

End Of Life Signs: Perspectives Of Family Members Of The Deceased

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ABSTRACT

The study explored the signs shown by the departing before their death. Semi- structured interviews were conducted among 24 families of recently deceased individuals. Narrative Analysis and phenomenological approach was used for analyzing data collected. There were notable physical, mental and social signs shown by the deceased before death like visions / dreams of their deceased elders, death-related talks, metaphorical messages, post-death rituals, changes in sleep cycle, eating habits, expressing unusual irritability or unusual care and love towards family members. While the cause is unclear, awareness and understanding of such signs is important to improve the end-of-life care

Key Words: End-of-life experiences, Nearing Death Awareness and Deathbed phenomenon.

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INTRODUCTION

Sudden natural death occurs due to an illness or malfunctions of the body and not directly influenced by external forces. There are several causes. Phases of dying include- pre-active and active, each stage characterized by signs. Emotional & personality changes, physical deterioration, declining cognitive functions and other significant changes are observed before death. Deathbed Phenomena (DBP) as described by Brayne and colleagues (2006) “death may be heralded by deathbed phenomena such as visions that comfort the dying and prepare them spiritually for death”. It is defined as the range of paranormal experiences claimed by the dying. DBP appears to be common but not well understood phenomena; DBP have a potential to offer hope, meaning and connection; DBP has a significant impact on patients both psychologically and spiritually (Devery, K., Rawlings, D., Tieman, J., & Damarell, R, 2015). experiences include visual, auditory & sensed presences; DBPs are comforting hallucination. (Houran, J., & Lange, R, 1997)

“Nearing death Awareness” a word coined by Callanan and Kelly in their book, refers to the special communications made by the dying. Deciphering the meaning of the communication can reveal significant information. Elderly may exhibit behaviors such as unusual language, gestures, describe odd dreams, report visions of died, mood swings and so on. As death nears, dying may do life review, bid farewell, predict the time of their death; verbal and non-verbal symbolic language is expressed; pre-death visions can be beneficial and therapeutic; Dreams may contain pre-monitions of death; Sometimes individuals can predict the timing of their death and also are able to time their own death; NDA prepares for death whereas

NDE aid to live better in future; It can lessen fear about death. (Sanders, M. A, 2007). Change in sleep patterns & food preferences, fatigue, tiredness, difficulty in swallowing, breathing difficulty, rise or lowered body temperature; change in urine and stool output, etc.. are noted when a person's death is near.(Callanan, M., & Kelley, P, 2012)

Deathbed Visions refer to the paranormal experiences that occur in people who are dying. DBVs are apparitions; appearances of ghostly beings to the dying near the time of their death. These are usually deceased loved ones, family, friends, and famous religious figures. Nearing-death awareness and NDEs offer comfort and reduces death anxiety as it instills the belief that the dying can exist in some other form. (Horacek,1997). It lessens the solitary feelings about death experience. Interviewees' reports (first-hand and second-hand accounts from relatives, patients and residents) suggested that ELEs are not uncommon; ELEs included deathbed phenomena (DBP) such as visions, coincidence and the desire to reconcile with estranged family members. ; these experiences comfort both the dying and the bereaved; ELEs different from drug- induced hallucinations and occurred in clear consciousness; there is a lack of ELE training and education; further research is required in this area to find is true validity. (Fenwick, P., Lovelace, H., & Brayne, 2010) The content and subjective significance of ELDVs was examined using inductive content analysis and there exist 6 categories like: comforting presence, preparing to go, watching or engaging with deceased, loved ones waiting, distressing experiences and unfinished business. (Nosek, C. L., et al, 2015)

An interview-based study was conducted in Northern Kerala, in India with 104 families (Muthumana, 2011). Thirty families reported that the dying person displayed behavior consistent with deathbed visions— interacting or speaking with deceased relatives, mostly their dead parents. Also, precisely, there were six cases of reported premonitions of death. Author Carla Wills-Brandon argues DBVs to be unique & distinct and not as a result of physical illness (oxygen deprivation, neurosis, chemical imbalances). She supports her statement by pointing out the consistent strong themes of DBVs among individuals. *'There seems to be a huge area of the brain that is devoted to having just such experiences'* (Morse with Perry 1994, p.71). Hallucinations of deceased humans & religious figures were often experienced that is contrast to the hallucinations experienced by normal populations; most dying responded positively to the apparitions that seems to take patients away to a post-mortem mode of existence; Death-bed visions were found to be independent of medical, psychological & cultural factors (Osis, K., & Haraldsson, E., 1997)

Several studies have pointed out the fact that there is no common and apparent physiological explanation for these behavior and communications; changes are independent of age, gender & ethnicity. (Callanan, M., & Kelley, P, 2012). Knowledge about the process of dying and death may aid in perceiving death from a broader perspective rather than as destructive event. (Sanders, 2007)

For years, studies have been done by researchers in the topics such as near- death experience, deathbed phenomenon and end- of- life experiences. The results are that these experiences are found to be common among dying population. They have significant psychological and spiritual impact on the person. Common themes exist though individual variations in experiences are critical. End-of- life experience is important for both the dying as well as for the family. They aid in facilitating transition and acceptance of death. These experiences offer comfort, reduce death anxiety and in most cases have a positive impact. Visions of deceased relatives/ friends are commonly reported. Gradual physical and mental deterioration are noted.

The authenticity of such occurrences can be attributed towards the surprise or bafflement shown by the dying individual, care taker's observation as well as the similarity in results conducted in different parts of the world. Altered temporal lobe functioning is responsible for the hallucinations as well as for the near-death experience (Britton & Bootzin, 2004). Yet majority claim that these experiences are independent of medical, psychological & cultural factors. They are neither drug- induced nor due to psychopharmacological medication (Fenwick, 2007, 2010). They are experienced when the dying is in clear consciousness. Awareness, recognition & understanding of these experiences among care takers and medical professionals are essential as they mark the end of the individual's life.

Method

Aim: The aim of the study was to find out whether the deceased showed signs before their death. The objective was to understand and analyze the end life signs as reported by the deceased and as observed from the family perspective.

Research design: The phenomenological and narrative analysis was used in the study. This is to understand the nature and meaning of the subjective experience. It enables us to keep our existing understanding in abeyance and have a fresh look at things. In narrative analysis, individual stories are arranged in chronological order, from which themes are formed

Participants: Sample selected were 24 through snowball sampling or chain-referral sampling technique. They are the recently deceased's family members. They were from few parts of Coimbatore city. Sample size smaller because for the fact that occurrence of information is more important than the frequency (Ritchie., Lewis et Elam, 2003). Inclusion and exclusion criteria are as follows:

Inclusion criteria -Deceased- 1) the deceased' age was 60 years & above who had a natural death. 2) He/she died between the periods of January 2018- December 2019. 3) Conscious at least till 3 days before death. **Interviewee/ Participant-** Close family member of the deceased who is willing to participate

Exclusion criteria- Deceased- 1) Died in accidents or suicide 2) unconscious or in coma for a longer period 3) Drug abuse or alcohol abuse 4) Suffered from psychotic disorder. **Interviewee/ participant-** 1) Nurses or doctors.2) He/ she don't know about the deceased in person 3) Language barrier

Protocol: Open- ended questions were designed to elicit more information from the participants. The participants who met both the exclusion and inclusion criteria were selected for the study. They were called and asked for consent. Participants were told about the purpose of the research, what was expected out of them, about voluntary participations (to not to expect monetary benefits and can withdraw at any point of time without any negative repercussions) and confidentiality measures.

In- depth interview is optimal for collecting data on individual's perspectives, and experiences are being explored. Semi- structured interview with each individual, separately was followed. On an average the interview took 30-40 minutes. The participant provided the information through verbal interchange or conversation. It was audio recorded which was later converted into transcripts. The transcripts were analysed and extraction of significant statements- a process known as horizontalization happened. For each significant statements, meaningful themes are clustered. Resulting themes are integrated to form a rich description of the phenomenon under study.

We developed questions partially based on the information from the literature on death- related variables, which are the potential predictors of academic performance

RESULTS & DISCUSSION

Deceased- related Dreams

Dreams that occur before death have been reported and recorded by many researchers. On analyzing the narratives, it is found that many of the study's subjects had an odd dream few days/ weeks before their death. Dead loved ones/ relatives of the deceased person such as father, brother, mother, etc... are reported to be seen. Also other dead people whom the deceased had known (such as neighbors, people who resided in the same village) have also appeared. Dream contains not only the appearance of dead person but also in some cases, they called out the subject. When it was a known person, it was associated with greater emotional significance and less fear. These dreams may have caused an expectation in the subjects to expect their upcoming death. In the dreams of those who face death, the unconscious seems to be preparing the conscious for what is ahead – a dramatic transformation and continuation of life that the everyday conscious is unable to imagine (Franz, 1987, p. 156). However, the participants i.e., the family members didn't enquire about the content of the dreams sufficiently. So, it is vague about the impact of the dreams. Also, the subjects themselves told about such dreams and due to lack of enquiry from the family's part there may be loss of significant information.

Excerpts taken from the participant's interview about the subject in connection with the passage is shown below

“He suddenly woke at night and he told, “I'm going to die, I won't live for long time, my father is calling me and I wanted to see him and I wanted to take care of him”..... He only did in it once. It happened a month before his death”

Christopher W. Kerr et al. (2014) had conducted a longitudinal study on end-of-life dreams and visions. The results were most of the participants had experienced at least one dream/ vision. The most common dreams included deceased relatives/ friends and they gave comfort to the dying as well as to the care takers. Pre-death dreams can be beneficial and therapeutic (Sanders, 2007).

Visions of deceased

Visions of dead, gods, angels have been reported and recorded for several centuries. After analyzing the narratives, it is evident that the deceased had reported visions of their dead loved ones (father, brother, uncle, wife). A sister whose younger brother died few months back had mentioned in her last month that he was calling her.

“.....she mentioned that her brother is calling her and asked us permission to go.... last month of her death, once or twice...”

Similarly, a husband whose wife died 4 months back had reported visions of her, frequently before his death.

“He spoke mostly about my deceased grandmother.... He started to see my grandmother’s photo often..... The frequency increased..... One week before, he again told me that my grandmother is calling him”

Also, when death is near, the dying in her last hour stated that her father called her to join with him.

“An hour and a half before her death, she stated that her deceased father is calling her...”

An Indian study conducted by Muthumana et al. (2011) in Northern Kerala about deathbed visions concluded that the 30 out of 104 patients displayed behavior that is consistent with deathbed visions. In most of the cases, they are seen to be interacted with the deceased relatives.

Several studies conducted in different regions validate the occurrence of visions of deceased in dying population. Deathbed visions are not uncommon; they are different from drug-induced hallucinations and occur in clear consciousness (Fenwick, 2010, 2011). Nearing death awareness is not explainable in terms clinical hallucination, prior medication or psychological expectancy; Deathbed visions are not associated with psychopharmacological medication; the authenticity of the experience is also attributed to individual’s expressions of surprise or bafflement, frightening; DBVs are relatively rare in India (Gibbs, 2010)

According to Sanders (2007), a common behavior that occurs in deathbed visions is “the stare”, “a transfixed gaze where their eyes are fixated on the ceilings and seem to be following a moving object”. They sometimes also act based on their perception of the unseen and it suggest that they are concentrating on apparitions of the dead loved ones but unable to express it (Sanders, 2007). A similar incident have been recorded in our study where the individual concentrated on the ceiling few minutes prior to dying. She then suddenly told that she felt good and died minutes later.

“...she was staring at the ceiling...She was feeling quite uneasy, like she had some problem.... In her last 10 minutes she told, “I feel good”

Also, participants have reported that the dying person in his last hours stared at their loved ones for a long moment, when asked about the reason, they refused to reply. The loved one’s view this event as deceased’s desire to look at them one last time.

These visions may aid both the person and his family by providing comfort and peace as they believe that someone is there to take care of them after their death i.e., a survival after death in another realm. However when asked about the family member’s response towards such reporting, they considered such statements with less value and didn’t bother much.

Death-related talk

Some are able to predict or have an insight about their upcoming death. Countless documentations exist that bear the recurring theme of death premonition, often with the dreamer actually learning the accurate time of his or her passing from a previously deceased loved one or friend.

On analyzing the narratives, a number of subjects predicted their death. They told their family that they will die sooner or later. Excerpts from the interview in connection with the statement as follows:

“.... grandmother called me and told “I will die within some days”, after a week she died...”

Sometimes they are accurate enough that their death occurred at the time they predicted.

“He told.... he might die at any time, but he was physically well at that time.... He died the next day”

In one case, the subject predicted that her funeral would be grand and many people would know about her death. Surprisingly the same happened, her death was telecasted in news channel for some reason (Following her death, the villagers protested for a new graveyard and many news channels telecasted it.)

“She said that her death will be grand and everyone in the village will take part in her funeral....The same happened”

Another case went one step forward where the deceased made her funeral arrangements before her death

“Last one month she made preparations for her funeral; she was arranging bricks and sticks and told her son to use those bricks and sticks to burn her after her death....”

The results are similar to the views expressed by Sanders (2007) in her book *“Nearing death awareness: A guide to the language, visions, and dreams of the dying.”* Several incidents were collected in the book. An extract is given below:

“Christopher Landon, son of actor Michael Landon, recalled his eight-year-old sister asking her father if he was going to die, and when. Michael replied that he was and that it would probably be the next day. On the following day, he called his family together for a few moments, and then asked them to all leave the room. A few minutes later he passed away alone (Kessler 2000, p.115).”

A research by Muthumana et al (2011) in northern Kerala region gathered data and found out that 6 out of 104 cases had pre-monitions of death. But it still remains an element of mystery that why some are able to predict while majority couldn't.

Metaphorical messages

Symbolic messages can be vocally expressed or can be non-vocal. In some cases, the deceased's relatives reported to have a dream or a premonition about their loved ones nearing death. Most of the time, they didn't reveal it. Deceased had died after such occurrences within a week. The deceased had also expressed certain symbolic behavior such as quotes related to death; sudden desire to hear the death song (that is usually sung in their place when someone dies); covering their face with blanket & refusing to uncover it and also a sudden interest to travel. The person may pick at their sheets and clothing in a state of agitation. These behavior and action may seem aimless (Morrow, 2020). The metaphor of travel expressed is most commonly used as a symbolic message (Sanders, 2007). Excerpts taken from the interview about the subject is shown below:

“The previous day night, she suddenly told, ‘After dying the body will be in soil, does it require mattress now”.

Many instances, caretakers failed to decipher the meaning. Sometimes symbolically they can express their desire, need or wish or even past regrets that they wish to rectify. So it is essential to be sensitive to the elderly words rather than neglecting it as blabbering.

Unexpected unusual behavior

Sudden emphasis to see their dear ones, unexpected offerings and a sudden desire to visit places are seen. One factor may be that the dying had acknowledged his deteriorating physical condition which led to his desire to share and engage with his loved ones. A sudden surge of energy is noted in last couple of days. Other factor may be that the dying had an insight about his death which led to these positive behaviors. Expression of love by giving, creating cherished memories also fulfilling their final wishes are observed

Post-death related talk

It is quite common among elders to be concerned about the wellness and future of their next generation. However it has been considered significant because of their sudden occurrence or due to greater emphasis. Few subjects had advised them, while some requested a member of his family to look after the entire family. Few expressed their concern about who might take care of a particular family member in their absence. These communications were made either on the day of the death or few days before. When asked about family member's response towards such statements they usually agreed with them but later after their demise they were surprised. Participants commented that the deceased would have known about their upcoming death which led to these words. Excerpts taken from the participant's interview in connection is given below:

“Two hours before death he told my mother to take care of me and my brother if he is not alive”

The interpretation is that the person would have known about his imminent death. He aims for satisfaction by making amends so that his family can lead a life in his absence. He is worried about his loved one's condition after his death.

Emotional changes and change in attitude towards family

Emotional changes without any marked reason were observed in the last days before death. Kubler-Ross in her book *On Death and Dying* elaborated that anger is one of the stages among dying patients. But it seems to exist in non- patients (who isn't terminally ill) too. Increased agitation, frequent anger outburst and moody nature existed among the subjects. Even usual conversation and behavior of the family members was sometimes met with anger. When asked for the reason behind their behavior, frequently it was avoided or vaguely answered. So the reason is not clear. Excerpts from the interview in connection with the passage:

“He was getting angry for a small issue....2 days before dying.... my father scolded my mother in bad words.... my mother was shocked because he never had scolded anyone like this and he never had behaved like this”.

Contrary to anger, fear, anxiety, low mood and sometimes persistent silence was also observed among the dying group. There was no particular cause for these emotions. Anxiety can occur at any time in the dying process, independent of other symptoms (Angela Morrow, 2019). These distinguishable emotions can be considered as a response to their approaching death. However, no subject directly mentioned this as the reason.

As the body begins to shut down, the dying person may lose interest in person around them. They will stop talking, interacting or keeping up with the conversation (CRHCF, 2015). Avoiding communication or decrease in nature to engage in a conversation was observed. This can be perceived as the person's dejection state due to his nearing end. It can also be viewed as his sorrow as he had to leave his loved ones shortly. One of the excerpts from the interview that is in link with the above mentioned statements, as follows:

"She used to shout and talk. But last two weeks, she didn't talk much. She didn't talk to anyone"

As a person begins to accept their mortality and realizes that death is approaching, they may begin to withdraw from their surroundings. They are beginning the process of separating from the world and those in it. The person may also decline visits from friends, neighbors, and even family members (Morrow, 2020). They tend to focus inward and begin to detach from the world around them. (Morrow, 2019))

"....she started to avoid family function and sometimes she doesn't like seeing the relatives visiting her and even sometimes she starts yelling at them"

But few subjects on the contrast spoke more than usual to their family members. Also positive emotions such as heightened care, affection and love towards family members were noted. The most appreciable quality is that there was an increase in time spent with family. But strange ecstatic behavior was also reported the day before death. Excerpts taken from the interview in connection is as follows:

'A day before dying he cooked for the entire family and he was very much caring with us and he told "I'm very happy today for no reason and this day is my happiest day". My father cooking for the entire family was very strange'

They may crave for closeness or bonding with those they love (Morrow, 2019). In an article "Safe Passage When Death Nears: Signs and Symptoms" by Kansas City Hospital and Palliative Care, states that someone close to death may experience a temporary increase in energy and alertness; the person may become talkative and expects or encourages visitors.

Decline in cognitive and physical functions

When the person comes near to death their body system and function begins to slow down. As death nears, the person's condition deteriorates gradually. There is a decline in both mental and physical functions. They may show disorientation, frequent forgetfulness, restlessness and confusion. They may fail to recognize familiar faces and frequently forgets. Restless behavior included pulling bed sheets out, increased movement, agitation and so on. Confusion, agitation, restlessness and forgetting occur due to metabolic changes, decrease in oxygen supply to brain, dehydration and other chemical changes in the body.

"....she was confused.... not able to concentrate and she forgot things often. She was not able to recall some memories so she gets annoyed easily"

Other common signs are tiredness, fatigue, bowel and urinary incontinence. Both urinary and bowel incontinence are common near the end of life (David Hui, 2015). On the other hand, constipation can occur due to decreased mobility and decreased appetite. Physical weakness can lead to pain at time and the person

may sleep for long hours to restore the strength. Excerpts taken from the interview in connection with the above statements are as follows:

“But last two weeks, she refused to move. She seemed to be tired”

“... continuous vomiting and diarrhea, and loss of fluids from her body”

Pain and swelling of the extremities of the body occurs as death approaches. A very common cause of edema in a dying person is protein malnutrition. Fluid is most evident in dependent areas that are below the heart like the ankles and feet (CRHCF, 2015)

When death is within hours, the person’s breathing pattern changes. It may be rapid, shallow breathing; there may be a gurgling sound as air passes through in and out of the secretions such as mucus collected in the throat (Death rattle) or periods of rapid breathing followed by short periods of no breathing is very common, also known as Cheyne- Stokes respirations. Cheyne- Stokes respirations is caused by unstable ventilatory control as the heart and/or brain fails (CRHCF, 2015).

Change in food eating habits and preferences

Weeks or days before death, many individuals refuse to eat. There is a decline in food consumption. Since solid food is not taken, fluid intake such as water, grinded food, juices and other beverages increases. As the body begins to shut down, it loses the ability to process food and fluids. The person may show little interest in eating or drinking (Kansas City Hospice and Palliative Care). This is a natural and normal part of dying process. As the body’s metabolism slows down, the person needs less nutrition. Swallowing and eating may cause discomfort. So it is best not to try to force someone to eat. (Bolt et al 2015.) This decreased food intake won’t hurt and does not cause any suffering.

Sudden preferences for particular edibles, insistence to cook and eat only their favorite food and even teetotalers asking for alcohol and toddy happens. Excerpts taken from the participant’s interview in connection is:

“...past 2 weeks before death he was asking for his favorite food idly daily for dinner, lunch and breakfast and if we hesitate to cook then he will start scolding us”

Sleep cycle changes

Many subjects had sleep difficulty in last 1-2 months. They had trouble in sleep initiation, reduced sleep hours, sleep disturbances (usually waking in between the sleep) and some even mumbled in their sleep. This is in the contrary to the common findings i.e., as death nears, the person tends to sleep for long hours. However there was no significant reason behind these disturbances.

Family’s response/ reaction

There are many researches that support the viewpoint that these experiences are not drug- induced. They don’t occur due to medications. Also, there is no apparent physiological explanations for these behavior and communications (Callanan, M., & Kelley, P, 2012)

How do family members/ caretakers react to these behavioral changes of dying?

- Blame age as the reason
- Not able to understand them
- Use force or compel them to perform their activities/ routine

Loved one's presence is very important at this point of time. Empathetic listening, providing support and comfort, ensuring physical and emotional availability, offering an attentive and reassuring presence; empathy, acceptance and warmth is required. Respecting their needs & demands and efforts to fulfill it is necessary. Emotional outburst can be handled positively rather than getting offended.

The final days and hours of life can be rich with meaning and involve expressions of love. This is also a time of change and transition, both physically and emotionally. Handling it effectively can provide to comfort and satisfaction to both the dying as well as the family member. By utilizing the available resources and time, each and everyone can handle death in a better matured way.

SUMMARY & CONCLUSION

The research was done in order to understand whether the deceased had any awareness of his approaching death. Both the subject's verbal and non- verbal cues as observed by the family members were analyzed. Also family's response to these changes were also noted

The findings of the present study (& the insights derived) could aid in understanding the elderly better. It is important to respect the decline in condition in aged population. The changes observed are:

1. Deceased- related dreams
2. Reporting visions of deceased
3. Death- related talk
4. Metaphorical messages
5. Post – death related talk
6. Unexpected unusual behaviour
7. Emotional changes and change in attitude towards family
8. Decline in cognitive and physical functions
9. Change in food eating habits and preferences
10. Sleep cycle changes

By providing comfort, valuing their needs and demands, respecting their deteriorating condition, fulfilling their wishes and most importantly, honouring them with physical presence can help them in peaceful and meaningful death.

Knowledge about the process of dying and death may aid in perceiving death from a broader perspective rather than as destructive event. When people are able to sense their nearing death, some start to cherish their present and value their remaining time on Earth. Knowing about one's mortality, pushes individual to realize the importance of living their life to the fullest, at present, rather than passing through it.

For several years, research has been done on deathbed phenomenon. General consensus among those describing these death bed occurrences is that they are a source of consolation to dying patients and families (Wholihan, 2016). But it is mostly not recognized by health care providers and often considered as the result of medical delirium. Future research on its nature and causes is essential to validate its existence.

IMPLICATIONS

Near- death awareness and deathbed phenomenon are less explored concepts in Indian sub- continent. Only one study in Northern Kerala was published by Muthumana et al. (2011) on death bed visions. In science, confirming the reality of a concept generally comes not from a single observation or study but from many independent studies with different methodologies. This cross-checking among scientific studies has always been the foundation for validating scientific discoveries. Hence, future research in different regions of India, in different populations could be done.

Samples in most of the previous studies were terminally ill patients. They were patients in hospice and palliative care. The present study focused on deceased who functioned normally and who had a natural death. Future studies can target such samples who were healthy and who had attained a sudden natural death. Other scope is that that the present study's targeted population was 60 years and above, future study can consider sample below 60 years.

The cause of these experiences is unclear or vague; researchers can examine the various assumptions behind the origin. Also to analyze gender difference, comparative study between other countries and India, the impact of such experiences on both the care taker and the dying could be considered for further research.

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