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Expected deaths at home – a qualitative study of collaboration

ORIGINAL ARTICLE

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BACKGROUND

It is a goal of health policy that more patients with serious illness should be able to die at home. This study elucidates the collaboration between healthcare personnel and undertakers immediately after the death, the dignity of the deceased patient and the bereaved relatives is challenged.

MATERIAL AND METHOD

The study is primarily based on five focus group interviews with undertakers, GPs, nurses and healthcare workers in homecare nursing, a total of 23 participants in an urban municipality.

RESULTS

The GPs and homecare nurses experienced concurrency conflicts which resulted in the downgrading of tasks concerning the deceased patient and bereaved relatives. Lack of clarity was identified concerning the doctors' verification of the death and completion of the death certificate, and the homecare nurses' personal care of the deceased patient. If the issuance of the death certificate was delayed, this had an impact on the way in which the deceased patient was dealt with by other parties involved.

INTERPRETATION

The current GP system and the emergency primary health care scheme do not appear to have adequate resources for the doctor to be able to verify death and complete the death certificate, with potentially negative consequences for the subsequent work of undertakers and homecare nurses with the deceased patient and bereaved relatives.

Main findings

The study points to lack of clarity in the collaboration between undertakers, homecare service, GPs and out-of-hours medical services in cases of expected deaths occurring in the home.

Advance care planning should address what will happen immediately after the death has occurred.

Delays in the doctor's verification of the death and completion of the death certificate may have negative implications for the bereaved family as well as other professional groups involved.

Many terminally ill patients wish to end their life at home surrounded by the family (1, 2). There are numerous studies on good home palliation (2–5), but little evidence-based knowledge about procedures and collaborative relationships immediately after an expected death has occurred in the home. Neither empirical studies, nor the recommendations for palliation of seriously ill and dying patients highlight how the deceased person and the bereaved family should be cared for with dignity in this phase (6–8). However, the World Health Organization's (WHO) definition of palliation and the recommendations from the European Association of Palliative Care (EAPC) include care for the bereaved as one of the core areas (9, 10). When a person dies at home, the bereaved relatives will face challenges of an emotional, practical, ethical and legal nature, which include interaction between health personnel and undertakers. The Health Personnel Act states that 'medical practitioners shall issue certificates of deaths that they acquire knowledge of in their practice' (11).

The doctor must personally verify the death to provide the necessary information on cause of death and complete the death certificate (12).

In cases of expected death in the home, the homecare service and the family GP will normally be involved. The bereaved themselves will most often contact the undertaker, who will start their work. Our prior understanding, which formed the basis for the study, was our awareness of insufficient cooperation and an unclear distribution of responsibilities between health personnel and the undertakers in some municipalities, including reports that the deceased in some cases were transported to the A&E clinic in order to have the death certificate issued. The objective of the study was to gain insight into experiences and challenges as well as coordination and collaboration between health personnel and undertakers after expected deaths had occurred in the home.

Material and method

Data collection and analysis

The study is based on five focus-group interviews with health personnel and representatives of firms of undertakers, with a total of 23 participants. Focus groups are a qualitative research method which is suitable for obtaining rich descriptions of the participants' experiences and in-depth knowledge about complex phenomena. The method is especially suited for use in areas where there is little pre-existing knowledge (13, 14). One focus-group interview included three participants from different firms of undertakers in an urban municipality and one participant from a firm of undertakers in a rural municipality. The other four focus-group interviews included health workers: two groups with a total of seven nurses and four other health professionals, and two with a total of eight GPs. Separate focus groups were chosen for the different groups of professions, in order to-enable them to share common experiences from the perspective of their role. Nurses and health professionals were recruited via local nursing

managers. Seventeen GPs and five firms of undertakers were contacted by telephone and email. Eight GPs and representatives of four firms of undertakers attended the interviews. The interviews lasted 80–100 minutes. We asked for accounts of the participants' experiences in relation to the research question. Semi-structured interview guides were used (see Appendices 1 and 2).

The interviews were recorded-and transcribed verbatim by two of the authors (AMS and BVD) in the autumn of 2015 and spring 2016. We used systematic text condensation with four analytical steps (14, 15). All the authors read the interviews several times to obtain a general impression and identify main topics, with special attention to the descriptions of how the groups of professions interacted. We agreed that the interviews provided sufficient information for further analysis and proceeded to develop code groups based on the main topics. Meaningful units that represented the participants' experiences were identified in the text for each code group. In the next step we defined subgroups for each code group, where the text was systematically reviewed and condensed. In the last step we synthesised the condensed content from each code group to analytical text with descriptions of the informants' experiences of challenges, coordination and cooperation related to expected deaths that had occurred in the home.

To form an impression of procedures and experiences in locations other than the urban municipality in question, in the spring of 2018 we contacted the leaders of A&E clinics in ten large Norwegian municipalities and regional leaders of the trade association that represents approximately 90 % of all Norwegian firms of undertakers. These received a simple questionnaire on the distribution of responsibilities between the groups of professions involved. All eleven regional leaders and seven A&E clinics completed the questionnaire Appendix 3). The responses were subjected to thematic analysis and linked to the main categories from the analysis of the focus-group interviews ((16).

The study was approved by the Norwegian Centre for Research Data (project no. 45256). All focus-group participants were informed about the study in writing and provided written consent to participating.

Results

The analysis of the focus-group interviews resulted in three main categories.

Concurrency conflicts

All the groups of informants reported concurrency conflicts. The GPs normally prioritised their scheduled patient appointments over making a house call to verify a death and issue a death certificate after expected deaths. They tended to make an appointment to drop by the home and complete the death certificate after working hours, or on the way to work the next day. Some GPs gave the family the opportunity to call them in the evening when the death was expected, but they did not want to be contacted during the night.

'I make an appointment to come the next morning if the patient dies during the night. It also happens that I go to the home at night if the family asks me to' (GP 1).

The undertakers reported that the bereaved often felt that they had to wait too long before the GP arrived.

'The bereaved call us at two o'clock in the morning and the GP cannot come before 18.00 the next evening. That's quite a long time to have someone lying there. That's why we need to go out during the night time' (undertaker employee 1).

The A&E clinic was frequently used to verify the death and issue the death certificate. Most often, the homecare service or the police would make an appointment with the A&E clinic. The employees of the firms of undertakers reported that a doctor from the A&E clinic would never go to the home of the deceased to verify the death. This was confirmed by the questionnaire from the A&E clinic in the urban municipality in question. The undertakers transported the deceased to the A&E clinic once the police had given permission to move the deceased person. At the clinic, they had to wait with the deceased person in the hearse until the doctor on duty could inspect the body and issue the death certificate. They felt uncomfortable with this practice and had attempted to change it by having the A&E doctor come to the home instead, but with no success.

Nurses and health professionals in the homecare service wanted to spend more time than their schedules permitted in the home after a death, but needed to prioritise other tasks.

'You really want to be there, but then there's the rest of the worklist. That's hard, that the list means so much when you're in the middle of a vulnerable situation' (nurse 1).

Sequence dependency

The concurrency conflicts were closely associated with sequence dependency. If the issuance-of the death certificate was delayed, the natural handling of the deceased was disrupted and changed for the undertaker and the homecare service. As a result, the police often became involved and the deceased person transported to the A&E clinic.

The undertakers called for better coordination of the various agencies involved. They stated that the bereaved family was placed in a difficult situation with a perception of an undignified treatment of the deceased, who could not be placed in a coffin before the doctor or the police had confirmed that there were no suspicious circumstances.

'It's a strong experience to see the deceased in the coffin. They have had the sick person lying in bed for such a long time. It's not until *then* that you can bid farewell' (undertaker employee 3)

If the death occurred during the night or when the GP was unavailable, the situation was especially vulnerable. The undertakers reported being called by exhausted family members who could not be calmed down because they needed someone to take care of the deceased. They perceived the doctor's role as that of a gatekeeper for the subsequent procedures, in which verifying the death and completing the death certificate are critical functions. Since the GP was rarely available and the A&E doctor in this urban municipality was never on call-out in such situations, a frequent solution was to contact the police. The informants from the firms of undertakers reported that the bereaved were not prepared for the arrival of uniformed police officers or for the deceased to be transported to the A&E clinic, and that they tended to react negatively to this. The GPs, on the other hand, felt that the undertakers were too quick to react and ought to wait if they were called during the night.

'The fact that they choose to have a dialogue with the A&E clinic and transport the deceased there is a very unfortunate solution' (GP 2)

The representative of the firm of undertakers in the rural municipality reported that an A&E doctor would come to the home if the GP was unavailable. The questionnaire from the regional leaders of the firms of undertakers revealed that in general there were arrangements for the A&E doctor to come to the home if the GP was unavailable, but in their experience, transport to the A&E clinic could occur in some municipalities. Many reported that the waiting time could be long before the arrival of the A&E doctor.

'We want families who report deaths to feel that they are taken seriously and the A&E doctor to arrive quickly' (nationwide firm of undertakers 1).

Preparation and personal care for the deceased

The undertakers wanted the GPs and homecare service to engage in advance care planning to prepare the family for the process that would follow the death.

'Advance information to the family is very important: about what will happen when we have reached the point when the death occurs' (undertaker employee 4).

The doctors reported that finding the ideal timing for such advance care planning was difficult, and that these conversations often did not take place.

The undertakers, the homecare service and the GPs all agreed on the importance of ensuring calm and dignity in the aftermath of a death. The GPs spoke of the importance of a dignified farewell to the deceased and offering one's condolences to the bereaved family.

'When you have followed a patient during the final stage of life, little extra effort is required to go to the home to offer your condolences and complete the death certificate' (GP 3).

The homecare service made clear their wish to have enough time after a death to provide personal care for the deceased, preferably accompanied by the family. They wanted to arrange the deceased nicely, light candles and establish a setting for a dignified wake. Homecare service staff from the urban municipality reported to have been instructed that providing personal care for the deceased was the undertakers' responsibility. The homecare service would provide personal care for the deceased person only when this had been especially agreed.

'I miss being able to care for the deceased, preferably in the company of family members. We've been told by the management that we should not provide personal care for deceased persons' (nurse 2).

The firms of undertakers in the urban municipality were certain that homecare service staff provided personal care for the deceased. They thought it was strange that the homecare service could not take care of a deceased person, whom they had cared for over a long period as a patient. The undertaker from the rural community, on the other hand, reported that the deceased were always cared for by the homecare service.

The homecare nurses wanted to say their final goodbyes and provide support to the bereaved by attending the funeral of patients with whom they had developed a long-standing relationship. They experienced a varying degree of acceptance for prioritising this during working hours, and would therefore often do this in their leisure time.

Discussion

The study uncovers challenges in the cooperation between healthcare personnel, undertakers and the bereaved after expected deaths in the home (17). This includes the doctor's responsibility for the verification and death certificate, the homecare service's care for the bereaved and the deceased person, and the undertakers' work with the deceased and fulfilment of the needs of the bereaved family. If this interaction is not coordinated and planned, unfortunate *ad hoc* solutions may result. The study uncovered three main issues: concurrency conflicts, sequence dependency and challenges in providing personal care for the deceased. We have not identified any other Norwegian or international studies that investigate the collaboration between undertakers, homecare service and doctors in cases of expected deaths that have occurred in the home.

Concurrency conflicts are a result of the fact that healthcare personnel have no on-call preparedness or extra time available beyond their stipulated programme when someone dies at home. The study indicates some challenges that are inherent in a streamlined and task-specific health service. The bereaved and the doctor on duty may have very different perceptions of time, whereby the doctor's natural prioritisation of living patients means that tasks related to the deceased must wait.

Even though our informants reported that some GPs will do house calls for their own patients outside working hours, it is unreasonable and there is no contractual basis for expecting this kind of general preparedness from the GPs. The current GP system appears to provide insufficient parameters for GPs to quickly undertake the verification and complete the death certificate. However, the sequence dependency indicates that the doctor's tasks are crucial, because they pave the way for the further process. The responsibility for ensuring that a doctor undertakes verification at the place of death outside the GP`s working hours within a reasonable time frame is therefore often placed on the A&E clinic. The study indicates that delays in verification and completion of the death certificate can have negative consequences for the bereaved as well as for the other parties involved.

We found that tasks such as caring for the bereaved and personal care of the deceased are often delegated to the undertakers. This is not in compliance with the World Health Organization's understanding of palliation, which underscores that healthcare personnel are responsible for helping family members and the bereaved in their grieving process (10). The study indicates that the palliative follow-up is discontinued too early. Delegating the care of a deceased person to the undertaker violates fundamental nursing responsibilities (18, 19). Homecare nursing has normally been established before an expected death in the home, and we question whether municipal homecare services can disclaim responsibility for personal care for deceased persons. The deceased may change, and emit odours. The bereaved may perceive such changes as difficult and frightening. Care and preparation should therefore take place as soon as possible after the time of death.

According to prevailing legal regulations, a death must be declared at the place where it occurred (11, 12). The study shows that unfortunate and undignified practices may arise if the doctor fails to come to the home to undertake the verification and complete

the death certificate. Examples include calling the police and transporting the deceased to an A&E clinic to have the death certificate issued there. A situation that calls for calm and dignity may therefore be perceived as traumatic and undignified by the bereaved. A wake with the deceased in the coffin cannot be held if the deceased must be removed to have the death certificate issued. Appropriate care and respect for the deceased and bereaved mean that transport to the A&E clinic should be avoided. The police should only be involved if there is a question of death by unnatural causes or if the person has died alone (3, 11). The homecare nurses wanted to have more time to cater to the needs of the bereaved and the deceased person, and would prefer to conclude the contact by participating in the funerals of patients they had cared for over a long period. This is a matter of resource availability, but also of care for employees and bereaved relatives (20).

The quality of the Causes of Death Registry relies on the doctor who completes the death certificate having sufficient information on health issues of the deceased and knowledge of how to state the cause of death (21). The registry data provide an important basis for health monitoring and preparedness. Its degree of coverage is nearly universal, but studies indicate that non-specific codes for causes of death are too frequently used (22). Widespread use of A&E doctors to complete the death certificate with no access to necessary information in the patient records may conceivably contribute to this. A future solution for medical records that ensures access to relevant information about the deceased to the doctor who completes the death certificate will be likely to improve the quality of data in the Causes of Death Registry.

The study indicates that in order to ensure a dignified closure in the home, better collaboration and a clearer division of responsibilities between GPs, A&E doctors, homecare nurses and undertakers is called for. Guidelines and procedures should be designed to ensure that the deceased and the bereaved can be equally well cared for irrespective of whether the death occurs in a hospital, nursing home or at home (18).

The findings may also indicate that there is a need for procedures to ensure that homecare nurses and GPs take responsibility for advance care planning with the patient and his/her next of kin (6, 23). The planning should be specific and include information about the time immediately post mortem. Written information can be useful, but cannot replace advance care planning. Established collaboration during the palliative phase and joint home visits by the GP and the homecare nurse responsible can provide a good setting for advance care planning.

The municipalities should provide and organise necessary assistance by healthcare personnel when expected deaths occur in the patient's home. In light of the requirement for adequacy, the municipality must be expected to organise the service in such a way that a doctor can verify the death at the place where it occurred. The municipality should ensure access to necessary nursing and medical resources, including outside-the doctor's contractual working hours. Systems that ensure predictable forms of collaboration between homecare nurses, GPs, A&E clinics and undertakers can provide better care for the bereaved, dignified care for the deceased and better working conditions for the personnel involved.

A new national manual for out-of-hours services and emergency medical communication centres was published on 28 February 2020 (24). The manual also describes the doctors' responsibility for verification of deaths and completion of death certificates in cases of expected deaths in the home. No reference is made to care for

the bereaved, nor to preservation of the deceased person's dignity. We understand that long distances in some municipalities can represent a challenge, but we question that the manual permits use of audiovisual aids to replace home visits to verify a death, and allows transport of the deceased to a morgue before the death certificate is completed. In our opinion, the manual is at odds with the ideal of a dignified home death.

Our study has some strengths and limitations. The participating informants may have been especially concerned with the topic of the study and thereby not representative of their colleagues. Focus groups with colleagues from the same profession can focus on different information when compared to focus groups that include different professions. A study based on focus groups with several interacting professions might elucidate this topic in a different way. We believe that the groups of health professions included in this study play a key role in the interaction with the undertakers. Other professions, for example clergy, may play an important role. The findings in this study cannot be generalised to other municipalities. To elucidate practices in other regions we collected supplementary information from firms of undertakers and A&E clinics. This information indicated that practices differed, but the most common procedure in most municipalities was that the A&E doctor or the GP came to the place of death to verify the death and complete the death certificate.

The strength of the study is its elucidation of the experiences of collaboration among healthcare personnel and undertakers at a stage that has previously not been focused. In this description we have pointed out some prerequisites that should be met to ensure that the various actors involved immediately after a death can complete their activities appropriately.

The article has been peer reviewed.

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