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Abstract

Although there is evidence to support nursing as a moral practice, there is no formula or dose to describe how much the nurse is obliged to risk in order to meet the ethical demand placed on him or her as a professional and to preserve the vulnerable trust essential to establish and maintain a therapeutic nurse-patient relationship. On the basis of research and significant statements from interviews with five participants, this article discusses examples of nurses' moral responsibility stemming from knowledge of consciousness about the value of presence inherent in the relationship between nurse and patient. The challenge for the nurse is to understand that the trust and power embedded in his/her meeting with patients entails a demand for attentiveness and an ethical obligation to make changes from the stories shared by those who, through a disruption in life, find themselves in the presence of a nurse.

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Introduction

At the start of the 21st century, health care for women faces a number of critical challenges (Lee & Estes, 2003). As reported by Lee and Estes (2003) new data are challenging old ways of providing care and exposing large disparities in the health status of women. A woman's health status is influenced by factors such as age, income, race/ethnicity and marital status. Employer-sponsored insurance is the predominant form of coverage for nonelderly women, with six in 10 covered by their own or their spouse's employer.

Each year nearly 10 million individuals in the United States will face the loss of their spouse, 69% of these being women. Wylie (1997) stated that the average age at which women become widowed is 56 and they remain spouseless for an average of 14 years (U.S. Bureau of the Census (1999)). More recent statistics reported by the 2006 U.S. Census indicated 32% of women aged 55 and older are widows; while 9% of men aged 55 and older are widowers. Although the average age falls just outside the middle age range (35-55), there is limited documented data available regarding this age group.

Death of a spouse is described as one of the most stressful of all life events across all ages and cultural backgrounds. Kaslow (2004) describes the loss of a spouse for many individuals as one of the most tragic events that can occur. According to Holmes and Rahe (1967), bereavement increases stress and anxiety and can inhibit otherwise health-promoting behavior, thereby increasing negative health outcomes. Anxiety and stress in the bereaved is typified by decreased cognitive function, decreased problem-solving ability, inability to relax, and assumption of a hostile attitude (Lindermann, 1944). According to Kaslow (2004) even a

different scenario may occur when someone is confronted with the sudden, instantaneous death of a partner.

Parks & Weiss (1983) found that sudden unexpected death has been shown to have a debilitating effect on the bereaved in that shock acts to prolong grief, as well as to produce excessive physical and emotional traumas. Sanders (1980-1981) found that sudden death was such a shock that the capacity of the bereaved to cope was diminished greatly and full functioning was not recovered by some even four years following the death. Lundin (1984) describes participants who had experienced a sudden death and found they had more somatic and psychiatric illnesses, when compared to persons who had experienced an anticipated death. Miller and McGown (1997) discuss the variables of socioeconomic status, religiosity, stigmatic death and concurrent crisis as external mediators.

Purpose

The purpose of this article is to present results from a larger study (Williamson, 2010) and to propose new ethical guidelines based on the researcher's experience with respondents. New guidelines are needed regarding middle-age women's health and advocates are needed to bridge the work done on behalf of women's health and bereavement after the sudden death of a spouse. The aim is to advocate for earlier connections in the nurse-patient relationship. Many studies have shown that the presence of a nurse practicing from the ethic of caring will encourage positive mental health. Raising awareness of bereavement care and support as a primary prevention health issue can, thereby reduce morbidity from unresolved grief and resulting health problems and can promote the quality of life for those facing major changes in their lives. Grief is not the total experience of the survival process for mid-life women who have lost their spouse to sudden death. Mistaking grief for the whole of the experience of any

bereaved person is misleading because the experience is far more complex, entailing diverse

emotional, physical, intellectual, spiritual, and social components.

Background and Significance

Issues surrounding dying and death raise many ethical concerns and questions for nurses

as well as for the nursing profession. Many of these issues evoke a nurse's personal feelings of

ambiguity about death. Nurses should examine, individually and collectively, their own values in

relation to death, quality of life, the importance of the individual needs of patients, and the caring

dimensions of the nurse-patient relationship.

The phenomena of concern to nurses in all practice settings are human experiences and

responses and emotions to birth, health, illness, and death. Nurses focus on these phenomena

within the context of individuals, families, groups, and communities. The nurse's philosophical,

theoretical and research-based understanding of these phenomena and the preferences of patients,

families, or communities guide the formulation of plans of care. The American Nurses

Association (ANA) in Nursing's Social Policy Statement list the following values and

assumptions which undergird professional nursing's contract with society:

1. Humans manifest an essential unity of mind, body, and spirit.
2. Human experience is contextually and culturally defined.
3. Health and illness are human experiences. The presence of illness does not preclude health nor does optimal health preclude illness.
4. The relationship between nurse and patient involves participation of both in the process of care.
5. The interaction between nurse and patient occurs within the context of the values and beliefs of the patient and the nurse.
6. Public policy and the healthcare delivery system influence the health and well-being of society and professional nursing.

These values and assumptions apply whether the recipient of professional nursing care is

an individual, family, group, community, or population. The ANA emphasizes that it is

important for nurses to integrate objective data of the physical (cellular to anatomical levels) with knowledge gained from an understanding of the client's subjective experience. When nurses do not listen to the subjective experiences of patients, they are not practicing in an optimal healing environment as described by the ANA.

The lived-experience is context-bound and best understood by a person's perceptions (Benner, 1984). Perceptions are built upon one's contextual experiences and come about through an awareness of one's existential context (Benner, 1984; Munhall, 2007). An underlying assumption of the approach humans choose as they encounter events in their life-world, based on the works of Merleau-Ponty (1962) is that the situated individual co-creates and is created by temporal, environmental, and historical contexts.

Scope of the Problem

Placing middle aged women in the context of their life-world

Burkhauser and Smeeding (1994) report eighty percent of all widows in poverty become poor only after their husbands die, and compared to men, elderly women are three times more likely to be widowed. Change in marital status and its subsequent effects were demonstrated by Shaw et al. who examined a group of women over a nine-year time span and found that poverty was relatively rare and did not increase among women who were married at both times in their study. Unfortunately, many of the fundamental political and economic structures that produce women's poverty are attributable to the death of or divorce of the spouse.

As nurses and nursing researchers reflected more on the bereavement experience of middle-age women, they began to question what it is that nurses do with the stories shared by these women. What connections do nurses make with the knowledge that they have gained from stories? What do nurses know about this experience? Maybe nurses do not listen to these women

until there is a pathological change that brings them into the system. Do nurses ignore women's stories of bereavement as part of their history? It is difficult to escape the realization that there are many things that nurses do not know, but there is a consuming desire to learn more about this experience as indicated in this research.

Ethical Concerns for Research

Vulnerable Groups

Researchers should pay particular attention to the ethical dimensions of a study when people who are vulnerable are involved. Adherence to ethical standards is straightforward. The rights of special vulnerable groups, however, may need to be protected through additional procedures and heightened sensitivity on the part of the researcher. Vulnerable subjects are defined by Polit & Beck (2004) as a special group of people whose rights in studies need special protection because their circumstances place them at higher-than average risk of adverse effects. Caplan (1990) writes that the loss of loved ones through death causes suffering and intense mental anguish in survivors. Certain topics such as the sudden violent death of a loved one are extremely sensitive and place participants in a vulnerable situation as the researcher asks the probing questions to elicit the necessary data.

Limited nursing research has been done in the immediate bereavement period particularly within four months to one year after the death; this is considered the suggested time frame to wait before research studies should be done. However, the review of literature, as well as findings from this present study, demonstrates that this is the period of time when the bereaved is the most in need of grief interventions. It would seem that data collected during this time frame would better define the type of interventions needed. Formal support groups such as the widow-to-widow programs have shown that this is the time that sharing of one's emotions

and experiences with other individuals who have had a similar experience is the most helpful. A nurse working from the perspective of the Theory of Health as expanding consciousness (HEC) would enhance this experience.

Speziale & Carpenter (2007) explain that given the intensity of the interaction between researcher and participant, the researcher also may be in a vulnerable position. Polit & Beck (2004) reported that subjectivity and collaboration makes the researcher vulnerable. They suggest that the researcher being emotionally immersed in the lived experience of others, continually sensitive to the potentially injurious nature of language, and experiencing the rights of passage as an interviewer/observer- all require an inner strength that can be enhanced by self care.

Bereavement resulting from death of a loved one includes a wide range of psychological and physiological responses that are frequently categorized as part of the grief process. Bereavement increases stress and anxiety and can inhibit health-producing behavior, thereby, increasing negative health outcomes. Some of the negative mental health outcomes experienced by the bereaved may develop into full-blown psychiatric diagnosis such as major depression, and anxiety disorders (American Psychiatric Association, 2000). Middle age women's health represents a complex interplay of medical, social, and economic factors that cannot be understood in isolation. Successfully addressing the needs of middle-age women's health requires the participation of both those interested in women's health and those concerned about bereavement issues to create a new agenda grounded in three areas: (1) there is a gendered relationship between socioeconomic structures and health over time; (2) there are gender-specific implications of health care financing and policy; and (3) there are health consequences associated with bereavement.

Speziale & Carpenter (2007) caution the researcher not to stray from the focus of the investigation. After each interview in the larger study each participant was asked if she needed follow-up. Contact information for additional help was provided if the participant expressed an interest. Douglas (2004) warns those who make use of narrative inquiry to guard against believing that their interviewing work is therapeutic for the participant and further warns researchers against being too personally intrusive. There is a significant difference between acknowledging that the research interview can function as a means for personal change (expanding consciousness) and holding a position that intensive interviewing is usually therapeutic. Douglas (2004) clarifies researchers are not therapist and the two roles should not be confused. As a special provision for this aspect of the study, the researcher relied on the experience of a Psychiatric Advanced Registered Nurse Practitioner (ARNP) employed by Miami-Dade County in Florida to design a handout which was available in the event of a setback or if the participant felt they needed further intervention or the option of exclusion from the study.

Theoretical Context / Philosophical Underpinning

This article comes from a larger study that was framed conceptually by Newman's Theory of Expanding Consciousness (Newman, 1994, 1997, 2008) and by the theories of developmental stages. One theory of development is presented for reference and as a means to situate the sample in the proper social context.

Newman's theory is a composite of her early influences and life and practice experience. As early as 1977, while Newman was preparing for a presentation entitled "Toward a Theory of Health" the theory of Health as Expanding Consciousness (HEC) began to take shape. Drawing

on the work of Martha Rogers and Itzhak Bentov and on her own experiences and insights, the

summary of what she proposed is that:

1. Health encompasses conditions known as disease as well as states where disease is not

   present;

2. Disease, when it manifests itself, can be considered a manifestation of the underlying

   pattern of the person;

3. The pattern of the person manifesting itself as disease was present prior to the structural

   and functional changes of disease;

4. Removal of the pathology in itself will not change the pattern of the individual;

5. If becoming "ill" is the only way an individual's pattern manifest itself, then that is health

   for that person; and

6. Health is the expansion of consciousness. (Newman, 1997, p.5)

Newman states, "The responsibility of the nurse is not to make people well, or to prevent

their getting sick, but to assist people to recognize the power that is within them to move to

higher levels of consciousness". (Newman, 1997, p.47)

She demonstrated that nurses wanted to go beyond combating diseases; that their goal

was to accompany their patients in the process of discovering meaning and wholeness in their

lives. Newman's theory can serve as a guide for them to do so. After identifying the basic

assumptions of the HEC theory, the next step for Newman was to focus on how to test the theory

with nursing research and how the theory could inform nursing practice. Newman began to

concentrate on:

1. The mutuality of the nurse-client interaction in the process of pattern recognition,

2. The uniqueness and wholeness of the pattern in each client situation,

3. The sequential configurations of pattern evolving over time,

4. Insights occurring as choice points of action potential, and

5. The movement of the life process toward expanded consciousness. (Newman, 1997, p.54)

Sequential configurations of pattern evolving over time

According to Newman's theory, each person exhibits a distinct pattern, which is constantly unfolding and evolving as the person interacts with the environment. She describes these patterns as information that depicts the whole of a person's relationship with the environment. Pattern is a manifestation of consciousness, which Newman defines as the informational capacity of the system to interact with its environment.

Newman points out that the nurse-client relationships often begin during periods of disruption, uncertainty, and unpredictability in patients' lives. When patients are in a period of chaos due from disease, trauma, loss, or other disruptive states they often cannot see their past or future clearly. In the context of the nurse-patient partnership, which centers on the meaning the patient gives to the health predicament, insight for action arises and it becomes clear to the patient how to get on with life. Newman sees this as experiencing an expanding present that connects to the past and creates an extended horizon of action potential.

Women's Role in American Society

Money does more than buy the goods and services that people use every day. It is a money world. Money influences individuals in their relationships with members of their own family as well as with others around them. It affects individuals' standard of living, their goals, and their emotions. There are some hidden benefits for the working wife that does not show up in the pay check. The Social Security benefits, after working a year and a half, have very substantial monetary value. And most workers get substantial fringe benefits in the form of

insurance-medical and hospitalization- and pension funds. Women employed in stores usually get discount privileges and perhaps bargain-sale opportunities. Finally, by knowing how to handle a job, a wife is acquiring economic security that would be valuable in the event of premature death of her husband.

Gilligan's theory of moral development

One study on moral development in women and men by Gilligan has demonstrated gender differences in describing high morality as described in Edelman & Mandle (2002). Women discussed issues of selfishness versus responsibility, of exercising care, and the avoidance of hurting others according to Gilligan's work. Men described terms of justice, fairness, and the rights of individuals. Gilligan's theory of moral development suggests that there is a different process of moral development in women in society (Edelman & Mandle, 2002). Women maintain a particular status in American society, in the labor market, and in the family as demonstrated by Estes (2000). Women play a unique role as society's caregivers.

Gender bias in nursing and nursing research is a hotly debated issue, according to Polit and Beck (2004). Using data from a consecutive sample of 259 studies published in four leading nursing research journals in 2005-2006, they examined whether nurse researchers favor females as study participants. On average, 75.3% of study participants were female, and 38% of studies had all-female samples. The found that bias favoring female participants was statistically significant and persistent. The bias was observed regardless of funding source, methodological features, and other participant and researcher characteristics, with one exception, "studies that had male investigators had more sex-balanced samples". So one wonders, is it simply because there are more female nurses than male, or is there a bias on the part of researchers in a predominantly female occupation to represent a female perspective on nursing?

These theories provide the nurse with a framework for observations, interactions, and health care planning for individuals and their family members. Each person and family exist in a larger community; this community, whether on a local, state, or national level, can greatly influence the availability of health care and the climate of health promotion versus a disease focus of care. Understanding care giving through gender and across the life course will promote solutions that address the disproportionate burden of care giving on women.

Becoming a Widow

Individuals make many choices that affect their health each day and multiple factors may influence how these choices are made. The stage of motor, social, and cognitive development can greatly influence how the person perceives a situation and the choices arising from that situation. The nurse who has studied development has a clearer idea of how a person may respond to a given idea or situation at a specific age or stage of development.

Some change can be positive; examples are personal change which enables growth and development and organizational change which can enhance personal and collective achievement, motivation and reward. Some change is negative and damaging and usually is related to the loss of personal power, self-esteem or able-bodiedness; examples are crime, accident or violence. Other change may hold mixed blessings and, therefore, means there is a struggle for growth pitted against the need for change; examples are the loss of a partner or loved one through death or divorce, moving to a new house or country, or changing of a job. The struggle may result in very positive development but it can also be painful and there is almost always some sense of uncertainty.

A researcher working from the phenomenological perspective is concerned with the lived experience of the people involved, or who were involved, with the issue that is being researched.

From the larger study a descriptive design was used and was appropriate because the goal was to gain additional information about a particular group or situation which is the lived experience of grief after sudden death of a spouse and to describe the meaning the survivors ascribe to the experience. In a descriptive design, the researcher does not manipulate the variables, but describes what becomes illuminated (Burns & Grove, 1997). With this design, there was no attempt to establish causality. The intent was to gain information that may be helpful in developing theory, to identify problems with existing systems, or to identify the manner in which situations are currently managed. The sample included participants who had experienced the sudden death of a spouse.

Research Question

The focus of this secondary analysis of the data was to identify themes related to ethical issues widows faced in the immediate bereavement period. Interviews from five participants from a larger study were used to identify these themes.

Findings from the Study

Thematic Analysis

Secondary analysis of the data provided significant statements related to the *ethics of care* of bereaved women's major stressors as they tried to assimilate the news of the sudden death of their spouse and at the same time carry out the responsibilities and activities of daily living. Significant statements, arrived at by their similarities, parallelisms, and key-word content were condensed into themes. Themes identified were; 1. *Intrusive encounters*, 2. *Financial concerns*, 3. *Health concerns,* 4. *Conflicts associated with caregiver role.*

Theme one

Significant statements and intact narrative exemplars were extracted from the interview regarding the first theme *Intrusive encounters.* Examples were: a) "…and then I started bein' called. The newspapers called. The TV stations called. The lawyers called." b) "Lawyers tried to get in to see me. One guy came and told one of my brothers that he was a real good friend of my husband's and that he had worked with him and wanted to talk to me. Well, when he got in the house, we found out he was an attorney. That was just really kind of heartbreaking." C) "We went through about a year of Coast Guard hearings." D) "So, she was kind of helpin' me to make decisions or not make decisions, but to in what order to do things kinda as far as callin', of course, they did an autopsy that night, and goin' to the funeral home." E) "And he did have a will, so I had that, you know." F) "But what I meant was what are the mechanics of what I need to do now, you know, a, a funeral, contactin' people, just what do I need to do first." G) "'It'll save you some money if you just let us get the hearse to come pick him up from the house.' And I said, 'Okay.' I mean it's, he was dead. There wasn't no sense in takin' him to the hospital just to say he was dead there. And they also said it was up to me whether he had an autopsy. I told 'em, cause I already knew what would be on the autopsy and I didn't want to know all that, I told 'em 'No. I didn't want no autopsy'" (Williamson, 2010).

Theme two

Theme two *financial concerns* were derived from statements such as: A) "…and then the company just kind of, they, they sent a very small amount of money." b) "They would not even talk to me about his life insurance." C) "I stayed home a couple of weeks and tried to get, you know, got things settled and I was…then I went back as a part-time. I didn't go back in full-time." D) "There was a policy in place to buy out a spouse or do whatever, so that they didn't have to come up with x amount of dollars to, to clear that out. So, that was taken care of through

them." E) "We was just not makin' enough money, so we was gonna lose our trailer, so we had already moved in with our son, and since I was livin' with him and I had got my new job, I felt like he could let go." (Williamson, 2010)

Theme three

Health concerns were identified as theme three and are demonstrated by the following examples: A) "I'd lost so much weight and I looked so white, my skin looked so pasty and I thought, 'This is horrible.'" B) "And I remember calling ▮▮▮▮ havin' to get something for my gut, you know, I sent my brother-in-law down to pick up my…I said, 'I need something to take to keep me from havin', my gut churnin'.'" C) "And that's when my head started hurtin'. I just thought it was just stress and Mama and everybody was worried." D) "And my blood pressure was so high, I can't even remember now but that was why my head was hurtin'. And the doctor told, he said he was gonna have to put me on some kind of blood pressure long enough to get it back down cause I've never had a problem with it ever since." (Williamson, 2010)

Theme four

Continuing with the analysis, theme four *conflicts associated with the caregiver role* immerged form the following statements: a) "And I don't know how my son survived. If it had not been for my family… ▮▮▮▮ took him and made him do his homework." B) "I went back part-time and it, you know, I was able to be there and do things with the kids and, and not go back into it, you know, 40, 50 hours a week." C) "But on hindsight, I should have taken time off, and I didn't." D) "That was the saving grace for them though, in a way, because they could get back into their routine at school. And I think I thought my saving thing was get, keep my routine going. Go back to work. But, I should have taken more time to let it soak in and think about the reality of it, the long term." E) "But, I think I kind of put things on hold then because I

was just tryin' to keep things, keep everybody goin', you know." F) "It, it was a blessin' that I knew that my son was not havin' to grieve as a child as I had to grieve as an eight year old child. The minus was he would not have any conscious memories of his dad." G) "Whatever memories he has are memories that we've created for him through pictures and through stories and through videos and so that helped me to know he was okay. You know, at this point, like today, he's not grieving. He's not hurting. That he's okay." H) "I know for me also, my nursing him was my medicine." I) "…and again that's me tryin' to make it right for everybody else, you know, which is like you said what most women do." J) "I told 'em all, (my kids) I said, 'Now, you have your lives to live and I don't expect you to give up your life to come back here just to look after me.'" (Williamson, 2010)

Participants in this study reported that during their most vulnerable periods following the news of the death of their spouse, they felt the most stress from the intrusive encounters of lawyers, newspaper reporters, and legal requirements regarding the disposal of the body in regards to autopsies, funeral arrangements and presence or absence of a will. Along with these responsibilities that had to also oversee the care of children and other family members. Although all participants stated they did rely on the support of friends and family and their faith in God, they expressed the lack of opportunity to just tell their story and have someone listen for who they did not have to "be strong".

Participants in this study reported that their access to care was often complicated by their financial concerns and greater responsibilities juggling work and family needs. Women maintain a particular status in society, in the labor market, and in the family; public policies reinforce and entrench these roles (Estes, 2000). Women play a unique role as society's caregivers. Estes (2000) reported that nearly two thirds of caregivers of the elderly are themselves older women,

many of whom, are caring for both children and older family members. Care- giving is widely accepted as a woman's issue. It reflects some of what is best about being a woman: compassion and concern for others as demonstrated by Gilligan's theory of moral development.

Implications for Nursing Theory, Practice and Research

Further study is needed to identify: (1) Long term preventive strategies which develop a culture of caring for the bereaved individual, (2) short-term interventions which support and help those who through misfortune and tragedy find their own resources depleted.

Perhaps the most important contribution of this article is that of being able to describe from a narrative perspective the unfolding patterns and underlying meanings of mid-life widows' grief reaction in a manner that has not been possible in previous studies. Patterns, as reported by Carper (1978) are "characteristic ways of thinking about phenomena and are distinguished according to logical type of meaning." (p. 13). Using ethically sound selection criteria based on individual readiness for participation in research, studies could be done in the early stages of bereavement that would allow nurses to bear witness to the unfolding patterns of bereavement as they occur from the participants own perspective. Through practice and research nurses could create a 'critical mass' of personnel with knowledge and skills to improve the quality of care and an *ethic of care* and support for those who are undergoing transition or grieving using as data the stories of women as they are experiencing them.

Recommendations for Future Studies

Nurses have a unique opportunity during the immediate bereavement period to demonstrate the type of caring that is not only the kind of attentiveness given to perform the scheduled interventions, but rather the attention bestowed on another person at the right time and place, something that is very different from the instrumental-technological attention and it's

"doing only what is necessary" philosophy. Nurses working from the phenomenological perspective are in a unique position to describe the meaning of loss after the sudden death of a spouse using the widow's own words immediately after the loss.

Conclusion

The needs of those bereaved by death should be a major concern for all health care professionals. The total cost of these unmet needs from human suffering, chronic health problems, and economic losses is incalculable according to Young (1998). As discussed earlier, grief and bereavement issues affect everyone who lives long enough and surface once pathology has occurred. Findings from this research study indicate that bereavement is a critical life event that has the potential for positive as well as negative effects. The cumulative impact, individually and socially, of unresolved and unexpressed grief is a major contribution to the levels of mental illness in the community. Although there is discourse about which way to proceed with this investigation the limitations are acknowledged. The intentions behind the assumptions that earlier connections in a nurse-patient relationship and the hope that this work makes a constructive contribution to the realization that health care policies regarding women's health issues need to be revised.

In the phenomenological perspective much emphasis is placed on the valuing of personal experience. The larger study details rich and moving accounts of individual's experience of loss and suffering. It is imperative that nurses attend to the immediacy and urgency of this experience, using theory to illuminate their understanding and frame their response. Nurses must resist the temptation to neatly categorize such experiences into a normative mould. They respect and draw upon each experience, including those recounted in literature, acknowledging the rights and responsibilities of both the bereaved as well as the nurse in the ethic of caring.

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