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Conversations with patients about death – experienced GPs' reflections and experiences

ORIGINAL ARTICLE

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Background

The ageing population in Norway is steadily increasing, and both the number and complexity of patient-related tasks assigned to the primary health service, including GPs, are growing. This study aimed to investigate how experienced GPs conducted and reflected on conversations with their patients about death.

Material and method

Semi-structured in-depth interviews with ten experienced GPs, all specialists in general practice, were analysed using cross-case thematic analysis.

Results

Almost all the GPs viewed talking about death with their patients as a natural part of a GP's duties. The conversations were perceived as both challenging and meaningful. Having sufficient time for the conversation and getting to know the patients over time were considered valuable factors for good conversations. The GPs looked for golden moments in which to address the topic. The content of the conversation could vary, from specific measures to alleviate symptoms to the more existential and philosophical. The GPs expressed that they lacked formal competence and largely relied on their experience and belief in their communication skills when interacting with patients. Several described the lack of clarity on treatment intensity from the specialist health service as a barrier to initiating and conducting good conversations about death.

Interpretation

Most of the GPs in this study talked to their patients about death and considered it a natural and necessary part of the GP's role.

Main findings

Most of the general practitioners (GPs) who participated in this qualitative interview study regarded conversations with their patients about death to be a natural part of the GP's role.

The doctors reported that they had not received training in communication about death, but nevertheless felt confident in this role.

Having known their patients for a long time and in various situations was seen as a strength, making it easier to initiate and conduct conversations about death.

The ageing population in Norway is increasing. Older adults are receiving treatment for longer and are living longer with acute and chronic illnesses (1). The increase in seriously ill older adults living at home, along with the higher death rates in this group in Norway (2), suggests that more situations will arise in the future where general practitioners (GPs) can and should have conversations about death with their patients. And GPs have considerable patient contact: patients over the age of 65 visit their GP five times on average per year, and the corresponding figure for frail older adults is 7.2 (3).

People who want to die at home should be accommodated as far as possible (4), and their GP should play a key role in this process (5). In Norway, few patients die at home (6), even though many wish to do so (7). Other Norwegian studies have shown that GPs are willing and eager to be involved in palliative care (8, 9), but are prevented from doing so by structural and individual barriers (10).

The ideological foundation of Norwegian general practice is based on continuity, comprehensiveness, personalisation and commitment (11). The GP-patient relationship often lasts for many years, with continuity sometimes spanning several generations.

International studies of patients' and their families' wishes for palliative care and conversations about death suggest that such conversations are infrequent and of a low quality (12–14). Even when patients were ready, the need for advance care planning was rarely met (15).

Deckx et al. (16) studied how hospital specialists in general practice can initiate a conversation about death, and identified four key themes: preparing the ground, finding an entry point, tailoring communication and involving the family.

Norway's recently published national clinical guidelines for planning in the context of limited life expectancy state that advance care planning should be offered to patients with severe, incurable illnesses or a high risk of severe illness episodes due to advanced age and significant physical frailty (17). The national clinical guidelines for end-of-life palliative care (4) stress the importance of communication and patient involvement. Effective communication with seriously ill and dying patients is also emphasised in the national action plan for palliative cancer care and in the national guide on decision-making processes for limiting life-prolonging treatment (18, 19).

The aim of this study was to investigate how experienced GPs conducted and reflected on conversations about death with their patients.

Material and method

We conducted semi-structured individual interviews with a strategic sample of experienced hospital specialists in general practice who were contract GPs. We chose this group because we expected them to be more confident in the role and to have more experience with such conversations than their less experienced colleagues.

Material

Relevant potential participants from the same county in Norway were contacted by the first author. None of the participants had a formal employment relationship or personal association with the interviewer.

Ten in-depth interviews were conducted between February and August 2022: nine at the participants' medical practices and one via a video call. The sample was made up of five women and five men ranging in age from 37 to 63 years. Their patient lists varied from 600 to 2500 inhabitants, with a median of 1050. The number of years in practice ranged from 9 to 28. Most of the doctors worked in group practices, with six participants in urban/suburban practices and four in small towns. All informants were specialists in general practice.

The interviews lasted between 27 and 73 minutes, with a median of 45 minutes. We used a self-developed thematic semi-structured and flexible interview guide (see Appendix 1).

The interviews were recorded on a portable tape recorder (Olympus VN-541PC) and transcribed verbatim. NVivo 12 software was used for initial coding and as a basis for thematic analysis. The authors developed the themes in a reflexive process consisting of themed meetings. All interview transcripts were sent to the respective participants for review and comment.

Analysis

We carried out a reflexive thematic analysis, as described and developed by Braun and Clarke (20, 21), which is a cross-case interpretative thematic analysis approach that is flexible and adaptable. Our analysis was a six-phase process: familiarisation with the data, coding the data, generating initial themes, reviewing and developing themes, defining, naming and refining themes, and synthesising the results. We were able to refine our focus and the interview guide during the simultaneous interview and analysis process. We focused on manifest content, basing our analysis on what the informants actually said rather than interpretations of this, and the analysis was primarily data driven.

FBE and HS developed the idea and devised the protocol and interview guide. FBE conducted all interviews and transcribed them. After the first three interviews, FBE and HS conducted an initial assessment of the thematic content in the preliminary data, coding process review and direction for subsequent interviews and the interview guide. FBE then coded the remaining interviews, employing a flexible approach with no fixed coding framework. All authors read all the interview transcripts and helped to develop and refine the themes. To ensure participant validation, FBE presented the main findings to three participants, all of whom recognised the main themes.

Ethics

The Regional Committee for Medical Research Ethics South East Norway assessed the project as not subject to reporting (application number 412496). The Norwegian Centre for Research Data approved the data processing and data protection in the project (case number 128597).

All participants gave oral consent to being interviewed and signed an information and consent form. Each participant received a universal gift card worth NOK 1500. Direct quotes were anonymised using fictitious names indicating gender but not age.

Results

Of the ten GPs, nine felt that conversations about death should be a natural part of the GP's role, and they had experience in discussing death with patients. This is described below in the three main themes defined in the reflexive thematic analysis: 'A natural part of the GP's role', 'An experience-based conversation', and 'Golden moments, sensitivity – and what the conversations cover.'

The other GP did not talk about death with their patients and did not see this as part of their role or duty. This GP believed that such discussions were adequately addressed in other settings and therefore never initiated conversations or reflections about death and their final moments. This GP explained their reluctance as a wish to avoid upsetting patients or adding to their burden.

A natural part of the GP's role

Most of the GPs described conversations about death as a natural part of their role. This was because they had cared for their patients for many years, often with regular check-ups, were familiar with the patients' social circumstances, and often had a close and long-standing professional relationship with them.

'It was me who did it. It usually is. I tend to do that when you realise they're seriously ill.' (Trine)

Several participants described how through their many years as a GP they had gained broad-based knowledge of people and experience in handling difficult patient issues. Their practical experience over a long period was essentially more critical than the individual doctor's personality or interest. They considered the GP's broad role to be of great importance.

'I think it's absolutely crucial that the GP is, or remains, the central figure in care, even in a patient's end-of-life phase.' (Knut)

Many of the GPs felt that their experiences with patient conversations over time, along with knowledge of what the patient had gone through previously, helped create a sense of reassurance in the conversation, both for the GP and the patient.

'But sometimes I had those conversations 20 years ago. Where it says previous illnesses or in the notes it might say, for example, "has a wish for a less proactive approach to intervention if they become acutely ill," so I can say, we talked about this a few years ago, that if you became acutely ill, you would just want to drift away.' (Tormod)

An experience-based conversation

The majority of the GPs in the study reported that they had not taken any courses or undergone any other training in communication about death. Nevertheless, they felt confident in these conversations after many years of experience as a GP. Some had relevant experience from working in intensive care or oncology departments.

The participants believed that the long-term GP-patient relationship enabled them to develop strong skills in communicating with their patients, regardless of the topic. They drew on their experiences from previous encounters with individual patients and 'followed their gut instincts' or took an intuitive approach to when and how to talk with their patients.

'It's true, you work with people, so it really depends on the communication you have with the patient and how well you know them. So, I don't think I have any special abilities; it's part of the job that you pick up as you go.' (Trine)

Many participants pointed out that the initial conversations they had with patients about death were challenging. Some expressed that exploring different approaches in these discussions gave them a sense of mastery.

'These are difficult conversations regardless; they are … … but at the same time, once you've done it a few times, you kind of peel away a lot of those difficulties, but they're definitely heavy conversations, that's for sure.' (Knut)

Most of the GPs reported that they rarely planned conversations with patients about death, preferring instead to address the topic when it arose. They typically did not prepare for such conversations as they felt they had developed a sufficient understanding of their patients over time.

Golden moments, sensitivity – and what the conversations cover

The majority of the GPs interviewed had followed their patients for several years. However, the frequency of conversations about death with patients who had a short life expectancy varied. Some rarely had such conversations, while one informant described having almost weekly discussions about death due to the large proportion of older patients on their list.

The GPs all agreed that sufficient time was absolutely crucial for providing adequate patient care. In cases where they could plan the timing of the conversations, they often preferred to do this in the last consultation of the day or at the patient's home.

The GPs who talked to their patients about death approached the conversation with caution, and the vast majority initiated the discussion themselves. They reported approaching the situation with sensitivity, maintaining a curious and open-ended style, and described how they tried to follow the patient's lead. They also looked for 'golden moments', either by drawing on their knowledge of the patient or by responding to cues indicating that the patient was willing to discuss death:

'I try, yes, I try to bring it up, but I try to wait until the patient seems open to talking about death. But I start with, "What are your thoughts moving forward?" How, you know, by asking a few open-ended questions.' (Kari)

Many of the GPs tried to help the patient broach the subject, often choosing open-ended questions. If they sensed a patient's reluctance to discuss death, they would not pursue the subject. They wanted to be considerate towards the patient in order to avoid adding to their worries.

'The most important tool you have, I feel, is being open and inquisitive, showing interest, and validating their experience.' (Ola)

The participants asked questions about what the patients were afraid of and about symptoms, as well as practical plans.

'What are your thoughts about your final moments, for example? And again, it's sort of up to the patient and maybe... yes. Which direction they want to take it, whether its practical matters or those kinds of things, and then... I often ask, are you afraid? Or do you have anxiety? Are you restless? Are you sleeping at night? Those types of things.' (Peder)

Several of the GPs were aware of their responsibility to talk to patients about death, recognising that it would be of great benefit to both the patient and their family, as well as for the doctors themselves.

'So, I ended up just recommending that: you've said you don't want to die at home, and I don't think we're far off now, so we'll go to the nursing home or into palliative care, and I think she was very relieved. But she wanted a recommendation; she didn't want to say if she was ready to leave home.' (Ruth)

For some of the participants, the conversation about death led to a change in roles, moving away from the purely medical aspect and becoming more of a companion and source of support. They found this to be positive, as they could be more personal and draw on their long-standing relationship with their patient. Several emphasised that being present was the most important factor.

'I think, you're a fellow human being in the conversation, and I think that's the most important thing. Of course, you bring your medical knowledge and such like, which you can draw on. But I think the most important thing in conversations like this is just to be there.' (Knut)

Several of the GPs described that the hospital specialists' focus on treatment made it difficult to find an appropriate time to talk to patients about death. They expressed concern that patients might perceive this as a disagreement between the hospital specialist and the GP on their prognosis and further care.

The GPs felt that many patients were very dependent on the specialist's advice. If the patient had not been informed that their treatment was ineffective or had been discontinued, it was difficult to initiate a conversation about impending death.

'I have called the oncologist several times and said, "Excuse me, but I read this as if things are starting to look bad. Have you discussed with the patient what to expect? Have you talked about death? Have you talked about the practicalities?"' (Kari)

Discussion

In this individual interview study of experienced GPs' conversations about death with their patients, almost all of the GPs described these discussions as a natural part of the GP role. For patients with a short life expectancy, they believed it was a necessary aspect of follow-up care. None of the doctors had taken any courses or undergone any other training in communication about death; the conversations were based on experience. The lack of clarification regarding treatment intensity from the hospital specialists was described by several as a barrier to effectively initiating and conducting conversations about death.

Method

Semi-structured individual interviews are well-suited for dialogical reflection on identity, meaning and professional roles (22).

We had a strategic sample of experienced GPs who were willing to reflect on this aspect of their practice. The interviewer was a GP with field knowledge (22). We believe that our well-defined research question and dataset consisting of ten interviews with meaningful dialogues provided us with sufficient information power, as defined by Malterud et al. (23), despite utilising a cross-case and data-driven analytical approach. Participant validation of themes and content enhanced the study's validity. (24).

It is possible that the study was subject to a selection effect as it is likely that those who believe GPs should discuss death with patients, and who actually do that, are more willing to be interviewed. Perhaps the dissenting voices are far more prevalent than reflected in our study.

All interview studies based on voluntary participation are subject to this limitation.

Experience-based conversations

In a well-functioning GP system, all inhabitants have a designated doctor who knows them and their patient history (25). Discussing death with patients aligns well with the broad and patient-centred approach of general practice. The participants in this study; experienced GPs and specialists in general practice, considered conversations about death with patients a natural part of their work. This finding is consistent with studies from other Western countries (26–28).

The GPs were confident in their role and had extensive experience in discussing serious topics with patients. They did not typically prepare for conversations about death, which closely aligns with the reality of general practice. Hospital specialists in general practice have a patient-centred focus, and it is often the patient who directs the topic of conversation in a consultation. Additionally, the work of a GP varies considerably from day to day, making it difficult to predict when a conversation about death might arise. If the GP knows that discussions may touch on death, as described in publications by the Norwegian health sector on advance care planning and the palliative care setting, preparations should be made for such discussions (17, 29).

None of the participants in the study had taken any courses or undertaken other training in communication about death. This is consistent with studies from other European countries, which found that the proportion of hospital specialists in general practice with formal competence in this area was low, but that such conversations are not unusual (30). The Netherlands stands out in the European context, with its guidelines stating that palliative care is mainly the responsibility of the primary health service. Furthermore, the Netherlands does not have formal competence requirements, but offers training (30, 31).

We do not have data on the quality of GPs' conversations with patients about death. Fasting et al. have shown that GPs rarely refer to guidelines or recommendations in follow-up palliative care (32). Similar results have been seen in countries like Australia, where a long-term GP-patient relationship was found to facilitate such conversations (16). Austad et al. have shown that the desire to see the whole person, rather than just applying a single disease focus, may be the reason why not all guidelines are followed (33). Conversely, studies from other fields have shown substantial variation in the quality of care among GPs (34). Enhanced training and guidance would likely benefit both experienced and less experienced doctors, and could potentially lead to high-quality, equitable care and a better patient experience (4, 17). Good procedures and guidelines for facilitating conversations could help to ensure that more patients have the opportunity to talk about end of life and death, if they wish to do so.

Several studies show that patients are more satisfied with conversations where the doctor is accessible and supportive, but that doctors often avoid emotional and existential topics (35, 36). Our study found that GPs try to tailor their approach to each patient's needs, drawing on their relationship with the patient, with the aim of engaging with the patient in a way that best serves the patient's interests. For some patients, the doctor should take a clear and direct approach, while in other situations and with other patients, it may be more appropriate to adopt a more cautious stance. The GPs interviewed generally took a careful approach but could be more direct when dealing with specific questions about symptoms or practicalities. A sensitive approach can be perceived as respectful by patients, but it could also be argued that GPs should initiate these conversations earlier and be more proactive. A strong body of evidence shows that early planning and discussions about death can improve the patient's mood, quality of life and satisfaction, as well as reduce the use of unnecessary treatments (37–39).

After participating in a structured training programme, GPs in Australia reported feeling more comfortable when addressing questions about death, and felt more confident in their palliative care work (40). There is likely to be a similar need for training in primary health care in Norway.

Advance care planning, palliative care and home deaths

The potential role of GPs in home deaths has been described in several studies, highlighting the importance of the doctor being available and their role as coordinator (28, 41). Our findings support Fasting et al.'s study on GPs' role in palliative care, where they regard themselves as key participants, though there is significant variation in their degree of involvement (9). Kjellstadli et al. have shown that GPs play an important role in facilitating home deaths (42), and our study shows that they also view discussions about death as an integral part of their responsibilities.

Our participants have known their patients for several years, which is a key factor for mastering conversations about death. Long-term familiarity with the patient, home visits and interdisciplinary cooperation with palliative care units are highlighted as crucial for the successful facilitation of home deaths (42). A number of local authorities in Norway are in the process of establishing and systematising the provision for advance care planning and palliative care plans for various patient groups (43, 44). Norwegian studies (8, 9) and national recommendations (4, 17, 45) confirm the role of GPs in this field, but doctors' participation and involvement still vary widely (9). The home care pathway (46), where the GP or other primary care service conducts discussions after diagnosis, can be a suitable introduction to the patient's thoughts about death. The National Comprehensive Cancer Network's Distress Thermometer (47) can be used as a tool to introduce the topic, with the patient indicating whether they have thoughts about death.

There is still a need to clarify the delineation of responsibilities and improve the interaction between the specialist health service, primary care and GPs in relation to seriously ill patients and palliative care. The GPs interviewed report that the specialist health service has a strong focus on treatment, both in its interactions with seriously ill patients and with other services. The infrequency of discussions on poor prognoses with patients in the specialist health service are a long-standing concern (48). One concrete measure to improve interaction is to systematically integrate advance care planning and palliative care plans into patients' summary care records, ensuring that the details of these discussions remain part of the patient's medical history. Better communication with patients at all levels, combined with improved interaction between these levels, will provide a more robust foundation for delivering the appropriate level of care in hospital settings and facilitate smoother transitions and follow-up in the primary health service.

GPs meet patients at all stages of illness and in all phases of life, and discussions about death can take place both early in the course of an illness and during the terminal stages. Previous studies have shown that patients wish to engage in such conversations (49), but these discussions take place all too rarely (15). By talking to their patients about death – both proactively and when the opportunity arises – GPs can support their patients and provide them with the opportunity to express their values and wishes for medical care, as well as facilitate their involvement in decisions about their own health. These conversations can also have a dimension of empowerment (50). Open and informative dialogue can help equip patients to make informed choices for a positive end-of-life experience, together with their family and healthcare personnel. In order to implement the changes they desire, patients need to understand that they are seriously ill and approaching death, and be involved in the decision-making.

Conclusion

The results of this qualitative study of experienced GPs suggest that the GPs are willing to conduct conversations about death and that they feel capable of doing so. All seriously ill and older patients should be given the opportunity to talk about death with a view to ensuring active participation in their final days. A broad patient-centred approach, along with a good understanding of the patients, provides a strong foundation for this work within general practice.

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