

Final Report

Metasynthesis Study of Family Caregivers of Community Dwelling Persons with Advanced Cancer



september **2015**

Funding for this study was received from the Institute for Continuing Care Education and Research (ICCER) Special Projects Grant.



Research Team

Wendy Duggleby, PhD, RN, AOCN (Project Lead), Professor and Research Chair Aging and Quality of Life Faculty of Nursing University of Alberta, Director of Innovations in Seniors Care Research Unit

Jasneet Parmar, MBBS, Dip COE, Associate Professor, Department of Family Medicine University of Alberta, Medical Director, CH Network of Excellence in Seniors' Health and Wellness and Medical Lead, Home Living, Edmonton Zone Continuing Care

Cheryl Nekolaichuk, PhD, R.Psych, Associate Professor, Department of Oncology University of Alberta, Psychologist, Palliative Care Program Grey Nuns Community Hospital

Mehrnoush (Noush) Mirhosseini, MD, CCFP, Palliative Care Medicine Consultant Alberta Health Services and Associate Professor Faculty of Dentistry and Medicine

Lorraine Holtslander, RN, PhD, CHPCN(c), Associate Professor, College of Nursing University of Saskatchewan

Peter Hudson, RN, PhD, Director Center for Palliative Care University of Melbourne Australia

Michelle Peterson Fraser, RN, BN, Lead, Provincial Palliative & End of Life Care Practice and Development Team Community & Seniors Health, Alberta Health Services

Jamie Tycholiz, RN, BSCN, End of Life Consultant, Policy Development & Community Partnerships Unit, Strategic Planning and Policy Development Division Alberta Health

Thane Chambers, MLIS, Research Librarian, Faculty of Nursing

Anna Mann, RSW, Alberta Caregivers Association

Jenny Swindle, PhD, Research Coordinator Innovations in Seniors Care Research Unit

Angele Alook, MA, Research Assistant

Tony Wu, Research Assistant

Abstract

Objectives: The aims of this metasynthesis study were to (1) explore the transition experience of family caregivers caring for persons with advanced cancer receiving palliative/hospice care and living in the community and (2) describe potential triggers and what influences this experience.

Methods: Sandelowski and Barroso's methodology for synthesizing qualitative research was used and included (a) a comprehensive search, (b) appraising reports of qualitative studies, (c) classification of studies, and (d) synthesis of the findings. Research team members guided this process. Following a comprehensive search, 15,472 studies were reviewed and assessed against five inclusion criteria: (a) studies on the experiences of caregivers of persons with advanced cancer (all genders, 18+ years of age) living in the community, (b) studies published in English from any country, (c) studies using qualitative and mixed methods designs, and (d) studies published between 2004 and 2014.

Results: Preliminary findings from the 72 studies that met the inclusion criteria, suggest that caregivers of persons with advanced cancer living in the community experience multiple, concurrent transitions. The types of transitions were reflected in 5 overlapping themes: a) environmental, b) roles and relationships, c) physical and mental health, d) spirituality and e) priorities. The triggering events were: a) complexity of care, b) changes in the condition of the person they were caring for (i.e. functional decline/activity limitations and acute exacerbation of illness/ symptoms), c) conflicting demands d) financial strain, and e) family role conflict. The participants dealt with the transitions through the processes of: a) coming to terms, b) connecting with others, and c) redefining normal. The findings provide a beginning understanding of the transitions experiences of caregivers of persons with advanced cancer living in the community and are a foundation for future research.

Background

Transitions are processes triggered by change during which a new situation or circumstance is incorporated into their lives (Meleis et al., 2000). Caregivers of persons receiving hospice/palliative care and living in the community experience multiple significant transitions that impact their physical and mental health (Duggleby et al., 2010). Although several qualitative studies have been conducted in this topic area (Funk et al., 2010), there are no reported metasynthesis studies. Metasynthesis is a method that brings together qualitative exploratory studies to enhance their contribution to the development of more formalized knowledge (Zimmer, 2006). Funding was awarded from ICCER to conduct a metasynthesis study to understand the transitions experienced by family caregivers of persons at the end of life and what influences their transitions.

Purpose

The aims of this metasynthesis study were to (1) explore the transition experience of family caregivers caring for persons with advanced cancer receiving palliative/hospice care and living in the community and (2) describe potential triggers and what influences this experience. Family caregivers will be broadly defined as including family and friends who provide ongoing assistance to a person at the end of life. End of life was defined as receiving hospice/palliative care.

Inclusion criteria for the studies were: a) published qualitative studies (and mixed-method designs) of the caregiving experience of caregivers of community living persons with advanced cancer receiving hospice/palliative care, b) caregivers and care recipients are adults (18 years of age and over), c) studies published in English in any country, d) studies published between 2004 and 2014 and e) abstracts, metasyntheses, and secondary analysis will be excluded.

Methodology

A metasynthesis of qualitative research studies on caregivers of persons at the end of life was completed using the procedures outlined by Sandelowski and Barroso (Sandelowski & Barroso, 2007). The procedural steps were: (a) comprehensive search, (b) appraising reports of qualitative studies, (c) classification of studies, and d) synthesis of the findings.

Demographic information about the studies (sample age, disease/illness, gender etc.) was entered into SPSS 22 for descriptive analysis. Qualitative studies were evaluated for their quality using the Critical Appraisal Skills Program (CASP). The CASP is a recommended tool of the Joanna Briggs Institute and provides a standardized mechanism for appraising qualitative studies using metasynthesis (Feder, Hudson, Ramsay, & Taket, 2006). The CASP was used to describe the quality of the studies as the context for the metasynthesis findings. Studies were not excluded based on the CASP score.

The reported findings from the articles were entered into NVivo 10 software for qualitative analysis. Synthesis of the findings occurred using taxonomic analysis, constant target comparison, and reciprocal translation. The purpose of the taxonomic analysis was to identify significant underlying concepts and conceptual relationships. Five of the identified studies were focused specifically on exploring the transition experience (Duggleby et al., 2010; Penrod, Hupcey, Shipley, Loeb, & Baney, 2012; Read & Wuest, 2007; Reinke et al., 2008; Sutherland, 2009;

Waldrop, Kramer, Skretny, Milch, & Finn, 2005). These were analyzed first to develop an initial conceptual framework. Then the study findings were evaluated for similarities and differences compared to the initial framework to clarify defining and overlapping attributes of transitions experienced by caregivers and discern relationships among the interpreted concepts. Reciprocal translations of the concepts were then used to integrate the metasynthesis findings.

Validity

The descriptive validity for this metasynthesis was maintained by (a) a comprehensive search for literature, (b) team discussion and decisions on search terms and inclusion criteria, (c) appraisals by two members of the team, and (d) keeping an audit trail of search results and decisions. The team discussed the findings of the studies and themes until agreement was reached through consensus.

Comprehensive Search

Search Terms

The research team met with the experienced librarian (Thane Chambers) to determine the search teams. The librarian then searched MEDLINE, Embase, PsycINFO, CINAHL, Web of Science, and ProQuest Dissertations & Theses Full Text using key search terms and subject headings for caregivers, carers, family, friends, significant other, terminal illness, palliative, and end of life. A qualitative and mixed methods study filter was also used. Depending upon the database and controlled vocabularies available, each search was modified using a combination of subject headings/key words in the title as search strategies.

Literature searches yielded 15,472 results, of which 6575 were duplicates, and 8709 were excluded for various reasons (e.g., bereavement/grief studies, not end of life, participants not caregiving in community setting, unclear as to which populations are captured, etc.). The initial screening (of titles only) resulted in 219 results, which were screened by reading the abstracts. Of these abstracts 188 references from the data base search were downloaded as full text articles. In addition, 52 articles from other sources were reviewed for duplicates, of which 31 full text articles were kept. In total 219 full text articles were downloaded, but 104 were excluded for the following reasons: abstracts only, duplicate publishing, quantitative studies, secondary analysis, narratives/editorials/case studies, studies not generalizable to Canadian context, studies not on community living persons at end-of-life, studies not focused on family caregivers' experiences at end of life, studies on bereavement and grieving, studies on children, studies on chronic illness but not end-of-life illness, studies on intervention evaluations or services evaluations. After that review 115 full text articles remained to be included. Another review in which demographic data of each study was entered into an excel spreadsheet revealed 43 more should be excluded for the above stated reasons, which resulted in 72 full text articles that were included in the metasynthesis (see Appendix 1 for attached reference list of articles included in the metasynthesis).

Challenges associated with determining the eligibility and inclusion

Understanding the care setting of each study was the most challenging to determine. Some studies clearly stated the focus of the study was on family caregivers providing care in the home.

Some studies had a sample of mixed care settings interviewing family caregivers providing care at home, community, hospital and/or hospice. However many studies only stated where the sample was recruited, for example recruitment from oncology clinic, recruitment from family support groups, or recruitment from hospice. Many studies recruited through hospices, which were the most challenging to determine as many hospices (especially American) provide inpatient care, home based care, day programming, respite, etc. As well some reveal during the course of the study the care setting changed, for example from hospital to home to hospice. Perhaps, the lack of clarity and ambiguity of care settings in these studies reveals that change in care setting may be one of the ongoing environmental transitions of end-of-life care.

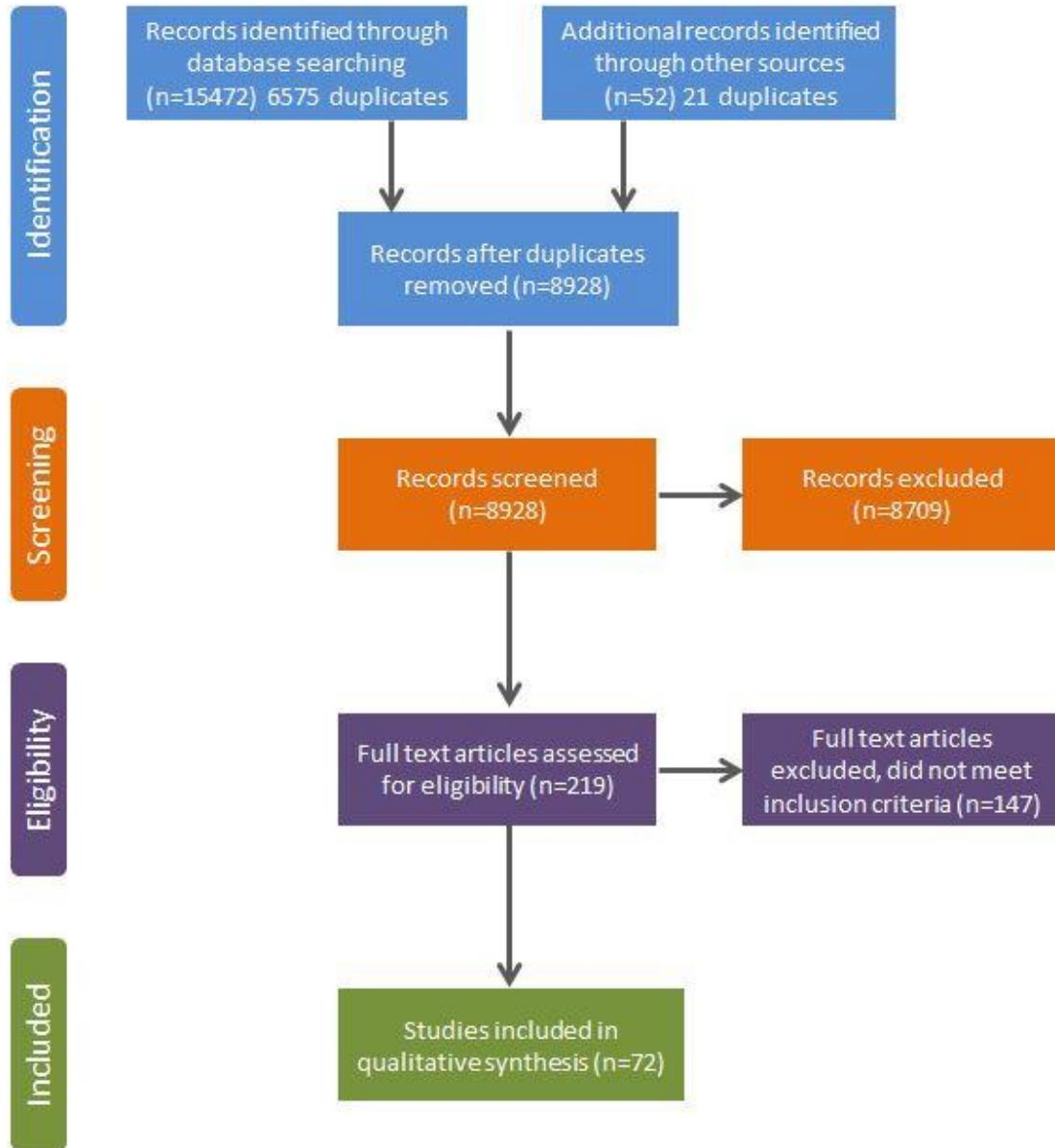


Figure 1: Results of Search

Most studies did not define end-of-life care. If a definition was provided, it was often the World Health Organization’s definition of palliative care (World Health Organization, n.d.), with the quality of life of the patient and of the family caregivers was a main tenet. Many studies mainly explained the aim of their study focusing on end-of-life care or caring for a patient with a life-limiting illness or a terminal illness, often merely naming the terminal illness to indicate focus on end-of-life care.

Results

Demographic Characteristics of Studies

The demographics of sample size, gender, diagnosis, age, age range, race/religion/culture, and education were not always clearly stated. Many studies did not indicate the demographics of education, and race/religion/culture, in fact only about a quarter of the studies disclosed educational levels and just over half disclosed race/religion/culture.

In the 72 articles the total number of caregivers were 1565 of which 767 were spouses (49%), 332 were adult children (21%), 134 siblings (8%), 107 other relatives (6%), 52 parents (3%), 25 friends (1%) and 5 grandchildren (.3%). The mean age of the caregivers was 58.57 (SD= 6.46) range 44.9- 73.8 years. The persons they were caring for were 70.58 years of age (SD=7.96). The majority of the caregivers were female [n= 1105 (70.6%)] and 359 were males (22.9%).

Thirty percent of the studies were conducted in the USA (22/72). Canada had the second highest number (17) and the UK had 16. Nine of the studies were conducted in Sweden, 5 in Australia, with Demark, Brazil and Switzerland having one study each.

Stated Study Methodologies

The studies reviewed reported using a variety of methodologies. Grounded theory was used the most frequently (18) (25%) followed by phenomenology (17) and thematic analysis (11). Ten stated they used a descriptive qualitative approach, 8 content analysis, 3 narrative inquiry, 3 ethnography and 2 mixed methods. Some of the articles did not report a specific methodology, but often reported the type of analysis in the analysis section. If not they were classified as descriptive studies.

Quality of the Studies

The mean CASP score was 18.67 (SD= 2.49) with a range of 13-23 out of a possible score of 24. Using Sandelowski and Barroso’s (2007) Classification System (see Table 1 below) most of the articles were classified as thematic survey followed by Conceptual Thematic Description.

Table 1 Sandelowski and Barroso’s Classification

Classification	Frequency	Percent
Topical Survey	10	13.9
Thematic Survey	26	36.1
Conceptual/Thematic Description	22	30.6
Interpretive Explanation	14	19.4
Total	72	100.0

Preliminary Synthesis of Findings

The findings from the 72 studies suggest that caregivers of persons with advanced cancer living in the community experience multiple, concurrent transitions. The types of transitions were reflected in 5 overlapping themes: a) environmental, b) roles and relationships, c) physical and mental health, d) spirituality and e) priorities. The triggering events were: a) complexity of care, b) changes in the condition of the person they were caring for (i.e. functional decline/activity limitations and acute exacerbation of illness/symptoms), c) conflicting demands d) financial strain, and e) family role conflict.

If these significant changes were not resolved, or dealt with, consequences occurred such as feelings of stress, anxiety, depression, guilt, shame, isolation fear and anger. What helped caregivers deal with the transitions were influencing factors such as timely communication, information, formal and informal support networks, faith. Other influencing factors in determining their experience were their own person and societal values and beliefs about caring, ethnicity/culture and caregiver, care recipient relationship.

Caregivers did adapt to their transition experiences through the processes of: a) coming to terms, b) connecting and c) redefining normal. Several sub-processes for each of these main processes were also identified. If the caregivers were able to engage in these processes, there were positive outcomes of: emotional and psychological stability, meaning making, living with hope, self-efficacy, and they were able to engage in end of life decision making. Figure 2 (Appendix 2) illustrates the conceptual framework of the transition experience of caregiver of persons with advanced cancer living in the community.

Implications of Findings

At the last research team meeting several implications for the study findings were discussed. The findings of the study provide a framework to assess current programs to support caregivers. For example, the program could be assessed to determine if it supports family caregivers to engage in the processes to achieve positive outcomes. This also includes information and websites, as the information provided should cover all areas included in the framework to help caregivers. As well there are several implications for advanced care planning as the data suggests that until the caregivers have come to terms with the changing situation they are not ready to connect with information and make decisions.

Next Steps

The research team has agreed to work together to submit a CIHR Knowledge Synthesis grant in January, 2015. The purpose of this grant will be to use the framework that was developed to evaluate existing interventions and programs that were developed to support family caregivers. This will provide further information for policy-makers and practitioners in regards to the best interventions and programs for caregivers.

A dissemination plan was also developed beginning with a one page lay summary that will be developed and distributed through the Alberta Caregivers Association. Jamie Tycholiz will arrange for presentations with Alberta Health policy makers. Also an abstract will be submitted to share the findings at the International Congress of the Terminally Ill in Montreal in September 2016. A publication will be submitted to Journal of Palliative Medicine.

Summary

Several outcomes have been achieved with the funding from the ICCER grant. The first was a greater understanding of the transitions experiences of caregivers of persons with advanced cancer living in the community, which can be used by practitioners and policy makers. Secondly, a dissemination plan has been developed, and the international research team will be submitting a grant to build upon this metasynthesis study.

References

- Duggleby, W.D., Penz, K.L., Goodridge, D.M., Wilson, D.M., Leipert, B.D., Berry, P.H., . . . Justice, C.J. (2010). The transition experience of rural older persons with advanced cancer and their families: a grounded theory study. *BMC Palliative Care*, 9:5. doi:10.1186/1472-684X-9-5
- Feder, G.S., Hutson, M., Ramsay, J. & Taket, A.R. (2006). Women exposed to intimate partner violence: Expectations and experiences when they encounter health care professionals: A meta-analysis of qualitative studies. *Archives in Internal Medicine*, 166, 22-37.
- Funk, L., Stajduhar, K.I., Toye, C., Aoun, S., Grande, G.E. & Todd, C.J. (2010). Part 2: Home based family caregiving at the end of life: A comprehensive review of published qualitative research (1998-2008). *Palliative Medicine*, 24(6), 594-607. doi:10.1177/0269216310371411
- Meleis, A.I., Sawyer, L.M., Im, E., Messias, D.K.H. & Schumacher, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science*, 23(1), 12-28.
- Penrod, J., Hupcey, J.E., Shipley, P.Z., Loeb, S.J. & Baney, B. (2012). A model of caregiving through the end of life: seeking normal. *Western Journal of Nursing Research*, 34(2), 174-193. doi: 10.1177/0193945911400920
- Read, T., & Wuest, J. (2007). Daughters caring for dying parents: A process of relinquishing. *Qualitative Health Research*, 17(7), 932-944.
- Reinke, L.F., Engelberg, R.A., Shannon, S.E., Wenrich, M.D., Vig, E.K., Back, A.L. & Curtis, J.R. (2008). Transitions regarding palliative and end-of-life care in severe chronic obstructive pulmonary disease or advanced cancer: Themes identified by patients, families, and clinicians. *Journal of Palliative Medicine*, 11(4), 601-609. doi:10.1089/jpm.2007.0236
- Sandelowski, M. & Barroso, J. (2007). *Handbook for synthesizing qualitative research*. New York: Springer Publishing Company.
- Sutherland, N. (2009). The meaning of being in transition to end-of-life care for female partners of spouses with cancer. *Palliative & Supportive care*, 7(4), 423-433. doi:10.1017/S1478951509990435
- Waldrop, D.P., Kramer, B.J., Skretny, J.A., Milch, R.A. & Finn, W. (2005). Final transitions: family caregiving at the end of life. *Journal of Palliative Medicine*, 8(3), 623-638.
- World Health Organization. (n.d.). WHO Definition of Palliative Care. Retrieved September 14, 2015 from <http://www.who.int/cancer/palliative/definition/en/>
- Zimmer, L. (2006). Qualitative meta-synthesis: A question of dialoguing texts. *Journal of Advanced Nursing*, 53(3), 311-318.

Appendix 1

Reference List

August 24, 2015

- Alexander, S.J. (2010). An intense and unforgettable experience: the lived experience of malignant wounds from the perspectives of patients, caregivers and nurses. *International Wound Journal*, 7(6), 456-465. doi:10.1111/j.1742-481X.2010.00715.x
- Anngela-Cole, L. & Busch, M. (2011). Stress and grief among family caregivers of older adults with cancer: A multicultural comparison from Hawai'i. *Journal Of Social Work In End-Of-Life & Palliative Care*, 7(4), 318-337. doi:10.1080/15524256.2011.623460
- Arber, A., Hutson, N., de Vries, K., & Guerrero, D. (2013). Finding the right kind of support: a study of carers of those with a primary malignant brain tumour. *European Journal of Oncology Nursing*, 17(1), 52-58. doi: http://dx.doi.org/10.1016/j.ejon.2012.01.008
- Arber, S. & Venn, S. (2011). Caregiving at night: Understanding the impact on carers. *Journal of Aging Studies*, 25(2), 155-165. doi:10.1016/j.jaging.2010.08.020, 25
- Benzar, E., Hansen, L., Kneitel, A.W. & Fromme, E.K. (2011). Discharge planning for palliative care patients: a qualitative analysis. *Journal of Palliative Medicine*, 14(1), 65-69. doi:10.1089/jpm.2010.0335
- Benzein, E.G. & Saveman, B. (2008). Health-promoting conversations about hope and suffering with couples in palliative care. *International Journal of Palliative Nursing*, 14(9), 439-445.
- Bialon, L.N. & Coke, S. (2012). A study on caregiver burden: stressors, challenges, and possible solutions. *American Journal of Hospice & Palliative Medicine*, 29(3), 210-218. doi:10.1177/1049909111416494
- Braun, U. K., Beyth, R. J., Ford, M. E., & McCullough, L. B. (2008). Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *Journal of General Internal Medicine*, 23(3), 267-274. doi:10.1007/s11606-007-0487-7
- Cagle, J.G. & Kovacs, P.J. (2011). Informal caregivers of cancer patients: perceptions about preparedness and support during hospice care. *Journal of Gerontological Social Work*, 54(1), 92-115. doi:10.1080/01634372.2010.534547
- Cavers, D., Hacking, B., Erridge, S.E., Kendall, M., Morris, P. G. & Murray, S.A. (2012). Social, psychological and existential well-being in patients with glioma and their caregivers: a qualitative study. *CMAJ Canadian Medical Association Journal*, 184(7), E373-382. doi:10.1503/cmaj.111622
- Chattoo, S. & Ahmad, W.I.U. (2008). The moral economy of selfhood and caring : negotiating boundaries of personal care as embodied moral practice (English). *Sociology of health & illness (Print)*, 30(4), 550-564.
- Cherlin, E., Fried, T., Prigerson, H.G., Schulman-Green, D., Johnson-Hurzeler, R. & Bradley, E H. (2005). Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said? *Journal of Palliative Medicine*, 8(6), 1176-1185.
- Clayton, J.M., Butow, P.N. & Tattersall, M.H.N. (2005). When and How to Initiate Discussion About Prognosis and End-of-Life Issues with Terminally Ill Patients. *Journal of Pain and Symptom Management*, 30(2), 132-144. doi:10.1016/j.jpainsymman.2005.02.014
- Cowan, M.M. (2014). The lived experiences of the Sikh population of South East England when caring for a dying relative at home. *International Journal of Palliative Nursing*, 20(4), 179-186.

- Dahlborg Lyckhage, E. & Lindahl, B. (2013). Living in liminality--being simultaneously visible and invisible: caregivers' narratives of palliative care. *Journal of Social Work in End-of-Life & Palliative Care*, 9(4), 272-288. doi:10.1080/15524256.2013.846885
- Donovan, R., Williams, A., Stajduhar, K., Brazil, K. & Marshall, D. (2011). The influence of culture on home-based family caregiving at end-of-life: a case study of Dutch reformed family care givers in Ontario, Canada. *Social Science & Medicine*, 72(3), 338-346. doi:10.1016/j.socscimed.2010.10.010
- Duggleby, W., Williams, A., Holtslander, L., Cunningham, S., & Wright, K. (2012). The chaos of caregiving and hope. *Qualitative Social Work: Research and Practice*, 11(5), 459-469.
- Duggleby, W.D., Penz, K.L., Goodridge, D.M., Wilson, D.M., Leipert, B.D., Berry, P.H., . . . Justice, C.J. (2010). The transition experience of rural older persons with advanced cancer and their families: a grounded theory study. *BMC Palliative Care*, 9, 5-13. doi:10.1186/1472-684X-9-5
- Edwards, S.B., Olson, K., Koop, P.M., & Northcott, H.C. (2012). Patient and family caregiver decision making in the context of advanced cancer. *Cancer Nursing*, 35(3), 178-186. doi:10.1097/NCC.0b013e31822786f6
- Esbensen, B.A., & Thomé, B. (2010). Being next of kin to an elderly person with cancer. *Scandinavian Journal of Caring Sciences*, 24(4), 648-654. doi:10.1111/j.1471-6712.2009.00756.x
- Forbat, L., McManus, E., & Haraldsdottir, E. (2012). Clinical implications for supporting caregivers at the end-of-life: Findings and from a qualitative study. *Contemporary Family Therapy: An International Journal*, 34(2), 282-292.
- Foxwell, K.R., & Scott, S.E. (2011). Coping together and apart: exploring how patients and their caregivers manage terminal head and neck cancer. *Journal of Psychosocial Oncology*, 29(3), 308-326. doi:10.1080/07347332.2011.563343
- Gardner, D.S., & Kramer, B.J. (2009). End-of-life concerns and care preferences: congruence among terminally ill elders and their family caregivers. *Omega-Journal of Death & Dying*, 60(3), 273-297.
- Griebeler Oliveira, S., Manuel Quintana, A., de Lourdes Denardin Budó, M., Henriqueta Luce Kruse, M., & Beuter, M. (2012). Home care and hospital assistance: similarities and differences from the perspective of the family caregiver. *Texto & Contexto Enfermagem*, 21(3), 591-599.
- Gysels, M.H., & Higginson, I.J. (2009). Caring for a person in advanced illness and suffering from breathlessness at home: threats and resources. *Palliative & Supportive Care*, 7(2), 153-162. doi:10.1017/S1478951509000200
- Harding, R., Epiphaniou, E., Hamilton, D., Bridger, S., Robinson, V., George, R., . . . Higginson, I.J. (2012). What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention. *Supportive Care in Cancer*, 20(9), 1975-1982. doi: 10.1007/s00520-011-1300-z
- Harrop, E., Byrne, A., & Nelson, A. (2014). "It's alright to ask for help": findings from a qualitative study exploring the information and support needs of family carers at the end of life. *BMC Palliative Care*, 13, 22. doi: 10.1186/1472-684X-13-22
- Hebert, R.S., Schulz, R., Copeland, V., & Arnold, R.M. (2008). What questions do family caregivers want to discuss with health care providers in order to prepare for the death of a loved one? An ethnographic study of caregivers of patients at end of life. *Journal of Palliative Medicine*, 11(3), 476-483. doi:10.1089/jpm.2007.0165

- Holtzlander, L.F., Duggleby, W., Williams, A.M., & Wright, K.E. (2005). The experience of hope for informal caregivers of palliative patients. *Journal of Palliative Care*, 21(4), 285-291.
- Houldin, A., Genevieve, H., & Lewis, F. M. (2007). A qualitative study of caregivers of patients with newly diagnosed advanced colorectal cancer. *Oncology Nursing Forum*, 34(1), 176.
- Hudson, P. (2004). Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing*, 10(2), 58-65; discussion 65.
- Jo, S., Brazil, K., Lohfeld, L., & Willison, K. (2007). Caregiving at the end of life: perspectives from spousal caregivers and care recipients. *Palliative & Supportive Care*, 5(1), 11-17.
- Kazanowski, M. (2005). Family caregivers' medication management of symptoms in patients with cancer near death. *Journal of Hospice & Palliative Nursing*, 7(3), 174-181.
- Kogan, N.R., Dumas, M., & Cohen, S.R. (2013). The extra burdens patients in denial impose on their family caregivers. *Palliative & Supportive Care*, 11(2), 91-99.
doi:10.1017/S1478951512000491
- Kukeya, C.B. (2006). Home caring for spouses with terminal cancer in the last stages of their illness: A phenomenological study of middle-aged caregivers. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 67, 851.
- Linderholm, M., & Friedrichsen, M. (2010). A desire to be seen: family caregivers' experiences of their caring role in palliative home care. *Cancer Nursing*, 33(1), 28-36.
doi:10.1097/NCC.0b013e3181af4f61
- Lockie, S.J., Bottorff, J.L., Robinson, C.A., & Pesut, B. (2010). Experiences of rural family caregivers who assist with commuting for palliative care. *Canadian Journal of Nursing Research*, 42(1), 74-91.
- McIlpatrick, S. (2007). Assessing palliative care needs: views of patients, informal carers and healthcare professionals. *Journal of Advanced Nursing*, 57(1), 77-86. doi:10.1111/j.1365-2648.2006.04062.x
- Mehta, A., Cohen, S.R., Ezer, H., Carnevale, F.A., & Ducharme, F. (2011). Striving to respond to palliative care patients' pain at home: a puzzle for family caregivers. *Oncology Nursing Forum*, 38(1), E37-45. doi:10.1188/11.ONF.E37-E45
- Melin-Johansson, C., Axelsson, B., & Danielson, E. (2007). Caregivers' perceptions about terminally ill family members' quality of life. *European Journal of Cancer Care*, 16(4), 338-345.
- Milberg, A., & Strang, P. (2004). Exploring comprehensibility and manageability in palliative home care: an interview study of dying cancer patients' informal carers. *Psycho-Oncology*, 13(9), 605-618.
- Mosher, C.E., Jaynes, H.A., Hanna, N., & Ostroff, J.S. (2013). Distressed family caregivers of lung cancer patients: an examination of psychosocial and practical challenges. *Supportive Care in Cancer*, 21(2), 431-437. doi:10.1007/s00520-012-1532-6
- Murray, S.A., Kendall, M., Boyd, K., Worth, A., & Benton, T.F. (2004). Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliative Medicine*, 18(1), 39-45.
- Penner, J.L., McClement, S., Lobchuk, M., & Daeninck, P. (2012). Family members' experiences caring for patients with advanced head and neck cancer receiving tube feeding: a descriptive phenomenological study. *Journal of Pain & Symptom Management*, 44(4), 563-571. doi:10.1016/j.jpainsymman.2011.10.016
- Penrod, J., Hupcey, J.E., Shipley, P.Z., Loeb, S.J., & Baney, B. (2012). A model of caregiving through the end of life: seeking normal. *Western Journal of Nursing Research*, 34(2), 174-193.
doi:10.1177/0193945911400920

- Persson, C., & Sundin, K. (2008). Being in the situation of a significant other to a person with inoperable lung cancer. *Cancer Nursing, 31*(5), 380-388. doi:10.1097/01.NCC.0000305763.89109.60
- Phillips, L.R., & Reed, P.G. (2010). End-of-life caregiver's perspectives on their role: generative caregiving. *Gerontologist, 50*(2), 204-214. doi:10.1093/geront/gnp116
- Probst, S., Arber, A., Trojan, A., & Faithfull, S. (2012). Caring for a loved one with a malignant fungating wound. *Supportive Care in Cancer, 20*(12), 3065-3070. doi:10.1007/s00520-012-1430-y
- Read, T., & Wuest, J. (2007). Daughters caring for dying parents: A process of relinquishing. *Qualitative Health Research, 17*(7), 932-944.
- Reinke, L.F., Engelberg, R.A., Shannon, S.E., Wenrich, M.D., Vig, E.K., Back, A.L., & Curtis, J.R. (2008). Transitions regarding palliative and end-of-life care in severe chronic obstructive pulmonary disease or advanced cancer: themes identified by patients, families, and clinicians. *Journal of Palliative Medicine, 11*(4), 601-609. doi:10.1089/jpm.2007.0236
- Revier, S.S., Meiers, S.J., & Herth, K.A. (2012). The Lived Experience of Hope in Family Caregivers Caring for a Terminally Ill Loved One. *Journal of Hospice & Palliative Nursing, 14*(6), 438-446. doi:10.1097/NJH.0b013e318257f8d4
- Riley, J., & Fenton, G. (2007). A terminal diagnosis: The carers' perspective. *Counselling & Psychotherapy Research, 7*(2), 86-91. doi:10.1080/14733140701327909
- Robinson, C.A., Pesut, B., & Bottorff, J.L. (2012). Supporting rural family palliative caregivers. *Journal of Family Nursing, 18*(4), 467-490. doi:10.1177/1074840712462065
- Sand, L., Olsson, M., & Strang, P. (2010). What are motives of family members who take responsibility in palliative cancer care? *Mortality, 15*(1), 64-80. doi:10.1080/13576270903537690, 15(
- Sherwood, P.R., Given, B.A., Doorenbos, A.Z., & Given, C.W. (2004). Forgotten voices: lessons from bereaved caregivers of persons with a brain tumour... including commentary by Krishnasamy M. *International Journal of Palliative Nursing, 10*(2), 67-75.
- Sjövall, K., Gunnars, B., Olsson, H., & Thomé, B. (2011). Experiences of living with advanced colorectal cancer from two perspectives - Inside and outside. *European Journal of Oncology Nursing, 15*, 390-397. doi:10.1016/j.ejon.2010.11.004
- Smith, P. (2009). The family caregivers journey in end-of-life care: Recognizing and identifying with the role of carer. *International Journal on Disability and Human Development, 8*(1), 67-73.
- Stajduhar, K.I., & Davies, B. (2005). Variations in and factors influencing family members' decisions for palliative home care. *Palliative Medicine, 19*(1), 21-32. doi:10.1191/0269216305pm963oa
- Stajduhar, K.I., Martin, W.L., Barwich, D., & Fyles, G. (2008). Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nursing, 31*(1), 77-85. doi:10.1097/01.NCC.0000305686.36637.b5
- Stoltz, P., Willman, A., & Udén, G. (2006). The Meaning of Support as Narrated by Family Carers Who Care for a Senior Relative at Home. *Qualitative Health Research, 16*, 594-610.
- Stone, A.M., Mikucki-Enyart, S., Middleton, A., Caughlin, J.P., & Brown, L.E. (2012). Caring for a Parent with Lung Cancer: Caregivers' Perspectives on the Role of Communication. *Qualitative Health Research, 22*(7), 957-970. doi:10.1177/1049732312443428
- Sutherland, N. (2009). The meaning of being in transition to end-of-life care for female partners of spouses with cancer. *Palliative & Supportive Care, 7*(4), 423-433. doi:10.1017/S1478951509990435

- Taylor, B. (2014). Experiences of sexuality and intimacy in terminal illness: a phenomenological study. *Palliative Medicine*, 28(5), 438-447. doi:10.1177/0269216313519489
- Terry, W., Olson, L.G., Wilss, L., & Boulton-Lewis, G. (2006). Experience of dying: concerns of dying patients and of carers. *Internal Medicine Journal*, 36(6), 338-346. doi: 10.1111/j.1445-5994.2006.01063.x
- Teschendorf, B., Schwartz, C., Ferrans, C. E., O'Mara, A., Novotny, P., & Sloan, J. (2007). Caregiver role stress: when families become providers. *Cancer Control*, 14(2), 183-189.
- Thomas, C., Morris, S. M., & Clark, D. (2004). Place of death: preferences among cancer patients and their carers. *Social Science & Medicine*, 58(12), 2431-2444. doi:10.1016/j.socscimed.2003.09.005
- Turner, W.L., Wallace, B.R., Anderson, J.R., & Bird, C. (2004). The last mile of the way: understanding caregiving in African American families at the end-of-life. *The Journal of Marital and Family Therapy*, 30(4), 427-438.
- Ugalde, A., Krishnasamy, M., & Schofield, P. (2012). Role recognition and changes to self-identity in family caregivers of people with advanced cancer: a qualitative study. *Supportive Care in Cancer*, 20(6), 1175-1181. doi:10.1007/s00520-011-1194-9
- Waldrop, D.P., Kramer, B.J., Skretny, J.A., Milch, R.A., & Finn, W. (2005). Final transitions: family caregiving at the end of life. *Journal of Palliative Medicine*, 8(3), 623-638.
- Ward-Griffin, C., McWilliam, C.L., & Oudshoorn, A. (2012). Relational experiences of family caregivers providing home-based end-of-life care. *Journal of Family Nursing*, 18(4), 491-516. doi:10.1177/1074840712462134
- Washington, K. (2013). Commitment to care: A grounded theory of informal hospice caregivers' development as symptom managers. *Qualitative Social Work*, 12(3), 358-371. doi:10.1177/1473325011429047
- Williams, A., Duggleby, W., Eby, J., Cooper, R. D., Hallstrom, L. K., Holtslander, L., & Thomas, R. (2013). Hope against hope: exploring the hopes and challenges of rural female caregivers of persons with advanced cancer. *BMC Palliative Care*, 12:44. doi:10.1186/1472-684X-12-44

Appendix 2

Transition Experience of Caregivers of Persons with Advanced Cancer

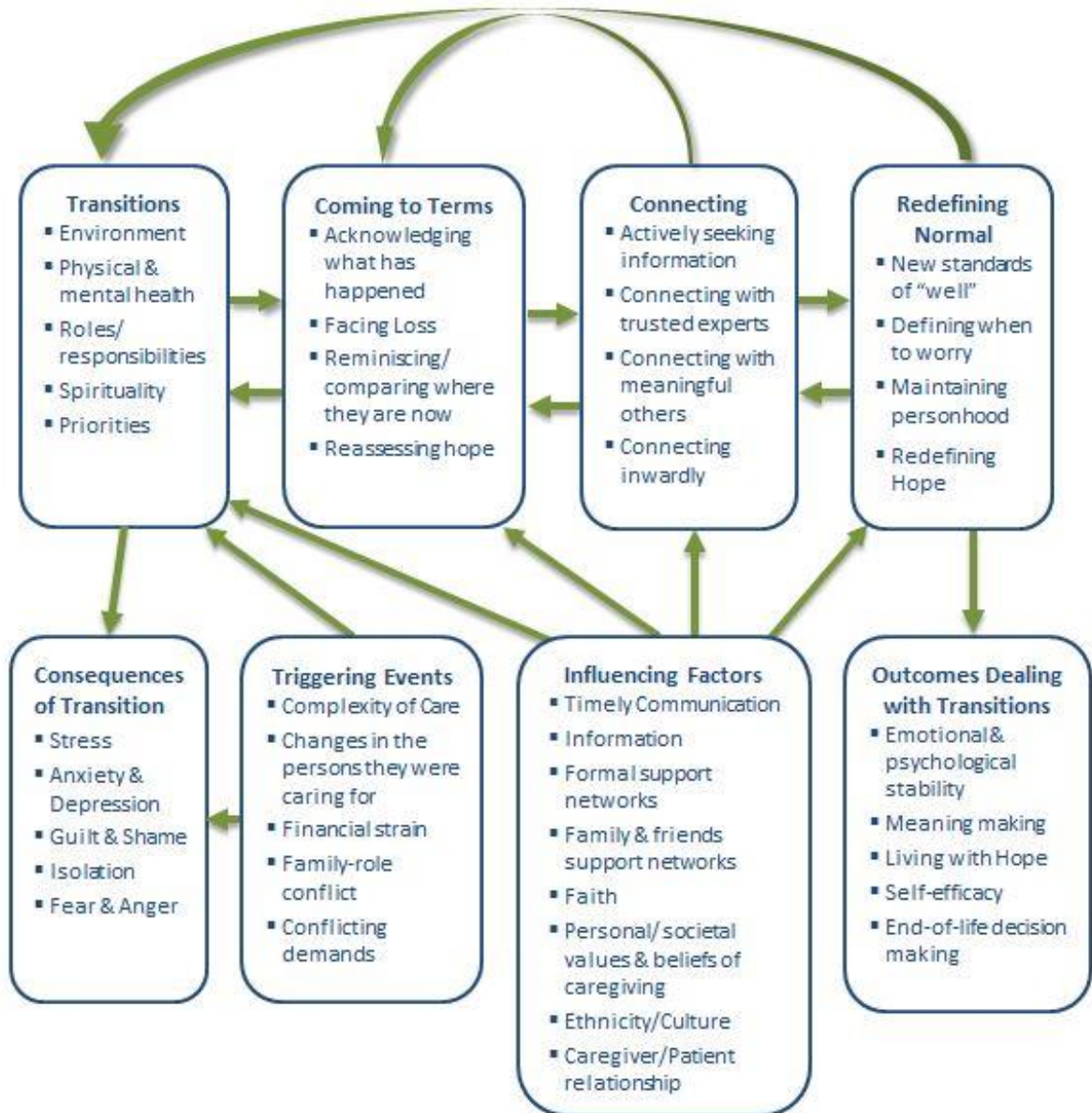


Figure 2: Synthesis Model