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Research Article

When Gps Initiate Conversation with Family Caregivers in End-of-Life Situations - What are their Goals?

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Abstract

Background: GPs play a crucial role in the provision of basic end-of-life care. Consequently, they are the ones to share information with not only the patient, but with the patient's consent, also with his/her family caregiver (s). The intention of GPs to start conversation about end-of-life contents is in this respect essential for the quality of care perceived. For these reasons our paper focuses on GPs understanding, purposes and rationales when initiating communication with family caregivers in end-of-life situations.

Methods: Qualitative, Swiss-wide, semi-structured, face-to-face interviews with 23 GPs. Data was analysed using content analysis.

Results: GPs stated to communicate with family caregivers a) to prepare them for impending important decision-making processes, b) to ensure every family member receives the same pertinent information, c) to enable open communication between all parties, d) to integrate family members into the caregiver network and e) to have the opportunity to offer emotional support for relatives' specific needs.

Conclusions: GPs were reflective and aware that patients and their caregivers have different communication needs. Their main rationales to initiate conversation with family caregivers was to ensure that their patients can rely on the support of their families during challenging decision-making processes, to facilitate mutual communication involving difficult topics between patients and their family, to strengthen relatives for their tasks as caregivers in the caregiver network, to prepare family members for their upcoming loss and to give them emotional support.

ABBREVIATIONS

GP(s): General Practitioner(s)

INTRODUCTION

General practitioners (GPs) play a crucial role in the provision of basic end-of-life care for patients and their family caregivers [1]. Often, they are also the ones to communicate palliative issues with the terminally ill and their relatives [2]. In most cases, a patient's family greatly contributes to the practical and emotional aspects of a patient's care. As a result, these family caregivers often carry additional burdens that add to the emotional strain of the impending loss of a beloved person [3]. For this reason, one of the most important and guiding principles in palliative care requests that the treating GP not only focuses on the patient but also offers information and support to the family [1].

Existing literature often describes the communication process between all involved parties as "family conference "and/or" family meetings" [4-6]. Family meetings are well implemented in other settings, such as in intensive and clinical care [4-6]. Data from these settings has shown a significant increase of satisfaction regarding patients'needs and their physicians after the attendance of a family meeting [5]. For clinical palliative care settings, these meetings were found to be helpful in relieving the burden of care giving which may decrease the number of patient institutionalizations [7]. Nevertheless, the current body of literature is often limited to interventions in inpatient settings. For Switzerland, recent research has identified gaps in doctor-patient-communication, especially when relatives need to be integrated into the process [8,9]. A recent guide from the Swiss Academy of Medical Sciences (SAMS) for communication in clinical practice highlighted many specific situations such as

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addressing substance abuse, or discussing patients' advance directives. However, no specific guidance is provided as to how patients and families should be informed about such topics as the process of dying, change of symptoms or costs of the process of caring for a family member. As a result, Swiss health care professionals often depend on their own which kind of information they provide and how.

Thus, this paper aims to shed light on the actual state how Swiss GPs communicate with their patients and relatives in ambulant palliative care settings and elaborates on the structures and aims when they initiate communication with family caregivers.

METHODS

This paper references results from a Switzerland-wide study entitled "Conditions and Quality of End-of-Life Care in Switzerland – the role of general practitioners" which is funded by the Swiss National Science Foundation (study number: 406740_139341). A purposive, Swiss-wide sampling of 30 GPs was chosen from the FMH list in order to obtain maximum variety concerning doctors' gender, age, their practice size (group versus single) and location (practices in different cantons and in urban, rural or suburban regions). Semi-structured face-to-face interviews, approximately one hour in length, were conducted with the participants. Along with question sets about administering palliative care and their teamwork with other institutions and stakeholders, participants were asked about their way of communicating with patients and their relatives in ambulant palliative care settings. Questions varied from more general questions about the role of relatives in this setting and their integration into the process to more specific questions regarding the relationships between all involved parties. The interview guideline was pilot tested and subsequently adapted during the first interviews.

The participants were practicing in the French, Italian, and German speaking areas of Switzerland. The study was approved by the competent ethics committee (EKBB) in November 2012. All participants provided informed consent. The data was analysed following May rings' steps of content analysis [10]: (a) the relevant data was defined, (b) the context of appearance of the data registered, (c) a formal characterization of the data material described, (d) the course of analysis specified, (e) a theory-lead differentiation checked, (f) technique of analysis defined (summarization, explication, structuring), (g) the unit of analysis defined, (h) data material analysed, and (i) finally interpreted.

For a more detailed methods section please see the methods section of our paper on "advance directive and the impact of timing: A qualitative study with Swiss general practitioners".

RESULTS

Of the 30 general practitioners who were invited to participate, 23 physicians from French, Italian and German-speaking regions in Switzerland agreed to participate (positive respond rate of 76%). The sample consisted of 14 German-speaking physicians (two of them practising in an Italian-speaking region) with a mean age of 54.2 years (range from 43 to 62) and nine French-speaking physicians aged 52.6 years on average (range from 37 to 63).

Impending decisions

Many GPs reported the initiation of end-of-life conversations with family caregivers as soon as important decisions had to be made.

GP18: (...) after a discussion with the patient and his family, his wife, his children, he had agreed to undergo surgery (...).

Some of the GPs also stated to do so as to implement the concept of advance care planning: they precociously talk to relatives about possible future scenarios which they anticipate from the projected course of the patient's disease in order to discuss and assess future decisions.

GP15: I alluded to them (family members and patient) the questions, when this and that happens, where do we want to go? What do we have to do then? (...) If oncologists offer a third chemotherapy what do you think about that?

GP19: (...), in order to prepare for the end of life, when we prepare the patient slowly, I would say within the weeks, months before the difficult decisions, I am often the one who has to talk or initiate, you know, this kind of discussion in order to prepare the important decisions that will soon have to be made.

Getting everyone on the same page

GPs said they also often have to face situations in which different family members have varying levels of information. In cases where it is necessary to assess their opinions and interests, especially when they are involved in care, GPs have to make sure they have a robust and sufficient level of information.

GP6: Often, for example, the son of the patient comes to me and tells me something and then the wife of the patient tells me something different but they don't talk to me at the same time. That is the moment when I say, okay, it would make sense to have a meeting with all of them at the same time, so they can also ask questions and so they can talk about their difficulties and explain their positions and reach a mutual conclusion in the end.

GPs also mentioned that relatives often prevent talking about approaching death in order to avoid placing an additional burden on the patient. In these cases, GPs initiate conversations with all parties involved and offer emotional support in order to improve the situation. Providing information in a straightforward manner as well as supporting a frank conversation about everybody's needs, helps to prepare the patient and his/her relatives for upcoming death/loss and offers the chance to support them in coping with their emotional burden:

GP21: (...) because people often don't talk about certain topics to each other or they don't dare to talk about death, to talk about what will happen after. (...) In conversations with me, they feel free to express themselves, with somebody from the outside who can care, who can take care of things, etc. So I often organize meetings in order to be able to help, a little bit, so that each one can express him/herself.

GP14: (..) So, I talk to relatives, I inform them, mainly to cautiously prepare them for what is coming, that the end of the patient's life is near, that they soon will lose him or her, and I try to be there for them, I try to help them to carry the emotional burden.

These conversations with involved family members can not only be helpful to update the information of every involved member but it can also give family members the feeling of being better integrated into the caregiver network.

GP18: So this is the reason why I think that when we start an end-of-life procedure, palliative care, involved persons, especially relatives, might have to be mobilized, to participate at some point, they have to be integrated, so they are able to express their needs.

Offering emotional support

GPs in this study state from experience that they found relatives to be often hesitant when it comes to psychological support provided by a psychologist. However, participants feel that emotional support from the side of the GP seems to be easier to accept for them:

GP21: So they refused the psychological follow-up, they were saying they were not in need of it, so they were coming to me to talk.

Family meetings can also help to inform caregivers about the ramifications of their care giving and the possible effects it can have on them. In that way these meetings can not only support caregivers emotionally but can be as well a reminder to also take care of their needs and to be proactive in asking for support in order to limit the risk of burn out and exhaustion.

GP14: (...) I communicate with them, I inform them, I try to prepare them that we might be facing the end of our possibilities and that death is approaching and how we can handle it when it occurs at home, I experience this to be one of their biggest fears "how do I handle it when it happens at home?", and I try to support them with their grief and emotional distress. I also try to remind them that they need to take care of themselves too; often they forget that they have needs too.

DISCUSSION

As more and more palliative care patients wish to die at home, family members take a more active role in end-of-life care, providing care for patients at home [11]. The progressing of a disease as well as approaching death is moments that evoke fear and emotional pressure in patients and relatives. Our results show that family meetings can play a significant role in the communication in end of life scenarios and can help GPs to support family caregivers [11]. They allow the opportunity for GPs to not only impart information to patients and their families and to optimize treatment plans, but also to assess the needs of family caregivers and to react accordingly.

Physicians have the obligation to adequately inform patients of their diagnosis and prognosis as well as to create the conditions necessary for an autonomous choice in future treatment options. With the consent of their patient, GPs are also allowed to integrate relatives into the information and decision-making process [12]. Especially in cases where relatives provide care for the patient as their wish for early and effective provision of information about the patient's prognosis and available treatment options should be taken into consideration [13]. However, physicians should be also aware that the patient and family relationship is often a dynamic system which is subject to entering into a stage of crisis [14]. Therefore, personality characteristics as well as family structures play a crucial role in determining the information strategy and the way family should be approached [14].

Most patients want information about their illness fully disclosed to their relatives [15]. This is useful considering that family caregivers are often involved in critical medical decisions and even more so when the patient is no longer capable [16]. It is also known that when making important decisions, patients often take factors such as future consequences for relatives into account [17]. As a result, higher levels of shared decision-making between patients and family caregivers often lead to a greater family satisfaction [18]. In our study, GPs pointed out that conversations held in the framework of family meetings can help to strengthen the communication and mutual decision-making process of all involved. Therefore they consider initiating conversation with family caregivers as an important element in the advance care planning process.

However, to reach this goal it is necessary to get ever involved family member on the same page. Having the same level of information is a necessity to have a mutual basis for an open conversation for example about approaching death between patient and spouse [19]. Dying patients often face complex and unique challenges during their disease that threaten their physical, emotional, and spiritual integrity [20]. According to the participants of this study, open communication helps to reduce some of this emotional burden for the patient as well as for the relatives since preparation for death, and the opportunity to achieve a sense of completion are important to most [20].

Without the support of family and friends, it often would be impossible for many terminally ill patients to stay at home [21,22]. In most cases, family members are willing to take on the role of informal caregivers, even though this is at a considerable psychological, physical, social, and financial cost to themselves [23,24]. Therefore, informal caregivers have a range of needs which not only includes information and education about the patient's illness as well as guidance on how to care for the patient, but also psychosocial support [23,25]. Furthermore it is known that relatives often feel overwhelmed by their tasks, since the majority of them never received any medical training [25]. For this reason, relatives may often feel insecure when it comes to medical aspects of the patient's care (like pain management). Nonetheless, they are also often unsure of how and which topics to communicate with their sick family member [25]. GPs in our study also acknowledged these aspects and stated to initiate conversations with family members to better inform, prepare and support them in taking care of their relative.

However, GPs' assistance for the caregiver often primarily includes providing information and referral to ambulant care services to ensure that the caregiver gets practical assistance in caring for the person. Often GPs are less able to provide caregivers with the necessary emotional or psychological support [26]. Interviewees in our study point out that relatives not only need this support, they also emphasize that their specific emotional needs differ from those of the patients. Patients have to deal with their own upcoming death, while their relatives will be confronted with the loss of the person. They also see the provision of emotional support as a task of the treating GP, since relatives often do not want to contact a psychologist. Therefore, GPs should proactively access the emotional needs, fears and worries of involved relatives and should keep in mind that emotional support is necessary in order to support relatives to take adequate care of their sick family member [27].

CONCLUSIONS AND IMPLICATIONS

Communication is crucial when it comes to providing palliative care in ambulant settings. However, the choice of whom to inform as well as the delivery of the information is often critical to the process. While GPs have an obligation to inform their patient, further inclusion of family members can be essential to ensure the best provision of care possible. Especially since guidelines on communication with family members are not available in Switzerland yet, our study aimed to further elaborate on the ways, rationales and aims of Swiss GPs to communicate with family caregivers. During our interviews, GPs were reflective and aware that patients and their caregivers have different communication needs. Their main rationales to initiate conversation with relatives was to ensure that their patients can rely on the support of their families during challenging decision-making processes, to facilitate mutual communication about difficult topics between patients and their beloved, to strengthen relatives for their task as caregivers in the caregiver network, to prepare family members for their upcoming loss and to give them emotional support. While this paper therefore shows the importance of communication in ambulant palliative care settings, further research should be conducted with the aim to complement existing guidelines in order to ensure family caregivers and patients are both supported and cared for in the best possible way.

STRENGTHS AND LIMITATIONS

A clear strength of this study is the use of a qualitative method to explore a multifaceted topic, in which general practitioners could express when and why they initiate family meetings. However, the generalizability of our study is somewhat limited since our data refers to GPs in Switzerland. Nevertheless, our paper shows that the usage of interventions such as family meetings in ambulant care settings is important and this can be applied equally to other local contexts.

Since our study is a qualitative study, some additional limitations have to be noted: first of all, we are not able to reach a conclusion regarding the quantitative aspects and distributions of opinions among GPs. Secondly, the results may be biased as study participants tend to answer accordingly to social desirability and this is a known effect.

However, since we (1) have strictly respected confidentiality and anonymity and also (2) have obtained a variety of distinct answers that are not limited to what would be expected to be socially desirable, we are confident that we present evidence that this bias remains small. Furthermore, because our results rely only on our qualitative data source, triangulation from other methods of data collection, such as a survey, may increase the validity of the results.

For this reason, the next step of our study is a large-scale questionnaire to quantify the results that we obtained from the interviews.

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