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REVIEW ARTICLES

Human relationship: The forgotten dynamic in palliative care

DENISE L. HAWTHORNE, R.N., M.A.[1] and NANCY J. YURKOVICH, B.S.N.[2]
[1]Douglas College, New Westminster, British Columbia, Canada
[2]Community Advisory Council, Rotary Hospice House, Richmond, British Columbia, Canada

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ABSTRACT

Objective: Palliative care is a philosophy of care for individuals experiencing progressive, incurable disease. It encompasses two dynamics, science-based practice and relationship between patient, family, and health professional. Each dynamic is essential for quality palliative care, yet the requisites for each are different.

Methods: The scientific process of observation and measurement requires differentiation, distance, and detachment to fulfill its demands for objectivity, whereas relationship, unobservable and immeasurable, requires sameness, closeness, and connection of a shared humanity. It is science, however, the prevailing world-view, that shapes our thinking and consequently, influences the education and practice of health professionals.

Results: We explore the dynamics of science and relationship and the incongruities between them. We examine the prominence of science in palliative care and its impact on relationship.

Significance of results: We contend that questioning the current emphasis of science in palliative care and discovering the joy and rewards of shared human experience will enrich the quality of life for patients, families, and health professionals.

KEYWORDS: Palliative care, Human relationship, Science, Patient, Health professional

> *Death is not the ultimate tragedy of life. The ultimate tragedy is depersonalisation, dying . . . separated from the spiritual nourishment that comes from being able to reach out to a loving hand, separated from a desire to experience the things that make life worth living, separated from hope.*
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> N. Cousins, 1981, p. 133

INTRODUCTION

Palliative care is a philosophy of care that "seeks to prevent, relieve, reduce or soothe the symptoms of disease without effecting a cure" (Field & Cassel, 1997, p. 31). At the center of palliative care is concern for quality of life for patients; helping them to "face the end of life with comfort ensured, values and decisions respected, and their family supported" (Portenoy, 1998, p. 1). Science provides a framework to assist with the challenge this brings. Palliative care is also a profound human experience, where life-threatening illness brings patient and health professional together in human relationship that unfolds in unique and mysterious ways. In palliative care, both science and relationship are paramount; however, the focus of each is different and the requisites incongruous. The sci-

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Corresponding author: Denise L. Hawthorne, Douglas College, P.O. Box 2503, New Westminster, BC V3L 5B2, Canada. E-mail: hawthorne@telus.net.

entific method of observation and measurement requires differentiation, distance, and detachment between scientist and object of study, whereas relationship, unobservable and immeasurable, requires sameness, closeness, and connection between two human beings. In the present worldview, science dominates and is reflected in the thinking of those in health care and palliative care. Although science advances knowledge and skill, improving the diagnosis and treatment of disease, it cannot extend to human relationship. In fact, the current emphasis on science impacts the relationship between patient and health professional in a negative way (Hawthorne & Yurkovich, 2002). The authors contend that with the prominence of science, human relationship is often overlooked and may even be forgotten. The purpose of this article is to raise awareness of the incongruities between science and human relationship, to address the impact an emphasis of science has on relationship in palliative care, and to encourage health professionals to discover the joy and rewards that await in each shared human experience with patients.

Palliative Care

The philosophy of palliative care forms the foundation of care for individuals with terminal illness. It is care that "honors and protects those who are dying, and conveys by word and action that dignity resides in people" (Field & Cassel, 1997, p. 1). This fosters a value for life that transforms and enriches the experience for patient, family, and health professional. Within this philosophy, two dynamics coincide—the dynamic of science and the dynamic of relationship, both of which are inseparable and essential for quality of life. The potential for one to take precedence over the other is ever present.

The Dynamic of Science

Throughout time, humans have sought to understand the world and their place in it. Science is one of the many ways they search for truth and seek solutions to problems. Since the 17th century, it has been a dominant and enduring feature of Western thought and the authoritative explanation of phenomena. Science generates knowledge through observation and measurement, using the scientific method to reduce the world to simpler components in order to manage and control. To meet the requisites of science for objectivity, a particular relationship of differentiation, distance, and detachment is necessary in a subject–object distinction between observer and observed, and between scientist or expert and object of study (Perlman, 1995).

Contribution of Science to Palliative Care

Modern science produces knowledge that is enormous in its extent and application and powerful in its impact on society. For example, understanding and unravelling the human genetic code provides unimaginable possibilities for medical science and for humankind. New imaging and visualizing technologies and high tech medical and surgical procedures advance the diagnosis and treatment of disease and assist in the management and control of symptoms in palliative care. Powerful new drugs and delivery systems for medication aid in the attainment of comfort and peace. Through the benefits of research studies, valuable empirical data helps unravel the complexities inherent in palliative care. These and other contributions create a sense of awe in both patient and health professional. Consequently, science is embraced wholeheartedly, and often without question.

The Dynamic of Relationship

Relationship is a fundamental dimension of human experience; it confirms one's existence and is essential to life. It is the means by which humans achieve not only meaning but also purpose in life. In relationship, humans share a common bond through an experience that unfolds in unique and mysterious ways. They join together and accompany each other on the journey through life, affirming the significance and value of being fully human. Each experience reveals that one is like the other and expressions of love bring a sense of belonging and feelings of peace, joy, and fulfilment. Human relationship, described by Bolen (1996) as "a sanctuary, where it is safe to be oneself, to be unguarded . . . for grace to enter, for love to be present, or for one soul to touch another" (p. 5), is the essence of care that sustains faith and hope in the most difficult situations.

Importance of Relationship in Palliative Care

Nowhere is relationship more important than in illness, especially terminal illness. As a human experience, it overwhelms the body, mind, and spirit and defines one's existence. It distorts one's sense of self and one's connection with others (Toombs, 1995); consequently, one is less able to reach out for help. As pain diminishes the human spirit, one feels vulnerable, afraid and alone, and may suffer a crisis of faith and hope. Roy (2002) captures the profound nature of illness as a "feeling of being no longer a part of life's game or of being far out on the sidelines of it; the sense of being hollow, emptied of abilities, strengths, and the dreams these serve, all lost now and never to return; the feeling of being . . . so reduced . . . as to be no longer noticed or worthy of notice" (p. 75).

Numerous accounts from the work of Barnard et al. (2000), Davies et al. (2002), and Stanworth (2002) underline the importance of human relationship to quality of life in palliative care. It is on the journey through terminal illness that patient and professional meet and come face to face with their own mortality. Relationship in palliative care offers both patient and health professional an opportunity to reaffirm purpose in life and to be profoundly transformed. Their relationship reaffirms sameness, closeness, and connection; they relate to one another "simply and richly as a human being" (Roy, 1988, p. 36). Sharing a common humanity in life's triumphs and tragedies brings a profound sense of oneness, strength, and peace and an experience of what it means to be fully human.

Patients and health professionals describe the profound meaning of relationship in illness. For example, a patient, Mark, describes his experience in the following way:

> Mysteriously and powerfully, when I look deeply enough into you, I find me, and when you dare to hear my fear in the recess of your heart, you recognise it as your secret, which you thought no one else knew. And at that unexpected wholeness that is more than each of us, but common to all—that moment of unity—is the atom of God. (Nepo, 1997, p. 138)

Another patient, Jean, explains her experience from a different perspective.

> When a person looks at you and loves, you are no longer ugly and unclean with disease and each day seems a precious gift to be cherished and savoured to the full. (Pope, 1997, p. 34)

Nurses too, explain what it means to be fully human. One account follows:

> It was the one place I could be totally me. The place I could be as smart, as kind, as giving, and as real as I was capable of being. My patients and I had an understanding past words; we needed each other; we healed each other; and neither of us judged the other. There was no mask, no preference; we were just human beings. (Gino, 1985, p. 30)

Another nurse expresses her feelings this way:

> I learned so much from Candy about life, living and ultimately about dying. These are the gifts given to us by our patients at the end of life. (Matzo & Sherman, 2001, p. 10)

Clearly, the profound nature of human relationship in palliative care goes well beyond the limits of science. It encompasses "unique experiences of grace, of gift, of presence that can redeem tragedies of the past, fill a present threatened by absence and emptiness, and light a lamp in a future seemingly so short and dark." (Roy, 1992, p. 4)

The Impact of Science on Relationship

The dynamics of science and relationship are inseparable and essential to the quality of life in palliative care. But what happens when scientific advances astound and amaze so much that science is considered the only way to solve problems? What happens to the dynamic of relationship when science takes precedence? Is it possible that relationship is affected in a negative way? We assert that with the current emphasis of science in palliative care, human relationship between patient and health professional is diminished, overlooked, and may ultimately be forgotten.

The prominence of science in palliative care is evident in both education and practice, and the impact on relationship is clear. For example, all aspects of palliative care are reduced to procedures and techniques that can be observed and taught, ones that guarantee a measurable, predicable outcome. Backer et al. (1994) suggest that even the human experience of dying has become "less important than the technical order in which it occurs" (p. 53). When health professionals focus mainly on scientific solutions to the problems they encounter, a distinction is made between patient and health professional, a differentiation of one as the problem, and the other as the one seeking a solution. References to the patient as "the dying" or "the terminally ill" abound and the health professional as "the expert" ensures distance and detachment by "standing outside the relationship," observing and "managing the patient."

According to the literature, it seems as though the consequences of these practices go unquestioned. Authors such as Dudgeon (1992), Murphy (1997), Pellegrino and Thomasma (1997) and Hawthorne and Yurkovich (2002) raise concerns regarding the emphasis of science on human relationship.

However, little has been written regarding the impact this has on the relationship between patient and health professional and quality of life.

DISCUSSION

We contend that the current emphasis of science has serious consequences for human relationship and ultimately quality of life. This emphasis is present in both education and practice in palliative care, and the implications are serious for patient and health professional. Despite efforts to improve the quality of care and quality of life for patients and families, studies by SUPPORT (1995), Danis (1998), Sulmasy and McIlvane (2002), and others indicate that patients, families, and health professionals continue to voice discontent and dissatisfaction with their experience of palliative care. The following accounts are from patients.

> Hospitals are "healing factories." The human body is a machine that has broken down and needs to be serviced by trained health mechanics. As I sat in this line-up, I felt as though I were on an assembly line. (Pope, 1997, p. 67)

> We were reeling from the diagnosis—our whole world was turned upside down. My husband and I felt alone and afraid and we wanted the nurses to acknowledge this. Couldn't they imagine how they would feel under similar circumstances? If they could, they would support us, encourage us, give us hope—help us with this difficult part in our human journey. Instead, they came and went, attended to IVs and catheters, but didn't seem to notice we were there. (Smith, N., personal communication, 2000)

We contend that the requisites for objectivity between expert and object of study, the use of relationship as a process for problem solving, and the belief that only scientific solutions are acceptable for palliative care impact the relationship in ways that disconnect, dehumanize, and diminish patient and health professional. This devalues the profound experience of palliative care. At a time when both need sameness, closeness, and connection with one another, they are different, distanced, and detached. Unable to accompany each other on the journey through illness and dying, they miss the opportunity to become more fully human and to experience the sense of belonging, peace, joy, and fulfilment.

Recommendations for Education and Practice

It may seem that this problem in palliative care is insurmountable, yet we believe that the resolution is simple. It requires a shift from an exclusive focus on science to the recognition and acknowledgment of the profound nature of relationship between patient and health professional and its contribution to quality of life. It requires relating as human beings.

Health professionals are encouraged to reflect on the impact that science has on their shared humanity with patients, to discover what it means to be fully human and the rewards this brings, and to remember that each meeting with patients holds immeasurable promise of something greater than the moment—something that goes well beyond the boundaries of science. As reflected in the words of Davies et al. (2002) "simply connecting with another human being will take away the confusion, the suffering, and the sense of isolation and fear" (p. 64). Pellegrino and Thomasma (1997) ask health professionals to see the patient "as a fellow human being" whose experiences cannot be penetrated fully, but can be touched because of a shared humanity (p. 29). Reflecting on moments with patients, such as Roy (2000) describes as "profound and lasting meanings as though an echo of eternity reverberates . . . awakening the mind to thoughts and perhaps the heart to feelings, that one has never had before" (p. 3), brings one closer to being more fully human.

SUMMARY

In palliative care, the dynamics of science and relationship are inseparable; however, the focus of each is different and the requisites incongruous. Science continues to astound and amaze, and the belief that it provides the solution to all problems prevails. Consequently, an emphasis on science has emerged in contemporary thought. We contend that this emphasis has serious consequences for the relationship between patient and health professional and ultimately quality of life. In the profound experience of terminal illness when sameness, closeness, and connection can offer comfort, peace, and hope, science insists on differentiation, distance, and detachment. This results in diminished relationship and demoralizes both patient and health professional.

The experience of palliative care reaches far beyond the boundaries of science. We call upon health professionals to reflect on the emphasis of science in education and practice and the impact this has on their relationship with patients. We endorse the words of Murphy (1997) that science, like technology, has an important place in palliative care, but "as an invited guest rather than as overarching presence" or as "a visiting wizard rather than as all consuming incubus" (p. 143).

The end of a person's life is immensely important. It is a time for forgiveness and thanksgiving, a time for a gentle closure to life. There is room for wisdom, hope, and even the joy of final understanding. There is the possibility to experience a depth of relationship, an understanding of the human condition, the human spirit, the human journey that cannot be replicated in any other way. Health professionals "co-journey" and "witness the precious moments of life as patients and their families say their last good-bye and express eternal love" (Matzo & Sherman, 2001, p. 324). This profound experience is as Roy (1992) suggests "a first meaning of quality of life" (p. 4).

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