventionist

According to one study participant (#138), 'It feels good to be paid attention to.' Numerous other caregivers agreed, citing *partnering with an interventionist* as a key benefit of the problem-solving intervention. This theme comprised data that described or made reference to the relational aspects of their work with the study interventionists rather than the concrete steps or tasks involved in the actual intervention. Many caregivers indicated they liked 'having [someone] listen' or 'having the opportunity to talk to somebody.' Others commented on specific attributes or behaviors of the interventionists, such as being 'really supportive,' 'easy to talk to,' 'a really good listener,' providing 'undivided attention,' and creating an environment in which caregivers felt 'comfortable.' A few caregivers became emotional when discussing their relationship with the interventionist. One woman (#918) cried as she told her interventionist, 'I actually liked it because it gave me a chance to meet you.' Other similar comments were offered to interventionists such as, 'You've become part of my life here' (#920.)

According to some participants, in addition to serving as a source of support, interventionists held caregivers accountable for progressing through the problem-solving process. For example, one caregiver (#128) stated, 'If I know you're calling me in five days, I think I need to make sure I've actually made some changes since you left.' This aspect of the intervention was cited as a benefit by some, while others cited it as a potential drawback. One woman (#121) discussed feeling as if she had disappointed the interventionist when she did not follow through with her problem-solving action plan: 'I feel guilty I said I would work on this and then I didn't.' Caregiver perceptions of this aspect of the intervention were mixed: some cited it as a source of guilt, while others viewed it as supporting the overall process. For many, however, partnering with an interventionist was central to their progress toward eventually resolving problems.

Resolving problems

Given that caregivers simultaneously learned and applied the ADAPT method as part of the study protocol, many commented on the benefits associated with making progress toward solving a problem. Analysis of data that referred to the resolution of problems as a result of the intervention led to the generation of a theme labeled *resolving problems*. For numerous participants, 'charging ahead' and 'getting things done' (2019); was cited as helpful. A caregiver (#926) described the intervention as an antidote to inaction: '[The intervention] helped me to crystallize and actually make a decision, doing something to resolve the issue.' One caregiver (#150) contrasted the problem-solving process with the one she had used when working with her hospice social worker:

I don't think I could have gone as far with [the hospice social worker] as I have with this program you've given me ... [with the hospice social worker], we just kept talking the problem over, you know. We weren't really getting going.

Another participant (#122) commented, 'I [found] it useful because I saw results.' Seeing results of the significant time and energy invested in caregiving was important for others as well. One woman (#111) explained:

I talk to other people who have parents or in some cases siblings who are on hospice... and I find they're just kind of going in circles. They just don't know what to do and it uses up all their energy, and yet they haven't gotten to where they need to be.

For these caregivers, working through the problem-solving steps was as important as learning them. This led to gaining a sense of confidence and control.

Gaining confidence and control

At the conclusion of the intervention, caregivers commonly reported feeling an enhanced sense of confidence and control over problems they encountered. Reports in this vein were initially labeled with codes such as 'in control,' 'mastery,' 'empowering,' and 'reassuring. 92019; Eventually, these segments of data collectively comprised the theme *gaining confidence and control*. One caregiver (#128) summarized this idea in the following way: 'It gives you more a sense of calm and control, and I like control.' While some caregivers implemented novel solutions to caregiving problems as a result of the intervention, others discussed feeling more confident that the approach they were using was most effective. They described feeling 'reassured' after working through the steps of the ADAPT model. One woman (#109) explained, 'It's nice to have the validation that what I am doing [will] result in a good decision.'

A number of participants observed that the problem-solving process was applicable to non-caregiving challenges as well, resulting in feelings of empowerment in multiple areas of their lives. One caregiver (#925) noted, 'I could see using [the problem-solving method] for anything, when I'm trying to figure out what [the problem] is and ... how to fix it.' Although each of the study participants was aware that their caregiving responsibilities would end, many anticipated continued use of the ADAPT method post-hospice. A participant (#152) explained, 'Once you do it with one thing, I think you can translate it to others.' In addition to gaining control over caregiving problems, participants felt empowered to more effectively address a wide range of challenges.

Discussion

Findings from the present study illustrate the intervention processes that brought about change for study participants: reflecting on caregiving, structuring problem-solving efforts, partnering with an interventionist, resolving problems, and gaining confidence and control. This study did not test the efficacy of the intervention itself, but rather sought to deepen the field's understanding of problem-solving interventions, some of which have been shown to reduce anxiety,^{12,13} improve quality of life,^{9,12,13} and reduce symptom- and task-related burden⁹ among informal hospice caregivers. Existing research indicates that problem-solving approaches are effective in improving outcomes for informal hospice caregivers; findings from this study describe why. In addition, findings concerning aspects of the intervention that caregivers deemed problematic can be used to inform future efforts to enhance these empirically supported interventions. For example, the participant (#121) who described feeling guilty when she failed to execute her problem-solving action plan between intervention visits serves as a powerful reminder that caregivers experience very real barriers to participating in interventions, whether as part of research or routine care. Efforts to support informal caregivers must be structured and presented in such a way that they are viewed as resources, not additional demands.

Findings from the present study have other important implications for delivery of psychosocial support to informal caregivers. Specifically, data highlight the importance of using a structured approach to reflect upon challenges. Caregivers described a wide range of barriers to thought and reflection: feeling overwhelmed, lacking time, and engaging in tasks that had become automatic and routine. Members of the health care team can be instrumental in encouraging introspection among caregivers and, through interventions such as the one described here, in providing a focused process for analyzing problems and challenges.

There is much debate regarding the relative merits and limitations of delivering ‘manualized’ services to clients. In terms of establishing an evidence base for practice, many believe treatment fidelity is critical, leading to increased practitioner acceptance of detailed intervention manuals and protocols.¹⁸ However, putting scientific rigor aside, it is interesting to note that the focused, ‘manualized’ nature of the intervention was an aspect many study participants cited as beneficial. At least in this instance, adoption of a structured approach supported both good science and good care. Rather than feeling ‘overwhelmed,’ ‘going in circles,’ or failing to make progress toward goals, caregivers were able to apply the problem-solving method to achieve desired outcomes. It is important to note, however, that provision of quality psychosocial care is undoubtedly broader than assisting with problem-solving efforts. Indeed, many situations at end of life are inherently distressful and not easily reduced to ‘problems to be solved.’ It is, therefore, essential that any psychosocial intervention be preceded by thorough assessment to ensure subsequent intervention efforts are a good fit with the patient and family and their specific circumstances.

Study limitations and considerations for future research

The present study was limited by a number of factors that warrant careful consideration. Firstly, caregivers’ strong comments about the beneficial nature of the relationship with the interventionist underscore the need for incorporation of an attention-control group in future testing. An attention-control group serves as the placebo group that captures any effects that may be observed simply due to increased attention subjects receive by participating in a study, rather than any potential benefits of the intervention. In an attention-control group, subjects receive ‘friendly visits’ matching the communication frequency patterns of the intervention, including reflective listening and encouragement, without provision of suggestions, solutions, or recommendations.¹⁹ Comparing outcomes of study participants receiving the full problem-solving intervention with those receiving only informal social interaction would allow researchers to determine the relative contributions of the actual intervention and of any human interaction effects. Secondly, future research may be improved by limiting the involvement of the interventionists in evaluation efforts. While the rapport the interventionists had already established with participants enhanced the caregiver interviews to some degree (see earlier discussion of prolonged engagement), these benefits were potentially outweighed by the risk of caregivers opting not to provide negative feedback out of concern that criticisms would reflect poorly on the interventionists themselves. Finally, future studies would be enhanced by inclusion of repeated post-test measures. Several caregivers indicated that the problem-solving intervention was generalizable to other areas of their lives and that they planned to continue addressing problems using the ADAPT method. This suggests the need for measuring intervention outcomes longitudinally. If, in fact, positive outcomes persist over time, support for the intervention would be further enhanced.

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Table 1Additional participant characteristics ($N = 126$).

	n
Relationship to patient	
Adult child	59
Spouse/partner	38
Sibling	4
Adult grandchild	4
Parent of adult patient	5
Friend or other	16
Residence	
Resides with patient	68
Resides elsewhere	58
Race	
African American	6
American Indian	1
Asian American	7
Caucasian	110
Native Hawaiian/Pacific Islander	2
Ethnicity	
Hispanic	3
Non-Hispanic	123

Table 2

Identified themes.

Theme	Description	Sample quotation
Reflecting on caregiving	Stepping back, taking time to examine thoughts, feelings, and behaviors related to caregiving	<i>It made me think more about things that I really didn't think about: how I feel, how I'm handling things.</i>
Structuring problem solving efforts	Adopting a focused, rational approach to dealing with challenges	<i>It helped me think logically as opposed to just feeling everything.</i>
Partnering with an interventionist	Developing a supportive relationship with study personnel delivering the intervention	<i>It feels good to be paid attention to.</i>
Resolving problems	Seeing results of problem-solving efforts	<i>The intervention helped me to crystallize and actually make a decision, doing something to resolve the issue.</i>
Gaining confidence and control	Feeling empowered to solve current and future problems	<i>It gives you more a sense of calm and control, and I like control.</i>