
REVIEW ARTICLE

Applying feminist, multicultural, and social justice theory to diverse women who function as caregivers in end-of-life and palliative home care

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ABSTRACT

Objective: Women are largely responsible for providing care to terminally ill family members at home. The goal of this review is to conceptualize diverse women's experiences in palliative home care from feminist, multicultural, and social justice perspectives.

Methods: Peer-reviewed manuscripts were identified using the following databases: CIMAHL, psycINFO, and pubMED. The following search terms were used: women/mothers/daughters, Caregiving, family caregivers, feminism, culture, multiculturalism, and palliative home care. Article reference lists were also reviewed. The majority of pertinent articles which formed the basis for the arguments presented were drawn from nursing, medicine, and counseling psychology scholarship.

Results: The application of feminist, multicultural, and social justice theory brings to attention several potential issues female caregivers may experience. First, there exist diverse ways in which women's Caregiving is manifested that tend to correspond with variations in culture, relationship, and age. Second, it is important to attend to changing expectations placed on women as a result of Caregiving at the end of life. Third, the changing power dynamics women may experience in end of life Caregiving are very complex.

Significance of results: The principle finding of the review was the highlighting of potential risks that culturally diverse female caregivers are likely to face at the end of life. The application of social justice theory provides a number of implications for practice and policy. Specifically, the identifying significant concerns regarding female caregivers in palliative home care, as well as suggesting ways to appropriately attend to these concerns, and oppression of women is less likely to be perpetuated, specific areas for future research in this domain are identified.

KEYWORDS: Women, Caregiving, Feminism, Multiculturalism, Palliative home care

INTRODUCTION

Dying at home is on the rise in North America. Home-based palliative care is a response to the trend

of more individuals* both choosing and having access to these services. As such, it is a service that is becoming increasingly offered to terminally ill individuals and their family caregivers. However, important social justice issues remain, given that not everyone

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*The terminally ill person will be referred to in this article as the individual rather than the patient as is found in the majority of the literature surveyed.

has access to these services and that the majority of family caregiving is done by women. Furthermore, there is a lack of reports examining the experience of women caring for a terminally ill member at home from a feminist perspective. The present work addresses this gap in the literature. After first highlighting some of the present research on current trends in palliative home care, I consider the experience of women as caregivers in palliative home care from a feminist perspective. Multicultural and social justice concerns that are closely linked to feminist theory are examined. Implications for practice and policy conclude the report, as well as directions for future research.**

CURRENT TRENDS IN HOME-BASED PALLIATIVE CARE

There has been a large increase worldwide in terminally ill individuals and their familial caregivers being offered, and choosing, home-based palliative care programs (Stajduhar & Davies, 1998; Fleming et al., 2006). However, not everyone has the benefits of professional palliative and supportive services while caring for a family member at home (Carlsson & Rollinson, 2003). Rosenwax and McNamara (2006) reported that families of higher socioeconomic status and education level, as well as those who are white skinned, are more likely to benefit from palliative home care services. In a systematic review of the struggle of obtaining access to palliative care, Ahmed et al. (2004) identified several barriers to receiving service. There was a lack of knowledge and education among health care professionals with regards to palliative care, which leads to insufficient referral criteria. Grande et al. (1998) found that fewer people are able to die at home than would wish to do so. This may be due to multiple factors, including discrimination, lack of services available, limited access to services, or family caregivers being unable to care for complex medical needs at home. Therefore, several prominent factors have emerged concerning how some individuals and their caregivers have the privilege of dying at home with concurrent access to palliative home care.

There are several factors behind the expansion of home care services, including an aging population and cutbacks to the health care system, which results in families bearing more responsibility (Costantini et al., 1993). In addition, there is often a desire on the part of individuals who are dying and their care-

givers to go through the process at home (Karlsen & Addington-Hall, 1998). There is also a reported increase in chronic life-threatening illnesses (Mount et al., 1993; Morof-Lubkin & Larsen, 2002).

Current researchers are focusing more and more on the experience of family caregivers, given that their health and well-being during this time may be at risk (Hauser et al., 2006). The 2 weeks prior to death have been noted as a particularly difficult time (Stoltz et al., 2006). Due to a growing life expectancy for people with chronic illnesses, providing care is often an extensive and complex task, in particular when the individual is dying (Visser et al., 2004). In response, a significant amount of literature has focused on the development of psychometric instruments to assess family caregivers' quality of life (e.g., Axelsson & Sjoden, 1998; Hagedoorn et al., 2000; Cohen et al., 2006; Fleming et al., 2006).

Correspondingly, there is also a great deal of literature on both the positive and negative aspects of caregiving in palliative home care. A randomized controlled trial by Hudson (2004) found that of 47 primary family caregivers who had recently commenced palliative home care, 60% of participants were readily able to identify positive aspects of the process of caregiving. Stajduhar and Davies (2005) found that the opportunity to provide care can be a highly meaningful experience that strengthens and deepens familial relationships. Caregivers have also reported that facilitating death at home may be more satisfying than death in an institutional setting. A retrospective study by Catalán-Fernández et al. (1991) indicated that bereaved informal family caregivers were more likely to state that the place of death was correct and suffer less distress after death if the individual died at home rather than at the hospital.

Conversely, caregiving can be a time of extreme stress and difficulty. Research has shown that the needs of the caregiver can at times surpass those of the dying individual (Higginson et al., 1990; Ferrario et al., 2004). Jo et al. (2007) found that caregivers reported physical strain, emotional fatigue, sadness, and feelings of depression and anger. A lack of time to attend to both one's own daily activities plus caregiving responsibilities has also been reported (Proot et al., 2003). Financial stress and uncertainty are also a commonly reported concern (Stajduhar & Cohen, 2009). Caregivers find that the expenses associated with treatment are considerable and often necessitate a rearrangement of fiscal priorities (Emanuel et al., 2000). The same authors report that there is also anxiety associated with financial survival following the individual's death. This situation will vary across countries depending on how health care is funded. For instance, Williams et al. (2006) studied

**It should be noted that although the topic of family caregiving at the end of life crosses gender lines and does not apply exclusively to women's experiences, the objective is to portray the issues for women.

the efficacy of Canada's Compassionate Care Benefit, a financial compensation program to aid family caregivers at the end of life. Though Canada offers universal health care to its citizens, the researchers reported that the period of funding was often insufficient in length, and hence presented particular difficulties for families caring for an individual with a non-malignant advanced chronic illness. Finally, the situation can be particularly difficult if the family member has no prior experience in dealing with finances.

If one looks more closely at the positive and negative aspects of caregiving in both the caregiving and palliative care literature (Wuest, 2001; Haley et al., 2003; Hudson, 2004), it might be best to conceptualize caregiving along two continuums, one of positive and the other of negative interactions, rather than simple dichotomies. The importance of the relationship between caregiver and individual emerges as a key component of caregiving, with the family member concurrently experiencing degrees of positive and negative interactions. Hauser et al. (2006) found that caregiving was not just a phenomenon of a caregiver perfectly reflecting an individual's needs but rather a dynamic interaction in which both caregiver and individual care about each other. In fact, the same authors go on to note that each person in the caregiving dyad may be more concerned with the issues of the other than about ones that affect themselves.

As we shall see below, the emphasis on the relationship is both particularly relevant to the literature on women as caregivers and has significant implications in considering the experience of women in palliative home care.

WOMEN AS CAREGIVERS: FEMINIST PERSPECTIVES

The decision to bring a feminist lens to this current article was largely influenced by the ideas of Laura Brown. She argues that investigating women's issues in the absence of feminist theory may result in making women, rather than the social order that has habitually devalued women, the focus of the problem (Brown, 2000). Feminism (as well as multicultural and social justice) theory and practice has been described as the fourth wave of the psychological movement. It is a response to the perpetuation of gender-biased and ethnocentric constructs that are embedded in the first three theoretical forces (psychodynamic, cognitive behavioral, and humanistic-existential; Ivey et al., 2007). Intervention models stress an emphasis on the identification of individuals' strengths (Sue & Sue, 2008) as well as fostering wellness. Feminists carefully weigh the impact of

gender and gender bias in shaping experience, for instance, gender role socialization (Gilligan, 1993) and the impact of patriarchy (Kaufman, 1994). Giving a space for women's voices and women's experiences across culture is paramount. For instance, in the therapeutic dialogue there is an intentional awareness and examination of how power is used in society in the perpetuation of oppression (Enns, 2004). For our purposes, a consideration of women as caregivers in palliative home care is enhanced by the use of a feminist lens.

Particular sensitivity must be exercised when using the term caregiver or conceptualizing women in this role. A feminist critique of caregiving argues that it hinders women's progress toward equality in society by perpetuating a rigid stereotype of caregiving as the domain of women (Gordon, 1996). This may be true for some women who object to the term of caregiver, itself a term that has been constructed by health care professionals (Schwartz, 1993). Conversely, other women, specifically those providing end-of-life care, may see it as a natural or expected part of their role. The question is, does caregiving at the end of life perpetuate women's oppression or does it carry with it aspects that can contribute to women's well-being and liberation? We consider this delicate nuance below.

Women have traditionally been cast in the role of caregiver. Baines et al. (1991) argued that caregiving is the result of traditional gender roles and rigid family structures where women have been socialized to be responsible for various tasks. These tasks include not only bearing and rearing children, but providing family members with emotional support. In addition, completing domestic labor is expected even if they have employment outside the home. Unfortunately, women's caregiving largely remains invisible and underappreciated (Enns, 2004).

The question of whether or not women have a voice in the decision of functioning as caregivers is a particularly salient one. The process by which heterosexual couples negotiate this can be used to illustrate. Often there are implicit assumptions instead of explicit negotiations surrounding caregiving that results in a woman's voice being silenced. Gilligan (1993) argued that both women and men implicitly collude in not allowing a space for women's experiences and tend to develop relationships that maintain men's dissociation from women. Although men carry a degree of responsibility in not giving space for their female partner's voice, women may to some extent unknowingly or unwillingly go along with caregiving. This may be motivated by gender-role socialization and the expectation that women not show anger or resentment they may have in functioning as caregivers (Lerner, 2005).

Overall, caregiving can be conceptualized as a relationship between the family caregiver and his or her dying loved one. The importance of the relationship has been identified by feminist scholars as a central component of women's identity. Gilligan (1993) theorized that women are more likely to define their identity through relationships of intimacy and care. Many women report that being a caregiver increases their feelings of well-being (Moen et al., 1995). Therefore, caregiving per se may not be an entirely negative or positive experience in and of itself. However, as I consider below, when caring for a terminally ill family member, women's experiences may move along both positive and negative continuums simultaneously.

WOMEN PROVIDING CARE: MULTICULTURAL CONSIDERATIONS

The experience of women will vary across cultures. For instance, clinicians will likely be working with women caregivers who are not of the same culture as themselves, and the need to do so both sensitively and competently should be a priority. Although culture has been a relatively popular topic in the palliative care literature (Kwak & Haley, 2005), the majority of cultural research in palliative care has tended to treat culture as a simple variable for predicting treatment (Duffy et al., 2006).

I was able to locate only sparse literature on multicultural competence in end-of-life care (e.g., Schim et al., 2006). Although cross-cultural training is increasingly being integrated into health care training programs, it is often not seen as contributing to overall competence (Taylor, 2003). The reasons for this are somewhat unclear. Culture itself is a controversial and somewhat elusive concept, with some contending it does not exist and others claiming it is a transcendental construct that is indispensable lest discriminatory practices take place. Taylor (2003) argued that the institutional culture of medicine and medical education assumes itself to be a culture that assumes no culture. This essentially culturally blind approach in health care may lead services to be primarily ethnocentric and cater to the dominant culture and possibly neglect those of the minority (Sue & Sue, 2008). This has profound implications for women, in particular those from marginalized groups. Unfortunately, current cultural guidelines in mainstream health care seem to endorse insensitive care by encouraging practitioners to slot particular individuals into generalized cultural stereotypes (Turner, 2005).

Perry et al. (2006) conducted a feminist ethnography to examine the experience of culturally diverse families and the nature of the support they require

when navigating the health care system. They found that families can experience circumstances that contribute to their lacking sufficient resources and support, which can create a sense of vulnerability. The authors comment that some participants and their families did not obtain information they needed about the hospitalized person's condition, the expectations for the hospital stay, and how to manage their subsequent discharge. However, Perry et al. (2006) urged that professionals assess the families' subjective and contextual experience, in particular giving weight to whether or not the person(s) lay claim to the term of vulnerability. The importance of persons identifying with vulnerability ensures that it not be used as a construct of health care professionals who may affix this label to them. The implications for palliative home care are substantial. There is a clear need to assess and sensitively manage cross-cultural situations where the potential for misunderstanding may occur, which likely results in creating a situation where family caregivers are increasingly vulnerable. In the case of women who are functioning as caregivers, allowing a space for voicing their experience will allow them to resist being vulnerable.

Overall, the experience of women in the caregiving role will be highly influenced by culture, and there is need to develop a model of multicultural competence training (e.g., applying the R.E.S.P.E.C.T.F.U.L model of Ivey et al., 2007) for the palliative home care setting. This wellness and strength-based model allows for understanding of both the external contextual factors at play as well as the caregiver's internal realities and avoids the tendency towards pathologizing.

WOMEN AS CAREGIVERS IN HOME-BASED PALLIATIVE CARE

There is a relatively large amount of literature that considers how gender impacts the experience of palliative home care. However, I was unable to find any literature that used a feminist perspective. A general trend in palliative home care is that the majority of individuals who die at home are men and that the majority of individuals who care for them are women. One reason behind this trend is the tendency for men to be older than their female partners (Ahmed et al., 2004). Although the number of male caregivers in general seems to be on the rise as gender roles become more flexible (Kramer & Thompson, 2002; Calasanti & King, 2007), a study by Gill et al. (2003) found that approximately 68% of caregivers are women in end-of-life care. When a severely ill individual is female, the majority of care is provided by a female member, either within the family (daughter or daughter-in-law) or outside the

family (close female friends; Shawler, 2007). Hagedoorn et al. (2000) found that female partners in heterosexual relationships perceived more psychological distress and a lower quality of life than male partners when providing cancer care.

Why is it that women are nominally providing care for a terminally ill family member? The answer is complicated. For one, research indicates that many caregivers agree to provide care willingly, whereas others do so out of a sense of duty or obligation (Stajduhar, 2003). This suggests that women caregivers feel they cannot refuse. It is likely that a woman who refuses, for whatever reason, to provide home-based palliative care will likely receive a degree of social stigmatization.

A second factor lies in the importance of the relationship between the dying individual and the caregiver, especially in light of the literature highlighting women's role in caregiving. The importance of the quality of the intimate relationship was explored in a gerontological study by Allen et al. (1999). Wives were found to select their spouses as primary caregivers only one third of the time as compared to their male counterparts. Significantly, spouses who name their male partners as confidants were found to be three times more likely than those who did not to also name them as caregivers. The authors argue that the intimacy inherent in the caregiving role renders an emotionally close partnership as a decisive factor for women in selecting their male partner as their primary caregiver. A history of difficulties within the intimate relationship is also an important factor to consider here and how it may or may not be affected by a terminal diagnosis. It would appear that both men and women, when confronted with their own death, feel that women are more acceptable caregivers. These findings may generalize to the palliative home care setting.

WOMEN PROVIDING CARE: VARIATIONS IN AGE AND RELATIONSHIP

Women may be nominally cast in providing care for a terminally ill family member because they have been providing some form of care at most stages of their lives (Ward-Griffin et al., 2007). Women of any age range can be implicated in caregiving. Older women are often cast as caregivers for their older male partners who are ill or dying. This can be particularly difficult for women who themselves are struggling with health concerns. Schwartz (1993) argued that a relatively high amount of research portrays older female caregivers as frail, clinically depressed, and dependent on others. Although it is true that such women are often at risk for feelings of severe depression, she supplies a convincing argument that reframes

the experience of older women as individuals who benefit from years of experience and are more than just individuals who are vulnerable. This argument is particularly relevant in palliative home care, as older women may be viewed as life experts and allies by health care professionals in supporting their loved ones.

As was stated above, the relationship between aging mothers and their caregiving daughters has been the subject of a number of investigations. It is very likely that daughters will function as their mother's primary caregiver, given both the tendency for men to die sooner and mothers to see their daughters' caregiving as more satisfactory than their husbands'. A study by McGraw and Walker (2004) explored the relationship between aging mothers and their caregiving daughters. The study found that finding a balance between the mother's need for both autonomy and connection through their communication was fundamental to the success of the caregiving relationship. The tendency for both parties to be attentive and responsive to the other's needs and a desire to minimize conflict and tension were identified as contributing factors to a positive outcome. The ability for daughters to help preserve their mothers' autonomy predicted a more constructive and positive relationship. Again, the emphasis on relationship is seen as an important aspect of women's caregiving experiences and will likely be the situation in home-based palliative care.

Furthermore, caregiving by women tends to cross filial lines. Specifically, daughters-in-law can be found providing care to their mothers-in-law during times of illness. Ingersoll-Dayton et al. (1996) confirm that women provide more care for the elderly but also discovered that daughters and daughters-in-law experience more stress during caregiving than do their male counterparts. This stress is largely due to a discrepancy in the amount of care daughters and daughters-in-law provide, which is greater than that given by sons and sons-in-law. The study also suggests that daughters-in-law are particularly vulnerable because they are more likely than their male counterparts to experience the negative effects of caregiving without the supportive resources that are given to daughters. This is likely due to stronger filial obligations with daughters. The implications for palliative home care are striking, as daughters-in-law may find themselves providing for their husband's mother. The question of giving women a voice and examining their ability to choose to provide care are again raised. One could hypothesize that if daughters-in-law refuse some caregiving to their husband's parents, difficulties may arise in their relationship with their husbands. This is particularly true if males operate from within

traditional gender lines and are expecting women to do the majority of the caregiving.

Finally, other uncommon situations may draw women to caregiving at the end of life. Some mothers are responsible for providing care to a dying child (including adult children). This is a particularly difficult situation in which mothers are reported to underreport their own difficulties in order to protect the well-being of their child (Grinyer, 2006). This tendency for women to mask their distress may also occur in other home-based caregiving situations, including palliation. In the case where the partner is diagnosed at a young age, it is likely that even though women may be caring for the individual, they may also be responsible for caring for children the couple may have. This is an intensely arduous scenario. Finally, some women may function as secondary caregivers during a time of illness, providing support to a primary caregiver.

CHANGES IN CAREGIVER IDENTITY

Some women are likely to experience changes in their own identity when caring for a terminally ill family member. Specifically, when family members are called upon to provide care, they are often required to take on new roles in addition to those previously held. This can be quite difficult, especially if these were domains in which they have no prior experience (i.e., those managed by the ill partner). When these new roles are assumed, they are likely to affect the power dynamics of the relationship.

In a comprehensive review of the literature on family caregiving at the end of life, Stajduhar and Cohen (2009) identified six distinct roles that usually are required of caregivers. I consider each, but through a lens of women's experience and feminist theory. The first two roles concern how the individual's health needs affect the family caregiver. (1) Caregivers become *physical care providers* in the sense that they need to take on the responsibilities of nurses without necessarily having any education in the everyday physical care of their family member. (2) In addition, caregivers need to become *symptom management specialists* and skilled in the appropriate means of intervening. These two domains are likely suddenly learned by women, sometimes through trial and error, which can in itself be quite stressful and adds to their caregiving responsibilities.

The following four roles emphasize the relational aspects of identity, which has profound implications for women caregivers. (3) If not already doing so, caregivers must function as *psychological, social, and even spiritual caregivers*. Women, in general, may function as the sole emotional support for the in-

dividuals (Bunting, 1992). This can be especially complicated when the relationship between caregiver and individual was either turbulent prior to terminal diagnosis, became turbulent upon diagnosis, or both. It can also be very challenging providing care in a domain in which they may have little previous experience, for instance dealing with one's own death anxiety (Yalom, 2008). (4) Caregivers often function as *advocates* for individual care. For instance, the caregivers function as the primary decision maker for treatment in times when the individual is incapacitated. They may also have to give or assume voice to the individual during encounters with family members. Finally, they may serve as the advocate with the health care system if they perceive that they, or the individual, are not receiving adequate care. A paradoxical situation may arise when a woman is asked to give a voice to her dying husband, which may or may not be something she can do. (5) Caregivers often act as *communicators* with others on behalf of the individual. They may manage social gatherings, including providing food and drink for visitors, and indicate when visitors should leave. In this sense, caregivers take on a form of managerial role. There is a tendency for women to be the ones responsible for proffering food in the home. Women also maintain connection with the extended family system (Rosenthal, 1985). This may be particularly true during the period leading up to death. (6) Caregivers also may function as the *coordinator of treatment*. This can include managing appointments, keeping records of patient tests and symptoms in order to report these to the health care team, and buying prescription medication.

The final role that I consider is that of *financial manager*. For some family members, this will be learning to manage the household income for the first time if there was a strict division of labor in the home and they may not have been the financial manager. For others, this will involve questions of how to survive financially both during the palliative stage and after the individual's death (Harding & Higginson, 2003). At times it will be blending with the advocate role, for instance, arguing for the proper funds from health insurers. Women have also been marginalized in terms of having less income than men (Major & Konar, 1984), which may put their future survival at risk.

In addition to new identities assumed, the experience of women who hold employment outside of the home should be carefully considered. Work is an important part of women's identity, and many provide care at home concurrently. The question of whether caregiving and employment are complementary or competing roles in elder care was the subject of a study by Scharlach (1994). Although he was not

looking at gender experiences, his investigation found that the negative aspects of combining work and caregiving roles were often outweighed by positive effects, including enhanced interpersonal relationships, a sense of achievement, and opportunities to compensate for limitations experienced in other life roles. The question of whether or not his findings would hold true across the experience of women in palliative home care is unclear.

CAREGIVING AND POWER

In addition to the changes in identity, it is important to note changes in the power dynamics of the relationship in light of a terminal diagnosis. As individuals die, they become a patient in their own home. How couples negotiate this transition is an important topic. A large body of feminist literature focuses on striving toward equality in relationships across gender and cultural lines (Enns, 2004). When the ill partner was traditionally the person with more power, caregivers may now find themselves in a situation where they have more power than the patient. This may cause considerable strain in the relationship. In the majority of situations, it will be the man who held more power. In this case, a woman may suddenly find herself with more influence than she ever had previously.

However, the situation may arise where a woman is placed in the position of power and does not wish it. Specifically, the caregiver role may be thrust upon her if there is no one else present, and the question of whether this is empowering or oppressive become important. Caregiving at the end of life is a role with tremendous amounts of responsibility, and there may be a corresponding feeling of lack of control (a decrease in power) experienced by the caregiver. Therefore, it would appear that any change in the power dynamic may manifest as an unempowering experience for women as their caregiving responsibilities increase. The importance of examining women's subjective reality is clearly necessary.

The notion of facilitating equality in power by allowing women to voice their needs and experience has guided several research studies in the area of power. Although they occur outside the domain of palliative home care, I endeavor to draw links where appropriate. The process of empowerment was studied with mothers of neurologically challenged children by Gibson (1995). Empowerment was constructed as a social process of promoting, recognizing, and improving an individual or group's facility to meet their own needs. It also involves the aptitude to solve troubles and mobilize the necessary resources in order to feel more in control. Although Gibson (1995) argues that the empowerment was a largely intrapersonal

process for these women, she also emphasizes relational elements. Not only do mothers grow in the required knowledge, confidence, and ability in dealing with their child, but they also found a way to make their voices heard in the important relationships in their lives. However, Gibson (1995) cautioned that mothers who are deemed to be empowered may not necessarily receive the support they require to deal with stressors. Mok et al. (2002) similarly looked at the process of empowerment, focusing on the experience of nurses offering support to family caregivers in an institutional palliative care setting. The researchers argued that fundamental to facilitating an empowering process is the formation of a positive relationship. Overall, both these studies highlight the importance for women providing care in attending to the relationship, and suggest that examining how power is used and shared can be productive.

SOCIAL JUSTICE CONSIDERATIONS

Social justice in health care is primarily concerned with providing equal access and opportunity to all groups. There is a focus on effecting social change to favor inclusivity, removing individual and systemic barriers to fair treatment and ensuring that treatment is directed at the micro, meso, and macro levels (Szapocznik et al., 1994; Enns & Sinacore, 2005; Sue & Sue, 2008). Enns and Forrest (2005) argued for the need for social change to address multiple oppressions faced by individuals. The application of social justice theory to the experience of women caregivers in home-based palliative care will now be considered.

The fact that women are implicated as caregivers needs to be challenged in the interest of their overall well-being. Given that there is a tendency of family members to move away from home, coupled with smaller family units and changing household structures, there is an increased likelihood that there will be fewer family members available as secondary caregivers (Harding & Higginson, 2003). Therefore, women who function as primary caregivers may be isolated. Males can step in here and serve as primary or secondary caregivers and relieve women of some of the negative aspects of caregiving. However, this may involve paying particular attention to the relational aspects of caregiving and focusing on developing ways of facilitating emotional support (Calasanti & King, 2007).

Furthermore, in an ethnographic study that examined the social context of home-based palliative caregivers, Stajduhar and Davies (2005) found that assumptions about dying at home and health care reforms led to the perception in some caregivers that they were compelled to provide home care. Although some caregivers willingly put their own needs to the

side, she suggests that the context surrounding such choices can be problematic when societal expectations or a lack of alternatives are present. These societal pressures need to be addressed. For instance, if women feel pressured to be the caregiver and health care providers reinforce this, they may be exploited. This conclusion invites two salient questions: (1) Does the health care system naturally tend to assume that women will provide care for the dying individual? (2) With this in mind, does this perpetuate patriarchal norms and the oppression of women?

The final social justice argument revolves around the ability of individuals and families to have access to both palliative home care and institutional services. We have already mentioned that palliative home care largely remains the domain of white-skinned families with a higher socioeconomic status and education level (Rosenwax & McNamara, 2006). Families of ethnic minority communities, older individuals with nonacute conditions, and marginalized peoples are also likely excluded (including those living homeless; Ahmed et al., 2004).

IMPLICATIONS FOR PRACTICE AND POLICY

Given the above arguments, it is imperative to pose the question, "What types of interventions might best support women caregivers in palliative home care?" Adding a feminist lens to the dialogue ensures that women are not pathologized when showing symptoms of distress. When they synthesized the literature on palliative home care, Stajduhar and Cohen (2009) noted that four distinct experiences in palliative home care tend to lead to more positive outcomes during the bereavement stage for family caregivers: (1) there was sufficient collaboration between the patient and caregiver, which resulted in a negotiated process; (2) there existed a relatively equal consideration by all stakeholders to meet the needs of both caregiver and individual; (3) caregivers were an integral part of the health care team and respected for their contribution and expertise; and (4) caregivers perceived they had met the individual's needs satisfactorily. In considering these four trends, one notices that they are not only significant guidelines for informing clinical practice, but that the tenets of sound feminist theory and practice are embedded within them. Specifically, one notes the feminist notions of (a) striving for equality in relationships (points 1–3; Enns, 2004) and (b) that the relationships be collaborative in treatment planning (points 1–4; Brown, 2000). Below, I consider research on current interventions strategies and provide a feminist critique to emphasize the need for strength- and wellness-based approaches (Myers et al., 2000).

During the last 2 weeks of life, the needs of both the individual and his or her caregivers become acute. Providing support to caregivers throughout the dying process appears to be necessary. Health care professionals have been accused of assuming that if caregivers report no difficulties, they have no unmet needs. It is only when a crisis occurs that services are provided (Harding & Higginson, 2003). This crisis intervention model, where success tends to be ignored and failure is reinforced, can contribute to considerable distress for caregivers. The tendency may also exist for professionals to shame and blame caregivers during acute episodes for not seeking services earlier. Unfortunately, Jo et al. (2007) identified that difficulties in communication with health care providers and poor coordination of care exist among the services offered in Canada. These disparities become crucial as the individual becomes progressively more ill, and the desire and/or ability of caregivers to continue home care may change (Stajduhar, 2003). Being attentive to caregiver stress appears crucial. Health care professionals might do well to use a strength-based approach to view female caregiver symptoms of difficulties as attempts at communication and coping with extremely difficult circumstances (Enns, 2004).

As previously stated, the relationship for women in general and functioning as caregivers in particular calls for it to be integrated in intervention strategies. The importance of the relationship between individual and caregiver and between caregiver and health care professional should be a priority. Using collaborative interventions seems appropriate. Unfortunately, a great deal of research refers to family caregivers as informal caregivers, whereas health care professionals are called formal caregivers. This label may have the tendency to reinforce the unbalanced power dynamics in health care service provision and increase the likelihood that caregiving by families is regarded as somewhat less effective. For instance, Harding and Higginson (2003) noted that some caregivers feel like "strangers" and "pushed aside" by health care professionals in a palliative home care situation. Some felt they and their home were disrespected and their expertise minimized. Collaborating will likely ensure that caregivers, in particular women, are given a space for voice, not only in treatment planning, but for their own needs.

However, Gibson (1995) put forward several potentially negative consequences of power sharing in working with mothers of children who suffer chronic illness. When health care professionals recognize a woman's competence, they may place too much responsibility on women to make the right decisions and expect them to assume total care. Women who

were deemed to be empowered may not receive the support they require to deal with the stresses they encounter. Therefore, health care professionals need to be sensitive to the negative possibilities of power sharing in palliative home care.

When we look at the relational aspects of caregiving from Gilligan's (1993) ethics of care perspective, in order to bring forth the feminine voice it may be necessary to gauge at which stage of Gilligan's moral development a given woman is: (1) caring for self as self-protection, (2) caring for others as altruism and self-sacrifice, or (3) a balance between concern for self and concern for others that focuses on the relational dimension. When we build on this from a wellness perspective, it would seem important to ensure that any interventions target the strengths of the woman caregiver wherever she is at and strive not to pathologize her symptoms.

All interventions should be grounded in sound multicultural practice. The importance of developing multicultural competencies in end of life care has already been stated. In addition, considering the broad cultural literature in palliative care may be useful in providing some guidance for practitioners. For instance, Payne et al. (2005) examined some of the key factors in end-of-life care for individuals and families who emigrated from China to North America. Their study found that the following areas required particular sensitivity: (1) the disclosure of diagnostic and prognostic information to families instead of individuals, (2) the preference for family roles in decision making, (3) the preferences for life-sustaining treatments, and (4) preferences for death at home. Although the study did not examine the experience of women directly, the findings can be useful, as place of death may be associated with women in the caregiving role. Elioff (2003) examined the experience of African Americans who have not been well represented in hospice care. The author noted that African Americans may have barriers to accessing hospice service that may result from cultural differences, including values and spirituality, and from a lack of trust in medical doctors. The salient question emerges of whether or not the message being conveyed to African Americans is that they need to adjust themselves to the services available. Hospice and palliative home care practitioners may provide more appropriate and sensitive interventions if they avoid forcing families, including women in palliative home care, to adjust to them.

Finally, policy makers may need to consider a number of factors when developing future guidelines for palliative home care. First, policy should be gender sensitive and include an awareness of how women's caregiving experiences are informed by cultural factors. For instance, clearly outlining the

importance of forming collaborative relationships and attending to power dynamics with women caregivers will lead to palliative home care policies being more inclusive and appropriate. Second, education policy should include both multicultural competence training and an emphasis on reflexivity given that most practice and policy appear guided primarily by White ethnocentric worldviews. Finally, research funding agencies should create procedures that can critically examine gender and cultural research so as not to perpetuate harmful practice that takes women's caregiving for granted.

DIRECTIONS FOR FUTURE RESEARCH

There are numerous directions for future research in the area of women caring for a terminally ill family member at home. First, the impact of health care reforms on palliative home care should be carefully examined with regards to societal expectations of women caregiving. Second, more research is needed on the relationship between the individual and the caregiver. Although Hudson's (2004) suggestion that it is likely that the positive aspects of care giving may serve as a buffer against the negative aspects of the role warrants further exploration, further research should assess whether this is the case as well as the long-term impact of the caregiver role on those who are unable to recognize positive elements. Also, researchers could examine how the relationship between individual and caregiver may change before and after diagnosis and in the advanced stage of a terminal illness.

Third, there is a clear need to explore issues of diversity in home-based palliative care. For example, most of the literature in home-based palliative care concerns heterosexual couples and not families from the same-sex oriented, bisexual, or transgendered communities. Fourth, although some guidelines and policies that address working cross culturally in palliative care have been developed (Payne, 2002, 2005; Schim et al., 2006), there is a need to develop practices for home-based end-of-life and palliative care.

Finally, do the caregiving issues discussed in this report transcend gender lines? Although there is a lack of research to address this question at present, future research can assess the ways in which individuals and practitioners behave in both gender specific and gender nonspecific ways (West & Zimmerman, 1987) at the end of life. This flexibility in gender identity gives rise to a number of potential questions. For instance, if a man is providing end-of-life care, how "feminine" or "masculine" is the caregiving role? Is a man who provides care somehow acting more feminine, and what is the impact of this? Does the value of

caregiving change depending on how masculine or feminine it is, and how does this affect current policy and practice? How do male and female caregiving styles differ, and does this juxtaposition diminish the unique gifts of each approach (Arber & Ginn, 1995; Thompson, 2002)? Although a number of men are coming to embrace the tenets of feminist theory and practice (Brown, 2006), does this carry into palliative home care? Feminist practice includes a deconstruction of language and power as well as a consideration of the impact of patriarchy and oppression on women's and men's lives. How ready are men to engage in this analysis, as there is often a resistance to discussing feminist topics (Sinacore & Boatwright, 2005)?

CONCLUSION

The experience of women who provide care for a terminally ill family member is very complicated. Numerous factors emerge, including the tendency for women to provide care, the complex multicultural implications, the centrality of the caregiving relationship, the changes in identity, the institutional barriers, and the need for social justice. The future of palliative home care appears to place women caregivers in a critical role. Feminist theory and practice, with its emphasis on egalitarian relationships, an analysis of power, and the function of gender role socialization, bring to light the possibility that research, policy, and practice in end-of-life home care may be guided, (intentionally or unintentionally) by oppressive tendencies toward women. If this is indeed the case, it seems important that it not be perpetuated.

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