

Preference for Dying at home – what is meant and what is said

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RESULTS

We were surprised by the fact that only half of the patients in our sample died at home, although the hospice and palliative care service provided 24/7 support for patients and their families and admission criteria included, amongst others, a preference for dying at home.

Comparison of data from documentation analysis with observations and interviews showed a diverse picture. Open awareness and communication of dying and death issues had a big influence on place of death, and place of death issues, where important, worked as a trigger for open communication. Even if open communication about place of death was observed, what was said was often not what seemed to be meant. We worked out three specifications and of a “preference for home (death)” and a further dimension primarily important for family carers:

(2) Staying at home until at last

Some expressed a wish to be cared for at home until at last, which implies that “at last” is something separated from this care and might take place somewhere else. This group illustrates best the difference between “place of care” and “place of death” [3]. In our sample this difference was not communicated clearly, neither by patients nor their families. Especially care needs which went along with progression of decline, worked as a marker for the limits of staying at home (see example of Ms. M.)

(4) Death entering the home

Even if family members supported the care for the dying at home, it did not necessarily mean a preparedness to confront themselves with death entering the home, which was often perceived as impossible for going on living there. The wife of Mr. U., who finally died in a hospital, talked openly about her preferences for the first time in the interview five months after her husband's death:

(1) Living at home

The home usually is associated with normality and living. Some people who expressed the wish to stay at home were by doing so denying the fact of dying and impending death. They mainly used “living at home” as a metaphor for “going on with living as if nothing had happened at all.” Indeed, these trajectories were not characterized by open communication of dying and professional support by the hospice team turned out to be a challenging endeavour. None of these cases in our sample ended up dying at home (see quote Ms. D.).

(1) *“Well, all I want is sitting here in my chair with Lizzy [cat], things will turn out the right way, they have always, didn't they?” (Ms.D.)*

(2)

*“The doctor then asks Ms. M, if she has already thought about when it would be time for her to move, when she feels she could not go on at home any longer. Ms. M. replies quickly and vehemently that she cannot imagine staying at home, when she is not able to go to the toilet on her own or in case of incontinence.”
(Field note, visit at Ms. M.)*

(3) *“She said that she wanted to die at home. She made clear, that she would never enter that hospital again and she did not want to go to a hospice. She wanted to die at home, and this raised the question of “how can we manage this at home?”
(Ms. Z.'s sister, retrospective interview)*

(3) Dying at home

Family members who really committed themselves to dying at home were well aware of the challenging process of caring for a dying person. It became clear in these trajectories how fragile dying at home is, even if they were supported by a specialist palliative care team. We observed for example that the decision against aggressive had to be continually negotiated and confirmed between all parties involved. However, if patients were very explicit in their wishes, family members found it easier to comply. (see quote Ms. Z.'s sister):

(4)

*Ms. U: “I saw that when my father died, and I did not want to have this again. It was so important to me, that he [her husband] did not die at home.”
I: “Why so?”
Ms. U: “Well, because of the memories. You will always have the picture in your mind, and the room, I did not want to have this happen where I was expected to go on afterwards.”*

BACKGROUND & AIMS

Preferences for places of death have become a key issue in the wider discussion on good end-of-life care. Though there is some evidence for factors influencing death at home stressing the importance of social factors like stability of preferences for family carers and patients, little is known about the complex process of negotiating place of care and place of death throughout the process of care [1, 2]. An ethnographic study on recognizing and acknowledging dying in home care puts light on this issue and adds some insight why preferences and outcomes regarding place of care and death might differ.

METHODS

We applied an ethnographic approach to reconstruct trajectories of 15 dying patients in a specialist home care service (see Table 1). All patients involved had cancer. Data were drawn from observations, interviews and analysis of patients' records with the latter being recorded and transcribed verbatim. The observation period reached from admission to the service until death of patient, perspectives of bereaved carers were gained by interviews 3-5 months later. Theoretical sampling as well as several coding procedures supported by Atlas/ti software were used in analysis following a grounded theory approach. Recruitment of patients and carers for observations was done by staff members of the service.

Characteristics of Patients (n=15)	
Age	46-90 (Ø 67)
Gender	10 female, 5 male
Observation period (first contact until death)	11 to 105 days (Ø 33)
Diagnosis	Cancer - n. bronchii (n=4) Cancer - n. mammae (n=4) Cancer, other (n=7)
Place of death	At home (n=7) Hospital (n=4) Inpatient Hospice / Palliative Care unit (n=4)
Relationship to Informal Carers involved in study	son (n=7) daughter (n=4) husband (n=4) wife (n=4) Neighbour/friend (n=2) granddaughter (n=1) parents (n=1) partner (n=1) sister (n=1)

CONCLUSION

- It is necessary to look for unspoken wishes and fears behind preferences for place of death, what is said is often not what is meant.
- However, they might not be easy to reveal in practice, they might change over time [3] and we have to be aware of the different perspectives of the parties and persons involved.
- Therefore professionals have to organize ways of communicating and negotiating these wishes openly within the families, especially if death at home should be possible.

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References

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