
Struggling in change at the end of life: A nursing inquiry

DEANNA HUTCHINGS, R.N., B.SC.N., M.N., C.H.P.C.N.(C.)
School of Nursing, University of Victoria, Victoria, British Columbia, Canada
(RECEIVED July 13, 2006; ACCEPTED August 27, 2006)

ABSTRACT

Objective: The purpose of this human science nursing inquiry is to explore the meaning of struggling in change for persons at the end of life.

Methods: Guided by Parse's theory of human becoming, a descriptive exploratory method was used to answer the research question: What is the meaning of the experience of struggling in change for persons at the end of life? Eight persons who were living with dying described experiences of struggling in change during face-to-face audiotaped interviews.

Results: A process of analysis–synthesis revealed three themes that are discussed in relation to extant related literature and interpreted in light of the human becoming perspective.

Significance of results: Findings from the study contribute new knowledge about human experience at the end of life from a human science perspective and offer new insights on struggling in change as a rhythmical pattern of living and dying. Implications for palliative practice, research, and education are discussed.

KEYWORDS: Human becoming, Human science, Nursing inquiry, Struggling in change, End of life

INTRODUCTION

Competent and compassionate palliative care requires a wide range of relevant knowledge such as symptom control, ethical decision making, communication, the dying process, loss and grief, and quality of life (Latimer, 1998; Special Committee on Social Affairs, Science and Technology, 2000), as well as a broad understanding about the meaning of experiences of people who are nearing the end of life. To that end, it is imperative that medicine, nursing, and allied health professionals conduct studies and develop knowledge that expands our understanding of human experience at the end of life.

Corner's (1998) systematic and critical review of published research in palliative care reveals a

concentration of research on evaluation of hospice palliative care services and quantification of troublesome symptoms but demonstrates a paucity of studies on the human health experiences of persons living with dying. Further, Corner's meta-analysis reveals that most of the extant palliative care research emerges from the prevailing paradigm of biomedical science. However, leading palliative care researchers and practitioners assert that a single paradigmatic perspective is unlikely to capture the diverse and disparate range of topics relevant to hospice palliative care and call for both greater diversity of paradigmatic perspectives and greater creativity in study design and methods (Phillips, 1992; Macdonald, 1993; Byock, 1994; van Manen, 1997; Corner, 1998; Special Committee on Social Affairs, Science and Technology, 2000). Moreover, they emphasize a need for research designs that elucidate greater understanding about existential and spiritual concerns of persons at the end of life

Corresponding author: Deanna Hutchings, 1449 Clifford Street, Victoria, BC, V8S 1M1, Canada. E-mail: dmhutchi@uvic.ca

and methods that are congruent with the basic tenets of hospice palliative care (Macdonald, 1993; Wilkes, 1998). As Mount (2003, p. 42) states, we stand on “the brink of the third epoch of healthcare, the epoch of Whole Person Medicine,” wherein the wholeness of persons is fully recognized and compels us to look beyond the biology of disease to the broader considerations that underlie human suffering. With its emphasis on the study of human health experience and a rich heritage of multiple paradigmatic perspectives, nursing, as a discipline, can make a valuable contribution to such knowledge development to guide and inform professionals in practice with persons at the end of life.

The purpose of this research article is to report the findings of a nursing inquiry designed within a human science paradigm perspective that responds to Corner’s call for an alternate perspective on human experience for persons at the end of life. Although there are differing interpretations of the meaning of the term *human sciences* found within research literature, for the purposes of this article, *human science research* is understood to be the study of the unitary human being’s participative experience with the world (Parse, 1992; Newman, 1996). The term *unitary human being* refers to an understanding of persons as unitary entities who are indivisible in nature and cannot be reduced to particulate components to be measured or judged against a set of normative values. I suggest that a unitary view of human beings is both consistent and consonant with the articulated values of hospice palliative practice (Hutchings, 2002) and its emphasis on Whole Person care (Mount, 2003).

A human science perspective stands in contrast to the traditional natural science or positivistic perspective that is concerned with issues of measurement, categorization, prediction, regulation, and control in order to predict and control phenomena. Although research drawn from the natural science paradigm has contributed significantly to advances in pain control, palliation of symptoms related to advanced disease, and prognostication and delivery of palliative services, some researchers assert that the natural science paradigm is limited in its capacity to shed light on the broader landscape of human health experiences (Stanworth, 2004). The purpose of this study was to explore the meaning of the experience of struggling in change for persons at the end of life. Struggling in change is a phenomenon described in nursing literature (Smith, 1990; Cody, 1991; Kelley, 1991) as “living the tension of pushing–resisting in the fluctuating rhythms of change” (Smith, 1990, p. 23). A review of health-related literature reveals that the phenomenon has not been studied with persons at the end of life.

This inquiry sought to answer the question: *What is the meaning of the experience of struggling in change for persons at the end of life?*

The theoretical framework chosen to guide this inquiry is a human science theory known as Parse’s human becoming theory. This theoretical perspective is particularly consonant and congruent with the values that shape hospice palliative care (Hutchings, 2002). Although it is beyond the scope of this article to explicate the theory of human becoming, the essence of the theory is concerned with themes of meaning, rhythmicity, and transcendence. These themes will be further discussed and integrated into the discussion of findings.

RESEARCH METHOD

The method used for this study was a descriptive exploratory inquiry, a qualitative method originating in the social sciences and considered congruent with and suitable for human science inquiry (Parse et al., 1985). This method offers an opportunity to discover common health patterns and rhythms of dying persons who live the experience of struggling in change.

Methodological rigor and standards of scientific merit were established by adhering rigorously to processes of the descriptive exploratory method set forth by Parse et al. (1985) and Parse (2001) by designing the study from conceptualization through to completion according to their criteria specified for the appraisal of qualitative inquiry. Although issues of validity and generalizability are fundamental to natural science inquiry methods predicated on a foundational belief in an objective reality, such issues are not congruent with assumptions that underpin human science inquiry with its foundational belief in multiple realities.

Participant Selection

The population chosen for this study consists of persons approaching the end of life. Although the questions involving “Who is at the end of life?” or “Who is dying?” frequently evoke variable and controversial responses, the definition of this study population arises from two sources: (1) the Canadian Hospice Palliative Care Association (CHPCA) definition of palliative care for persons “living with or dying from advanced illness” (CHPCA, 2002), and (2) the growing number of palliative care practitioners and gerontologists who assert that older adults with and without defined terminal illness are at the end of life, and accordingly, require competent, compassionate end-of-life care (Ross, 1998; Fisher et al., 2000). Therefore, for the purpose of

this study, eligible persons were defined as (1) over 19 years of age, (2) able to speak English, (3) living with or dying from advanced illness, and (4) an older adult approaching the end of life. There is no set number of participants required for this qualitative method (Parse, 2001).

Ethical Considerations

The study was approved by three ethical review panels representing an academic institution, the local health region, and the hospice agency involved to ensure protection for participants related to issues of anonymity, confidentiality, privacy, and the storage, transmission, and dissemination of data. All participants signed a consent form, were informed they had the right to withdraw at any time without penalty, and were instructed that a decision to participate or not participate did not influence the services they received or would receive. All participant names are fictitious.

Researchers and scholars set forth disparate views related to conducting research with persons at the end of life on the basis that dying persons constitute a vulnerable population. For example, de Raeve (1994) suggests that research with dying persons is an affront to the dignity of persons who are terminally ill and demonstrates a disregard for the emotional and physical state of such persons (Benoliel, 1980). However, Benoliel asserts that dying persons have as much right to participate in research as any other individual, as long as it occurs within the context of informed consent (de Raeve, 1994). I approached the inquiry with an underlying belief arising from decades of clinical experience that persons living with dying often long to speak of their experiences, a belief that echoes in Mair's (1989, p. 285) assertion that "we know more than we can say—and sometimes our unspoken selves long to say what we do not know." Study participants were drawn from a population of approximately 300,000 persons in a large health region comprised of rural and urban settings on Vancouver Island and the adjacent Gulf Islands along the southwest coast of Canada. Study participants were 19 years of age or older, diagnosed and/or self-identified as being in a terminal phase of a chronic or acute illness, able to speak English, and willing to participate in an audio-taped interview about their experience of struggling in change. Potential research participants were invited by means of a brochure designed by the researcher and distributed by health professionals providing palliative services in the region. Specifically, physicians, hospice nurses, and community nurses delivering pal-

liative services informed their clients of the study and distributed the invitational brochures to those who agreed to consider participation.

Data Collection

Data were drawn from face-to-face audiotaped interviews with the four men and four women who responded to the invitation to participate. Participants ranged from 48 to 97 years of age. Six participants were living with a diagnosis of cancer; two were living with advanced cardiac failure. Participants' life expectancies ranged from days to months. Some required periods of rest during the interview due to weakness; others spoke with ease. To protect their limited reserves of energy, participants were encouraged to select an interview time compatible with their greatest levels of energy. Audiotaped interviews ranged from 35 to 90 min. Audiotapes were coded by number and transcribed by the transcriptionist who signed an agreement of participant confidentiality protection.

Open-ended questions were used to initiate discussions with participants. The questions asked were: "What is the experience of struggling in change for you? How would you describe it? Can you describe particular situations that reflect your experience? How has the experience of struggling in change influenced the way you are with family and friends? What are your concerns about struggling in change? What are your wishes or hopes?"

Consistent with the method, I sought clarity and detail through being open and sensitive to the flow of the conversation guided by the descriptions given by the participants who were asked to expand and elaborate their responses through use of phrases such as "Can you expand on that? How was that for you?" Each participant received a single rose and a card of appreciation at the close of the interview.

Just as practitioners bear witness to powerful and intimate moments with dying persons, so, too, researchers bears witness to the sadness, fear, and joy of dying persons. In recognizing the potency of such shared times I spent time alone in contemplation and reflection before and after each interview in order to reflect on and honor the sacredness of the intimate sharing of each participant's experience.

Data Analysis

Data analysis was conducted using the processes outlined for the descriptive exploratory method by Parse (2001). First, I read the transcribed text of the interviews while simultaneously listening to the audiotaped interview. Next, I identified major

ideas or descriptions contained in the data about the experience of struggling in change. Major ideas that were common to all participants were identified and separated. These steps were repeated several times. The major ideas about struggling in change common to all participants were then synthesized into themes, using the language of the participants. Finally through contemplating the themes constructed in the language of the participants, I then synthesized the themes further and reinterpreted them to construct a descriptive statement in the language of the researcher. Finally, the answer to the research question “What is the meaning of the experience of struggling in change for persons at end of life?” was interpreted in light of the human becoming theoretical perspective.

FINDINGS OF THE STUDY

Findings of the study were reflective of the ways participants described their experiences of struggling in change. These major ideas were analyzed and synthesized to form three themes. The themes arising from the data, written in the language of the participants and the language of the researcher, comprise the findings for the inquiry and answer the research question. The three themes written in the participants’ and researcher’s language appear in Table 1.

DISCUSSION OF FINDINGS

Each of the three themes will be discussed in relationship to related extant literature.

Theme One

The first theme, “Beholding oneself anew surfaces sorrow and gratitude intermingled with diminishing abilities,” emerged from the data through participant descriptions of moments of sadness and

thankfulness as they viewed themselves in new ways amid their fading strengths and capacities. Their descriptions possessed a new wholeness of who they were. Far from becoming less in any way, notions of waning strengths and abilities were seen as adding to their self-perceptions. They described themselves in their own words as capable and incapable, able and unable, beautiful and decrepit, funny and feeble. As Sheila stated: “I was quite a beauty at one time . . . I’m still the same person, maybe a little decrepit, but I still want to be heard.”

This theme links to the notion of meaning, which, from a human becoming perspective, involves persons creating their own meaning in situations through choosing options explicitly and tacitly and bearing responsibility for their choices. Meaning is continuously changing as persons grow in diversity and generate new meaning moments in the process of becoming (Parse, 1992).

These findings support research and theoretical literature that portray dying persons’ perceptions of themselves as growing in complexity and diversity (Byock, 1994; Kearney, 2000; Kuhl, 2002). For example, Kuhl’s (2002) phenomenological study portrayed dying persons’ perceptions of themselves becoming more of whom they are simultaneously as their physical bodies weakened. One of Kuhl’s coresearchers explained it thus: “My cup of joy is filled to overflowing and that which overflows is also full, as that which is physical in me gets ever weaker, that which is spiritual gets ever stronger” (Kuhl, 2002, p. 260). Similarly, writing from decades of palliative practice, Kearney describes his belief that his dying patients were becoming more of whom they were, or “more human” and alive, as their bodies wasted (Kearney, 2000). Echoing a similar perspective from extensive practice in palliative medicine, Byock (1994) articulates a belief that human growth extends to the end of life and expounds a view of persons’ becoming more of the persons they are, as they live with dying. Byock

Table 1. *Study themes in the language of the participants and the researcher*

Themes in the language of participants	Themes in the language of the researcher
Looking at oneself in a new light brings sadness and thankfulness as strengths and capacities fade.	Beholding oneself anew surfaces sorrow and gratitude intermingled with diminishing abilities.
Thoughts of leaving loved ones mingle with focused planning surfacing the pain and pleasure of living day by day with questions and insights related to the unknown.	Treasured and loving moments surface amid the anguish of forsaking and sheltering cherished others while dispelling—embracing mystery.
Persevering in spite of hardships stirs the search for comforting life affirmations.	Persisting resolve amid exigent constraints kindles the unfolding of uplifting possibles.

purports the person remains integrated while becoming progressively less dense or corporeal, and progressively more light or ethereal as death approaches. Findings from this study gather support from recent research and theoretical writings (Byock, 1994; Kearney, 2000; Kuhl, 2002) but stand in contrast to traditional models of dying trajectories and predictable paths of dying processes that involve perceptions of “fading away” (Davies et al., 1990), emotional disorganization and disintegration (Potter, 2001), and psychological withdrawal (Pattison, 1977).

Moments of gratitude and sorrow surfaced for participants as they described people, projects, and activities that were important in their lives. The notion of being thankful surfaced in every interview in statements such as: “Life is inherently good and I have a great deal to be thankful for” or “I’ve come to the realization that I’ve had a good life.” Similarly, Roy (1999, p. 3) asserts that acts of thinking and thanking are of vital importance to persons nearing the end of life and purports that giving thanks is an act of existential importance for dying persons because “in the act of thanksgiving we recognize and we honour the presence of others as having been, and as being still, constitutive of our own existence.”

Although descriptions of gratitude arise in the literature, the notion of the coexistence of sorrow and gratitude is infrequently discussed in the research literature. Nonetheless, two nursing studies examine the copresence of sorrow and gratitude within human experience. Parse’s (1997) phenomenological study on the paradoxical rhythm of joy–sorrow revealed that remembrances of disappointments, hurt feelings, and sadness coexisted with memories of delight and satisfaction whereas Pilkington’s (1993) inquiry on grieving the loss of an important other with mothers who lost their babies at birth demonstrated that as the mothers reviewed their devastating losses, they also acknowledged the blessings they had in life. Both Parse’s and Pilkington’s studies illustrate the paradoxical aspect of human experience lived all at once and are consistent with the findings of the study reported here.

Theme Two

The second theme of the findings, “Treasured and loving moments surface amid the anguish of forsaking and sheltering cherished others while dispelling–embracing mystery,” was supported in the data as participants described moments of pain and pleasure intermingled in the flux of day-to-day living as death nears.

The pleasure of treasured moments in day-to-day living during times of sorrow finds resonance within a small representation of theological and nursing literature (Santmire, 1983; Epperly, 1985; Parse, 1997). Findings from Parse’s (1997) study of joy–sorrow revealed a core concept of *pleasure amid adversity* whereas Epperly (1985, p. 315) asserts that “the encounter with death can heighten and give vividness to life as it gives an immediacy to the possibilities that are still available to one.”

The knowledge that the participants’ cherished others needed love, assistance, support, and nurture generated anguish for the participants as they thought about leaving them. Their anguish was particularly acute if their adult children challenged a dying parent’s wish to surrender to their dying, in the form of statements like “You’re giving up.” or “Don’t give up, try harder.” The anguish with leaving-taking is poignantly present in Joan’s words:

Last night my son was saying, “You can’t give up, you can’t give up.” It’s awful, because he doesn’t understand and there’s no way to make him understand. It’s not that I don’t want to, it’s that I can’t do it. Everyday, all day long, I think about that. I do.

While participants’ descriptions revealed anguish at the prospect of leaving loved ones, they also described numerous efforts to shield and shelter loved ones from undue hardship, worry, and distress through chosen preparations and loving remembrances. Findings from this study, like those of Davies et al. (1990) suggest that persons drawing closer to death are likely to prepare for their death and time after death in a concerted attempt to protect family and loved ones from future worry. Preparations such as knitting afghans, buying a dress for one’s own funeral, and creating photo albums often occur.

The second theme of the study findings identifies a rhythmical pattern of dispelling and embracing mystery. The progression of a terminal illness is frequently peppered with unpredictable, reversible, and irreversible events that result in periods of declining health interwoven with periods of relative stability (Latimer, 1998; Ross, 1998) and contribute substantially to mystery and uncertainty as persons struggle in change. For the study participants, moments of mystery ebbed and flowed in cadence with moments of dispelling mystery, as they lived with knowing that death would come but not knowing when, how, or where.

The study findings of theme two link with the second theme of human becoming, rhythmicity,

wherein human beings are understood to live paradoxical rhythmical patterns of relating with the universe. The study findings identify a rhythmical pattern of dispelling and embracing mystery. Dispellling and embracing mystery in the living–dying process illustrates a rhythmical pattern of relating inherent in facing death. With each new loss, symptom, or development, new questions and uncertainties unfold. Illustrations of living with mystery are seen in Trevor’s statements:

The funny thing is that you don’t know when it’s going to be. If you knew, say plus or minus a month or something, maybe that would be good, maybe it wouldn’t. It’s probably better to not know.

In an attempt to reduce the discomfort that accompanies uncertainty and dispel the mystery, participants embarked on quests for answers to questions such as: “What can I expect?” “What will it be like?” “How long will I likely have to live?” and “What will happen to me?” Searches for certitude compelled participants to seek further medical consultations, conduct Internet searches for information, join support groups, and read extensively to know more about their illnesses.

The other side of this rhythmical pattern involves embracing mystery, which involves a form of yielding or surrendering in trust to uncertainty. As participants embraced mystery, they expressed a trust in the unknown future as seen in statements such as “I don’t know what it will be like, but I’m not worried.” and “I’ll just leave it in God’s hands.” Thus, the shifting rhythm of living with mystery was revealed as participants embraced and dispelled the mystery of what is and will be, all at once.

Participant descriptions describing the mysteries of living with dying reveal a pattern of acknowledging–not acknowledging that one is dying. In the human becoming tradition (Parse, 1992) acknowledging–not acknowledging the imminence of death is understood as a rhythmical cadence of ebb and flow. While struggling in change, participants moved toward and away from their sense of death’s imminence. For example, Brenda prepared for her death in packing her china for her grandsons and instructing her husband to prepay her funeral expenses. She stated, “I don’t want to leave things to the last minute because you don’t know.” Yet Brenda also said she did not think she was dying. Through her choice of chemotherapy treatments she continued to “fight” the progression of her cancer while stating, “I’m not going to fight if I’m dying.” Thus, Brenda acknowledged and did not acknowledge the closeness of her death.

Traditionally, dying persons’ patterns of acknowledging–not acknowledging death are linked to a diversity of perspectives and are identified in different disciplines with various labels and descriptions such as death awareness (Hinton, 1999), death acceptance (Doka, 1993; Hinton, 1999), full open awareness (Seale et al., 1997), middle knowledge (Weisman, 1972), and denial (Kubler-Ross, 1969; Doka, 1993). Within traditional views, death acceptance is perceived to mean resigning oneself and acquiescing to the nearness of death (Kubler-Ross, 1969; Doka, 1993; Victoria Hospice Society, 1998). Death acceptance has been conceptualized as residing on a spectrum of acceptance from “distress to insightful equanimity” (Hinton, 1999). Acceptance is often portrayed as ceasing to fight and yielding to the disease.

The themes arising from the participants’ descriptions suggest that perhaps acceptance is more complex than traditionally formulated. The findings indicate that acknowledging that death is near is not necessarily the same as ceasing to fight death. This distinction is apparent in Roger’s statement, “Within the limits that they’d given me, I proceeded on. I decided I will push this thing right to the outer limits.” and Lynn’s statement, “There is a change from accepting death and being willing to die, even though I don’t really want to die.” These two statements demonstrate Roger’s and Lynn’s recognition of the very real possibility of impending death while still struggling for life. Acknowledging–not acknowledging the inevitability of death for these study participants involves a rhythm of struggling in change.

Findings from this study are in contrast to linear, sequential, progressive, or fluctuating models of death denial, death awareness, and death acceptance but consonant and congruent with the fluid and dynamic understanding of knowing yet not knowing that death is near. Such models have been articulated by theologians Retsinas (1988), Epperly (1985), and Santmire (1983), and experienced palliative practitioners and scholars (Barnard et al., 2000). Recent qualitative studies on the experience of dying persons emerge from medicine, anthropology, thanatology, and theology. For example, Barnard et al. (2000, p. 10) conclude:

[T]he norm [of death awareness] is a frequent oscillation between hope for cure and acceptance of decline and death. A transition from active treatment to palliative treatment may happen smoothly and unidirectionally, but more often is a gradual, confusing, ambivalent process for all concerned.

Further, drawing from her qualitative study in the United Kingdom with dying persons in a hospice, Stanworth (2004) observes that dying persons might typically arrange for cremation after death while simultaneously planning a safari vacation to Africa. She concludes that where painful topics are concerned, complex paradoxes and tensions are often played out in a mental and emotional choreography of approach and avoidance (Stanworth, 2004). Similarly, Wright and Flemons (2002) were intrigued to discover “the doubleness of dying” as dying persons and their families found themselves simultaneously hanging on to life and reaching out to death in a recent U.S. study.

Theme Three

The third theme drawn from descriptions of the participants, “Persisting resolve amid exigent constraints kindles the unfolding of uplifting possibilities,” was supported in the data as participants imagined unique, creative, and uplifting ways in which to live. Participants’ descriptions revealed their stalwart perseverance throughout hardships imposed by their illnesses: treatment regimens, reduced energies, and the anguish of leaving loved ones. Still, they displayed resolute persistence in creating and imagining novel and unique ways to be all that they could be, incarnating their chosen hopes and dreams: to die at home, to maintain independence, and to be remembered. For example, Joan sensed she would die soon after her interview and knew she would not live to see grandchildren. With the assistance of her hospice team members, she created a videotape to address and bless her unborn grandchildren. This chosen, deliberate activity represented her unique expression for new possibilities of love to her family.

The third theme is linked to the theme of transcendence, which, from a human becoming perspective, is understood to involve moving beyond the now moment to what is not yet (Parse, 1992). Study participants propelled themselves beyond moments of anguish through envisioning and creating comforting life affirmations located in poetry, attempting to keep happy, hoping that one’s memory will love on, and having faith in one’s deity.

The findings of theme three stand in contrast with traditional perspectives in health-related literature that hold that persons living with dying face decreasing possibilities exclusively. Whereas the traditional views housed in stage and phase theories (Kubler-Ross, 1969; Doka, 1993) portray dying persons as fading away (Davies et al., 1990), detaching (Pattison, 1977), or disintegrating (Potter, 2001), the synthesized findings of this study

reveal a persistent kindling of hopes and ideas. Through their descriptions, participants revealed the uplifting possibilities they envisioned: seeing one’s child tomorrow, making amends for torn relationships, living on in the memory of loved ones, “haunting” a loved one with a caring presence (to use Joan’s words), being reunited with deceased loved ones, and resting securely in the presence of one’s deity.

However, the study findings hold congruence with the writings of experienced practitioners and scholars who assert that human growth extends to the end of life (Byock, 1994; Kearney, 2000; Stanworth, 2004) and are consistent with findings of qualitative studies by Dobratz (2002) and Reed (1991) that reveal that dying persons experience transcendence as they enact their concern for the present and future welfare of loved ones by integrating perceptions of one’s past and future to enhance the present.

IMPLICATIONS FOR PRACTICE, RESEARCH, AND EDUCATION

The findings from this study have implications for hospice palliative practice by providing health professionals with an understanding of the meaning of struggling in change for persons at the end of life from a human science perspective. The descriptions of the participants indicate that, although they were dying, they saw themselves anew while sorrow and gratitude surfaced amid their diminishing functional abilities. Health professionals are challenged to see dying persons unfolding in diverse and complex ways, during the course of cachexia, anorexia, wasted muscles, and ebbing strength. Thus, findings of this study reinforce the words of dying persons who often tell their care providers, “I am not what you see.” Furthermore, findings of this inquiry illustrate that persons at the end of life still envision new hopes and kindle a sense of possibilities despite exigent constraints of decreased energy and dwindling days. Their sense of possibilities persists. This new knowledge might help health professionals better understand the fluctuating kaleidoscope of hopes and dreams described when dying persons plan many months away for vacations that may not occur, a last fishing trip, or one more Christmas.

An alternate view of persons as unitary entities does not change the biomedical and pharmaceutical skills health professionals employ to arrest disease processes, mitigate distressing symptoms, or implement comfort measures for dying persons but will change how health professionals think about dying persons and their unique ways of co-creating meaning day by day. Practice methods may shift from an

emphasis on measurement, assessment, and interventions to bearing witness to the unfolding struggles and joys, hopes, and sorrows of dying persons. For example, guided by a traditional Kubler–Rossian notion of five stages of dying, a health care provider might believe his/her patient had regressed if an earlier response of death acceptance reverted to disbelief. However, guided by findings of this research based on the human becoming theory, the health care provider might explore the question, “What is it like for you now to live with uncertainty surrounding your illness?”

Two prominent health care leaders articulate notions of practice that are consistent and consonant with a view of persons as unitary beings: Dr. Michael Kearney from the discipline of medicine and Dr. Rosemarie Rizzo Parse in the discipline of nursing. Kearney articulates a vision of whole persons using arts involved in both *Hippocratic* and *Asklepian* medicine (Kearney, 2000). In a similar yet different manner, Parse sets forth a nursing theory and practice method predicated on a belief in unitary persons knowing “the way” somewhere within self (Parse, 1992). Both Kearney and Parse’s practice methods elucidate a respectful presence that honors the wholeness of persons and creates a healing space for the suffering person to move beyond the now moment to what will be. Findings from this research are congruent and consonant with a view of whole person practice with persons at the end of life, be that Asklepian (Kearney, 2000) medicine or nursing practice from a human becoming tradition (Parse, 1992).

Findings from this study have implications for education in all health disciplines where end-of-life care is traditionally located, but particularly in the fields of hospice palliative care, geriatrics, and gerontology. The study findings expand understanding of the meaning of struggling in change and shed further light on what is traditionally categorized as the spiritual and existential experiences of persons at the end of life. Findings reported here can add to the extant knowledge base that currently informs nursing and medical curricula in Canada, the United States, and the United Kingdom, as the findings expand traditional notions of the experiences of dying persons that are rooted in natural science perspectives. The study findings are both congruent and consonant with the foundational belief of whole person care that Mount (1993) and Macdonald (1993) describe as essential components of palliative care knowledge required for medical school curricula in Canada and the United States. Further, findings from this inquiry can contribute to the growing body of scientific knowledge required to meet the demands for increased education and

training for professionals preparing for, or in practice with, persons at the end of life.

Several recommendations for further research can be drawn from this study. Concepts emerging from the study findings such as the rhythmical pattern of dispelling–embracing mystery, the phenomena of saying goodbye to a loved one, or sheltering cherished others might further expand our understanding about living with dying. Two participants in the study described their sense of perplexity and mystery about the nature of time passing. Although research on this intriguing phenomenon has begun (Northrup, 2002) with persons living with HIV, more investigation on the phenomenon of time passing for persons at the end of life and other populations would shed further light on this human health experience. Whereas this study sheds light on the experiences of persons at the end of life who are struggling in change, further research on related rhythmical patterns such as communion/aloneness or confronting mortality would expand our understanding of the paradoxes and complexities inherent in the living–dying process. Human science studies already conducted on related concepts such as joy–sorrow, considering tomorrow, hope, suffering, serenity, time passing, and grieving a personal loss have been conducted with other populations, but would contribute much needed understanding about the living–dying process when conducted with persons at the end of life.

REFLECTIONS AND CONCLUSIONS

Findings from this study can provide new understanding to guide and inform health professionals in practice with persons at the end of life in all settings where persons live their final days: acute care hospitals, residential care facilities, hospices, palliative care units, and the community. New knowledge generated from this human science inquiry sheds light on the broader palette of human health experience and guides health professionals who bear witness to the richness of human experience unfolding for persons at the end of life.

REFERENCES

- Barnard, D., Towers, A., Boston, P., et al. (2000). *Crossing Over: Narratives of Palliative Care*. New York: Oxford University Press.
- Benoliel, J.Q. (1980). Research with dying patients. In *Patient, Nurses, Ethics*, Davis, A.J. & Krueger, J.C. (eds.). New York: American Journal of Nursing Company. Educational Services Division.
- Byock, I. (1994). When suffering persists. . . *Journal of Palliative Care*, 10, 8–13.
- Canadian Hospice Palliative Care Association Nursing Standards Committee. (2002). *Hospice palliative care*

- nursing standards of practice. http://www.chpca.net/marketplace/nursing_norms/Hospice_Palliative_Care_Nursing_Standards_of_Practice.pdf
- Cody, W. (1991). Grieving a personal loss. *Nursing Science Quarterly*, 4, 61–68.
- Corner, J. (1998). Is there a research paradigm for palliative care? *Palliative Medicine*, 10, 201–208.
- Davies, B., Reimer, J., & Martens, N. (1990). Families in supportive care: Part 1: The transition of fading away: The nature of the transition. *Journal of Palliative Care*, 6, 12–20.
- de Raeve, L. (1994). Ethical issues in palliative care research. *Palliative Medicine*, 8, 298–305.
- Dobratz, M. (2002). The pattern of the becoming-self in death and dying. *Nursing Science Quarterly*, 15, 137–142.
- Doka, K. (1993). *Living with Life-Threatening Illness: A Guide for Patients, Their Families, and Caregivers*. New York: Lexington Books.
- Epperly, B. (1985). Death and the human adventure: Process theology and human mortality. *Encounter*, 46, 315.
- Fisher, R., Ross, M., & MacLean, M. (2000). *A Guide to End-of-Life Care for Seniors*. Ottawa: University of Ottawa.
- Hinton, J. (1999). The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives. *Palliative Medicine*, 13, 19–35.
- Hutchings, D. (2002). Parallels in practice: Palliative nursing practice and Parse's theory of human becoming. *American Journal of Hospice and Palliative Care*, 19, 408–414.
- Kearney, M. (2000). *A Place of Healing: Working with Suffering in Living and Dying*. Oxford: Oxford University Press.
- Kelley, L. (1991). Struggling with going along when you do not believe. *Nursing Science Quarterly*, 4, 123–129.
- Kubler-Ross, E. (1969). *On Death and Dying*. New York: Macmillan.
- Kuhl, D. (2002). *What Dying People Want: Practical Wisdom for the End of Life*. Toronto: Doubleday.
- Latimer, E. (1998). Ethical care at the end of life. *Canadian Medical Association Journal*, 158, 1741–1747.
- Macdonald, N. (1993). Priorities in education & research in palliative care. *Palliative Medicine*, 7(Suppl. 1), 65–76.
- Mair, M. (1989). *Between Psychology and Psychotherapy: A Poetics of Experience*. London: Routledge.
- Mount, B. (1993). Whole person care: Beyond psychosocial and physical needs. *American Journal of Hospice and Palliative Care*, 10, 28–37.
- Mount, B. (2003). Existential suffering and the determinants of healing. *European Journal of Palliative Care*, 10(Suppl.) 40–42.
- Newman, M. (1996). Prevailing paradigms in nursing. In *Philosophical and Theoretical Perspectives for Advanced Nursing Practice*, Kenney, J. (ed.). pp. 302–307. Boston: Jones & Bartlett.
- Northrup, D.T. (2002). Time passing: A Parse research method study. *Nursing Science Quarterly*, 15, 318–326.
- Parse, R.R. (1992). Human becoming: Parse's theory of nursing. *Nursing Science Quarterly*, 5, 35–42.
- Parse, R.R. (1997). Joy-sorrow: A study using the Parse research method. *Nursing Science Quarterly*, 10, 80–87.
- Parse, R.R. (2001). *Qualitative Inquiry: The Path of Science*. Sudbury, MA: Jones & Bartlett.
- Parse, R.R., Coyne, A.B., & Smith, J.J. (1985). *Nursing Research: Qualitative Methods*. Bowie, MD: Brady.
- Pattison, E.M. (1977). *The Experience of Dying*. Englewood Cliffs, NJ: Prentice-Hall.
- Phillips, J.R. (1992). Choosing and participating in the living-dying process: A research emergent. *Nursing Science Quarterly*, 5, 4–5.
- Pilkington, F.B. (1993). The lived experience of grieving the loss of an important other. *Nursing Science Quarterly*, 6, 130–139.
- Potter, M. (2001). Loss, suffering, bereavement, and grief. In *Palliative Care Nursing: Quality Care to the End of Life*, Matzo, M. & Sherman, D. (eds.). pp. 275–32. New York: Springer.
- Reed, P.G. (1991). Self-transcendence and mental health in oldest-old adults. *Nursing Research*, 40, 7–11.
- Retsinas, J. (1988). A theoretical reassessment of the applicability of Kubler-Ross's stages of dying. *Death Studies*, 12, 207–216.
- Ross, M.M. (1998). Palliative care: An integral part of life's end. *Canadian Nurse*, 94, 28–31.
- Roy, D. (1999). At the end of life: Giving thanks and forgiving. *Journal of Palliative Care*, 15, 3.
- Santmire, P. (1983). Nothing more beautiful than death. *Christian Century*, 100, 1154–1158.
- Seale, C., Addington-Hall, J., & McCarthy, M. (1997). Awareness of dying: Prevalence, causes and consequences. *Social Science & Medicine*, 45, 477–484.
- Smith, M.C. (1990). Struggling through a difficult time for unemployed persons. *Nursing Science Quarterly*, 3, 18–28.
- Special Committee on Social Affairs, Science and Technology. (2000). *Quality End-of-Life Care: The Right of Every Canadian*. Final Report. Ottawa: Senate of Canada.
- Stanworth, R. (2004). *Recognizing Spiritual Needs in People Who Are Dying*. Oxford: Oxford University Press.
- van Manen, M. (1997). *Researching Lived Experience*. London, ON: Althouse Press.
- Victoria Hospice Society. (1998). *Medical Care of the Dying* (3rd ed). Victoria, BC: Author.
- Weisman, A. (1972). *On Dying and Denying*. New York: Behavioral Publications.
- Wilkes, L. (1998). Palliative care nursing research: Trends from 1987 to 1996. *International Journal of Palliative Nursing*, 4, 128–134.
- Wright, K. & Flemons, D. (2002). Dying to know: Qualitative research with terminally ill persons and their families. *Death Studies*, 26, 255–271.