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Aug 23rd, 9:00 AM - 11:00 AM

# Interventions in Hospice Caregivers' Coping Mechanisms

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Urbanski, Ollie, "Interventions in Hospice Caregivers' Coping Mechanisms" (2019). *Grace Peterson Nursing Research Colloquium*. 8.  
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# Interventions in Hospice Caregivers' Coping Mechanisms: An Integrative Literature Review

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## Abstract

There is an increasing awareness, and need for, hospice services in the United States. While some may choose to receive their care in an inpatient setting, many prefer the comforts of home. When they receive their care at home, their loved ones end up shouldering many of the burdens of that care. There is a noticeable lack in support for this specific population of caregivers. The purpose of this integrative literature review was to investigate current best practices in regards to coping mechanisms for informal hospice caregivers and to analyze potential areas for development of research in caregiver burden. Nine studies met the inclusion and exclusion criteria. Few extrapolated data based on common themes in familial caregivers, which lead to some suggestions on how to best care for this population. Some suggested that a mixture of educational material, psychological counseling, and group support while their ailing family member is still alive, would be most beneficial. The use of social media was focused on in one study, and that it could facilitate bereavement support to caregivers. There was a lack of strong evidence for effective coping strategies and support systems for informal or family caregivers of patients receiving hospice care. A needs assessment to identify priority areas of information on death and dying, guidance and support during the patient's last few dying hours and the bereavement that follows, is warranted in order to develop highly relevant interventions for this group of hospice caregivers.

## Introduction

The National Hospice and Palliative Care Organization (NHPCO) states that in 2016, 1.43 million people in the United States were receiving hospice care and that 55.6% were receiving their care at home (2018). Hospice goals are defined as maintaining the quality of life for a patient whose disease process most likely cannot be cured (Hospice Foundation of America, 2018). A hospice patient's team includes, but is not limited to, their: physicians, nurses, therapists, spiritual/religious advisors, and their caregivers. While many utilize the team of medical professionals for their hospice care, many also rely on their family to act as their caretakers when they can no longer care for themselves. Caretaking for a terminal family member may have some positive aspects, but it is not without its challenges. Sutanto (2017), hypothesizes that due to numerous issues such as caregiver burden, caretakers may have more unmet psychological needs than the hospice patients themselves. According to Washington & Rakes, when familial caregivers nurse their patient in advanced stages of terminal illness this creates barriers to their own self-care due to several stressors such as: social isolation, loss of control, financial burdens, communication issues, and even sleep disturbances (2018). The current climate within this research is that it is in its very early stages and there is much work to be completed in order to help this specific population.



<https://www.hunterdonhealthcare.org/services/home-health/hospice/hospice/>

## Methodology

The design that was utilized for the purposes of this study, was an integrative literature review. The review explored effective coping techniques intended for hospice familial caregivers. It included an exploration of caregiver burden and the specific stressors that this population faces. The decision to utilize this particular design was made due to the lack of reviews about these coping strategies. The resources that were utilized for this review were not focused on trials, but on personal accounts of caregivers and their experiences. Inclusion criteria included were limited based on: dates, as it had to be from 2013-2018, it had to be through DePaul's database or in an online database, they also had to be found in English, and they had to involve medicine, psychology, and/or nursing. The articles needed to include information specifically focused on coping techniques or strategies for the specific population of hospice caregivers.

Authors	Design/Info	Measurement/Ends/Statistics	Results	Weakness	Strengths
Stanton, L. 2017	The author wanted to investigate what the best support interventions were based on caregiver burden. The abstracts were slightly smaller than 157 articles.	Madison, Carben, Cochran, Carrel, Study, Sweeney, Questions, secondary	Several interventions were identified: psychological, psychological, with-based, and the authors considered content and psychosocial. The data was based on the results of the study.	They compared content to investigate because they did not have the data, which is why they did not have the data.	They defined caregiver, duration, and included several different kinds of interventions, which other studies did not.
Heggen & Pignone, 2013	The authors wanted to investigate the end of life quality of life measures, as they set out to create a more than the national care population.	Longitudinal, prospective study of 1310 caregivers, 1310 caregivers, 1310 caregivers, 1310 caregivers	They found that their study was not in the end of life. They found that caregivers were not in the end of life. They found that caregivers were not in the end of life.	They still need to confirm their findings because they did not have the data, which is why they did not have the data.	They included two questions about how to cope, and they found that others had not, which makes their intervention more valid.
Yoo, S. & Graham, T. (2013)	They wanted to create data and results on the experiences of caregiving during end-of-life research design.	Interviews, phenomenological design, 50 interviews of 11 people, 50 interviews, 50 interviews, 50 interviews	They found several themes from each caregiver: feeling a support person, feeling a support person, feeling a support person, feeling a support person, feeling a support person.	They study dealt with caregivers and their perceptions which makes the data difficult to document in all groups.	They design allowed for more complex data to be created because it was qualitative. It helped caregivers express and process their own role.
Wassinger, J. et al. (2015)	Found that which caregiver who is responsible for providing care with bereavement support for their loved ones has been used for necessary.	Used that Prevalence Model of Bereavement, a bereavement, bereavement, bereavement, bereavement	Found that a social Facebook group helps facilitate bereavement support to caregivers.	They did not have the data about people who were mentioned in the group and people support source and acknowledgment factors.	They results helped confirm an earlier study which was based on the population.
Uren, D. 2017	They wanted to identify the challenges and needs of hospice caregivers, and to determine if there are any differences in the way that caregivers cope with their own grief.	Qualitative, phenomenological design, 50 interviews of 11 people, 50 interviews, 50 interviews, 50 interviews	They found that the most common challenges were related to the patient's care and the caregiver's own health. They found that the most common challenges were related to the patient's care and the caregiver's own health.	They were able to obtain data from a small population.	The data they collected could be used to help create future designs that could help create caregiver interventions.
Washington, K., & Rakes, C. 2015	They addressed that caregivers suffer from psychological issues, and to determine if there are any differences in the way that caregivers cope with their own grief.	Used the Ways of Coping Questionnaire, a questionnaire, questionnaire, questionnaire, questionnaire	They found that coping responses in hospice caregivers were related to the patient's care and the caregiver's own health. They found that coping responses in hospice caregivers were related to the patient's care and the caregiver's own health.	They only studied the caregivers of hospice patients, not other caregivers. They were not able to obtain data from a small population.	It was beneficial for these caregivers to have their own coping. They were able to create their own coping strategies, and also the study that their research intervention solving for this population.
Parsons, S. et al. (2014)	The authors wanted to see positive coping responses for hospice caregivers, and to determine if there are any differences in the way that caregivers cope with their own grief.	Questionnaire of 123 family caregivers, and questionnaire, questionnaire, questionnaire, questionnaire	After analyzing the results the authors found that the most common coping responses were related to the patient's care and the caregiver's own health.	There have not been previous studies of caregivers and their coping. They were not able to obtain data from a small population.	This helped to support theories that caregivers need support services on a daily basis.
Overman, J., et al. (2017)	They recognized that there is limited research on support of informal caregivers, and to determine if there are any differences in the way that caregivers cope with their own grief.	72 caregivers for the National Burden of Disease, and questionnaire, questionnaire, questionnaire, questionnaire	They found that caregivers were not in the end of life. They found that caregivers were not in the end of life. They found that caregivers were not in the end of life.	Due to the limitations of the questionnaire study, it is possible that caregivers may not be coping.	Their findings were consistent with previous studies which gave more validity to their implications.
Chidambaram, 2015	This study explored the effects of caregiver burden, and to determine if there are any differences in the way that caregivers cope with their own grief.	They used a cross-sectional, questionnaire, questionnaire, questionnaire, questionnaire	They found that caregivers were not in the end of life. They found that caregivers were not in the end of life. They found that caregivers were not in the end of life.	Due to the cross-sectional approach, they were not able to obtain data from a small population.	It is one of the first to use multiple methods to understand the caregiver population which will make it more specific studies in the future.

## Results

Common self-reported caregiver coping strategies were studied by Uren and Graham and they posited that coping mechanisms in caregivers play a vital role in their well being, which affects their patient's health outcomes in palliative care (2018). The authors used self reports from nurses via interviews that could then be utilized by an informal population. They found seven themes that were common throughout these interviews: finding a support person, finding the right person, surviving the high workload, seeking alternative means of support, juggling home and work life balance, disillusionment versus acceptance, and the potential to fail to cope. Finding a support person was one of the easiest to define, and perhaps the easiest to disseminate to informal caregivers. The nurses found that having someone to reach out to, even just to talk about the stresses of their job helped them immensely. They did mention that this support person was something that they had to seek out and that one was not provided by their institution. This is a similar barrier that spouses or children could face when they care for their terminal family members. What the nurses struggled with however, was finding the right person that they could trust. Finding someone who would listen to them was not the difficult part, but rather trying to find someone who would keep what they told them confidential, and someone who would not look at them differently after they confided in them. They also worried about potential consequences in regards to their positions at the hospital. The nurses also struggled with shame in asking for help. This was a very common theme found in other aspects of the research, that no matter the profession of the caregiver, there was a perceived shame in admitting that they could not do it all on their own. The informal caregivers may struggle with finding someone to trust as they may not want to turn to other family members, friends or neighbors who may not understand what they are going through. As a family member, this feeling of a high workload could be increased tenfold. As a nurse, it is their job to care for their patients and they knew this going into the profession. More than likely, an informal caregiver would not expect to one day have to care for their family member. In addition to this care, they may have to continue going to their job which would be an added burden and stressor. This leaves less time to socialize outside of their homes and find a source of support that is unbiased. Something both nurses and lay people shared were the difficulties of creating an effective work and home life balance. Many described using substances such as alcohol, which they self identified as not being healthy for themselves. Others drew upon the use of music, religious beliefs and family support systems in order to distract themselves or process their emotions. Besides the substance use, these are potentially effective and easy to implement strategies for caregivers who do not work in the medical field. The most promising research came from Sutanto et al (2017), which focused on psychologically based interventions. The intervention that study participants responded the most positively to were education based psychotherapies. They also mentioned a study that focused on couples based interventions, where the couple participated in eight sessions of couples' therapy that focused on the unique experiences of cancer within a partnership. They saw an increase in their marital functioning and saw a statistically significant improvement in the couples. This may be an area to further research, but it is not applicable to all informal caregivers, as not all of them are caring for their partner, but rather another family member. The authors also reported that group sessions were available and some participants preferred those due to the social support they found. The authors concluded that the most effective intervention in terms of positive caregiver response were the ones that integrated education with psychotherapy. The participants found it accessible, effective and applicable and found it to be overall a positive experience.

## Conclusion

There was very limited research on informal caregivers in general, which means there was a dearth of information on how they address their own needs while caring for a family member. The few studies that focused on these issues were able to find few interventions, and even fewer that had been tested on a larger sample size. Without these studies, it was difficult to come up with suggestions that could be generalized to the whole group. Each person is unique as is the person they are caring for, and in order for future researchers to be successful they need to acknowledge this fact. These interventions should be based on an individual level and should be very specific. Some interventions could focus on timing of diagnosis, whether or not the person they are caring for is their partner, people who do have support systems versus those who do not. The studies that addressed both the obstacles caregivers faced and the coping mechanisms they reported being useful, were the ones that could be used and further expanded upon. Some of the newer suggestions came in the form of telephone and web based therapies. More and more people are relying upon technology to gain quick access to knowledge, and having programs that could be accessed across the country could be beneficial. The issue of individuality still remains, but many participants identified education as being extremely helpful. The interventions that coupled education with therapy were the ones that most participants reacted positively to. Knowing what to expect when it comes to caregiving can help prepare them for the aspects that non-caregivers might never know they face. Having a place to go when they have questions that aren't their other family members or a part of their social community could be beneficial as well. There were also a few studies that mentioned group psychoeducational sessions that a few participants enjoyed. A combination of these groups over the internet is a strategy worth exploring as well. Due to this lack of evidence, a needs assessment should be completed in order to identify priority areas on support, guidance, death and dying, what to expect in a patient's final hours and what comes after for this subpopulation. There is still much to be explored within this field and more that needs to be addressed in order to care for this specific group of caregivers.



<https://www.aumhc.org/programs-services/treatment/group/>

## Acknowledgements

This project was supported by the School of Nursing at DePaul University. Special thanks should be given to Dr. Tariman and Dr. Amer.