

A Phenomenologic Study of Family Caregivers of Patients With Head and Neck Cancers

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With the shift of caregiving responsibilities from the healthcare setting to the home, family members face what can, at times, be an overwhelming experience that is fraught with uncertainty about caregiving itself, as well as physical, psychosocial, and economic challenges. Caregivers require support as they balance the demands of everyday life with new caregiving responsibilities.

Family caregiver issues remain a domain of cancer research in need of further study, particularly with understudied populations, such as patients with head and neck cancers (HNCs) and their families (Longacre, Ridge, Burtness, Galloway, & Fang, 2012). Although HNCs are less prevalent than other cancers, many are diagnosed in advanced stages when treatment options require complex and multidisciplinary approaches, including a combination of surgery, radiation therapy, and chemotherapy (Menzin, Lines, & Manning, 2007). As a result, caregivers may need to cope with complex issues, including postoperative wound care, altered facial appearance, communication deficits, eating and swallowing problems, airway and pain management, changes in activities of daily living status, and the effects of myelosuppression (Baehring & McCorkle, 2012; Rodriguez & Blischak, 2010).

Background

A paucity of literature specifically addresses the actual and potential needs of caregivers when caring for patients with HNCs, and much of it relates to emotional issues (e.g., fear, emotional distress, anxiety, depression). Hodges and Humphris (2009) found that caregivers have more concerns about the recurrence of the cancer than the patients themselves. These high levels of fear positively correlated with emotional distress and anxiety (Hodges & Humphris, 2009; Longacre et al., 2012; Watt-Watson & Graydon, 1995). Anxiety reached clinical levels that required treatment and

Purpose/Objectives: To describe and understand the lived experience of family caregivers of patients with head and neck cancers (HNCs).

Research Approach: Phenomenology using van Manen's human science approach.

Setting: Two hospital systems providing regional cancer care in upstate New York.

Participants: Nine family caregivers of patients with HNCs who had completed treatment.

Methodologic Approach: Qualitative analysis of semi-structured, conversational interviews about the lived experience of family caregivers.

Findings: Five major themes emerged related to the lived experiences of this sample of caregivers: (a) absorption of a large amount of information regarding diagnosis, (b) the importance of support from others, (c) adaptation to new routines and responsibilities, (d) a desire to be vigilant and protect a loved one from harm, and (e) feelings of fear, sympathy, and guilt.

Conclusions: Family caregivers of patients with HNCs play a fundamental role in the post-treatment phase of care, including meeting specific physical and psychosocial needs. Further investigation should explore the relationship between information needs and the experience of vigilance and fear.

Interpretation: Nurses must include caregivers in physical and psychosocial plans of care. Balancing and meeting information needs of caregivers to avoid undue emotional stress and recognizing their support needs are valuable components of care.

Key Words: head and neck cancer; family caregiving; qualitative research

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was higher than that of patients with cancer. This was particularly true in female caregivers of patients with HNCs (Baghi et al., 2007; Hodges & Humphris, 2009; Verdonck-de Leeuw et al., 2007).

Although adequate evidence exists regarding the fears of caregivers, little is available to explain the factors that contribute to these emotions and caregiving burdens. One study of caregivers of patients

with oral cancer found that caregiver burden could be predicted by several variables, including a lack of family and social support, increased physical care needs of the patient, unmet health information needs, disrupted schedules, and financial issues (Chen et al., 2009). Caregivers of patients with HNCs may provide physical care, such as surgical site dressing, wound drain care, tracheostomy care, enteral nutrition, and pain management (Baehring & McCorkle, 2012; Gendron et al., 2002; Krouse et al., 2004; Mah & Johnston, 1993; Watt-Watson & Graydon, 1995). Caregivers may also face psychosocial issues that include body image disturbances in the patient, difficulty with clear communication, and the disruption of mealtimes with their loved ones (Agrawal & Malone, 2002; Dropkin, 1999; Happ, Roesch, & Kagan, 2004, 2005; Katz, Irish, Devins, Rodin, & Gullane, 2003; Swore Fletcher, Cohen, Schumacher, & Lydiatt, 2012). Sexuality for both partners may be affected if the patient is faced with alterations in facial structures, stomatitis, mucositis, xerostomia, or fatigue that affects sexual activity with their partner (Gilbert, Ussher, & Hawkins, 2009; Monga, Tan, Ostermann, & Monga, 1997; Siston, List, Schleser, & Vokes, 1998).

Much of this literature is descriptive and/or correlational, but qualitative approaches can identify undiscovered concepts and phenomena useful to nursing theory and practice (Morse & Field, 1995). A qualitative method was chosen for the current study because much remains to be learned about caregiving experiences and issues for patients with HNCs, particularly at the time of treatment completion, when caregiving needs at home are expected to be great.

Consequently, the purpose of this study was to describe and understand the lived experience of primary family caregivers of patients with HNCs. The major research question sought to define the lived experience of primary family caregivers of patients with HNCs following completion of treatment for new or recurrent disease.

Research Approach and Methods

To study the lived experience of caregivers of patients with HNCs, a phenomenologic study using van Manen's (1990) human science approach was conducted. Phenomenology is viewed by van Manen (1990) as a philosophy and a practice, and it combines descriptive and interpretive phenomenology (Dowling, 2007). Four processes essential to engaging in phenomenologic research are described by van Manen (1990) and are (a) turning to the nature of lived experience, (b) investigating the experience as it is lived, (c) engaging in hermeneutic phenomenologic reflection, and (d) participating in hermeneutic phenomenologic

Table 1. Patient Characteristics

Patient	Type of Cancer ^a	Cancer Treatment Received ^a
1	Tonsil	Chemotherapy, RT
2	Larynx	RT
3	Nasopharynx	Chemotherapy, RT
4	Tonsil	Chemotherapy, RT
5	Pharynx	Chemotherapy, RT
6	Pharynx, tongue	Chemotherapy, RT
7	Oral, tongue	Chemotherapy, RT, surgery
8	Oral, lip	RT, surgery
9	Tonsil	RT
^a Self-reported RT—radiation therapy		

writing. While engaging in these four processes, the phenomenologic researcher must stay oriented to the research question at all times to gather the true lived experience (van Manen, 1990). In essence, the hermeneutic, phenomenologic writing process transforms the meanings of experience of an individual so others may fully understand the phenomenon (van Manen, 2006).

Sample and Setting

A purposive sample of nine adult caregivers actively involved in the care of patients with HNCs after completion of treatment were recruited from two hospital systems in upstate New York. The time period following completion of treatment was expected to be where the major shift of care occurs (i.e., from the healthcare setting and healthcare providers [HCPs] to the home and family caregivers). During this time, caregivers are outside of the safety net of being able to regularly see HCPs if assistance is needed with care at home. Recruitment continued until data saturation was achieved and no new themes emerged (Morse & Field, 1995).

The nine caregivers ranged in age from 43–76 years (\bar{X} = 59 years, SD = 11.56), and included eight female spouses and one adult male child. Only one of the nine caregivers was employed at the time of the interview, and the others described themselves as homemakers (n = 2), retired (n = 4), on disability leave (n = 1), or a full-time student (n = 1). Table 1 reflects patient characteristics. The time since initial HNC diagnosis ranged from 4–34 months (\bar{X} = 17.22 months, SD = 9.54). The time since initial treatment completion ranged from 1–33 months (\bar{X} = 14.14 months, SD = 9.63). Two patients had completed treatment for a recurrence of a prior HNC.

Ethical Considerations

Institutional review board approval was obtained from the Office of Research and Sponsored Projects at Villanova University in Pennsylvania and the individual health systems from which participants were recruited. Written informed consent was obtained from each caregiver prior to participation in the study. Confidentiality was maintained by assigning pseudonyms to replace the actual names of individuals or places that were present on the demographic forms or written transcriptions of the interviews.

No predicted physical risks were associated with participation in the study. However, psychological risks were anticipated. The primary family caregivers were predicted to be anxious and emotional because patients had just completed treatment for cancer. Participants were told in advance that they or the researcher could stop the interview at any time for any reason. If caregivers appeared to be in psychological distress and in need of assistance, a referral process to the agency's on-call social worker or caregiver's primary care provider was in place.

Data Collection

Conversational, semistructured interviews were the main method of data collection and took place at a location of each participant's choosing. This method allowed the caregivers to freely share and reflect on their experiences with the researcher and to generate a descriptive and interpretive exhaustive text (van Manen, 1990). An interview guide was used to maintain consistency among the interviews. Broad opening statements used included the following: "Tell me about being the caregiver for someone with head and neck cancer," "Tell me about your personal physical needs during the caregiving process," and "Tell me what the diagnosis of head and neck cancer of your spouse/partner/significant other/family member meant to you personally as the caregiver." Probing questions were aimed at eliciting specific examples of caregiving challenges and the impact of cancer on the personal life of the caregiver. Interviews were conducted from 2008–2011.

Data Analysis and Management

Data collection, management, and analysis occurred concurrently while participants were enrolled in the study. All interviews were audio recorded and transcribed verbatim. The researcher listened to each interview and compared the recording to the transcription. All potential identifiers were removed and pseudonyms substituted to maintain confidentiality of the data, as well as the identities of study participants, the patients, and healthcare institutions or HCPs. The "cleaned" study

data were uploaded as primary documents to ATLAS.ti®, version 6.0. The researcher read the transcriptions several times to be fully immersed in the data. Digital voice recordings were deleted after verification of the transcripts. All interviews were analyzed using a hermeneutic, phenomenologic reflection process (van Manen, 1990). An iterative process was used to review individual elements of the interviews, the interviews as a whole, and the interviews in comparison to all of the interviews to uncover the most essential themes (Pollio, Henley, & Thompson, 1997; van Manen, 1990). A total of 371 meaningful statements were identified, coded, and refined to five themes and an exhaustive description.

Ensuring Rigor and Trustworthiness

Processes were put in place to ensure credibility, dependability, confirmability, and transferability of the data analysis and findings (Lincoln & Guba, 1985). Credibility was established through prolonged engagement with the data and the writing of a personal account of the phenomenon, as well as through member checks and participant verification of the analysis. Dependability and confirmability were established through creation and maintenance of an audit trail and research journal throughout the study. The final themes were confirmed through an external review process with doctorally prepared researchers. Prior to preparing the final report of the exhaustive text description, participants verified the findings and assisted the researcher in clarifying the final description of their lived experience (Lincoln & Guba, 1985; Pollio et al., 1997). The process of creating this rich description contributes to the potential transferability of the findings (Lincoln & Guba, 1985).

Findings

The hermeneutic, phenomenologic reflection and phenomenologic writing processes revealed five major themes related to the lived experiences of this sample of caregivers.

Absorption of a Tremendous Amount of Information

Many caregivers said they initially felt shock or surprise at hearing that their loved ones had been diagnosed with a type of HNC. The caregivers said they needed time to "absorb" the "tremendous" and "huge" amount of information being presented to them about the diagnosis, as well as treatments and care required during and after treatment. Some caregivers felt that although a lot of information was provided to them, they did not always feel confident in their caregiving ability when an HCP was not available. One caregiver stated that the information offered by HCPs was a tremendous amount to take in.

Each of us had different agendas in terms of treatment and care, and I was pretty much responsible for everything. . . . [The HCPs] did give us a quick run-through on these pieces of equipment. It worked, but it wasn't really enough that you felt confident you could do it. . . . You know, I am an educated person with a master's degree, and I can read and understand what I'm reading, but it's just the huge amount of stuff that you need to know.

Another caregiver echoed those thoughts.

I had to change the dressing around the tube, which scared me because I'm not a nurse and I wasn't exactly sure how to do it. The [HCPs] would show me how to do it and then, sure, when you get home, it's like a whole different thing.

The caregivers noted that they valued the information related to diagnosis and treatment and viewed it as a source of power in terms of making decisions about treatment and care. As one caregiver explained, "I was directly thrown into dealing with the illness, facing the outcome, and taking care of my best friend all at the same time, so having the information from the [HCPs], school, and other resources gave me power."

"So Many People Doing Different Things": The Importance of Support From Others

The caregivers reported that they were surrounded by HCPs, family, and friends, and they praised them for the physical and emotional support offered. One caregiver said the help of others was necessary.

You are paying so much attention to the person that needs help [that] you can't see what you need for help. You need someone to be your eyes and ears on that, because you are putting all of your effort and your energy into taking care of the person in the house.

The caregivers also spoke highly of the HCPs involved in care. One noted that the support offered "really makes a huge difference."

I know that it seemed to me that you need to have that kind of care and patience in terms of answering [my loved one's] multitudes of questions; [my loved one] wanted answers. [The nurses] were very, very patient, which you have to be, or it just would fall back on me.

Another caregiver saw the HCPs' presence as reassuring, describing a need for "the interaction with the doctor and the nurse." Caregivers described challenges and frustrations with receiving help and support. One caregiver spoke about the process of receiving home care support and the difficulty experienced with the large number of people involved.

The other thing that was real difficult for me was all the people that kept calling the house. Not necessarily friends and family—that you wanted—but it was speech people, social work people, this nurse, that nurse, and the other nurse. . . . In retrospect, I wanted to hear what the people had to say, but, at the same time, I got very annoyed at the constant calling at the house. . . . That was very exhausting for me.

In some cases, the number of HCPs involved in patients' care made the caregivers feel unsure about whom to contact to get an answer to a question. One caregiver said, "We started to feel lost in the mix. Who was supposed to be responsible for which parts of [my loved one's] issues? It was intermingled."

Despite these frustrations, the caregivers felt that they "could not have done it without the [HCPs, family, and friends]." The caregivers reported that, although they did not always need these support systems, knowing that they were there was helpful. In most cases, the support needed was not directly related to the physical act of caring for the patient with cancer; instead, it involved helping caregivers keep up with other daily chores or activities, as well as providing brief periods of respite.

Adaptation to New Routines and Responsibilities

All caregivers experienced changes in their normal routines of daily life to care for their loved ones during the period following treatment. Changes in roles and responsibilities were commonplace. One caregiver stated, "The routine changed. Everything that needs to be done has to be done by me." Most caregivers had picked up extra responsibilities that had typically belonged to the patient with cancer for a period of time. One participant expressed frustration regarding changing role responsibilities.

I thought I've got someone to take care of me, and, all of a sudden, [my loved one] was like a little child. So, that kind of bothered me because I wanted somebody to take care of me, and there I was taking [my loved one] back and forth to the hospital and holding my loved one up. . . . I was doing all of the work that I considered to be [my loved one's] work, and I wanted my loved one to do all of this stuff, but I was doing all that, and that was upsetting.

The caregivers spoke about how a portion of their lives in the post-treatment phase revolved around the processes of eating and mealtimes. The caregivers scheduled daily routines around the tasks of preparing and providing tube feedings or tracheostomy care, making them feel "tied down." Caregivers were very descriptive of their daily schedule. One participant explained, "We get

up at 8 am, feed my loved one at 8:30 am, 12:30 pm, 5:30 pm, and 11:30 pm to 12 [am]." One caregiver specifically described how the routine of feeding the patient with cancer affected life and curtailed usual activities.

We don't go out. We can't go no place. We used to always be going someplace. All summer long, we haven't done anything. We try to go to church, but we have to wait until [my loved one] gets done with [tube feedings]. [We try to] go back out and do some work, come back in, and do [tube feeding] again. . . . Then you've got to stop everything and go to the doctor's.

A Desire to Be Vigilant and Protect a Loved One From Harm

Each caregiving relationship was unique, but caregivers' overarching sense of being "careful," "watchful," and "vigilant" and wanting to protect their loved ones from further harm was prevalent. The caregivers did not want their loved ones to experience unnecessary distress. Caregivers were informed of the potential issues that could occur post-treatment and were "watching" and expecting them to happen. One caregiver said,

I just didn't want to leave [my loved one]. I was hypervigilant. [I watched] every little thing, then I had to catch myself, you know, and back down because [my loved one] would get annoyed by it. . . . [I was] really being a horrible nag about it.

Other caregivers were worried that their loved ones could get sick post-treatment when myelosuppressed. One caregiver spoke of allowing visitors in the home, saying, "You've got to be careful of people coming into your house because you can get sick, because your immune system is down. . . . They can give infections to you, and that would be bad."

Feelings Experienced: Fear, Sympathy, and Guilt

The feeling experienced by many caregivers during the caregiving process was that of being scared and fearful. Fear was expressed as being afraid, scared, and worried, particularly about the possibility of a cancer recurrence. It forced many of the caregivers to consider the future and the question of "What if?" The caregivers had a persistent feeling of not knowing what may still lie ahead for their loved ones after treatment. One caregiver stated, "It is life threatening. You don't trust cancer. You can't ignore this elephant that has moved into your life. There's just no ignoring it." Another noted, "You never know when it's going to come up again, and it could happen."

Sympathy was expressed through feeling sorry for the loved ones who may have been feeling sick, in

pain, or depressed. One caregiver observed, "That was the worst part for me: to see [my loved one] sick and sleeping. My loved one just doesn't fall asleep in the chair." In most cases described, the caregivers did not always know what would help their loved ones to feel better, other than to just be present.

Feelings of guilt were often associated with meals. This was exemplified in statements including the following: "[My loved one] would be hungry for food but couldn't have it. So, it kind of made you feel guilty" and "We can have a meal, and my loved one can't eat it, and we feel guilty to eat in front of [my loved one]. I hate that."

Discussion

Nine caregivers provided narratives that answered the research question from their perspectives. The caregivers had a strong need to feel prepared to provide the necessary care to their loved ones, which supported findings from previous research (Carter, 2001; Chambers et al., 2012; Morrison et al., 2012; Osse, Vernooij-Dassen, Schadé, & Grol, 2006; van Ryn et al., 2011). Information provided to caregivers by HCPs was an important part of being prepared, and they needed information regarding diagnosis, treatment, and responsibilities at home. The information was, at times, overwhelming, creating a sense of doubt and insecurity that the caregivers would not be able to fulfill all of the caregiving responsibilities, particularly after leaving the near constant presence of HCPs in the hospital or clinic setting. The support of HCPs and others from social networks (e.g., family, friends) proved particularly valuable. However, the most concerning finding of the current study was related to coordination of care and resources. Coordination of care had been previously identified as a challenge for caregivers of patients with cancer, and participants noted the need for a key contact person who could help them navigate formal care systems (Walsh et al., 2011). An oncology nurse navigator may serve as the key contact. Foxwell and Scott (2011) studied the perceived levels of support that HCPs provided to caregivers; those participants who felt a lack of support from HCPs felt helpless when they did not have information needed to make decisions.

In addition to those providing support in the formal healthcare environments, the informal networks of family, friends, and acquaintances were valuable assets to the caregivers in offering much needed physical or social support. The importance of social support for caregivers is documented in the literature. Social support helps to protect caregivers from undue stress and tension in family relationships (Gaugler et al., 2008) and serves as a means of emotional and

Knowledge Translation

Family caregivers are particularly vigilant in monitoring their loved ones with cancer for post-treatment side effects, as well as their overall health and well-being.

The heightened state of vigilance assumed by many family caregivers likely adds to sources of distress that all caregivers face when caring for a loved one.

Nurses are obligated to recognize and intervene when family caregivers experience issues with coordination of care to ensure safe, timely care.

practical help with day-to-day activities (Foxwell & Scott, 2011).

Changes in caregiver roles and responsibilities were expected. The caregivers experienced lifestyle changes related to adjusting to treatment plans and assuming responsibilities that were once shared with their ill loved ones, supporting previous studies (Ussher, Tim Wong, & Perz, 2011; Winterling, Wasteson, Glimelius, Sjöden, & Nordin, 2004). Caregivers commonly feel some level of distress and burden as they curtail personal commitments and valued activities to care for their loved ones (Cameron, Franche, Cheung, & Stewart, 2002; Chen et al., 2009; Longacre et al., 2012; Röing, Hirsh, & Holmström, 2008; Ussher et al., 2011). For some caregivers, entire days revolved around planning tube feedings or meals, overriding other responsibilities. However, whether these disruptions are more or less severe for caregivers of patients with other cancers is unknown.

The caregiver participants in the current study described a need to be vigilant in the care of their loved ones, as well as a strong urge to protect them from potential post-treatment complications. This vigilance seemed to stem from all of the information the caregivers had been given about treatment and its potential side effects, along with other ways of maintaining the health of their loved ones. The caregivers' attempts to pay attention and watch for potential care needs were evident. The theme of vigilance in this sample may be linked specifically to the emotion of fear.

Fear was the prevalent emotion experienced by the caregivers. It was connected with uncertainty about the future, the potential loss of a loved one, and a fear of cancer recurrence. Fear and uncertainty may be connected to the information needs of caregivers. If information needs are not met, this could create additional fear of the unknown future. Conversely, information overload may cause caregivers to become more vigilant and fearful if they anticipate that all of the possible complications will occur. Fear of recurrence is common in patients with HNCs, but fear of recurrence is usually higher in caregivers (Hodges & Humphris, 2009) and correlated

with distress and anxiety (Hodges & Humphris, 2009; Longacre et al., 2012; Watt-Watson & Graydon, 1995).

Limitations

Several limitations of the current study exist. The sample demographics were predominantly those of middle-aged spouses who were not employed. The experiences described may not reflect those of younger women, male spouses, or working women in the caregiving role. The relative homogeneity of the treatments experienced by the patients with cancer may also be a limitation. All of the patients with cancer underwent radiation therapy with or without chemotherapy, and only two had surgery included in the treatment plan. Extensive postoperative wound care, tracheostomy care, and issues related to intimacy and sexuality secondary to major changes in physical appearance were not experienced by this particular sample of caregivers, but may be true for other caregivers. The small sample size was also a limitation.

Implications for Nursing

Nurses have a significant responsibility in helping caregivers navigate the care of their loved ones facing treatment for HNC. Caregivers have strong information needs, will receive help and support from others, undergo role changes, and experience a wide range of emotions and feelings during and after the treatment process. As such, nurses must ensure that caregivers are incorporated into physical and psychosocial plans of care. Nurses continue to be a trusted source of information and support, but they must be able to balance and meet information needs while avoiding undue emotional stress. One new finding of the current study was related to the theme of vigilance; caregivers were particularly vigilant in monitoring their loved ones for post-treatment side effects, as well as their overall health and well-being. This state of vigilance is likely adding to sources of distress that all caregivers face when caring for a loved one. Nurses must address the emotional support needs of caregivers when they experience vigilance and fear in the care of their loved ones. In addition, nurses have a duty to recognize and intervene when coordination of care issues are experienced by caregivers to ensure safe and timely care.

Conclusion

The findings of the current study provide additional insight into the specific needs and experiences of caregivers of patients with HNCs. The study also reinforces the fundamental role that caregivers play in the care of patients with HNCs. Further research is still

needed regarding the needs of caregivers of patients with HNCs; this could be accomplished by incorporating them into future caregiving studies. Additional investigation is also warranted concerning the correlational relationships that may exist among information, vigilance, and fear.

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References

- Agrawal, A., & Malone, J.P. (2002). Dramatic change in physical appearance and function after cancer treatment: Focus on rehabilitative and reconstructive aspects of head and neck cancer. *Rehabilitation Oncology*, 20, 18–21.
- Baehring, E., & McCorkle, R. (2012). Postoperative complications in head and neck cancer [Online exclusive]. *Clinical Journal of Oncology Nursing*, 16, E203–E209. doi:10.1188/12.CJON.E203-E209
- Baghi, M., Wagenblast, J., Hambek, M., Radeloff, A., Gstoettner, W., Scherzed, A., . . . Knecht, R. (2007). Demands on caring relatives of head and neck cancer patients. *Laryngoscope*, 117, 712–716. doi:10.1097/mlg.0b013e318031d0b4
- Cameron, J.I., Franche, R.L., Cheung, A.M., & Stewart, D.E. (2002). Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer*, 94, 521–527. doi:10.1002/cncr.10212
- Carter, P.A. (2001). A not-so-silent cry for help. Older female cancer caregivers' need for information. *Journal of Holistic Nursing*, 19, 271–284. doi:10.1177/089801010101900
- Chambers, S.K., Girgis, A., Occhipinti, S., Hutchison, S., Turner, J., Morris, B., & Dunn, J. (2012). Psychological distress and unmet supportive care needs in cancer patients and carers who contact cancer helplines. *European Journal of Cancer Care*, 21, 213–223. doi:10.1111/j.1365-2354.2011.01288.x
- Chen, S.C., Tsai, M.C., Liu, C.L., Yu, W.P., Liao, C.T., & Chang, J.T. (2009). Support needs of patients with oral cancer and burden to their family caregivers. *Cancer Nursing*, 32, 473–481. doi:10.1097/NCC.0b013e3181b14e94
- Dowling, M. (2007). From Husserl to van Manen: A review of different phenomenological approaches. *International Journal of Nursing Studies*, 44, 131–142. doi:10.1016/j.ijnurstu.2005.11.026
- Dropkin, M.J. (1999). Body image and quality of life after head and neck cancer surgery. *Cancer Practice*, 7, 309–313. doi:10.1046/j.1523-5394.1999.76006.x
- 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, 308–326. doi:10.1080/07347332.2011.563343
- Gaugler, J.E., Linder, J., Given, C.W., Kataria, R., Tucker, G., & Regine, W.F. (2008). The proliferation of primary cancer caregiving stress to secondary stress. *Cancer Nursing*, 31, 116–123. doi:10.1097/01.NCC.0000305700.05250.9d
- Gendron, K.M., Lai, S.Y., Weinstein, G.S., Chalian, A.A., Husbands, J.M., Wolf, P.F., . . . Weber, R.S. (2002). Clinical care pathway for head and neck cancer: A valuable tool for decreasing resource utilization. *Archives of Otolaryngology—Head and Neck Surgery*, 128, 258–262. doi:10.1001/archotol.128.3.258
- Gilbert, E., Ussher, J.M., & Hawkins, Y. (2009). Accounts of disruptions to sexuality following cancer: The perspective of informal carers who are partners of a person with cancer. *Health*, 13, 523–541. doi:10.1177/1363459308336795
- Happ, M.B., Roesch, T., & Kagan, S.H. (2004). Communication needs, methods, and perceived voice quality following head and neck surgery: A literature review. *Cancer Nursing*, 27, 1–9. doi:10.1097/00002820-200310000-00002
- Happ, M.B., Roesch, T.K., & Kagan, S.H. (2005). Patient communication following head and neck cancer surgery: A pilot study using electronic speech-generating devices. *Oncology Nursing Forum*, 32, 1179–1187. doi:10.1188/05.ONF.1179-1187
- Hodges, L.J., & Humphris, G.M. (2009). Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psycho-Oncology*, 18, 841–848. doi:10.1002/pon.1346
- Katz, M.R., Irish, J.C., Devins, G.M., Rodin, G.M., & Gullane, P.J. (2003). Psychosocial adjustment in head and neck cancer: The impact of disfigurement, gender and social support. *Head and Neck*, 25, 103–112. doi:10.1002/hed.10174
- Krouse, H.J., Rudy, S.F., Vallerand, A.H., Hickey, M.M., Klein, M.N., Kagan, S.H., & Walizer, E.M. (2004). Impact of tracheostomy or laryngectomy on spousal and caregiver relationships. *ORL—Head and Neck Nursing*, 22, 10–25.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Longacre, M.L., Ridge, J.A., Burtress, B.A., Galloway, T.J., & Fang, C.Y. (2012). Psychological functioning of caregivers for head and neck cancer patients. *Oral Oncology*, 48, 18–25. doi:10.1016/j.oraloncology.2011.11.012
- Mah, M.A., & Johnston, C. (1993). Concerns of families in which one member has head and neck cancer. *Cancer Nursing*, 16, 382–387. doi:10.1097/00002820-199310000-00007
- Menzin, J., Lines, L.M., & Manning, L.N. (2007). The economics of squamous cell carcinoma of the head and neck. *Current Opinion in Otolaryngology and Head and Neck Surgery*, 15, 68–73. doi:10.1097/moo.0b013e328017f669
- Monga, U., Tan, G., Ostermann, H.J., & Monga, T.N. (1997). Sexuality in head and neck cancer patients. *Archives of Physical Medicine and Rehabilitation*, 78, 298–304.
- Morrison, V., Henderson, B.J., Zinovieff, F., Davies, G., Cartmell, R., Hall, A., & Gollins, S. (2012). Common, important, and unmet needs of cancer outpatients. *European Journal of Oncology Nursing*, 16, 115–123. doi:10.1016/j.ejon.2011.04.004
- Morse, J.M., & Field, P.A. (1995). *Qualitative research methods for health professionals* (2nd ed.). Thousand Oaks, CA: Sage.
- Osse, B.H., Vernooij-Dassen, M.J., Schadé, E., & Grol, R.P. (2006). Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nursing*, 29, 378–388. doi:10.1097/00002820-200609000-00006
- Pollio, H.R., Henley, T., & Thompson, C.B. (1997). *The phenomenology of everyday life*. Cambridge, UK: Cambridge University Press.
- Rodriguez, C.S., & Blischak, D.M. (2010). Communication needs of nonspeaking hospitalized postoperative patients with head and neck cancer. *Applied Nursing Research*, 23, 110–115. doi:10.1016/j.apnr.2008.04.001
- Röing, M., Hirsch, J.M., & Holmström, I. (2008). Living in a state of suspension—A phenomenological approach to the spouse's experience of oral cancer. *Scandinavian Journal of Caring Sciences*, 22, 40–47. doi:10.1111/j.1471-6712.2007.00525.x
- Siston, A.K., List, M.A., Schleser, R., & Vokes, E. (1998). Sexual functioning and head and neck cancer. *Journal of Psychosocial Oncology*, 15, 107–122. doi:10.1300/j077v15n03_05
- Swore Fletcher, B., Cohen, M.Z., Schumacher, K., & Lydiatt, W. (2012). A blessing and a curse: Head and neck cancer survivors' experiences. *Cancer Nursing*, 35, 126–132. doi:10.1097/NCC.0b013e31821bd054

- Ussher, J.M., Tim Wong, W.K., & Perz, J. (2011). A qualitative analysis of changes in relationship dynamics and roles between people with cancer and their primary informal carer. *Health, 15*, 650–667. doi:10.1177/1363459310367440
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: State University of New York Press.
- van Manen, M. (2006). Writing qualitatively, or the demands of writing. *Qualitative Health Research, 16*, 713–722. doi:10.1177/1049732306286911
- van Ryn, M., Sanders, S., Kahn, K., van Houtven, C., Griffin, J.M., Martin, M., . . . Rowland, J. (2011). Objective burden, resources, and other stressors among informal cancer caregivers: A hidden quality issue? *Psycho-Oncology, 20*, 44–52. doi:10.1002/pon.1703
- Verdonck-de Leeuw, I.M., Eerenstein, S.E., Van der Linden, M.H., Kuik, D.J., de Bree, R., & Leemans, C.R. (2007). Distress in spouses and patients after treatment for head and neck cancer. *Laryngoscope, 117*, 238–241. doi:10.1097/01.mlg.0000250169.10241.58
- Walsh, J., Young, J.M., Harrison, J.D., Butow, P.N., Solomon, M.J., Masya, L., & White, K. (2011). What is important in cancer care coordination? A qualitative investigation. *European Journal of Cancer Care, 20*, 220–227. doi:10.1111/j.1365-2354.2010.01187.x
- Watt-Watson, J., & Graydon, J. (1995). Impact of surgery on head and neck cancer patients and their caregivers. *Nursing Clinics of North America, 30*, 659–671.
- Winterling, J., Wasteson, E., Glimelius, B., Sjöden, P.O., & Nordin, K. (2004). Substantial changes in life: Perceptions in patients with newly diagnosed advanced cancer and their spouses. *Cancer Nursing, 27*, 381–388.