Academic Commentary

Palliation: A Parabolic Pathway

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Author Note

This article is a revised and updated version of an academic position paper made by the author in 2009 in his previous executive role as Ethicist to the Surgeon General of the United States Navy. The opinions reflected in this article are those of the author and do not reflect the official policy of any institutions the author has served or currently assists. The author has no conflicts of interest.

Abstract

Sickness and healing are central to the human experience. From the dawn of time, individuals and communities have struggled with the stark realities of our human finitude and how we best can cope with the same. Over the course of centuries in an unending myriad of ways from culture to culture, the human genius has developed an unending series of approaches that we have come to call "healthcare." In our modern era, social criticism has advanced concerning the inroads of the business model that seems to lead at times to the depersonalization of the healthcare experience. Critics point out that this depersonalization is inherently contradictory to the very nature of healthcare as the experience of healing that the human person needs and which is being appreciated today more and more as an ultimate right. Into this important boiling reality, there is a need for a pathway that can move the human imagination to understand, appreciate, reform, and renew systems of healthcare precisely as human care. Such a pathway, like parabolic images and stories of old, must have a deep and penetrating effect to change not just surface behaviors but also interior and subconscious beliefs, values and life stances. This article will explore palliation as that needed parabolic reality as a type of nova-paradigm. In the modality of a reflective academic commentary, the article will discuss a number of important historical background points, the fundamental foundations of healthcare as palliative, the establishment of palliation as a parabolic paradigm, and some practical pathways. The article will conclude with a series of reflective points to be considered for the future potential of this parabolic pathway for the continuing enrichment of health as a human experience, and healthcare as a human right.

Keywords: Palliative care, palliation, healthcare, systems of care, patient-centered, paradigm, medicalization, quality of life

Introduction:
Historical Reflections

The human tribe has long obliged the care of the indigent, poor, sick, and dying. Time honored codes in various and very diverse cultures give clear evidence that the care of the sick is a firm ethical obligation for preserving human dignity and personal value. This ethos is more fundamental than any agenda, civic obligation, precept, or sentiment. It arises from the essential nature and core experience of human life, human community, and good social order.

In the West at the end of the Roman Empire and the beginning of the medieval period, the care of the sick often was taken up within the charism of hospitality of monasteries and abbeys. As an extension of the monastic infirmary for sick members of the religious community, the civilian sick would be offered comfort, care and health as part of the mission of the religious body to the wider world. This mission also included welcome for the stranger and the pilgrim in an age of political fluidity and potential violence toward travelers, serfs and all those outside the ruling class, and vulnerable others. The hospitality of medieval religious houses was the context out of which the later concept of the hospital institution eventually developed.

Resulting from educational and intellectual shifts arising from scientific thought and discovery, the provision of healthcare over the centuries took on a particular identifying character that might be termed "medicalization," namely the provision of scientific cure by a licensed and certified profession with an assigned or recognized social status. With the coming of the Industrial and Nuclear Ages, the Information and Knowledge Management Explosion and skyrocketing costs, the need for efficient business modeling, and the advent of the hospital as a civic institution, the experience of healthcare has been modeled beyond medicalization even further into an organizational system of effective service delivery.

While respecting the need for increasing efficiencies and reducing unnecessary costs, industrial or business modeling has changed slowly and dramatically what might be termed the original "*fundamentum in re*" and experience of healthcare as an act of human solidarity. While understandable, this shift has also had unforeseen and undesirable consequences. In some cases, the provision of healthcare has been used for politicization. Examples of this include acts of violence against healers and healthcare professionals such as violence against Doctors Without Borders.

Complicated by discriminatory issues of class, race, gender, sexual orientation, and other forms of social injustice, community leaders in diverse cultures have, in various historical periods, reacted to such paradigm shifts or modeling changes in healthcare. In various decades, social critics and studied commentators have sought to promote a corrective re-balancing of effective institutional medical delivery with the core character of healthcare as a personalized and humanistic service. Such has been the case beginning in the 17th century in Europe to the present in the United States with the rise of new associations providing patients with the human comfort and care reminiscent of medieval hospitality toward the sick and dying.

One historical example of this was the work of Catherine Macauley, Frances Xavier Warde and company who left the traditional place of women in the home to venture into the alleys and streets of 19th century Dublin to care for cholera victims and those left to die alone and abandoned. Frances Warde brought this culturally stretching experience to the United States in a series of founding-ventures that eventually developed into what would become one of the larger hospital systems in America. The *fundamentum in re* of the Macauley/Warde system was the retrieval and re-imagining of the medieval experience of hospitality --- however no longer at society's peripheral vision but directly within the eyesight of the urban experience. This was a powerful phenomenon in a time of unbending and calcified class distinctions. The reaction against Macauley, Warde and company was strong, yet did not thwart their work.

In this same spirit, in 1967 Dame Cicely Saunders gave new expression to patient-centered healthcare at St. Christopher's Hospice in London. Notably for this discussion, this was care for the dying. There followed the founding of similar institutions in Canada and the United States. The founding of St. Christopher's is looked upon as the modern origins of palliative care, though underscoring here again that this was focused at that time as care for the dying. Under the rubric of this seminal hospice concept and in a time when living with long-term conditions was only beginning to become more widely understood, palliative care was a means of providing a holistic approach to care for the total human person in a time when death seemed near. Such care included pain management, alternative therapies, human spirituality, counseling, pastoral care etc. However, the concept of palliative care itself has been rapidly evolving over the last 50 years beyond its original singular focus upon end-of-life issues and care for those nearing death.

Palliative Care

Though the popular imagination in some corners still, whether consciously or subconsciously, relegates palliative care to hospice care for the dying, palliative care has mutated over time into a beneficial approach for patients in any long term condition of need. Under this aegis, palliative care as a concept has acquired a more universal definition that is not necessarily tied only to the care for those in proximate danger of death. Its principles of holistic and interdisciplinary/inter-service provision for the total healthcare needs of the sick quickly have come to be seen as an extraordinary benefit for those who have long-term care health requirements.

Today, palliative care includes a wide and diverse pallet of services, concepts, and perspectives: medical practice, nursing care, medical and healthcare research, pastoral care, counseling and psychological services, social welfare and advocacy, family service, healthcare mediation, law, the role of the medical arts and humanities etc. These and other related areas have become enfolded into palliative care as a result of what is a long and evolving definition that is still in process. The multidimensional expanse of palliative services in society can be observed within the WHO definition retrieved in 2009 that follows. It is to be noted, however, that the underlying approach in the text still focuses largely on end-of-life issues.

> *Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement;*

> *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

Within the United States specifically, the Third Edition of the National Consensus Project (NCP) in its *Guidelines for Quality Palliative Care* incorporates and expands many of the same aspects of the WHO definition. The document is a comprehensive discussion of the nature of palliative care, its interdisciplinary emphases, the synergistic approach that must be taken to palliative care, and the ability of the concept to be applied to a wide variety of patient conditions and circumstances. As would be expected, the document discusses palliative care and its applicability to the dying or those with life long or life threatening conditions.

However, when the document discusses palliative care as a general approach to healthcare even in the primary care setting, one can sense the beginning of an applicability of palliative care to the fundamental nature of healthcare itself. When read from a more studied and objective perspective, the eight domains of palliative care that NCP addresses may well be applied to all forms of healthcare not previously thought of as applicable under the rubric of palliative care. For the sake of completeness here, the NCP eight domains are:

- Structure and Processes
- Physical Aspects of Care
- Psychosocial and Psychiatric Aspects of Care
- Social Aspects of Care
- Spiritual, Religious and Existential Aspects of Care
- Cultural Aspects of Care
- Care of the Patient at the End of Life
- Ethical and Legal Aspects of Care

There is yet another social or cultural perspective influencing the developmental nature of palliative care today. While accepting the real benefits of efficiency models, a cultural reaction is occurring within the healthcare community across the globe. To understand this reaction, the following reflection may be helpful.

Linguistics teaches us that "language talks." In other words, the terms humans use reveal deep patterns of internal systems of valuation and meaning. This is true for individuals as it is for groups, including individual societies and cultures. Those who traditionally have been "patients" have become known in modern parlance successively as "clients, customers, consumers, and generators of metrics of productivity for electronic medical records." Though these alternative terms have their utility, there are prudent commentators who see in this system of nomenclature a progression that, unless balanced, promotes depersonalization and obscures, if not entirely contradicts, the core experience of healthcare as human care.

These contemporary and thoughtful commentators seek a qualitative balance to quantitative methods of outcome assessment and performance measurement. In addition, an increasing over-medicalization and hyper-professionalization of healthcare has, consistent with the characteristics of all institutions, inadvertently allowed the creation of silo-effects between diverse departments and services within hospitals and care centers. These silo-effects create compartmentalization and can erode the full effectiveness of even the most robust programs of existing patient-centered services such as social services, pastoral care, counseling etc. Greater impact is lost when departments are not connected and providers do not work as actual team members for holistic treatment of persons who are ill.

Against this backdrop and consistent with the overarching NCP approach above, an appreciation of palliative care as a human-centered paradigm for healthcare as a whole can be observed in the 2008 report of Wolfgang Wodard to the Parliamentary Assembly of the Council of Europe. Several passages of the opening summary follow:

> *The importance of palliative care as a comprehensive approach, with the potential to complete and improve existing care programmes, is now recognised in many of the Council of Europe' member states. Palliative care is a substantial and socially innovative addition to curative, highly scientific medicine, where subjective wellbeing of the patient comes after the goal of curing an illness and which involves therapy-related restrictions and sometimes massive side-effects. The report endeavours to highlight the central problem of the highly sophisticated and costly healthcare provided particularly in Western Europe, which, at ever shorter intervals, produces new medical techniques and medicines, raising high public expectations of curative success. At the same time, however, this type of healthcare is increasingly - and obviously - failing to meet the basic needs of people suffering from chronic or rare diseases. The rapporteur considers palliative care as a model for innovative health and social policies. Palliative care does not simply meet a cultural and humanitarian need of the most pressing kind. It also provides an innovative structure which, if intelligently developed, will not only produce sustainable change in the health sector, but may also serve as a recipe for success in other policy areas with serious, systemic and recurrent problems (eg drug prevention). The rapporteur therefore regards palliative care as an essential component of appropriate health care based on a humane concept of human dignity, autonomy, human rights, patient rights and a generally acknowledged perception of solidarity and social cohesion.*

Palliation as a Parabolic Paradigm

From all of the above, it can be posited that underneath palliative care there exists a paradigm that can be termed, “palliation.” Phenomenologically, palliation operates as the essential foundation for healthcare itself. It serves as a type of universal against which are best understood the subsets of specific clinical services. Without the universal of a paradigmatic concept such as palliation, individual clinical acts can be easily misperceived or caricatured in the contemporary mindset as assembly line activities. Palliation is a holistic and synergistic paradigm. In fact, it serves powerfully as a type of parabolic entity. Like parables and parabolas, the word and image indirectly but powerfully can lead us to understanding something that is far deeper than initially imagined. Palliation requires that the care of the sick and suffering integrate both scientific/medical cure and humane/humanistic care, medicine and human services, to create an ever-developmental, interdisciplinary, patient-centered approach to individuals, to their families, and the cultural communities in which they live.

To coin a new phrase, effective palliative healthcare is a *de novo* intentional approach to treatment team design and operations. It requires that sickness and health not be viewed as isolated phenomena in individual patients inhabiting individual beds. Palliative healthcare is a relational construct that touches the relational dimension of any sickness and disease as these are experienced within the condition of human beings who are themselves relational by nature. Academics and social scientists clearly attest that, underneath symptoms and diseases, patients suffer a more fundamental illness, namely alienation. Disease creates in patients both psychosomatic or somatic pain, as well as existential *angst*. Palliation/palliative healthcare might be the best underlying parabolic paradigm for contemporary healthcare delivery. It challenges providers and institutions to bring together and integrate medical/scientific cure and full humanistic care in the most robust fashion possible but in new and unprecedented ways.

The impact and importance of palliation is highlighted when we reflect upon the dimensions of the human experience itself. Traditionally, we are often taught that the human person is a creative combination of body, mind and spirit. While an easy vehicle for beginning to teach our young about what it means to be human, this tripartite image needs expansion and even deeper wording. This author suggests that we as human persons are constituted by matter, mind, motion and meaning. These "4Ms" lead us to understand that while we are made up of the physical and mental, we are deeply joined within ourselves and with others through those inner realities we call emotion and movement. And ultimately, our entire being is both joined together but also quantum leapt by one's moral meaning as a unique human person or as a unique human community and culture. Our experiences, including those of sickness, woundedness, and death, touch us deeply in all four substantial modes. Thus even new health and illness understandings such as "moral injury" need to be reimagined on these deeper levels as realities that can be experienced by any of us in this life. Ultimately, this 4M image or metaphor is a critically important horizon that calls us to understand the immediate need for healthcare as human care, for healthcare as palliation --- something far deeper than what modern society seems to embrace.

Of immediate historical importance is the contemporary drive in the United States to some form of nationalized healthcare such as is found in other democratic nations. Reactions to this national drive are plentiful and broadly diverse. Often, they are also divisive. One set of critiques questions whether any form of nationalized healthcare will be responsive to the total human needs of patients, their families, and communities. Models and approaches are needed to give flesh to the palliation paradigm. In this way, the existential disease of "alienation" can be met by a cure/care dynamic of "integration" bringing together in a unified way diverse services, approaches, analyses, resources, and outcomes. Such an approach will require careful delineation of new institutional doctrine as well as education/training to assist providers with new critical thinking skills and worldviews so that they might act more as healers and as team members serving the needs of patients who themselves are not isolated persons but relational beings.

Parenthetically, this author is reminded at this juncture of his experience as a hospital chaplain in the early 1980's assisting patients in a burn unit. There was no touch, no ability to express care through simple human contact. A plastic sheet separated the patient so there could be no contamination. There also was no means of conveying the simplest form of human communion via touch. While the medical need was clear that physical separation was needed, the existential disconnection was powerful and endures to this day as a profound memory of stinging wonderment.

In current discussions regarding potential national programs of healthcare, the Military Health System and Veterans Administration System (MHS-VA) is critically central. MHS-VA are themselves the original "socialized medicine" in the American experience. Despite surges and gaps over time, they remain as a context in which key elements of palliation/palliative healthcare are experienced and emergent. It is in the MHS-VA context that palliative healthcare can lead the nation's progress.

Potential Practical Pathways

- Based upon the previous reflections, it would be strongly recommended that executive healthcare leaders establish in their institutions Executive Task Forces (ETF) on Palliation and Palliative Healthcare Initiatives.

- These ETFs should explore the full nature of palliation as a cultural-metaphor, and palliative healthcare as the basic strategic doctrine for all healthcare delivery within the system and institution. ETF should explore tactical implementation of the doctrine especially for the education of healer/providers to "think and act palliatively." These ETFs should explore methods by which the institution/system effectively can integrate departments, resources, and capacities for patient-centered, holistic, and community-contextualized healthcare delivery.

- The ETFs should undertake a comprehensive review of contemporary literature and specifically analyze the NCP definition of quality palliative care for incorporation into the self-understanding of the community's mission. The ETFs should analyze and determine the best applicability in the institution's overall healthcare delivery systems and operations of the eight domains of palliative care as found in the NCP *Clinical Practice Guidelines for Quality Palliative Care.*

- ETF results should be used to augment long-term development for strategic planning and mission for the next decade. This aspect of the institution's mission should be used to address wider, emerging needs of national programs of healthcare.

- ETF membership should include a wider representation of leaders and healing providers whose diverse services are part of the expanse of palliative healthcare in contemporary society. Of particular importance will be those who have a strong background in the medical humanities. Of equal importance would be those who lead the local Healthcare Ethics Committees.

Concluding Reflections

Within the metaphor of "palliation" and the development of palliative healthcare there is nuclear cultural power for the advancement of model healthcare systems for the nation's future. Yet, how might one understand this power? A creative reflection upon the linguistic/etymological origins of the term "palliative care" will prove intriguing, challenging, and fruitful.

The word "palliative" has its origins in the Latin "*palliare*," meaning to cover or cloak. Using this as a rich metaphor, the monastic practice of hospitality toward the sick was an act of extending the monastic habit or cloak to wrap up and enfold the suffering from the doorway or porter's guard gate into the care of the religious community in fulfillment of the mandate of compassion central to the Western spiritual tradition. The care of the sick and suffering, not just the dying or long-term ill, is captured powerfully within this metaphor. While religious communities were the *loci* of pharmacology and medicinal care during the Middle Ages, they contextualized the offering of curative therapy as part of and within the healing event of human welcome. For them, the former made no sense without the latter. This is a powerful metaphor. However, all metaphors are symbols, and therefore are tensive or polyvalent. They are many meaning-ed. They can conjoin disparate even contradictory meanings. The following exemplifies this point.

"To enfold" is only one of the functions of a cloak. It also can conceal, hide or disguise. In children's stories and mythology, cloaks can be magical pieces of clothing allowing the wearer to disappear completely. Early medieval monasteries and abbeys often were located at the fringe of villages prior to the rise of the cities in the 13th century. They were relegated outside the normal civic population, partly to meet the theory of the time that a vowed celibate life was to be a "flight from the world" (*fuga mundi*). In a certain respect, they were a "hidden life" cloaked from regular daily view. Even after the 13th century when it became more common for monasteries, canonries, friaries, and convents to be located within city walls, religious houses were ordinarily still separated from the streets by a strict cloistered life. Religious life struggled then, as it does now, with being something "hidden" despite its powerful social witness in every century.

Within this context, the care of the infirm, the poor and the sick became cloaked, compartmentalized, even hidden, from the sight of society. Sickness and human dying were realities that could be forgotten, or treated as the unmentionables. They could be and many times were gladly ignored. Infection control, popular misconceptions, ignorance, and superstition contributed to a gradual, historical pushing of sickness to the fringes of perception. In other words, what developed in culture was a "denial" of sickness and dying.

In our own time, the analytic work of Ernest Becker and Elizabeth Kubler-Ross powerfully has underscored much of this tendency, namely a fear and denigration of aging and the human experience of finitude as experienced in a society where humans live longer and where we are commercially bombarded to take every measure to counter the aging process and the inevitability of death. In other words, building upon the poetry of Dylan Thomas, while we may never wish to go gently in that good night, it is another matter entirely to deny that the night exists in the first place.

Yet into this discussion it must also be recalled that from the Latin "*palliare*," another term evolved, namely pallium. The *pallium* is an ecclesiastical vestment in the Western church that has its origins in Greco-Roman garb. In the Western liturgy, it is a decorative stole worn around the neck given by the Roman pontiff to archbishops under his jurisdiction. The pallium signifies the induction of the individual archbishop into a close-knit circle of the highest-ranking leaders. It is a symbol of the highest form of cultural visibility. Interesting; in fact, very interesting. What might this curiously pose for understanding the power of palliation in culture today?

As Charles Gusmer discusses, the experience of human illness is revelatory of a deeper experience of alienation and identity-disintegration. The human animal in sickness experiences a crisis of communication and relationship with the other that is the physical world, the others with whom we share the world, the other that is the self, and the utterly other that is our ideal self or the self within us that gives us meaning. It is an experience of disruption and loss of control. One's time is no longer one's own. Space and the freedom to utilize it are ruptured. One's sense of being an active "agent" gives rise to a diffuse ambiguity between bodily or psychological pain and existential anxiety or meaninglessness. Perhaps it is precisely this internal chaos that makes sickness/death denial attractive. Much like the caricature of young adults in the 1970's film "Logan's Run," society seeks to terminate from its visual field anything that reminds us of our finitude, our inability to extinguish death. From a philosophical perspective, it is possible to consider that this fear of death and finitude is the ultimate disease that exacerbates our fear.

Into this volatile mix, the symbol of the pallium reminds us of some classical academic perspectives in the medical humanities arguing for an honored role of the sick and the suffering in society: that the sick and the suffering have as much a mission or service to society and community, as do society and community to them. With this as a reflective backdrop, it is then an interesting invitation to consider that palliation and palliative healthcare are systemic means by which we make acutely --- even uncomfortably --- visible within our worldview the sobering experiences of sickness and death.

While covering the ill and the suffering with care and compassion, palliative healthcare challenges us not to disguise or deny them, and how they carry in their bodies the universal human realities of disease and our inevitable finitude. Palliative healthcare may be itself the cure in this age for our blinding fear, urging us to face squarely, accept, and finally integrate within the individual and social psyche the age old problem of suffering that Western philosophy sees as part of what it calls "theodicy."

We humans are truly courageous. We have explored the expanse of the cosmos and plunge into the limits of the seas. We delve deeply into concept and configuration. But perhaps the journey that is most needed is the one we resist with the greatest energy and fear: the journey into the deepest shadow of our human existence --- a shadow that envelops the shades of sickness, but also is the necessary prelude to the glint that is our hoping.

I wonder, are we ready for such a journey?

General Bibliography

A Brief History of Palliative Care (2007), Victoria Hospice. Vancouver, British Columbia, CA.

Becker, E. (1973). The Denial of Death. Free Press. New York.

Clinical Practice Guidelines for Quality Palliative Care. Third Edition. (2009) National Consensus Project for Quality Palliative Care. Pittsburgh, PA.

Fins, J., A Palliative Ethic of Care: Clinical Wisdom at Life's End. (2006). Jones and Bartlett. Sudbury, MA.

Gusmer, C. And You Visited Me. (1984) Pueblo Publishing. Collegeville, MN.

Healy, K. Frances Warde. (1973). Seabury Press. New York.

Kubler-Ross, E. (1969) On Death and Dying. Scribner. New York.

Palliative Care. Wikipedia. Retrieved 17 June 2017 from https://en.wikipedia.org/wiki/Palliative_care

Palliative Care Explained. The National Council for Palliative Care. London, UK. Retrieved 17 June 2017 from: http://www.ncpc.org.uk/palliative-care-explained

Rosenberg, C. (1987). The Care of Strangers: The Rise of America's Hospital System. Johns Hopkins University Press. Baltimore, MD.

Strang, P., Strang, S., Hultborn, H, & Arner, S. Existential Pain – An Entity, A ` Provocation, or a Challenge? (2004) Journal of Pain and Symptom Management. Vol, 27 Issue 3.

WHO Definition of Palliative Care. World Health Organization. Retrieved 17 June 2017 from http://www.who.int/cancer/palliative/definition/en/

Wodarg, W. (2008) Palliative Care: A Model for Innovative Health and Social Policies. Parliamentary Assembly. Council of Europe. Retrieved 17 June 2017 from http://www.eapcnet.eu/Themes/Policy/EuropeanInstitutions/CouncilofEurope/WodargReport.aspx