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A Strengths Perspective on Caregiving at the End-of-life

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Abstract

The adverse effects of caregiving provided by family members, partners, and friends for people dying at home from a life-limiting illness have been extensively documented in the palliative care research literature, yet minimal attention has been directed towards the strengths of informal carers and their subsequent growth and development. Using in-depth interviews from a purposive sample of informal carers (n = 28), this paper reports empirical evidence from a subset of data analysed for an Australian qualitative study, illuminating a range of strengths frequently obscured beneath the emotional-labour work of caregiving and further sequestered by the chaos of grief. A strengths perspective on caregiving at end-of-life is important because it helps to inform a reconstruction of caring and dying to include dimensions that relate to the growth of human potential and capacity, as well as enabling collaborative partnerships between workers and informal carers at the end-of-life.

Keywords: Palliative Care; Grief and Loss; Bereavement; Strengths-based Approaches; Heuristic Enquiry

Caring for a partner, relative, or friend dying from a life-limiting illness in the setting of the home is referred to in the health care literature as informal care, and is conceptualised as both labour work and emotional work (James, Andershed, & Ternstedt, 2009). Such care is intense and traverses deeply personal experiences, primarily motivated by an attachment to a close, private, and, in some instances, delicate and fraught relationship. It is theorised in the sociological literature as an embodied moral practice involving notions of interdependence and reciprocity, negotiated within a unique cultural and biographical context (Broom & Cavenagh, 2010; Chattoo & Ahmad, 2008). In the biomedical research literature, it is associated with: burdens (Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Fukui, Fujita, & Yoshiuchi, 2013); distress (Dumont et al., 2006; Hudson et al., 2013); comorbidities (Nijboer et al., 1998; Schulz & Beach, 1999); personal costs (Aoun, Kristjanson, Currow, & Hudson, 2005); and stigma (Powell-Cope & Brown, 1992), and in response

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to these adverse effects, informal carers have been identified as hidden patients (Kristjanson & Aoun, 2004) and vulnerable caregivers (Navaie-Waliser et al., 2002).

Caregiving does not cease at the time of death (Hughes, 2009; Singing, 2003) as during bereavement the focus of attention shifts to matters of body disposition, final ceremony, and memorialisation, collectively referred to as final arrangements (Bern-Klug, 2004). Confronted with a wide range of options offering greater choice, people can experience confusion, distress, and ambivalence; all happening when the shattering sense of loss is realised and many significant decisions of an irreversible nature must be made with a wide range of stakeholders (Bern-Klug, Gessert, & Forbes, 2001; Latham & Prigerson, 2004). The biomedical literature acknowledges the risks associated with bereavement, highlighting physical ailments, impaired mental health, and increased mortality rates (Sanderson et al., 2013; Wiese et al., 2010). Viewed in these contexts, the experience of caregiving at the end-of-life and throughout bereavement is clearly perceived to be a risk posing threats to people's wellbeing, warranting the intervention, monitoring, and management of health care professionals. This distinctive type of care presents significant challenges, and palliative care research duly highlights the need for more effective ways to incorporate comprehensive support for informal carers (Hudson & Aranda, 2013; Payne & Grande, 2013).

Alongside this accumulating evidence is a less prominent body of knowledge that highlights the positive aspects arising from having cared for a dying relative, partner, or friend in the setting of the home. Such aspects of the informal caring experience include a greater sense of family closeness, a more meaningful purpose in life, and enhanced coping abilities (Grbich, Parker, & Maddocks, 2001; Hudson, 2004; Keeley, 2007; Strang & Koop, 2003). The lived experience of bereavement is also recognised for enabling a heightened understanding of the impermanence of life: a corresponding appreciation for the importance of relationship; a shared sense of common humanity; and an increased sensitivity, humility, and compassion for others (Calhoun & Tedeschi, 2001; Kellehear, 2007; Meeker, 2004). While studies have identified a range of positive outcomes emerging from the lived experience of informal care-giving, carers' strengths are yet to feature in the palliative care research literature. Funk et al. (2010) reviewed 105 published qualitative articles between the period of 1998 and 2008 on home-based family caregiving at end-of-life, and carers' strengths were not mentioned.

The strengths perspective is both a moral and pragmatic approach used predominantly in social work, recently gaining momentum in the field of nursing (Gottlieb, 2013). Coined in 1989 by the authors Weick, Rapp, Sullivan, and Kishardt, the strengths perspective assumes that people have the capacity for growth and change even during periods of hardship and crisis (Weick et al., 1989). Adversity, difficulties, and suffering all offer the potential for learning and growing, with knowledge gained from one experience able to be applied to subsequent life situations. Operating in contrast to the more traditional problem-solving approaches, which "tilt toward the pathological" (Weick et al., 1989, p. 350), a strengths perspective regards people as active agents possessing "a wide range of talents, abilities, capacities, skills, resources

and aspirations” (Weick et al., 1989, p. 352). Saleebey (2013), a leading authority in this humanist approach, defined strengths as:

Personal qualities, traits and virtues that people possess [acquired by] what people know about the world around them, from those things learned intellectually or educationally, to those that people have discerned and distilled through their life experiences. (p. 103)

This paper contributes to the understanding of the informal care experience by amplifying a strengths perspective to the analysis of the lived experience of caregiving at the end-of-life in the setting of the home. By reporting a subset of data from findings from an empirical study undertaken in Australia, this paper reconstructs caring and dying as concurrent growth and development, giving meaning to one of life’s “hardest thing(s) ... ever done” (Hughes, 2009, p. 246).

Method

Design

For this study, heuristic enquiry was used to investigate how people experienced the death and final arrangements of a significant other person who died at home from a life-limiting illness. This research evolved from my own lived experience with death and bereavement, instilling within me a deep curiosity to discover meaning within human experience. Recognising that subjectivity would influence this research, I decided to illuminate new meaning by the application of the research method known as heuristic enquiry. Heuristic enquiry is a qualitative approach conceived and developed by Clark Moustakas (1990), restricted to researchers able to claim inside membership (Adler & Adler, 1987) with the people being studied and always investigating matters of personal significance (Atkins & Loewenthal, 2004; Djuraskovic & Arthur, 2010; Truelsen, 2003). Borne from a personal experience of caring for my mother who died at home from cancer, and further inspired by the wisdom I acquired from working as a palliative care social worker, this type of enquiry provided a genuine reason to enter deeply into the lived experiences of others. By locating myself at the centre of the research, heuristic enquiry facilitated transparency, exposed biases, and gave value to subjectivity. While resembling other qualitative approaches involving autobiographical narratives, it is the deliberate positioning of myself in the research that distinguishes heuristic enquiry from other qualitative research, because the researcher becomes a legitimate participant, integrating personal experience with the experiences of other participants, sometimes referred to as coresearchers (Moustakas, 1990). The researcher’s lived experience, subjectivity, and reflexivity become primary sources of data and valid elements of the research process, and it is through the application of a range of concepts and a framework of six distinctive phases that heuristic enquiry offers “a way of engaging in scientific research through methods and processes aimed at discovery, a way of self-inquiry and dialogue with

others aimed at finding the underlying meanings of important human experiences” (Moustakas, 1990, p. 15).

Participants

Ethical clearance for the study was obtained from the University of Tasmania, Australia, and triangulated sampling was used to recruit participants through purposive, snowballing, and opportunistic sampling strategies. The research was advertised by means of posters displayed in public places; presenting at research forums; featuring in a local newspaper; and being interviewed on radio by the Australian Broadcasting Commission. Selection criteria for eligibility as a research participant included: the ability to speak English; living in Tasmania at the time of being interviewed; aged 18 years or older; had cared for someone significant at home throughout the course of a life-limiting illness; had attended to the person’s death in the site of the home; and had experienced the death of the person more than 10 months ago. Twenty-eight people were recruited for the study, self-identifying as the wife ($n = 11$); husband ($n = 2$); sister ($n = 1$); daughter ($n = 8$); mother ($n = 4$); father ($n = 1$); and family friend ($n = 1$) of a person who had died at home from a life-limiting illness. While all shared a similar experience, the people in this study were not a homogenous group, varying in gender, age, socioeconomic status, length of time spent caring for a dying person, and duration of time since the death. Most participants reported that the person they had cared for had died from 2 to 16 years ago; one person explained that her friend had died within the past 12 months; and another two participants reported that their informal caring ended 20 years ago. Given that the aim of the research was to discover people’s constructed realities rather than verifying facts, the duration of time following a death was considered to be of no importance.

Data Collection

Data were generated from in-depth semistructured interviews undertaken in locations chosen by participants with one participant choosing not to be interviewed but instead providing her manuscript narrating her son’s story. People were interviewed face-to-face and all interviews were digitally recorded ranging in duration from 45 minutes to 3 ½ hours. A pilot interview was initially undertaken for the purpose of checking the quality of the recorded information and to seek feedback concerning the types of questions asked and the manner in which I conducted the interview. Congruent with a heuristic approach, interviews were influenced by the collaborative process of reflexive dyadic interviewing (Ellis & Berger, 2002), facilitating a conversational-like dialogue between the researcher and the person being interviewed. Parkes (1995) and Rosenblatt (1995) both state that interviews have a therapeutic value and regard the expression of grief to be normal throughout studies of bereavement, but caution that there must be established guidelines for conducting ethical bereavement research to avoid the risk of harm. I recognised the potential harm that could be generated from

conducting a deep exploration of people's experiences of end-of-life and considered the ethical challenges raised by this project. I knew that I would be asking people to recall memories that were private, some of which may never have been shared, and I also knew that I was asking people to return to a time that some would regard as terrible. I also knew from practice wisdom that a consequence of recalling these experiences can impact upon people for days afterwards, so I always checked how people were at the conclusion of their interviews and usually waited for a period of time before I departed to ensure that people were feeling comfortable to be left alone. I would offer to phone people who became distressed in the interview throughout the following days to see how they were faring, although all participants declined this offer.

While a commitment to heuristic enquiry required a deep and passionate exploration of other people's experiences, it also meant that I was deliberately identifying with the focus of enquiry. By revisiting my past, connecting with other participants, and listening, reading, transcribing, rereading, relistening, analysing, re-examining, and plunging many times again deeper into the stories of other people's loss, I became acutely aware of the intimate relationship I developed with the data and an understanding of the impact of researching a topic of such personal significance. Vulnerability was not merely an issue for people participating in this research, but also something that I needed to recognise in myself, as the researcher. Self-awareness alone risks a myopic preoccupation, yet a combination of critical reflection enhanced my understanding of the value of reflexivity and ultimately research rigour. Engaging with reflexivity demanded a "thoughtful conscious self-awareness" (Finlay, 2002, p. 532) and a constant review of how my values, beliefs, and emotions shaped the overall enquiry. This process was facilitated by discussions with my supervisors and research colleagues, as well as an immersion in the literature on positionality.

I transcribed all interviews and, with consent, returned transcripts to participants either in person or by post. To enhance the rigour of the study, participants were invited to respond to correct errors in translation and to add or delete information to their transcripts. Recognising the potential impact of seeing one's story in print I also highlighted to participants the need to consider their personal wellbeing when and if they chose to read their transcript. Journaling was also used in combination with interviews for recording ideas, reflections, and questions.

Data Analysis

An immersion of the data was achieved from listening to, transcribing, reading and rereading the interviews, making notes, and reflecting on the meanings in the transcripts. Given that the study was undertaken for a doctorate, I was also able to access the mentorship of two skilled and experienced research supervisors throughout the data analysis. In heuristic enquiry, "after the data are collected they must be organized and presented in a way that depicts and illustrates the themes, meanings and essences of the experiences that have been investigated" (Moustakas, 1990, p. 43). An inductive approach was used to analyse the data by applying a thematic analysis.

I adopted the definition of a theme from DeSantis and Ugarriza (2000), who claim that a theme is “an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole” (p. 362). Analysis of the data began during the immersion stage of the research process and continued via the organisation of participants’ quotations into segments of experience. By paraphrasing and reflecting on the meanings of the experiences, I applied codes to identify core meanings, eventually labelling 45 inductive codes. The data were further analysed, ultimately generating 24 categories of experience. Finally, a thematic map helped to make sense of the relationships between the codes, categories, and themes (Braun & Clarke, 2006). The themes I constructed were my interpretations from the shared experiences of people. Themes are understood to be reductions (Van Manen, 1997) or condensed meanings (Luborsky, 1994) of notions that “unite a large body of data that may otherwise appear disparate and unrelated” (DeSantis & Ugarriza, 2000, p. 355).

Findings

The informal carers in this study did not portray themselves as being extraordinary or capable of achieving remarkable outcomes, often emphasising their regrets, uncertainties, and limitations. Many expressed a concern that their stories of caregiving would be of no value for this study. Some reported criticism from family members, friends, work colleagues, and medical staff, and few said that they were encouraged to pursue their endeavour to enable their friend, relative, or partner to die at home. While describing the total experience as “hard work”, “intense”, “distressing”, “horrendous”, and “traumatic”, participants also said it was “a privilege”, “rewarding”, “very, very satisfying”, “probably the best family time [since being a child, but also] the worst”, and “a great thing to be able to do”.

A deep investigation of carers’ experiences showed in spite of the references to exhaustion, distress, fear, confusion, doubt, guilt, worry, and deep loss, a range of strengths operated. In this study, the strengths that emerged included: courage, determination, acceptance, humour, and empathy. People’s strengths were not clearly apparent, obscured beneath stories of struggle, adversity, and irreplaceable loss, as well as from the chaos generated by grief, and a widespread propensity to direct attention towards the negative aspects of caregiving and bereavement.

Courage

Being courageous was not a feeling or emotion that people experienced but an attitude which enabled people to do what they believed needed to be done at a particular point in time. Courage operated in people’s lives at the same time when fear or dread existed. People explained that they had to frequently move beyond their familiar frames of reference and respond to the unknown. People also used courage during decision-making, especially when opting to participate in ways alternative to

mainstream society, such as challenging authority, assuming responsibility for unfamiliar duties, and remaining in the presence of suffering.

Determination

Achieving a death at home demanded a concerted effort and a willingness to adjust to an altered lifestyle. Determination assisted people when others criticised their efforts or undermined their ability to do the best for the person who was dying. Even when carers were exhausted, they still managed to make decisions and apply their strengths to action. This capacity was in large part due to people's determination.

Acceptance

Acceptance was not synonymous with being helpless or powerless. Acceptance involved making a conscious decision to be open to what was happening, often resulting in a sense of comfort. Acceptance was also evident in carers allowing the depth of grief to be felt, signifying that they had experienced a profound and life-changing loss. Seeking and accepting help was also a strength demonstrated by participants. Visiting the doctor for advice about physical and psychological symptoms was a strategy that people employed as an attempt to alleviate their distress, while some attended grief and bereavement support groups.

Humour

Many participants employed humour to help manage adversity. Sharing their humour with others was a prosocial behaviour that helped to lighten situations and ease anguish. Remembering amusing moments or making light of some incident prevented people from being overwhelmed by deep sadness or grief.

Empathy

Carers' skills in observing nonverbal cues often enabled them to intuit what another person was experiencing, evident in the experiences of seeking pain relief or staying with their significant other person as death approached. Staying with a person in the active stage of dying usually caused people anguish but it also offered greater insight and a deeper understanding of the lived experience of dying. People's empathy often extended beyond the person who was dying to include others in their community, particularly children and the elderly. The anguish and sorrow also felt throughout bereavement caused by a profound personal loss enabled a shared understanding and a bond with others. From the lived experience of attending to the death and final arrangements, participants explained how they gained greater insight to the journey and empathised with others who chose to follow a similar pathway. [Table 1](#) provides selected examples of carers' strengths.

Table 1 Selected Examples of Informal Carers' Strengths

Strengths	Representative Quotations from Research Participants
Courage	<p>I was still afraid and I had never gone through it before ... it was really scary to think that he was going to die there ... I didn't know what to do ... my heart started to beat ... I thought, "What am I going to do?" so I started to sing to him ... our wedding song. He sort of opened his eyes and looked at me and his breathing just calmed right down...I sat down next to the bed and I held his hand and I told him all the things I wanted him to know. He looked over at me and said, "I love you" and then he died.</p>
	Participant 17
	<p>I felt scared, I felt honored and I was unsure whether I could do it ... but I suppose I knew I could and that I had the strength to do it.</p>
	Participant 6
	<p>There's fear in going off to somewhere completely unknown to be with a whole lot of people I don't know ... in one of the men's activity groups [throughout bereavement] they decided to have a concert and they were asking people to perform and I thought, "Oh God, I can't!" and I said "Right, put my name down" ... I knew that was something I had to face.</p>
	Participant 25
Determination	<p>The GP became quite offensive in so far as he suggested we couldn't do it at home and that we, being my friend and myself: and he throwing that challenge out, really upset the two of us, so we were more determined to achieve the ultimate.</p>
	Participant 10
	<p>I think, "How did I ever get through that?" ... the last 3 months were the hardest ... 2 months of that I was still working full time ... I think it's just sheer determination.</p>
	Participant 21
	<p>I was determined that he was going to have a beautiful funeral, which he did.</p>
	Participant 11
Acceptance	<p>He'd been home for a week or so. I just sort of said to him, "Look, I hope you don't mind me saying this, but being very sort of ignorant about what has to happen, do you mind if I go out and do some homework?" So I went around to three funeral places ... I chose a casket and decided upon a celebrant and I actually invited the celebrant to the house to meet him before.</p>
	Participant 3
	<p>Even when she died ... we had a little discussion, "What do we do? Do we ring a doctor ... what's the point?" " Yeah, what's the point? The doctor knows she's sick. We'll wait for the morning". It was in the middle of the night. We just put her in the middle of us and lay down and went to sleep. She was our baby and it didn't matter that she was dead, so she just slept in between us.</p>
	Participant 22
	<p>A few weeks after the funeral I was feeling rather depressed and very lonely, so I joined [a group] that supports people whose loved ones have died. I also tried to keep busy.</p>
	Participant 13

(Continued)

Strengths	Representative Quotations from Research Participants
Humour	My sister and I have this very black sense of humour ... we did lots of joking around. Participant 1
	You do a lot of laughing as well as a lot of crying. Participant 26
	We just weren't going to let it overwhelm us ... we just laughed our way through life most of the time, and we just tried to keep that up as well. Participant 23
Empathy	I started immediately worrying about my brother and sister and my nephews ... I was worried about all these other people, particularly the boys. Participant 24
	All I could do was sort of hang on tight and hold his hand and try and sort of reflect what I thought he was feeling. It was just empathy ... be guided by the way he was feeling. Participant 11
	Our lives have taken on a new light and our outlook has changed ... to all other Mums and Dads who may face the loss of a child, remember, someone else understands. Participant 27

Discussion

Empirical data from this study illuminated a range of informal carers' strengths, including courage, determination, acceptance, humour, and empathy. These strengths operated concomitantly among feelings of exhaustion, doubt, anguish, worry, fear, and deep sadness. It was from engaging in the practices of caregiving at end-of-life that enabled the expression of strengths. Strengths provided benefits not only for the person receiving care but unveiled the potential for the carers' self-growth and transformation. The findings from this study do not intend to minimise the struggles, challenges, and risks associated with caregiving at end-of-life but seek to restore some balance to the lived experience moving beyond the prevailing deficit model. By giving recognition to carers' capacities, skills, resources, qualities, and talents, this study demonstrates how caring for someone at home dying from a life-limiting illness can mobilise strengths and generate change and growth at the end-of-life, offering meaning to a time of crisis.

People's strengths were not always obvious to others nor were they to the individuals who possessed them. This can be attributed in part to the dominant discourses silencing or subjugating certain experiences or sources of knowledge, as well as a propensity for the Western world's "fascination with problems and pathology" (Saleebey, 2013, p. 2). When strengths are overlooked or minimised, carers' "untapped, undetermined reservoirs of mental, physical, emotional, social and spiritual abilities" (Weick et al., 1989, p. 352) risk remaining sequestered and

potentially immobilised for future use. In the Western world, grief and bereavement are deeply rooted in a disease paradigm and the prevailing influences of medicine and psychology dominate people's understandings of these experiences. Knowing the authoritative and persuasive powers invested in the medical model increases the likelihood that some people who have experienced the death of a significant other person and sought help from professionals, will have had their strengths and resources overlooked with greater attention given to the naming of symptoms and a diagnosis of disease.

Alternatively, when strengths are recognised, "this capacity acknowledges both the being and the becoming aspects of life" (Weick et al., 1989, p. 352), offering "hope and possibility" (Saleebey, 2013, p. 11). Such recognition helps to challenge the assumption that the destiny of informal carers will always end in strife. This way of thinking is echoed by Hudson (2004) who cautioned that a maligned identity and a dominant focus on the negative aspects of caring for a dying person at home may perpetuate inherent risks of "pathologising care giving and inadvertently socializing caregivers to expect burden" (p. 58). While critics may claim that the strengths approach merely reframes misery, is "Pollyannaish", or unrealistically extols people's virtues through positive thinking, Saleebey (2013) argues that using a strengths approach for understanding the human condition goes some way to restoring a balance so that the strengths and capacities of people are recognised as well as their adversity, afflictions, and agonies.

A strengths perspective is important because it has practice implications for palliative care. The application of a strengths perspective is an interactional model of working with people founded on principles of respect and empowerment (Saleebey, 2013). The approach requires the practitioner to honour carers' self-determination and to understand carers' goals. During initial assessment and throughout the journey of caring, it is important to discover and rediscover carers' strengths by asking such questions as, "How have you managed so far? What has enabled you to continue caring given all the challenges you've had to face? What are your hopes? What would be helpful to enable you to achieve your goals?". Such questions have a client-directed orientation rather than a worker-directed orientation, expanding the scope for possibilities of which the worker may never have anticipated.

Worker and client relationships develop through dialogue and collaboration, requiring from the practitioner a commitment to explore what is meaningful to the person who lives the experience rather than having assumptions imposed upon them, ultimately determining others' limitations and capacities. When workers assume greater knowledge, impose values, or seize control, carers' strengths are ignored and such practice impedes progress to working collaboratively. Instead, by employing a spirit of curiosity, being sensitive to cultural and structural contexts, respecting diversity, and applying skills of careful observation, listening and understanding, a strengths orientation promotes a person-centered approach in which "the helping relationship becomes one of collaboration, mutuality and partnership" (Saleebey, 2013, p. 60).

My argument for adopting a strengths perspective at the end-of-life is based on two premises. In the first instance, carers' strengths can be identified and used to facilitate the empowerment of people for the purpose of achieving personal goals, to celebrate achievements and to recognise the wisdom and insight that comes from lived experience. Secondly, these assets can be shared, not only with the people receiving care, but with others in the community, including people providing palliative care.

Conclusion

Caring for a relative, partner, or friend diagnosed with a life-limiting illness in the setting of the home is a huge undertaking requiring intense labour and emotional work. Accumulating evidence highlighting poor outcomes drives the need to invest in better caregiver support so that the wellbeing of carers can be improved. This paper argues that the application of a strengths perspective will contribute towards better support for informal carers by deepening the understanding of the lived experience of caregiving, promoting collaborative partnerships between workers and informal carers, and building community capacity at end-of-life. The strengths perspective does not disregard the distress and trauma operating in people's lives but deeply explores and validates experience, opting not to leave the painful story of survival, coping, and change submerged beneath the more dominant ways of knowing grief and bereavement. It is an approach deserving greater attention and social workers are well positioned to apply their skills and knowledge to support family members, partners, and friends caring for people dying at home from a life-limiting illness.

References

- Adler, P., & Adler, P. (1987). *Membership roles in field research*. Sage University Paper Series on Qualitative Research Methods, Vol. 6. Denver, CA: Sage.
- Aoun, S. M., Kristjanson, L. J., Currow, D. C., & Hudson, P. L. (2005). Caregiving for the terminally ill: At what cost?. *Palliative Medicine*, 19, 551–555. doi:10.1191/0269216305pm1053oa
- Atkins, D., & Loewenthal, D. (2004). The lived experience of psychotherapists working with older clients: An heuristic study. *British Journal of Guidance and Counselling*, 32, 493–509. doi:10.1080/03069880412331303295
- Bern-Klug, M. (2004). The ambiguous dying syndrome. *Health and Social Work*, 29(1), 55–65. doi:10.1093/hsw/29.1.55
- Bern-Klug, M., Gessert, C., & Forbes, S. (2001). The need to revise assumptions about the end-of-life: Implications for social work practice. *Health and Social Work*, 26(1), 38–48. doi:10.1093/hsw/26.1.38
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. doi:10.1191/1478088706qp063oa
- Broom, A., & Cavenagh, J. (2010). Masculinity, moralities and being cared for: An exploration of experiences of living and dying in a hospice. *Social Science and Medicine*, 71, 869–876. doi:10.1016/j.socscimed.2010.05.026

- Calhoun, L., & Tedeschi, T. (2001). Post-traumatic growth: The positive lessons of loss. In R. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 157–172). Washington, DC: American Psychological Association.
- Chattoo, S., & Ahmad, W. I. U. (2008). The moral economy of selfhood and caring: Negotiating boundaries of personal care as embodied moral practice. *Sociology of Health and Illness*, 30, 550–564. doi:10.1111/j.1467-9566.2007.01072.x
- DeSantis, L., & Ugarriza, D. N. (2000). The concept of theme as used in qualitative nursing research. *Western Journal of Nursing Research*, 22, 351–372. doi:10.1177/01939450022044467
- Djuraskovic, I., & Arthur, N. (2010). Heuristic inquiry: A personal journey of acculturation and identity reconstruction. *The Qualitative Report*, 15, 1569–1593.
- Dumont, S., Turgeon, J., Allard, P., Gagnon, P., Charbonneau, C., & Vézina, L. (2006). Caring for a loved one with advanced cancer: Determinants of psychological distress in family caregivers. *Journal of Palliative Medicine*, 9, 912–921. doi:10.1089/jpm.2006.9.912
- Ellis, C., & Berger, L. (2002). Their story/my story/our story: Including the researcher's experience in interview research. In J. Gubrium & J. Holstein (Eds.) *Handbook of interview research: Context and methods* (pp. 849–875). Thousand Oaks, CA: Sage.
- Emanuel, E. J., Fairclough, D. L., Slutsman, J., & Emanuel, L. L. (2000). Understanding economic and other burdens of terminal illness: The experiences of patients and their caregivers. *Annals of Internal Medicine*, 132, 451–459. doi:10.7326/0003-4819-132-6-200003210-00005
- Finlay, L. (2002). “Outing” the researcher: The provenance, process and practice of reflexivity. *Qualitative Health Research*, 12, 531–545. doi:10.1177/104973202129120052
- Fukui, S., Fujita, J., & Yoshiuchi, K. (2013). Associations between Japanese people's concern about family caregiver burden and preference for end-of-life care location. *Journal of Palliative Care*, 29(1), 22–28.
- 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, 594–607. doi:10.1177/0269216310371411
- Gottlieb, L. N. (2013). *Strengths-based nursing care: Health and healing for person and family*. New York, NY: Springer.
- Grbich, C., Parker, D., & Maddocks, I. (2001). The emotions and coping strategies of caregivers of family members with a terminal cancer. *Journal of Palliative Care*, 17(1), 30–36.
- Hudson, P. (2004). Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing*, 10(2), 58–64.
- Hudson, P., & Aranda, S. (2013). The Melbourne Family Support Program: Evidence-based strategies that prepare family caregivers for supporting palliative care patients. *BMJ Supportive & Palliative Care*. doi:10.1136/bmjspcare-2013-000500
- Hudson, P., Trauer, T., Kelly, B., O'Connor, M., Thomas, K., Summers, M., ... White, V. (2013). Reducing the psychological distress of family caregivers of home-based palliative care patients: Short term effects from a randomized controlled trial. *Psycho-Oncology*, 22, 1987–1993. doi:10.1002/pon.3242
- Hughes, M. (2009). *The lived experience of compassionate love at end of life* (Unpublished doctoral dissertation). University of Tasmania, Launceston, Tasmania.
- James, I., Andershed, B., & Ternstedt, B. M. (2009). The encounter between informal and professional care at the end of life. *Qualitative Health Research*, 19, 258–271. doi:10.1177/1049732308329309
- Keeley, M. P. (2007). “Turning towards death together”: The functions of messages during final conversations in close relationships. *Journal of Social and Personal Relationships*, 24, 225–253. doi:10.1177/0265407507075412
- Kellehear, A. (2007). *A social history of dying*. Cambridge: Cambridge University Press.

- Kristjanson, L., & Aoun, S. (2004). Palliative care for families: Remembering the hidden patients. *Canadian Journal of Psychiatry, 49*, 359–365.
- Latham, A. E., & Prigerson, H. G. (2004). Suicidality and bereavement: Complicated grief as psychiatric disorder presenting greatest risk for suicidality. *Suicide and Life-Threatening Behavior, 34*, 350–362. doi:10.1521/suli.34.4.350.53737
- Luborsky, M. (1994). The identification and analysis of themes and patterns. In J. Gubrium & A. Sankar (Eds.), *Qualitative methods in ageing research* (pp. 189–210). Thousand Oaks, CA: Sage.
- Meeker, M. A. (2004). Family surrogate decision making at the end of life: Seeing them through with care and respect. *Qualitative Health Research, 14*, 204–225. doi:10.1177/1049732303260501
- Moustakas, C. (1990). *Heuristic research: Design, methodology and applications*. London: Sage.
- Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C., Kuerbis, A. N., & Donelan, K. (2002). When the caregiver needs care: The plight of the vulnerable caregivers. *American Journal of Public Health, 92*, 409–413. doi:10.2105/AJPH.92.3.409
- Nijboer, C., Tempelaar, R., Sanderman, R., Triemstra, M., Spruijt, R. J., & van den Bos, G. A. M. (1998). Cancer and caregiving: the impact on the caregiver's health. *Psycho-Oncology, 7*(1), 3–13. doi:10.1002/(SICI)1099-1611(199801/02)7:1<3::AID-PON320>3.0.CO;2-5
- Parkes, C. M. (1995). Guidelines for conducting ethical bereavement research. *Death Studies, 19*, 171–181. doi:10.1080/07481189508252723
- Payne, S., & Grande, G. (2013). Towards better support for family carers: A richer understanding. *Palliative Medicine, 27*, 579–580. doi:10.1177/0269216313488856
- Powell-Cope, G. M., & Brown, M. A. (1992). Going public as an AIDS family caregiver. *Social Science and Medicine, 34*, 571–580. doi:10.1016/0277-9536(92)90212-9
- Rosenblatt, P. C. (1995). Ethics of qualitative interviewing with grieving families. *Death Studies, 19*(2), 139–155. doi:10.1080/07481189508252721
- Saleebey, D. (2013). *The strengths perspective in social work practice* (6th ed.). Upper Saddle River, NJ: Pearson Education.
- Sanderson, C., Lobb, E. A., Mowl, J., Butow, P. N., McGowan, N., & Price, M. A. (2013). Signs of post-traumatic stress disorder in caregivers following an expected death: A qualitative study. *Palliative Medicine, 27*, 625–631. doi:10.1177/0269216313483663
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA, 282*, 2215–2219. doi:10.1001/jama.282.23.2215
- Sinding, C. (2003). “Because you know there’s an end to it”: Caring for a relative or friend with breast cancer. *Palliative and Supportive Care, 1*(2), 153–163. doi:10.1017/S1478951503030189
- Strang, V. R., & Koop, P. M. (2003). Factors which influence coping: Home-based family caregiving of persons with advanced cancer. *Journal of Palliative Care, 19*(2), 107–114.
- Truelsen, M. (2003). The meaning of “reconstruction” within the lived experience of mastectomy for breast cancer. *Counselling and Psychotherapy Research, 3*, 307–314. doi:10.1080/14733140312331384313
- Van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy* (2nd ed.). London: Althouse.
- Weick, A., Rapp, C., Sullivan, W. P., & Kisthardt, W. (1989). A strengths perspective for social work practice. *Social Work, 34*, 350–354.
- Wiese, C. H., Morgenthal, H. C., Bartels, U. E., Vossen-Wellmann, A., Graf, B. M., & Hanekop, G. G. (2010). Post-mortal bereavement of family caregivers in Germany: A prospective interview-based investigation. *Wien Klin Wochenschr, 122*, 344–389. doi:10.1007/s00508-010-1396-z