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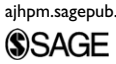

Deathbed Phenomena: Its Role in Peaceful Death and Terminal Restlessness

April Mazzarino-Willett, BS, CHPN[1]

Abstract

Dying patients and their caregivers frequently experience that which is known as deathbed phenomena, that is, visions of past deceased relatives or friends, religious figures, and a visionary language pertaining to travel. Collective research supports mounting evidence that deathbed visions typically yield peaceful deaths. Yet within the literature, numerous hospice patients experience the symptoms of terminal restlessness and frequently succumb to anguished deaths. Why are some patients and caregivers guided by peaceful deathbed phenomena and others are not? Does a relationship exist between the lack of deathbed phenomena and the onset of terminal restlessness in dying patients? This clinical paper intends to answer these questions and might elucidate the factors that contribute to a dying patient's death ending as either a peaceful event or the one affected by terminal restlessness. This knowledge gained could lessen the occurrence of anguished deaths and perhaps change our way of viewing dying.

Keywords

deathbed phenomena, terminal restlessness, peaceful deaths, anguished deaths, deathbed visions, DBVs, ELEs, end-of-life experiences, DRSEs, death-related sensory experiences

Purpose Statement

> And in my hour of darkness she is standing right in front of me speaking words of wisdom, let it be . . . [1]

Although the Beatles probably never meant their song to speak of the visionary Christian "Mother Mary," the lyrics do however resemble the deathbed phenomena observed by many dying patients (adults and children) and their caregivers. Deathbed phenomena commonly classified in the texts as either veridical; those encounters which present with evidence that negates the theory of hallucinations or nonveridical without verification have been repeatedly found throughout many Western and Eastern cultures with a shared commonality of visionary elements that appear, guide, and comfort those that are dying.

The interval to death of the patient after experiencing a deathbed vision varies, sometimes within hours, days, weeks, and even months.

Although prior researchers were systematic within their approaches testing for prevalence and variety of deathbed visions, none have presented incontrovertible evidence for the existence of an afterlife; however, via veridical deathbed phenomena there is supported evidence that some visions are not hallucinations; the dying see an appearance of a dead relative not told to the patient yet appearing as a vision coming forward to guide the patient to an afterlife.

It is important to note that not all dying patients succumb peacefully. Many patients experience that which is called "terminal restlessness," an anguished death, which may present as a result of unfinished business and is characterized by the symptoms of increased physical, emotional, and or spiritual pain.

Why is there a difference in the dying events? Does a correlation exist between the lack of deathbed phenomena (veridical and nonveridical) and the onset of terminal restlessness in dying patients? This clinical paper intends to elucidate the relationship between deathbed visions and a peaceful death and to perhaps shed light on a possible relationship between terminal restlessness and the absence of deathbed phenomena.

Themes of Deathbed Phenomena

Present within the literature are recurring themes of visions reported by the dying; past dead relatives, deceased friends, bright vaporous presences that emanate warmth and peace within the dying and their caregivers, angelic-like figures (appear to children and are without wings), religious figures, and glimpses of a heavenly place not of this world. "Dying children often expressed surprise that the angels they saw waiting for them didn't have wings."[2(para8)] Deathbed visions involving religious figures were observed predominantly

[1] From the Yale University School of Nursing, New Haven, Connecticut

Corresponding Author:
April Mazzarino-Willett, 48 Drury Lane, New Haven, CT 01106.
Email: April.mazzarino-willett@yale.edu

among Eastern Indian patients, whereas American patients most frequently reported seeing dead people.[3]

Caregivers, that is, clinicians and family members, report a convoluted speech in active dying, a type of visionary language indicative of a transition, "I'll be getting into the car then, but I know I haven't done anything wrong."[4(p20)] These travel analogies via trains, cars, planes, needing a ticket, and searching for home are sometimes heralded as a prognostic sign of a nearing death.

Prevalence of Deathbed Phenomena

Deathbed visions have been documented via biblical works, art, and literature. The Grotto paintings of the 15 century Assisi tell the story of a dying monk who had a vision of the death of Saint Francis and cried out, "Wait for me, Saint Francis, I'm coming, I am coming" whereupon he died.[5(p316)]

The deathbed vision witnessed by obstetrician Lady Barrett of a dying young mother was the impetus for the first systematic study, *Deathbed Visions*, 1926, by Sir Barrett who was succeeded by Hart, Hyslop, and later Osis. Osis's pilot study, *Deathbed Observations by Physicians and Nurses*, published in 1961 surveyed 35 540 deaths revealing that deathbed phenomena occurred even in clear consciousness.[6] In 1977, Osis and Haraldsson[3] collaborated with clinicians in India in their research study, which revealed not only prevalence but also confirmed that deathbed phenomenon does indeed cross cultures and religions.

Approximately 10% of all dying people are conscious shortly before their deaths, and of these people, it is estimated that 50% to 60% experience deathbed phenomena.[7]

Barbato, Kellerhear, Ried, Irwin, and Rodriquez (1999) research study (was cited in O'Connor, 2003) entitled "Parapsychological phenomena near the time of death" via the *Journal of Palliative Care* in 1999.[8] The findings revealed that there exists an underestimate of deathbed phenomena disclosure due to a lack of awareness of vision existence compounded by the fear of witness ridicule. In 2006, the pilot study by Brayne, Farnham, and Fenwick sought to include experienced clinicians and enlisted the Camden Palliative Care Team, located in London, United Kingdom; their findings confirmed the prevalence noting that, "Deathbed visions occur relatively frequently and that patients and relatives tend to talk about them to nurses more than doctors."[4(p18)] Morse, a pediatrician and researcher considers deathbed phenomena to be an integral aspect of the dying process and "... should be interpreted as being part of the spectrum of spiritual events that happens to the dying, their families and their caretakers."[9(p109)] Fenwick proposed, "phenomena such as visions or apparitions comfort the dying person and prepares him or her spiritually for death or for the crossing over to a reality."[10(p316)]

The Horizon Research Foundation benefactors of the original Camden pilot study is presently conducting a retrospective study, *Deathbed Visions Study*, with Internet access in efforts to extend the sample findings of prevalence of deathbed phenomena and to provide models of best practice to caregivers of the dying.[11]

Veridical Visions and Non-Veridical Hallucinations

Nandor Fodor defines nonveridical perceptions as those that by a distinct reflection are recognized as lacking the objective basis that they suggest, that is, a hallucination, crawling, and bugs.[12] If the sensory perception coincides with an objective occurrence or counterpart, the hallucination is called a veridical perception or rather, a truth telling, that is, a vision of a family member not yet known to be dead but seen by the dying patient and or patient/caregiver witnessed visions.

In the literary text, *One Last Hug Before I Go; the Mystery and Meaning of Deathbed Visions*, Carla Wills-Brandon demonstrates a credible argument that deathbed phenomena are not hallucinations caused by a dying brain. She writes, "If deathbed visions are the result of a dying brain, oxygen deprivation, neurosis or chemical imbalances,"[13(p162)] why are most of the visions of past deceased persons? Why are the themes of these visions so similar among the dying? If the byproducts of the dying brain were arbitrarily firing, then chaotic visions would result.

Researcher Angela Ethier argues that the visions among the dying are different from those expressed by mental illness; dying people report more visual hallucinations, whereas those afflicted with mental illness report more auditory hallucinations.[14] The interim study of deathbed phenomena by Brayne, Lovelace, and Fenwick at Gloucestershire Nursing Home concluded that deathbed visions most impressively differed from hallucinations via the responses they invoked; inner peace, death acceptance, and nearing death (Table 1).[15]

Impact of Deathbed Phenomena on the Dying and their Caregivers

Melvin Morse correlates the presence of deathbed phenomena as an event of empowerment for the dying, reminding them that they still have purpose; teaching those (family members and clinicians) about end of life, something to share.[9] Second, Carla Wills-Brandon writes the dying person is reassured by the experience and expresses great happiness with the vision.[13] "Lack of fear is expressed verbally and nonverbally i.e., facial expressions by the majority of the dying at the time of the vision and during communication of the visions to others."[13(p108)]

> Author Ethier of "Death Related Sensory Experiences", encourages validation of a child's vision to open the discussion of death. In an excerpt from her article, she cited the literary work of Yale University Pediatric Oncologist Diane M. Komp's 1992 book, *Window to heaven: When children see life in death*. Before she died, she mustered the final energy to sit up in her hospital bed and say, the angels are so beautiful! Mommy, can you see them? Do you hear their singing? I've never heard such beautiful singing! Then she lay back on her pillow and died. Her parents reacted as if they had been given the most precious gift in the world.[16(p107)]

Table 1. Comparison of Deathbed Phenomena and Hallucinations[a]

Categories	Deathbed Phenomena	Hallucinations
Mood/affect	Calm, peaceful state, or elation	Frighten, agitated, paranoid states
Occurrence	Months to moments at death	At agitated/delirium states
Forms	Visual/humanoid, angels, religious icons, dead relatives/friends	Predominantly auditory/but can be visual: insects, snakes, creatures
Impact on person	Spiritually transformative	Having little significance
Witnessed	By caregivers/family/clinicians	Individual only
Veridical/nonveridical	Veridical	Nonveridical

[a] In Table 1, a comparison between the inherent differences of deathbed phenomena and that of hallucinations is represented. Adapted from "The Impact of the Family of Terminal Restlessness and its Management," by S. Brajtman, 2003, *Palliative Medicine 3* 454-460. "Death-Related Sensory Experiences," by A. M. Ethier, 2005, *Journal of Pediatric Oncology Nursing*, 6, 104-111, "Terminal Restlessness as Perceived by Hospice Professionals" by B. Head, 2005, American Journal of Hospice & Palliative Medicine, 9, 277-278.

Palliative nurses report a common theme in response to their experiences with deathbed phenomena and their religious beliefs " . . . something else that happens or more out there than any of us really understand."[8(p3)]

Deathbed Phenomena and Peaceful Death Transitions

The deathbed phenomenon seems to permeate the dying person's outlook untoward death encompassing also their caregivers, and both the dying and their caregivers are defined and inwardly changed by this vision of peace. Death heralded by these types of phenomena via the literature reviewed typically the result in a peaceful passing for the patient. "Feelings of peace, joy, happiness, serenity, ease, excitement, and the lack of fear are expressed verbally and nonverbally (eg facial expressions) by the majority of the dying at the time of the vision and during the communication of the vision to others."[14(p108)] "Deathbed visitations soothe both the living and the dying. They make the death transition easier for the dying and lessen the burden of grief for surviving family members."[7(p61)]

Visions witnessed by patients and their caregivers in the active dying stage guide the end-of-life clinicians on the meaning and significance of deathbed phenomena. Knowledge gained via research studies support not only the vast prevalence of deathbed visions but also the striking similarity in vision themes across cultures, countries, age, and religion. Tantamount is the knowledge that deathbed phenomena existence can and do result in peaceful deaths and assist caregivers in the bereavement process. These attributes of deathbed visions give credence for inquire and incorporation awareness of spiritual visions in dying patient care.

Terminal Restlessness and the Anguished Death

Encouragement of venting feelings of loss, fear, anger, guilt, shame, and concern for the unknown has been a staple of hospice care practiced by all visiting clinicians in efforts to assist patients in the acceptance of death and promote a peaceful passing. However, despite our best efforts, predominance of patients still die anguished deaths.

Terminal restlessness may be observed during the last days and/or hours before death. Patients may exhibit symptoms of agitation, restlessness, myoclonus, and physical irritability in addition to impairment to their level of consciousness. The more dramatic symptom of agitated delirium may or may not be accompanied by nonveridical hallucinations/paranoia and or nightmares. Patient suffering is evident and typically ensues till death.[17]

The syndrome referred to as terminal restlessness, anguish death, or delirium prevalence is devastatingly high reaching approximately 25% to 85% of all deaths.[18] Terminal restlessness remains, "the third most common admission reason"[18(p277)] either into an acute palliative unit and or hospital at the end of life. Its onset can be insidious over several days or abrupt, within hours. Response time to treat is perhaps the greatest predictor for preservation of quality for the dying and restoration of communication between patient and family caregivers.

The origin of terminal restlessness is a multidimensional state encompassing the physical, spiritual, and psycho/social distresses of the patient. Symptoms are varied and interconnected. In the study by Head and Faul,[18] frequent symptoms observed in early terminal restlessness include anger, despair, insomnia, inability to settle, progressing to repetitive movements, nonpurposeful movements, calling out, climbing out of bed, jerking, picking at sheets, and removing clothes. Intensifying symptoms are inherent in the latent stages of terminal restlessness, confused speech, striking out at others, incoherence, wild-eyed look, difficulty focusing, absent eye contact, nonveridical hallucinations, and paranoia.

Physical causes can be related to constipation, retention of bladder, positional pain, and dyspnea. Other causes can be related to body system failures, that is, renal or hepatic failure, hypercalicemia, cerebral metastasis, and adverse response to metabolites.[19] Agitated delirium may be a result of existential or psychological distress.

Treatment is cause directed with a combination of an interdisciplinary and polypharmacy approach. Sometimes the cause is the patient's medications, those prescribed to address the end-of-life symptoms can contribute to terminal restlessness,

that is, opioid toxicity; "plasma morphine metabolites M-6-G and M-3-G increase in terminally ill patients ... during the dying process" and contribute to terminal agitation.[20(p3)] High dose steroids often used to address cranial tumors, metastasis, and inflammation can contribute to a psychosis during the end of life.[20]

Frequently effective treatment includes reassessment of the patient's medication regime, that is, the elimination of unnecessary medications to further decrease demands on the patient's liver.[20] Other important aspects of the treatment of terminal restlessness are electrolyte assessment and hydration, rotation of opiods, concomitant use of benzodiazepines, neuroleptics and control with lessening of environmental stimuli, and the involvement of the interdisciplinary team members, that is, nurses, social workers, and chaplains.[18-20]

Hospice clinicians also "give credence to the hypothesis that psychosocial and spiritual issues are often at the root of terminal restlessness."[18(p281)]

Impact of Terminal Restlessness on the Caregivers

There is evidence to suggest that patients' terminal restlessness may adversely affect caregivers' quality of life and the levels of experienced stress affecting grief and the bereavement process.[17]

The 2 most concerning themes reported in the literature for families were the "multidimensionality"[17(p10)] of witnessed patient suffering and the urgent need to communicate with their dying relative.

Polypharmacy required to adequately address symptoms of restlessness/agitation and delirium often sedate patients and as a result families loose precious communication time. Some families even expressed wanting to "hold" medications in an attempt to preserve communication.[17]

Both the patients and their families are deprived of closure, which results in a sense of isolation, and added loss for those caregivers left behind. Spiritual distress compounds the fear of dying for family members and creates difficulties in bereavement. In episodes of terminal restlessness both the patient and the family suffer.

Reduction of Terminal Restlessness

To reduce the prevalence of terminal restlessness, the end-of-life clinicians require in-depth training in signs and symptoms of early terminal agitation. Utilization of education into presenting signs and symptoms of onset of terminal restlessness with the concomitant use of the terminal agitation scale by Jones et al[19] via the research study by Head and Faul proved to be moderately effective in scale reliability analysis. This knowledge gained could significantly reduce the intensity and resulting anguished deaths experienced by approximately "42 percent of all dying patients" in the last 48 hours of life.[18(p278)]

Supportive Literature Reveals a Correlation

Literature supports a relationship between the occurrences of deathbed phenomena and a peaceful death. What defines or rather supports one's dying ability to transition peacefully from this external world is only conjecture at this time. We know via research that deathbed visions transcend religion and are seen and witnessed in various religious sects. Researchers Osis, Morse, Fenwick, and Wills-Brandon concurred that deathbed vision transitions cross all cultures, affecting both male and female, young and old, and educated and uneducated.[3,6,7,9,13]

Researcher Betty equates deathbed visions as an outward expression of a "merging of two worlds ..."[21(p48)] that is, the physical and spiritual planes.

In Morse's book, *Parting Visions*, he cites Alexandra David-Neel's work regarding Tibetan monks, she writes, "Tibetan monks spent many years developing the spiritual area of their brain ... and are able to have out of body experiences and visualize spiritual beings."[9(p119)] Morse postulates that deathbed visions occur to those who possess an openness to the existence of spirituality an extra-sensory perception mediated by their right temporal lobe region of the their brain. Morse writes, "For those with natural right-temporal-lobe talents, the communication often comes in the form of an angel or being of light ...."[9(p169)]

This explanation could also address certain aspects of terminal restlessness and the absence of deathbed visions noting that terminal restlessness is more frequently seen in patients who life's work has been rooted in rigidly defined frameworks. These patients would be seen as possessing more "left brain talents i.e., math and language" [9(p119)] rather than right brain talents, that is, extra-sensory perception and an openness to the existence of deathbed visions.

In Table 2, the literature used for this clinical paper addresses the differences inherent in patient and caregiver response to hallucinations and that of visions, and also the origin, and impact of terminal restlessness. However, not currently written but suggested within the literature researched is the possible correlation between the absence of deathbed visions by patients and the onset of terminal restlessness.

A colleague of pediatrician Morse describes the effect of deathbed visions on the dying as, "morphine for the soul."[9(p124)] Carla Wills-Brandon writes, "Deathbed visions have a powerful influence over the dying and they should be used in a positive healing manner."[13(p247)]

The specialty of hospice and palliative care is known for its innate sensitivity of embracing the teachings by its dying patients into treatment algorithms; inclusion of deathbed visions would be an imperative phenomena to temperate the frequency of terminal restlessness.

Improving the Quality of Dying for Patients

There are a number of strategies that could improve the quality of dying for patients and their caregivers. They include the utilization of the derived benefits from deathbed phenomena via

Table 2. Literature Related to Deathbed Phenomena and Terminal Restlessness

Source	Design	Purpose	Sample	Instruments	Selected Findings
Brayne et al	2008 Gloucestershire Nursing home retrospective 5 yr. study	Two part study: (*a*) explore clinician perception/recognition of ELE, and (*b*)1-year retrospective post ELE education	10 clinicians with greater than years experience in EOL care	74 question Likert survey of ELE	All interviewee agreed: ELEs differed from hallucinations via patient' reactions of inner peace, with resulting death acceptance. ELEs hallmarked nearing death
Fenwick, Lovelace, Brayne	2007/clinical paper	Enlightenment of Camden study			Need for new "Ars Moriendi"; development of ELE; workshops for caregivers
Brayne, Farnham, Fenwick	2006/small pilot study in Camden Palliative Care Team 1000 referrals per year	Occurrences of DBVs	Nine Clinician interviewees: all with greater than 5 years, experience in palliative medicine	Questionnaire; (*a*) Demographics, (*b*) professional observations of DBVs and medications effects, (*c*) DBVs impact	(*a*) DBVs are prevalent, intrinsic to dying: clinically different from drug-induced hallucinations and have meaning for patients. (*b*) Deficit of workshops to teach caregivers/ clinical personnel regarding DBVs existence/ positive impact
Stafford	2006/Doctoral Thesis	Authenticity and spirituality of DBVs/NDVs: real vs hallucinations			DBVs origin point to an inclusion in the spirituality of death: a "merging of two worlds"
Ethier	2005/clinical paper	DRSEs in children/adolescences; their occurrences, and impact on dying	Dying children/adolescences with a diagnosis of cancer and their families	Clinical observations of DRSEs and their impact on patients/families	DRSEs are purposeful; providing spiritual transformation, open communication with the dying/caregivers, and elicits a peaceful death for patient and caregivers alike
Braitman	2003 Phemonological Research Study	Exploration and impact/treatment of terminal restlessness on bereaved families	Focus groups: bereaved families and individual interviews/(clinical staff)	20 interviews conducted with; (identified via Jones et al, scale for terminal restlessness) bereaved families	Families and patients collectively suffer due to effects/management of terminal restlessness, and are at greater risk for an adverse bereavement process
Jones et al	1998/Qualitative research study 2 stages: August 1994-February 1996	Development of an observation-based scale to assess for terminal restlessness	32 bed palliative unit/@250 deaths per year 2 stages: (*a*) prototype T.R. scale developed, (*b*) enactment: testing/revisions	Last (4th) version, prospective study: 298 dual ratings on 28 patients over 6 weeks	Scale appears to have validly; may improve clinician response time/treatment of terminal restlessness

Abbreviations: DBV, deathbed visions; DRSE, death-related sensory experiences; ELE, end of life experiences; EOL, end of life; NDV, near death visions.

written literature formatted for terminal patients and their caregivers and public television access to teach and inform those not yet dying regarding the potential of deathbed visions in preparation for future death.

Clinicians also need to create and maintain palliative/hospice environments that foster both an openness and an integration of the benefits of deathbed phenomena for all patients. Lastly, health care leaders need to assimilate the benefits and prevalence of deathbed visions into the end-of-life care education for all health care clinicians.

These implementations would create opportunities to proactively teach awareness of deathbed visions, that is, their impact, prevalence, and normalcy of occurrence. Perhaps, an informed awareness by patients and caregivers (professional and nonprofessional) of the benefits of deathbed visions might increase the practice of peaceful deaths and ultimately lessen the occurrences of terminal restlessness.

In acknowledging that these visions may not be appreciated by all our dying, we as clinicians must respect and advocate the wishes of our patients to choose to die without the phenomena of deathbed visions.

Clinician Presence and Supportive Environment

Clinician presence along with a supportive environment can enhance not only the patient/caregiver relationship but also a discussion of death. If clinicians are diligent in their efforts to introduce the possibility of deathbed visions to patients and their caregivers and the role they play in peaceful death, perhaps more patients and their caregivers will experience comforting deathbed phenomena and feel less stigma in reporting such phenomena.

Clinicians must update their knowledge and skills regarding the end-of-life care and be vigilant in their observation to the early signs of terminal restlessness, because early treatment negates suffering for both patients and families (see Table 2). All clinicians need to make early and appropriate referrals to interdisciplinary members of the hospice and palliative teams, that is, chaplains, social workers. Community agencies, hospitals, and nursing homes need to offer and require continuing educational units for all clinicians in spirituality training. Hospice and palliative care clinicians need to promote an empowerment in dying patients, reminding them (patients) that they are the leaders/teachers of their families in the act of dying with dignity and courage.

All health care clinicians need to become masters in the art of active listening and appropriate touch, assisting patients to live their unique style of dying. Elias sums it best in his quote referencing dying, "To make the end, the parting from human beings, when it comes, as pleasant as possible, for others as well as ourselves."[15(p205)]

Literature reveals that deathbed visions are probably more frequently experienced but due to a fear of ridicule and embarrassment, deathbed phenomena goes under reported. Perhaps with the utilization of the research findings via education of patients and caregivers, a truer picture of deathbed phenomena can be gained via future studies (Table 2).

The specialty of hospice and palliative care would benefit from future research studies to investigate the relationship between deathbed phenomena and resulting peaceful deaths. Conversely, if deathbed visions do lead to peaceful deaths than conceivably a lack of such visions could result in terminal restlessness. In the literature studied, no reference or vision study has correlated terminal restlessness and the presence and or absence of deathbed phenomena.

Accurate testing of this relationship is needed to lessen the anguished death and increase the likelihood of peaceful deaths for all dying patients.

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