Deathbed Phenomena: Real or Imagined?

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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

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

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

- 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

Barbato et al, 1999
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?
References