

The Attitudes and Perceptions on Death and Dying in Hospital, of Adult Patients and Families Who Have Received Palliative Care

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Nurse Maude

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"You slip in and out of my room, give me medications and check my blood pressure. Is it because I am a student nurse, myself, or just a human being, that I sense your fright? And your fears enhance mine. Why are you afraid? I am the one who is dying!"

"Don't run away - wait - all I want to know is that there will be someone to hold my hand when I need it. I am afraid. Death may get to be routine to you, but it is new to me. You may not see me as unique, but I've never died before. To me, once is pretty unique."

(Anonymous, as cited in Kübler-Ross, 1997, p.26)

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Methodology

- Systematic review of qualitative journal articles
- 17 databases, past 10 years
- Total 18 articles
- Thematic analysis
- Findings reported in narrative format

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Findings

- Preference for place of death
- The hospital setting
- The influence of health professionals
- Addressing the personhood
- Family dynamics
- Communication
- Death and dying



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1. Preference for place of death

- Hospital as the right place to be

"I'm forced to think about myself and only myself and not 10,000 other things around. And I'm helped by professionals who know how to help me to help myself...For me this is the right place."

- Hospital as a last resort as a place to die

"My husband was roaring, it was like animal noises, and he was punching out and flailing with his arms, so [the ambulance crew called to the scene at home] decided to bring a chair to put him in. Well, he fought and he fought [...] In hospital they gave him something to sedate him every 10 minutes, but then he was back again fighting, with his arms and what have you" (wife)

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- Home as the preferred place of death

"Imagine being in a cold, sterile hospital room. At home, the children and myself had contact with her all the time." (family caregiver)

- Hospice as the preferred place of death

"I know she's not going to be alone, that someone will sit next to her. That's reassuring, [...] I know she's in good hands. It's not like in the hospital here. You feel guilty if you leave because she's alone because they don't have time." (daughter)

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2. The hospital setting

- The environment

"I do think that four people to a room for people who are seriously ill is hard on everybody there, because nobody has any privacy. You know, you've got TVs going, you've got people in and out.... I felt by moving him to a private room that he was allowed to die with some dignity and love and in a peaceful environment with people he loved around him, and we were allowed to ... express our feelings and emotions in a private way.... I truly consider that a gift...." (daughter)



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3. The influence of health professionals

- Positive qualities displayed by health professionals

"I remember sitting there ... and people coming in and (seeing) that we had what we needed..." "Do you need a pillow? I'll get you a blanket." ... I never felt alone. I felt like there were people out there that I could call on.... I just want to stress how secure I felt in the hospital, how cared for, that they cared about him, and they cared about me." (75-year-old wife)

- Negative qualities displayed by health professionals

"The nurse did just the absolute minimum that she had to do. There was the medications at night. She entered, didn't say "Good evening", did something with the equipment and, "Good night", and out and gone. Didn't ask "How are you", ring the bell, if you don't feel well or whatever."

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- The intricate relationship between the patient and the health professional

"I was alone of course after I had been told my diagnosis and it is not a very nice thing to be told that you have maybe months left to live. I was very touched that afterwards one of the nurses came and sat by me."

- The complex relationship between the family and the health professional



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4. Addressing the personhood

- Tending to the patients' biopsychosocial needs

- Family members' needs and unmet needs

"I wanted the nurses to care about us more, to come and show their concern for us... to support us so as to reduce our feeling of helplessness." (family member)

- Effects on family members

"And then I had to get him up into a sitting position in bed, and even if he only weighed sixty kilos, it was a tough job. To describe the final days, it was simply work, work, work, work." (wife)

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5. Family dynamics

- The interwoven relationship between the patient and their spouse

"To me it felt safe to be there, but for him you might say it was a need. And to be able to help I felt was a good thing. Yes, I thought it was very good!" (wife)

- The varied and complex relationship between the patient and their family



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6. Communication

- Effective communication is a skill and an art. It is an essential skill when conveying the good, the bad and the sad news

"Well I was in hospital a fortnight after the tests and all that and I was informed it was terminal. I was just lying in the bed there. The other patients were getting seen to and I was not. There was nobody who came up to me."

- To be listened to

"Oh, a listener, a listener and somebody who will listen to you and doesn't talk. You want to talk to somebody and you don't want to have to listen to them."

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- To be informed and updated

"I found that period really hard, and maybe the hospital could have given me a bit more support at that point. You're faced with your husband in that state, but nobody sort of said: 'He won't get well'" (a bereaved wife who felt angry that she was not updated about her husband's condition during his final days of life)



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7. Death and dying

- Acceptance of the imminence of death

"Nobody said to me, look we should talk about what you might face at the end." (91-year-old female family caregiver)

- Before death

"We were able to tell him goodbye before he passed away. We were encouraged by a nurse there on the unit that it would make us feel much better afterwards." (wife)

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- Being present at the time of death

"I was right there beside him . . . when he died. While it was upsetting, it was also a little reassuring. . . . I don't have to wonder what it was like for him. I don't have to worry that he wanted me and I wasn't there. And I was there. . . . It was a gift 'cause it helped me to be able to help him." (wife)

- Not being present at the time of death
- "Not being here to actually be with my brother when he passed (very tearful) left me so upset. He had no one. . . . Nobody, nobody. And he was a good guy (tearful). I didn't want him to know that he was alone." (sister)



- After death

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Discussion

"We have one attempt at this journey; we need to get it right"

- "How people die remains in the memories of those who live on" - Dame Cicely Saunders

"What matters to you?"

- Lack of conversation around preparation for death and dying
- Advance care planning (ACP) enables patients to have a say in what they want, especially when they are unable to speak for themselves

"Guests of necessity"

- How can we be good hosts to our guests?
- It is the little things that matter the most

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