

Deathbed Phenomena: Real or Imagined?

Presented by:

Margot Sondermann BScPT, BSc, MEd

Catherine Janzen RN, BSN, MN

Palliative Consult Team

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Definition:

Deathbed Phenomena (End-of-Life Experience):

Any one of a wide range of phenomena that comfort the dying and prepare them spiritually for death.

(Brayne, Farnham & Fenwick, 2006)

Are powerful, subjective experiences that contain profound personal meaning for those who experience them.

(Brayne, Lovelace & Fenwick, 2008)

Collective research supports mounting evidence that deathbed visions typically yield peaceful deaths.

Characteristics:

- More common than we think
- Similar themes across cultures, religions, ages
- Not often associated with a religious aspect
- Interpersonal connections
- More often experienced and reported by women.

Calgary survey data

- 77% report that a patient has told them about a DBP.
- 72% report that a relative has told them about a DBP.
- 65% report that they have witnessed a DBP.

Categories:

- Transpersonal:
 - Visions
 - Coincidences
- Final meaning:
 - Dreams and waking dreams
 - Desire to reconcile, say goodbye

Themes of transpersonal DBP

- Deceased relatives
- Deceased friends
- Angelic-like figures
- Religious figures
- Glimpses of places not of this world
- Changes in room temperature
- Synchronistic events e.g. clocks stopping, bell ringing, changes in pet behaviour
- Visions of vapours, mists & shapes around the dying person

Characteristics:

Are similarly described throughout the literature as:

- Calming
- Soothing
- Greeting
- Comforting
- Beautiful
- Readying
- Quieting
- Loving



Thoughts on DBP

- “approximately 10% of all dying people are conscious shortly before their death, and of these people, it is estimated that 50-60% experience DBP”
(Willis-Brandon, 2003)
- “DBP should be considered to be a part of the spectrum of spiritual events that happens to the dying, their families and their caretakers”
(Morse, 1994)

History of DBP

- Documented in Biblical references, art & literature
- Mentioned in 15th C. account of a dying monk
- First systematic study was in 1926 by Sir William Barrett.
- 1961 study by Karlis Osis revealed that deathbed phenomena occurred in patients with clear consciousness.
- Further studies done in other countries confirms that DBP are experienced in very similar ways around the world.

History of DBP

- For many years, medical culture has attempted to find ways to explain DBP.
- Recent increase in studies since the 1990's.
- Recent western culture shift and interest in the paranormal
 - Still requires well-planned and rigorous study protocols in order for study outcomes to be accepted by mainstream medical science.

Research

- 1999 study by Barbato et al found that:
 - DBP are underestimated due to a lack of awareness of vision existence and a fear of witness ridicule.
 - Pts & relatives tend to talk about DBP more to nurses than to doctors.
 - Many lack the language skills to explain what is happening.
 - Health care staff don't ask.
 - Medical training teaches us to ignore this phenomenon.

Research

- 2006 study in a hospice in Camden, England (N=9) found:
 - DBP occur relatively frequently.
 - As previously found, pts & relatives spoke to nurses > doctors.
 - All staff felt DBP to be an intrinsic part of the dying process.
 - DBP appear to be personal.
 - DBP are spiritual – help pts to reconcile events in their lives.
 - 8/9 witnessed pts experiencing a DBP.

Research

- 2008 study at British LTC facility:
 - A combined 5 yr retrospective study & 1 year prospective study.
 - Retrospective part focused on reports of kinds of DBP experienced and effect of this on residents, families and caregivers.
 - Prospective part examined whether more frequent reporting changed what kind of DBP were reported and also if the culture of the LTC shifted towards a greater awareness & acceptance of DBPs.

Findings

- Some staff had difficulty identifying DBP vs. confused or hallucinating residents
 - How a resident spoke about what they saw gave clues to whether it was a DBP:
 - Calm, reassured, inner peace, no fear = DBP
 - Fearful, anxious, eyes darting = hallucination
- Staff reported a variety of DBP :
 - Episodes of terminal lucidity
 - Dreams with significant meaning for the dying

Findings continued . . .

- Visions of deceased relatives just before death, sitting on or near the bed
- Visions of groups of children
- Visions of birds or animals around the time of death
- Reports of a change in room temperature at time of death
- Caregiver reports of a sense of being “pulled” shortly after death
- Synchronistic events e.g. clock stopping, bell ringing
- Dying person speaking of “transiting” to new reality

Calgary survey results

Agree or Disagree?	Agree	Disagree	Fenwick study
Altered state of consciousness	75%	25%	45%
Profound spiritual event	95%	5%	68%
Chemical change in brain	0%	100%	34%
Manifestation of the imagination	3%	97%	5%
Caused by meds, fever, organic cause	7%	93%	33%
Happens in last 48-24 hrs of life	54%	46%	35%
Happens in last month of life	59%	41%	29%
Provides spiritual comfort to dying person	100%	0%	92%
Provides spiritual comfort to relatives	83%	17%	86%
Patients reluctant to talk about DBP	51%	49%	28%
I feel comfortable talking about DBP with colleagues	92%	8%	79%
I feel comfortable talking about DBP with pts & families	95%	5%	82%

Outcomes of LTC study. . .

- Staff wanted more training in how to talk to residents about death & dying, including DBP.
- Staff wanted to normalize DBP & change the work culture from disbelief to belief.
- Identified need for a broader understanding of different religion & spiritual beliefs.
- Identified need for further existential training but staff didn't want to become spiritual mentors.

Common medical explanations for DBP :

DBP are hallucinations:

- caused by a dying brain (↓ oxygen, neuro or chemical imbalances)
- which are the same as those with mental illness
- caused by confusion, dementia, delirium or drugs
- related to body systems failure (renal, hepatic, pulmonary)
- related to metabolic changes (hypercalcemia)
- related to uncontrolled symptoms (pain, dyspnea, etc.)

Recent literature supports the argument that all of these explanations are incorrect.

Arguments against:

- Dying brain – O₂ deprivation, neuro or chemical imbalances result in **chaotic** visions
- Mental illness – hallucinations tend to be auditory
- Confusion, dementia, delirium, drugs, body systems failure, metabolic changes, uncontrolled symptoms
 - all result in hallucinations which are annoying to the patient, have little significance, and many patients acknowledge that they are seeing something that isn't "right".
 - these hallucinations are of insects, wallpaper moving, animals, devils or dragons in the light, etc.

Comparison of DBP & hallucinations

Categories	Deathbed Phenomena	Hallucinations
Mood/affect	Calm, peaceful or elation	Frighten, agitated, paranoid
Occurrence	Months before to moment of death	At agitated/delirium states
Forms	Visual/humanoid, angels, dead relatives	Predominantly auditory, but can be visual (insects, snakes, creatures)
Impact on person	Spiritually transformative	Having little significance
Witnessed	By caregivers/family	Individual only
Veridical/non-veridical	Veridical	Non-veridical

Explaining DBP

- Deathbed phenomena differ from drug or disease-induced hallucinations because they hold some kind of profound meaning for the patient.
- “There is NO rational explanation for DBP but so many have had similar experiences that it cannot be discounted” (MacConville, 2010)

Why don't all patients experience DBP?

- Mazzarino-Willett (2010) postulated that many pts are in a state of “terminal restlessness” & are not in a physical, mental, emotional or spiritual state to be able to experience DBP.

Terminal Restlessness

- Terminal restlessness or delirium is devastatingly high, reaching approximately 25-85% of all deaths.
- Third most common admission into acute care.
- Multi-factorial cause
- Can adversely affect grief and bereavement process.

(Mazzarino-Willett, 2010)

Why don't all patients experience DBP?

- Mazzarino-Willett argues that the medications required to alleviate the problems associated with terminal restlessness often cause the patient to be sedated at the end of life
 - Pt misses out on the possibility of experiencing a DBP.
- Author suggests that early & aggressive management of symptoms may result in the patient being able to experience a DBP.

Impact of DBP

- Reassurance
- Happiness
- Event of empowerment
- Lack of fear
- Sense of an easier transition
- Families & caregivers are assisted in their bereavement

So what is “Best Practice” for DBP?

- Non-judgemental support for patients, families and staff
- Respectful curiosity
- Open & honest discussions about DBP between all members of the healthcare staff



Responding to reports of DBP:

Barbato et al, 1999

- Ask person to fully describe the experience
- Listen attentively
- Ask person what they think the event means; how does it make them feel?
- Normalize the experience by stating how well known & fairly common these experiences are
- Address any emotional/spiritual issues
- Avoid interpretation of someone else's experience
- Reassure the person he/she is not insane or going crazy

Communication

- Pts/families might use a “tester” question with you.
 - E.g. “What do you believe will happen to you after death?”
 - Best approach is to answer honestly
- LISTEN – use engaging body language, eye contact, be alert & attentive
- RESPOND with open questions, avoid trying to explain away or fix the situation

Care for the caregiver:

- Listening to people's DBP stories can be a burden
 - Use your team and colleagues for support
 - Offer support to others
 - Trust yourself – while these phenomena and discussions about them can be daunting, you have the skills to talk about them.
 - If you feel your personal or spiritual beliefs have been challenged, withdraw from the situation & seek advice from your colleagues &/or a spiritual advisor.

Questions? Other stories?



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