

Sharing information in ambulant palliative care settings: Swiss general practitioners' communication with patients, patients' families and other healthcare professionals

Inauguraldissertation

zur Erlangung der Würde eines Doktors der Philosophie
vorgelegt der Medizinischen Fakultät der Universität Basel

von

Ina Carola Otte

aus Holzminden, Deutschland

Basel 2015

Original document stored on the publication server of the University of Basel
edoc.unibas.ch

Genehmigt von der Medizinischen Fakultät auf Antrag von:

Referat: Dr. Klaus Bally

Co-Referat: Dr. Corinna Jung

Externer Experte: Prof. Yousri Marzouki

Fakultätsverantwortliche: Prof. Bernice Elger

Basel, den 15. Juni 2015

Prof. Thomas Gasser
(Dekan)

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Acknowledgements

I am very grateful for the financial support for this doctoral project, which – together with my salary - came from the Swiss National Science Foundation. However, my research would not have been possible without the support, both professional and personal, of the research team I had the pleasure to work with during these three years:

First, **Klaus Bally**, my first supervisor, I would like to thank you for encouraging my research and for allowing me to grow as a research scientist. Thank you for your patience, your aspiring guidance and your commitment, for sharing your knowledge and for your continuous support. I am extremely thankful for your always invaluable constructive criticism and friendly advice during the entire project work.

Secondly, I like to thank **Corinna Jung**, who co-supervised this project, and who contributed an immense amount to my maturation as a researcher. You prepared me excellently for academic life and always kept the glimmer of hope for post-dissertation normalcy alive. I am extremely thankful for every minute of your time spent on this work and I vow to always switch off the coffee machine – from now on and forever.

Yousri Marzouki, who kindly agreed to become the external expert of this project as soon as he was asked, and whose collaboration and advice enabled me to complete this project. Thank you!

I also thank **Bernice Elger** for her valuable expertise and her contribution to this project. I am sincerely grateful for sharing your illuminating views on ethical issues discussed in this thesis and for giving me the opportunity to work at the IBMB and its fruitful and interdisciplinary environment.

This work is my thesis, but it is also the product of the hard work of many other people. Therefore, I'd also like to thank **Dr. Heike Gudat**, **Prof. Elisabeth Zemp** and **Dr. Hans-**

Ruedi Banderet for being part of a research team that always supported me and which was so pleasant to work with.

I am also particularly grateful to **Brandon Williams**, who tirelessly proof read every chapter and who continuously provided me with moral support. Thank you for accepting nothing less than completion from me. Without you, this thesis would not be what it is today. I definitely owe you an endless amount of Swiss chocolate.

I'd also like to thank everyone from the Transdiss scholarship network, especially **Prof. Michael Decker**, for his academic advice.

Special thanks to my **fellow doctoral students**: those who have already graduated, those in the middle of the quagmire, and those just beginning— thank you all for your support, your feedback, and for all the coffee breaks together. Keep going.

Nils Kubischok, for never letting me doubt myself and for reminding me that there is still a whole world outside of my PhD. Thank you for encouraging me, supporting me and making me realise that I should never let my doubts hold me back from what I want to do. Words cannot express my gratitude for everything you have done. Thank you for accompanying me on this adventure, I look forward to our next one!

To **my closest friends** all of whom who were my support in the moments where I could not see past May and who never tired to reassure me that it will be okay: You guys were right. I cannot thank you enough for all the last minute favours, the emergency phone calls and your humour which have rescued me from peril more times than I can recall.

Last, but not least, I am eternally grateful to my family, particularly to my father, **Reiner Otte**, who always encouraged me to strive towards my goal and who always believed in me.

Summary

While they are usually the first point of contact for individuals with all kinds of health related questions, knowledge about Swiss general practitioners' (GPs) practice of communicating with patients, patients' families and other healthcare professionals in ambulant palliative care settings is still fragmentary. This thesis sheds light on GPs' ways of counselling patients in an important topic in palliative care, namely advance directives (ADs), while also focusing on physician-patient-communication regarding other sensitive topics such as assisted suicide. Further, this thesis illuminates GPs' communication processes with patients' families and other healthcare professionals.

The topic of ADs was chosen as a special focus since they were found to be a particularly important tool in ambulant palliative care settings. As a legal document signed by a competent person they offer GPs, other healthcare professionals and patients' families guidance for medical decisions in case the patient becomes incompetent. The focus on GPs' ways of communication with family members and other healthcare professional was set since the quality of this communication was shown to be directly linked to the quality of care that can be provided in this setting.

Four main research questions are structuring this thesis:

- 1) When and how do GPs initiate conversations about ADs?
- 2) What difficulties have arisen in the context of conversations regarding sensitive topics such as assisted suicide?
- 3) How and where does communication with the patient's family fit in?
- 4) How do GPs communicate with other healthcare professionals and what are their perceptions of possible improvement or barriers?

Answers given to these questions are based on the analysis of the qualitative data collected via semi-structured face-to-face interviews with GPs from the German, Italian and French speaking parts of Switzerland.

As for the first research question, guidelines such as the guideline on communication in

clinical practice from the Swiss Academies of Medical Sciences, often only cover the content but not the appropriate timing and initiating of ADs. Thus, results from our data show that participants have very individual, often unstructured ways and timings of approaching this matter with their patients. It was presented that GPs often link the matter of ADs to the thought of approaching death. Therefore, GPs often chose to address ADs accordingly to this link. Stated moments could be split into two main categories: the first category “before illness” served the purpose to avoid additional burden by not having to talk about death and dying when the patient is already facing a severe illness. The second category “after an illness became predominant” was stated to be chosen in order to ensure that patients’ stated preferences are up to date and robust.

For the second research question, aiming at possible difficulties that can occur, GPs criticized the usage of pre-formulated templates for ADs with patients, stating that these forms often fail to express individual values. Standardized sentences, so the participants, cannot sufficiently illustrate a patient’s health and/or biographical background. Often these templates were said to contain broad or vague statements such as wanting to “maintain dignity” which participants stated as too general to provide a basis for individual treatment decisions. As an example, participants named the forgoing of an intervention when the patient's condition is “irreversible” or “terminal”. However, physicians often have trouble determining whether patients are in these states. Further, the theme of emotional discomfort emerged as a possible barrier. The latter not only occurred on the side of the participating GPs but also on the side of families and patients, potentially hindering effective communication.

The integration of families, as addressed under the third research question, was shown to be often achieved through individual communicative approaches with GPs falling back on and individually adapting tools they know from inpatient family meeting settings.

Concerning the fourth research question, the missing transparency and timeliness of information caused tension and barriers between GPs and specialists working in hospitals complicating the communication and collaboration between all stakeholders involved. Also the lack of accountability and the missing assignment of responsibility led

to GPs' perceptions of a rather unstructured and ineffective communication with specialists.

In conclusion, the decision of when to address the topic of ADs is surely a matter of sensitivity which should be left to the GP. However, for research question 2) we suggest that existing guidelines be fully completed, also covering possible effects of the timing on ADs. For 3) a more structured approach of how tools from inpatient family meetings could be adapted to and used in ambulant palliative care could help to optimize the informing of families in this setting. In regards to 4) we conclude that currently existing infrastructures concerning the mutual communication between GPs and other stakeholders are in need of more transparency and better structured information pathways. Nevertheless, this is difficult to accomplish, as it is not the official responsibility of any party yet. Therefore, responsibilities regarding this matter need clarification in order to optimize communication and subsequently patient care.

Part 1: Introduction

1.1 Importance of palliative care in Switzerland and the role of GPs

The Swiss health care system operates on two levels: primary health care services and specialist health services (1). For the primary health care level, according to the Swiss College of Primary Care Medicine¹ and the Swiss professional association of general practitioners², general practitioners (GPs) have the key role in the management of and caring for patients³ (2, 3). They usually diagnose, initiate and continue medical treatment, are the gate-keepers to specialist care, and are supposed to know about the available services offered in primary and secondary health care (2, 3). They are also often the first contact for patients with all kinds of health-related questions and play a central role in the management of patients with chronic diseases and patients in need of palliative care⁴ (4).

With the ongoing demographic development, particularly the task of GPs to care for patients with chronic or incurable diseases will soon become increasingly important. The Swiss Federal Government predicts a raise of the annual mortality rate from currently 60,000 to 90,000 people until the year 2050 (5). As in other European countries, most Swiss patients (up to 75%) wish to die at home, often requiring the medical assistance of a GP during the time before their death (6, 7). According to the World Health

¹ in German: Kollegium der Hausarztmedizin, KHM

² in German: Hausärzte Schweiz

³ Websites of both organisations are accessible online:

For the description of a Swiss GP's tasks from the Swiss professional organisation of general practitioners see: <http://www.hausaerzteschweiz.ch/themen/hausarztmedizin/>; for the version of the Swiss College of Primary Care Medicine please visit <http://www.hausarztstiftung.ch/der-hausarzt/aufgaben>. Please note, both websites are only available in a German and a French version (last access May 2015).

⁴ According to the World Health Organization (WHO), palliative care is defined as an "approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". This definition is accessible on their website: <http://www.who.int/cancer/palliative/definition/en/> (last access May 2015).

Organization (WHO), Swiss residents are being more likely to live with a chronic condition over the next few decades than they are today (1). Indeed, the WHO expects them to live with more than one chronic condition or morbidity (1). These patients are likely to face long and complex care situations in their later life, when palliative care becomes predominant. This will not only increase the number of patients who are in need of palliative care but also the demands on Switzerland's primary health services (1, 8).

Palliative care is an important approach to meet the needs of chronically and terminally ill patients and their relatives, ideally covering physical, psychological, social and spiritual dimensions of care (9). Its complexity makes palliative care labour-intensive, especially in-home care⁵, with a high demand on medical and care support, communication, coordination and networking (10). In-home palliative care requires specific knowledge and skills in symptom-management, family medicine, communication, team management, and physicians' self-reflection (11-13), which makes it challenging not only for the treating GP but also for all other parties⁶ involved.

1.2 Research concerning palliative care in Switzerland

Some states, especially Anglo-Saxon countries, as well as the Netherlands and Belgium, already have a large body of research examining the elements of palliative care which are considered to be important by patients, family members, GPs and other caregivers (14-16). While international approaches to identify quality indicators of palliative care, such as the UK Gold Standards Framework (17), the National Consensus project on palliative Care (18-20) or the SENTI-MELC study (21, 22) do exist, results are not necessarily transferable to the Swiss healthcare system. Healthcare systems differ substantially regarding many structural and organisational aspects (23). Further, also the perception of the quality of medical care is shaped by sociocultural conditions and moral beliefs (24).

⁵ In-home care and ambulant care are both terms used in this thesis to describe a form of health care provided at a patient's home.

⁶ Often GPs work together with other healthcare professionals and services but also with family members who care for the patient (commonly referred to as informal caregivers or family caregivers). A detailed illustration of the involved stakeholders in in-home palliative care is given under 1.3 and 2.5.

Thus, it is important to have access to data and findings based on research conducted in Switzerland. However, results from Swiss end of life research are rare and little is known about the provision and quality of palliative care in ambulant healthcare settings (25). Because of this, in 2010 the Swiss Federal Office of Public Health (BAG) and the National Conference of the Cantons (GDK-CDS) started the National Strategy for Palliative Care 2010-2012. Significant gaps were identified on various levels, for example in the provision of, financing of, information on, education about and research of palliative care (26). Patients' and relatives' limited access to palliative care was noted, especially at the level of primary healthcare. At this level, shortcomings in patient care could, for example, appear in the area of symptom management, but also in the areas of communication, emotional and spiritual support, or in the assistance with decision-making processes.

In 2012, the Swiss National Science Foundation (SNSF) launched a research programme (called NFP 67) consisting of 33 projects conducting research on end of life topics. The umbrella project in which the research for this PhD thesis was conducted was part of this programme. Under the lead of Klaus Bally, the SNSF project with the title "Conditions and Quality of End-of-Life Care in Switzerland – The Role of GPs" examined the conditions and the quality of ambulant palliative care in Switzerland. The project's research questions focused for example on the satisfaction of GPs and relatives with ambulant palliative treatment and the availability of support from and collaboration with ambulant care services and specialists⁷. Further, it elaborated on possible barriers and gaps GPs and families may face while caring for terminally ill patients.

In order to find answers to these research questions, a literature review as well as a qualitative methods part and a quantitative methods part was performed. For the qualitative part, 23 GPs with various regional, linguistic and structural backgrounds were interviewed. Additionally, eight interviews with family members and three interviews with patients in palliative care situations from the Basel and Zurich region were conducted. Three focus groups with healthcare professionals in the German, French and

⁷ The involvement of ambulant care services and other specialists is further explained in the paper "Stakeholders and structures in the Swiss ambulant palliative care setting" in chapter 2.5.

Italian speaking part completed the qualitative phase of the project.

Based on the findings gathered in this phase, a large-scale questionnaire for GPs in all parts of Switzerland was designed. The aim of this survey was to confirm the hypotheses and findings from the qualitative phase and to obtain valid data about the current state of palliative care in Switzerland. Further, the aim was to identify gaps in the provision of palliative care as well as opinions on feasible and widely acceptable quality standards⁸.

1.3 Development of the PhD project

During the first analysis of the qualitative data of the umbrella project, the importance of communication for the deliverance of good ambulant palliative care emerged.

While good communication with patients is already known to be an important aspect in medical care at the end of life (27, 28), these first findings also showed that GPs perceive a well-working communication with family members and other healthcare professionals to be equally relevant.

This is not surprising, considering that due to the complexity of ambulant palliative care (as illustrated above) GPs often work together with an interdisciplinary team⁹ (28, 29). In most cases, according to the GPs in the umbrella study, physicians and their teams were additionally supported by one or more members of the patients' family (30, 31)¹⁰.

This interdisciplinary team work requires well-functioning collaboration between all parties (including the patient's family) in order to be able to ensure best quality of care (28, 32). Well-functioning collaboration in turn requires coordination¹¹ as well as effective communication (33).

Acknowledging the lack of Swiss research concerning this topic and the importance of communication in ambulant palliative care, this PhD project elaborates on ways of communication between GPs, patients, patients' families and healthcare professionals.

⁸ Results from this survey will be available in the second half of 2015.

⁹ The composition of the interdisciplinary team is further described in research article "Stakeholders and structures in the Swiss ambulant palliative care setting" in chapter 2.5.

¹⁰ In Switzerland, nowadays there are approximately 250.000 individuals who care for sick relatives or friends who are in need of support (31).

¹¹ Yuen et al. show that GPs often prefer a model of care in which they coordinate the patient's palliative care (28).

It further focuses on possible barriers and difficulties that can occur in these communication pathways.

The PhD project consisted of two phases. First, a literature review was conducted with the objectives to examine the current status of research and to identify relevant gaps. In the next step, the 23 qualitative interviews with GPs were analysed a second time¹². This time the analysis focused in-depth on the research gaps found during the literature review while also concretizing the themes that emerged in the first analysis for the SNSF project. The results of the literature review are illustrated in the following paragraph. The findings based on the analysis of the qualitative data are presented in the research articles which can be found in the main part of this thesis (chapter 2 and 3)¹³.

1.4 Results of the literature review

1.4.1 GPs' communication with patients

Patients who will potentially need palliative care in the course of their disease can be usually divided into tumour- and non-tumour-patients. However, non-tumour-patients, often suffering from multi-morbidity such as progressive chronic, incurable diseases, are often not or only delayed recognized as patients in a palliative state (34, 35).

Consequently, research describing healthcare professionals' conversations about issues of dying and death with these type of patients is rare, especially in Europe (34, 36). Most studies focused on communication related to cancer or examined special issues such as overaggressive treatment of dying patients (27, 37). Only more recently, the first research projects concerning communication structures in palliative care that were not limited to a special patient group have been conducted (34, 38). Within these research projects it was shown that the training of physicians in regards to these conversations remains a major challenge (34, 39). Often healthcare professionals lack the necessary knowledge which kind of information should be provided and how (40, 41).

¹² For a detailed description of the analysis please see paper "Advance directives and the impact of timing" under 2.2.

¹³ The content of the papers is also briefly described under 1.6.

The most recent Swiss guideline for communication in clinical practice reflects these findings (42). This guideline highlights many specific situations such as addressing addictive behaviour sensitively or how to discuss DNR (do not resuscitate) orders. However, it offers only limited guidance as to when and on which topics palliative care patients should be informed. While generally giving advice on e.g. the breaking of bad news, specific guidance for communication with palliative care patients remains fragmentary. Moreover, whether or not Swiss GPs follow these guidelines is unknown since no empirical research examined their way of communicating with patients in practice yet.

In end-of-life communication, not only the sharing of information related to the patient's condition or prognosis but also the addressing and documenting of patients' preferences concerning future treatment options was shown to be very important (43). The latter is therefore particularly important, since it serves as a mean of preparation if an event renders the patient incompetent. It is also relevant since it was shown that communicating about patients' preferences improves the quality palliative care and reduces stress, anxiety, and depression in patients and their family members (44). In literature, the assessment of these patients' preferences is often described to be achieved via a process known as advance care planning (ACP) (44-46).

The NIH National Institute on Aging defines ACP as a process that involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know these preferences, often by putting them into an advance directive (AD). They identify ADs to be a legal document that goes into effect when a patient is incapacitated and unable to speak for him- or herself. Further they state that ADs allow patients to express their values and desires related to end-of-life care¹⁴. The latter, namely that ADs are an important mechanism for communicating patients' preferences in end-of-life situations, was also shown in empirical studies concerning this topic (47-49). Swiss data shows that most Swiss patients wish to talk about ADs with their GP (50).

¹⁴ This definition is accessible on the website of the NIH Institute on Aging: <http://www.nia.nih.gov/health/publication/advance-care-planning> (last access May 2015).

Even though ADs are often drawn up before a patient reaches a palliative state, the need for updates as a patient's disease progresses, ADs' importance in this setting and the lack of knowledge concerning the way GPs communicate about this topic led to the first research question of this PhD project: 1) When and how do GPs initiate conversations about ADs?

While answering the first question of this thesis, the analysis of our data showed that especially the communication of sensitive topics such as the prolonging or discontinuation of treatment was extremely challenging for the participating GPs. For example, they stated to feel discomfort talking about topics such as approaching death and dying. Based on this finding, the second research question emerged: 2) What difficulties have arisen in the context of conversations regarding sensitive topics such as assisted suicide?

1.4.2 GPs' communication with patients' families & healthcare professionals

Not only Swiss knowledge on how GPs communicate with patients is scarce. Also information on how GPs implement their families and other healthcare providers in ambulant palliative care settings is still fragmentary.

From other American, Australian and European studies it is known that family members, other healthcare providers and patients have different needs when it comes to communication and information. For example, for the United States, Steinhauser et al. reported that doctors, other care providers, and family members significantly more often agreed that talking about death was important while patients disagreed (14). For Australia, Clayton et al. also found out that family caregivers¹⁵ wanted more detailed information about the dying process than patients. In another Australian study, conducted by Kirk et al., patients and families showed a similar need for information at the beginning, however this changed with the progression of the patient's illness, resulting in caregivers wanting more information and patients less (51). Further, caregivers appreciated knowing as much as possible and argued to be in a better

¹⁵ In this thesis, family members who care(d) for a sick or dying relative are also referred to as "family caregivers" or in a shorter form as "caregivers".

position to assist the patient when having a high level of knowledge regarding the patient's prognosis (51). In the Swedish study by Friedrichsen, participating caregivers stated that information was important for them in order to have a full understanding of the situation. This, so Friedrichsen, would help these caregivers to mentally prepare, organize their lives, and be a source of information to others (52). For Germany, the authors and researchers of the PalliPA project¹⁶ introduced a two-step approach in 2012 (23). This approach was meant to enable GPs to develop feasible, acceptable and successful strategies to support and inform family caregivers of patients at the end of life (23). However, their approach is designed to be appropriate to primary palliative care in the German healthcare context and not necessarily applicable to the Swiss healthcare system. Nevertheless, all of these results demonstrate the importance of an effective communication with patients' family members and the need for Swiss research concerning this topic.

For Switzerland, Neuenschwander et al. gave some short recommendations for the interactions with family caregivers in their book "Palliativmedizin" (53). However, empirical research concerning how families are being informed in practice has been somewhat limited to inpatient settings, such as the sharing of information with families of patients in clinics (54, 55). For ambulant palliative care settings, with the importance of communication and information being the same or even higher¹⁷, knowledge on how GPs integrate families in this process is still very patchy. As a result the third research question of this PhD project elaborates on the way how patients' families are being integrated into the communication and information process in ambulant palliative care settings.

Nevertheless, not only GPs' collaboration and communication with family members is essential for good in-home palliative care. Empirical research suggests that the quality of patient care depends on the collaboration between GPs and hospital physicians (56, 57). Failure of co-ordinated actions among physicians was shown to result in poor health

¹⁶ PalliPa is a German abbreviation and stands for „Verbesserung der häuslichen Versorgung von **P**alliativpatienten durch Unterstützung pflegender **A**ngehöriger“. In English: Improvement of palliative care at home by supporting family caregivers.

¹⁷ In ambulant palliative care settings, family members often support GPs with tasks related to the care of the patient. Therefore, one could argue that information in this setting could be even more important than in clinics where most care tasks are delivered by the clinic staff.

outcomes for patients (58) and unhealthy work environments for the physicians themselves (59). It was further demonstrated that delayed communication or inaccuracies in information transfer among healthcare professionals may have substantial implications for continuity of care, patient safety, patient and clinician satisfaction, and resource use (59). The deficits of collaboration between GPs and hospital based physicians have been at the centre of several international studies. This research, which mainly took place in the UK and further Anglo-Saxon countries indicates delays (60, 61) or inaccuracy of information within the medical community (62-65). However, there is scarcity of Swiss data and in depth explorations of the reasons for these deficits. These explorations would be meaningful since they could serve as starting point to develop successful strategies to overcome communication barriers between GPs and specialists¹⁸. Furthermore and relevant from a policy perspective there has been little interdisciplinary analysis with regards to the appropriate level of collaboration between GPs and hospital based physicians. Respective justifications from a professional ethics perspective are also lacking. Based on these findings, the last question of this thesis arose: How do GPs communicate with other healthcare professionals and what are their perceptions of possible improvement or barriers?

1.5 Research objectives of the PhD project

Based on the identified research gaps which indicate a need for Swiss research concerning different communicative aspects in ambulant palliative care, four main research questions and study objectives of this PhD project emerged:

- 1) When and how do GPs initiate conversations about ADs?
- 2) What difficulties have arisen in the context of conversations regarding sensitive topics such as assisted suicide?
- 3) How and where does communication with the patient's family fit in?

¹⁸ Pirnejad et al. for example showed that it is essential to know the challenges and complexities involved in interprofessional teamwork in order to determine the appropriateness of strategies (66).

4) How do GPs communicate with other healthcare professionals and what are their perceptions of possible improvement or barriers?

In order to find answers to these questions, the author – together with other research team members - analysed the qualitative data gathered from the 23 interviews with GPs which were conducted within the umbrella project^{19 20}.

1.6 Contents of the thesis

As common for cumulative graduations, this thesis' main part consists of research articles written and published during the PhD project. The part labelled "empirical examination" consists of seven research articles. These are thematically organized: section A) presents research articles illustrating GPs' communication with patients and section B) consists of research articles covering the communication with patients' families and other healthcare professionals.

Section A "GPs communication with patients", begins with the research article "*Advance care planning and its importance for general practice*" which describes GPs' understanding of ACP, their interpretation, their definition as well as their implementation of the process into their daily practice. The second article in this section "*Advance directives and the impact of timing*" identifies advance directives (ADs) as an important tool of ACP and focuses on GPs' perceptions of the "right" moment to communicate this topic with patients. Since the analysis for this paper showed that GPs often use pre-formulated templates as a starter for conversations about ADs, the third article "*The utility of standardized advance directives: the general practitioners' perspective*" deals with the potential and risks of using standardized templates as a basis for this communicative process. The first section of part 3 then ends with an article on assisted suicide, illustrating how challenging communication about sensitive topics can

¹⁹ A detailed description of the contributions of the different team members are given in the methods section of the research articles (e.g. in 2.2) as well as in the appendices of this thesis under the first paragraph called "Collaboration" (4.1).

²⁰ For a detailed description of the used methods please see for example the methods section of the research article "*Advance directives and the impact of timing*" under 2.2.

be and which risks hasty rejections or missing communication can bear: *“We need to talk! Barriers to GPs’ communication about the option of assisted suicide and their ethical implications – results from a qualitative study”*.

Section B, which is dedicated to GPs’ communication with patients’ families and other healthcare professionals, starts with an overview of the different stakeholders involved in the setting of in-home care for palliative patients (*“Stakeholders and structures in Swiss outpatient palliative care”*). It proceeds with a research articles focusing on GPs communication with patients’ families *“When GPs initiate conversations with family caregivers in end-of-life situations – what are their goals?”*. It documents GPs’ ways of implementing so-called “family meetings²¹” into their practice routine, show GPs’ goals when communicating with families and illustrate the use of tools GPs know from family meetings in inpatient settings. The last research paper *“Interprofessional Silence at the End of Life: Do Swiss General Practitioners and Hospital Physicians Sufficiently Share Information About Their Patients?”* focuses on GPs’ communication with other specialists, mainly with physicians in hospitals, as well as on GPs’ perceptions of barriers hindering this communication process.

Each research article mentioned above contains a methods section; therefore the author resigns from adding an additional detailed methods chapter in order to avoid repetition. Further, each article includes a section in which the results are discussed. Therefore, the fourth and final part of this thesis, subsumed under the title “general discussion”, first summarizes the content of these discussions and secondly gives a general overview of ethical implications and potential for further research. The thesis then ends with the presentation of conclusions gathered from this study.

²¹ Family meetings are meetings between GPs and patients’ family members with the goal to address care related topics.

1.7 Research articles presented in this thesis

A: Research papers concerning the communication with patients

2.1 *Advance care planning and its importance for general practice – how do Swiss GPs proceed? Results from a qualitative study.* Published in: Schweizerisches Medizin Forum (2014);14(15):328–329 (translated version).

2.2 *Advance directives and the impact of timing: A qualitative study with Swiss general practitioners.* Published in: Swiss Medical Weekly, (2014);144(10):135-140.

2.3 *The utility of standardized advance directives: the general practitioners' perspective.* Published in: Medicine, Health Care and Philosophy (2016) 19:2: 199-206.
doi:10.1007/s11019-016-9688-3.

2.4 *We need to talk! Barriers to GPs' communication about the option of assisted suicide and their ethical implications – results from a qualitative study.* Published in: Medicine, Health Care and Philosophy (2016) doi:10.1007/s11019-016-9744-z.

B: Research papers concerning the communication with families and other healthcare professionals

2.5 *Stakeholders and structures in the Swiss ambulant palliative care setting.* Published in: Technologiefolgenabschätzung im politischen System. Zwischen Konfliktbewältigung und Technologiegestaltung. Edition Sigma, Editors: Decker M., Bellucci S, Bröchler St, Nentwich M, Rey L, Sotoudeh M, (2015):253-258 (translated version).

2.6 *When GPs initiate conversations with family caregivers in end-of-life situations – what are their goals?* Published in: Journal of Family Medicine & Community Health (2015) 2(1): 1025.

2.7 *Interprofessional Silence at the End of Life: Do Swiss General Practitioners and Hospital Physicians Sufficiently Share Information About Their Patients?* Published in: Journal of Palliative Medicine. (2016) 19(9): 983-986. doi:10.1089/jpm.2015.0377.

Part 2: Empirical Examination

A: Communication with patients

This part of the chapter consists of research papers presenting results from the qualitative data concerning GPs communication with patients.

Following research papers can be found in section A:

2.1 Advance care planning and its importance in general practice – how do Swiss GPs proceed? Results from a qualitative study

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2.1 Advance care planning and its importance in general practice – how do Swiss GPs proceed? Results from a qualitative study

Hans-Ruedi Banderet, Corinna Jung, Ina Carola Otte, Heike Gudat, Klaus Bally

Introduction

In 2012, the Swiss National Science Foundation (SNSF) started a national research program (NFP 67). For five years, 27 projects were funded in order to elaborate on the different questions concerning the last phase of life. In the framework of this national research program, the Klaus Bally et al. project titled “Conditions and quality of end-of-life care in Switzerland – the role of GPs” was designed and started in May 2012. The project’s main focus lies on the role of GPs and their work in end-of-life settings.

Members of the research team come from different interdisciplinary backgrounds such as the Swiss Tropical Health Institute (Swiss TPH), the Institute of Primary Care (IHAMB), the Institute for Biomedical Ethics (IBMB) and the Hospiz im Park, Arlesheim. The center piece of the study is the quantitative survey with Swiss general practitioners, which was sent out to all participants at the beginning of 2014. In order to prepare the large-scale questionnaire, 23 qualitative interviews were conducted. This paper covers the information on Advance Care Planning gathered during the interviews: What are GPs perceptions of ACP and how do they implement it in their daily practice routine?

Definition of Advance Care Planning (ACP)

Advance care planning is described as a voluntary mutual process of discussion between end-of-life patients and the health care professionals that treat them. This process can – if and only if the patient agrees – also include family members and friends. With the informed consent of the patient, results of this communication process should be documented. Also, regular updates are necessary in order to validate former statements. Documented and updated statements should be then distributed among the involved health care professionals as well as the patient’s family. Additionally, the

following aspects should be discussed: patients' anxieties and wishes, as well as his/her values and understanding of the situation, and future treatment wishes [1].

State of research

ACP is an instrument which was already in use during the seventies. In 2006, a research group, under the leadership of Luc Deliens, generated guidelines for Belgian GPs on how to communicate with palliative patients that wish to die at home. Their recommendations are based on knowledge gathered from literature reviews and interviews with patients, relatives and experts in this field [2]. Also in-patient patients experienced and described ACP in a positive way. An Australian study proved that a well-documented ACP (a) strengthens the implementation of patient preferences, (b) helps to lessen the burden on family members and therefore reduces stress and depression and (c) makes a patient's stay in hospitals less burdensome for them [3].

However, often the initiation of a first conversation on ACP is difficult. Perceived barriers are a) the hesitation of family members to participate in the process of planning, b) the passiveness of some patients who rely on others to decide for them (God, family members etc.) and c) patients' and relatives' uncertainty regarding prognosis and progression of the disease. Sharp et al. therefore view ACP as a patient's right. However, GPs are not obligated to discuss ACP related aspects in case the patient refuses.

GPs' interpretation of ACP

Interviews with Swiss GPs revealed that ACP was mainly discussed when a patient was considered as terminal or when patients' cognitive abilities were at risk. Often, these patients were tumour-patients as well as patients with organ failure or degenerative neurological diseases; the last two groups only offer a higher uncertainty in regards to their prognosis. A minority of patients is against ACP. In these cases, it is recommended to ask for any possible reasons why that is the case. At the very least, participants often asked their patients to appoint a surrogate decision maker. However, in cases where this was not possible, the GP should be in charge of any decision making.

Negotiations between patients and physician

Some participants recommend to not only focus on one conversation but to also assess the patient's values and – with the consent of the patient – the values of his/her family members in several consultations. These consultations should focus on worries, fears and burdens experienced by the patient and family as well as future treatment preferences. It is essential, according to some participants, to also address the patient's and family's resources in order to allow them to focus on something other than just their disease. As a result, a balance between happy memories and the current situation can be restored.

Further agreements between physician and patient should focus on therapeutic aspects, such as what treatments should be considered, if CPR (cardiopulmonary resuscitation) is an option and possible preferences regarding the patient's place of death. Some participants use this information for future decision making in cases where the patient is at risk and unable to make his/her own decisions. Any form of written directives however is legally binding.

A few interviews illustrated that patients experienced difficulties and talking about topics related to ACP and often change their mind later on. Participants recognised this ambivalence but also stated that the process of planning therefore becomes more difficult. This, several participants stated, requires a lot of flexibility from the treating health care professionals. Nevertheless, communication regarding ACP was still considered as a valuable tool to talk about impending death.

Networks

Once ACP had led to a common basis of understanding between physician and patient, the entire caregiver's network should be informed and should act in accordance with the results of the process. Usually these networks consist of different members, such as Spitex nurses, family members, friends, specialists, physical therapists and pastors. The patient him/herself appoints who from this network is a possible surrogate decision maker. The treating physician, often the GP, should support the patient in his/her choice and should coordinate the teamwork of all stakeholders. As coordinator, the GP often takes responsibility for each stakeholder meaning that the physician supports their work

but also pays attention to possible overburdening (especially of family members and friends).

Most of the participants agree that caring for a patient, especially at home, requires teamwork. A good standard of care is always the result of hard work of all persons involved. A functioning network, however, requires communication and the distribution of information. Participants stated that it is an important but also labor-intensive task to screen and distribute relevant information among all stakeholders. It is also considered as a sign of respect to inform all colleagues in a timely manner, which can also serve to motivate the network. Additionally, emergencies should be – ideally – anticipated in advance. In the best case scenario, the GP is always reachable by phone. In his absence, however, good documentation supports the work of emergency physicians. A sufficient supply of necessary medication is also considered essential.

After the patient's death

Some participants offer a debriefing of all involved family members after a patient's death. This debriefing was often used to thank everyone for the hard work, to address doubts, insecurities and fears, and to also give the relatives the opportunity to talk about their loss. Often, relatives experience a feeling of guilt after the patient dies. A debriefing can help to address such issues amongst others.

Conclusions

In this qualitative study, participants shared their experiences and perceptions of their work with terminal patients who need palliative care. They illustrated their use of ACP in their daily general practice and how it can support a dignified death.

Practice Points:

- Advance care planning (ACP) is a meaningful tool in the complex setting of palliative care
- ACP should be considered for patients at their end of life or for patients who are at risk of losing the mental capability to make their own decisions

- The main goal of ACP is the assessment of the patient's values and treatment preferences and to reach a mutual understanding between physician and patient.
- The establishing of a good network of caregivers is essential.
- The overall goal of good palliative care is to create the possibility for the patient to still focus on his/her quality of life rather than on his/her disease.

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2.2 Advance directives and the impact of timing: A qualitative study with Swiss general practitioners

Ina Carola Otte, Corinna Jung, Bernice Simone Elger, Klaus Bally

Introduction

Advance directives are written documents which give patients the opportunity to outline the treatments that they do or do not wish to receive if a future situation renders them unable to make decisions as to their medical care [1, 2]. Recently, the focus on patient autonomy and the wide variety of modern medical interventions have led to a substantial debate about advance directives [1, 3-5]. Topics of discussion include whether advance directives are valuable tools for assessing personal values [6, 7] and whether or not advance directives can express the will of different patient groups in situations in which communication or competent decision making is no longer possible [8-10]. Additionally, the possibility of bias based upon vague language or unclear phrasing in an advance directive were discussed [11].

Several qualitative studies showed that most GPs appreciate the positive impact that advance directives have on patients, families and health professionals [12-15]. For Switzerland, Harringer's study of Swiss patients in 2012 showed that 70% of patients who had no advance directive would be willing to draft one with the assistance of their general practitioner [16]. At the beginning of 2013, the legal status of advance directives has been strengthened via the new adult protection law (German: Erwachsenenschutzgesetz). This law now includes a passage that makes the application of any treatment described as unwanted in an advance directive a physical assault which can result in criminal charges brought against whomever delivered the unwanted treatment. Since advance directives have become stronger and the penalties associated with ignoring them have become more severe due to the changes in the law, it is of the utmost imperative that possible biases be minimized. While many aspects of advance directives have been discussed in recent decades, the proper time to address the topic with patients has not received sufficient attention.

As part of a continuing research project on the conditions and quality of end of life care in Switzerland, the authors conducted a series of interviews with Swiss general practitioners to explore their views on palliative care in general and specifically how advance directives should be facilitated and implemented. Based on the insights given during these interviews, we hypothesize that both the phrasing of an advance directive as well as the timing of its drafting plays a crucial role in its effectiveness to protect the patient's wishes [11]. Therefore, this research paper focuses on one of the four main themes that emerged from the analysis of the interviews in more detail: on general practitioners' perspectives to the best moment to initiate a discussion about the creation of an advance directive. In addition, it highlights general practitioners' reasoning for different timings as well as advantages and disadvantages of each of these timings.

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. The aim of this study is to conduct a detailed exploration of the functions of general practitioners who administer palliative care in primary practice. As one of the two steps of the qualitative section of the study, 23 qualitative interviews with general practitioners were conducted and analysed.

Sampling and data collection

Purposive sampling was chosen in order to obtain a diverse selection of physicians working in different types of practices (group versus single), regions (different cantons, rural versus urban region etc.), with a variety of gender, age, and professional experience characteristics. 30 general practitioners were purposively selected from the FMH (Swiss Medical Association) list, in order to represent the major characteristics of the Swiss population of general practitioners (proportional quota sampling). Participants were contacted via e-mail outlining the research. The email contained information about the title of the study "conditions and quality of end-of-life care in Switzerland – the role of general practitioners", information on the foundation who financed the study and

information on the approximate length of the interviews as well as the invitation to participate. In a one-hour (approximate) face-to-face interview in their surgeries, participants answered questions about administering palliative care in a primary care setting. Besides the interviewers and the interviewee nobody else was present during the interview. The interviews were recorded from December 2012 to February 2013 using Audacity software. Among question sets about administering palliative care and their networking with other institutions and stakeholders, they were also asked about the meaning of advance directives for their work. Additional questions explored when and how this topic was approached with their patients. The interview guideline was pilot tested and was adapted during the first interviews. The interviews were conducted by IO and CJ (both authors of this paper), both sociologists who have long term experience with qualitative methods. The French interviews were conducted by a Swiss-French nurse who is also trained in qualitative methods. Interviews were transcribed verbatim in the original language of the interviewees (French and several Swiss German dialects) and were analysed with the support of the analysis programme atlas.ti, Version 7.0. Participants were given the opportunity to review their interview transcripts. However, no participant made use of this option. A repetition of one or more interviews was not necessary.

Analysis

The analysis of all transcripts (mainly in their original language, some passages have been translated since not all authors are fluent in French) was conducted by four members of the research team (all authors included) with different disciplinary backgrounds (sociology, general practice and palliative care experts). The coders followed Mayring's nine steps of content analysis [17, 18], (1) the relevant data was defined, (2) the context of appearance of the data registered, (3) a formal characterisation of the data material described, (4) the course of analysis specified, (5) a theory-lead differentiation checked, (6) technique of analysis defined (summarisation, explication, structuring), (7) the unit of analysis defined, (8) data material analysed, and (9) finally interpreted. The data was repeatedly coded, moving from concrete passages to more abstract level of coding, deriving themes from the data and searching for

repeating concepts. In team meetings all findings were critically tested and discussed by all coders. Any disagreements were solved by discussion. Since the coding system remained the same for the last interviews and since the findings regarding timing did not significantly add something new to the interviews before, we conclude that we reached saturation with our number of interviews.

The study was approved by Basel Ethics Committee (Nr. EK 248/12) prior to its initiation. The informed consent of all participants was obtained and the interviewed physicians were given anonymity.

Results

Of the 30 general practitioners who were invited to participate, 23 physicians from French, Italian or German speaking regions in Switzerland agreed to participate (positive response rate of 76%). From the seven GPs who dropped out of the study, one GP who initially wanted to participate was excluded because he was acquainted with the research team. Our sample therefore consists fourteen German-speaking physicians (two of them practising in 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). All participants (23/23) stated that advance directives are very important tools for their work, especially for learning about patients' values. However, it was also stated by some participants that the available forms that are often used to create an advance directive are too short or too hypothetical in their content. Seventeen of the participants (17/23) shared more in-depth thoughts on advance directives. From their answers four main themes emerged: (1) the importance of advance directives for Swiss general practitioners; (2) the proper time to discuss the composition of an advance directive; (3) who should bring up the topic of advance directives and (4) how the advance directives should be worded in order to best protect the wishes of the patient. Of these four themes, the proper time for general practitioners to discuss the drafting of an advance directive is the main focus of this research paper.

Different "right" timings of an AD

Through the interviews, we identified three main trends regarding how general practitioners determine the appropriate moment to discuss an AD with a patient: (a) slightly more than half (9/17) of the interviewed general practitioners reported that they usually create advance directives with their patients when they are still healthy while (b) the rest (8/17) create advance directives with patients both while they are healthy but mainly when they are already suffering from a terminal disease. Some of these general practitioners (3/8) additionally stated that they would consider a possible change of perspective if a previously healthy patient became seriously ill. They also believe that advance directives should regularly be adapted to best meet the patient's current condition. Additionally, some general practitioners utilized (c) systematic approaches, such as age or during the first consultation of a patient, in their decision to discuss advance directives with healthy patients or patients with a severe illness. Another important point stated by general practitioners was that they are doubtful whether the available and often used advance directives forms contain enough information to enable them to make a justified treatment decision:

[GP11]: "When I fill in an AD with my patients, I always advise them to make a lot of changes to the available template, because especially the longer form includes so many situations that are highly hypothetical and very abstract, it does not make any sense to fill it in."

[GP10]: Well, so there is a form from the FMH, it is very short and here is a longer form. So the longer one, I always use that for the patients, but I find these situations highly hypothetical and very abstract, so I often see no sense in that.

Approach (a) "Sufficiently early" (before illness)

The majority of the interviewees (9/17) considered advance directives as a source of discomfort if they are not written "early enough". Different reasons were given for why they think that it is important to write an advance directive before an emergency or a terminal illness occurs. Some respondents mentioned that advance directives filled out during an emergency situation could be distorted by stress and would thus not properly reflect the patient's will. This could also become additional source of discomfort:

GP13 : It is very important to be able to draft one because you have to write it before you are in an emergency, because in an emergency the decisions you could make are not always obvious, whether it is for us or for others involved. I think it is even harder for others at the moment when

decisions have to be made. So I think this can be a source of extreme discomfort, whether it's for us dealing with such a situation if things haven't been settled in advance. Because, does a person, in an emergency, give us directives [that are] related to the emergency? Are they related to their physical suffering? Well, there are so many things which can intervene. And then we can also end up in conflict with the family, who may not see things the same way at all. So I think it's really, really important to address this early. To have a clearer idea and to agree that the direction that we take is the direction that everyone would like us to take.

Additionally, this general practitioner emphasized the possible conflicts for relatives in the decision making process, especially in the absence of an advance directive. The interviewee explained further that sufficient time is required to discuss the patient's wishes with the family to avoid future conflicts. If an advance directive is written during an emergency situation, the lack of time could lead to conflicts involving all parties.

Another stated reason to fill in advance directives "sufficiently early", was the feeling of unease when having to talk to already terminally ill patients about this subject:

GP4: So, I talk to them and ask if they have an advance directive, and I also say that it is always good to start thinking about it before it is necessary, because, if a patient is already terminally ill, it is much more uncomfortable to talk about this topic.

GP2: I really have inhibitions to talk to a severely ill patient, who is still in a critical state, about this topic. So I always try to cover this topic early enough, ideally sufficiently early, before a critical state can occur.

Approach (b) "When illness becomes predominant"

In contrast, a large number of interviewees (8/17) stated their doubts that it is possible to draw an advance directive with a healthy patient because the patient cannot imagine his or her future situation where an illness has become terminal:

GP17: Advance directives are something where I would take an hour or even two hours or time to talk repeatedly with the patients to know what they want and try to understand how they picture things. The problem with advance directives when we write them with patients, who are still healthy, is that they can't picture things.

Approach (c) as part of organisational and administrative requirements

Health and illness were not the only determinants of when to draft an advance directive. Another moment to draw up advance directives that was frequently named was the moment of transferring the patient to a nursing home.

GP 20: I often have to fill in an advance directive with a patient before I can transfer him or her to another institution such as a hospice or a nursing home. (...) More and more institutions make advance directives a mandatory requirement, which often results in what I call "last minute" advance directives.

GP9: In our canton, everyone who wants to move to a nursing home has to have an advance directive.

Discussion

Approach (a) "Sufficiently early" (before illness)

The majority of the interviewed general practitioners followed the approach "sufficiently early (before illness occurs)". They stated that they did so to avoid biases that can occur when advance directives are drafted during an emergency situation; to prevent the patient from additional stress; and to avoid the feeling of discomfort caused by discussing the approaching death with terminally ill patients. This third argument is already known from other studies [1, 19, 20]. This finding is also in line with studies where patients indicated the discussion about advance directives should occur earlier in age, earlier in the progression of the disease or even earlier in the relationship between physician and patient in general [21, 22] [19].

Since the wish of patients to draft an advance directive often gains importance with the progression of a disease [23, 24], the approach of only talking to healthy patients may require reconsideration. As also mentioned by the interviewees patient's preferences given during healthy days may not be very stable since patients are not always capable of imagining what their decisions will be when a disease becomes predominant [25] [26, 27]. Therefore, it is important to use advance directives as a precautionary measure and to give patients the opportunity to update advance directives later on during the course of their disease. This is an important ethical necessity to make sure that treatment

decisions are still in line with the actual preferences later on in the course of the disease [23, 28].

General practitioners participating in this study mentioned updates of advance directives only in very rare cases (3/17). While the mentioned concern that the conversation might put a strain on the patient is understandable, the option for the patient to update the advance directive may provide a feeling of comfort due to the patient having a say in what will happen in the future. The chance to define which treatments they want to receive in future situations may also reduce the feeling of the loss of autonomy as well as their dependency upon others [16].

Some respondents stated that the first step towards raising the topic is still often very difficult for many of them, especially when the patient is in need of palliative treatment. They reported feeling a sense of unease and stated to refrain from informing already ill patients because they fear talking about dying and approaching death could be a further burden upon their patients.

Fallowfield et. al. described that healthcare professionals often censor their information giving to patients in an attempt to protect them from potentially hurtful, sad or bad news. They showed a commonly expressed belief that what people do not know does not harm them. However, it has to be noted that the desire to shield patients from this topic may create even greater difficulties or harm for patients, relatives or involved healthcare professionals [29].

Our results show that the interviewed GPs consider advance directives to be strongly connected to forthcoming death, the main focus of advance directives might need reconsideration. Following different definitions of advance directives, the main focus of an advance directive is often described as giving the patients the opportunity to specify what actions should be taken for their health if they are no longer able to make decisions for themselves because of illness or incapacity – which is not necessarily related to upcoming death. We as authors therefore support that the first discussion about an advance directive should focus mainly on exactly this: on future treatment choices, but not necessarily on dying or death itself. Additional training could help general practitioners to phrase conversations about advance directives in a way that

gives patients a sense that advance directives are a mean to ensure their own autonomy. This way discomfort on both sides could be minimized, which could contribute to an open and honest patient-physician-relationship

Approach (b) "When illness becomes predominant"

The second approach [2] to informing patients, when illness becomes predominant, stands in direct contrast to that stated above. Earlier survey data [30] shows that also other general practitioners think only severely ill patients in an advance stage of their disease are capable of formulating stable preferences for their end-of-life care. One motivator for this approach that was mentioned by the interviewees was the fear that patients will record treatment preferences (and refusals) that are not in line with their actual preferences later on [31]. It was also shown by other studies that patients are more open to discussions about advance directives when death is already approaching [24, 32].

Our data shows that this general practitioners' association of advance directives with approaching death strongly influenced the choice of the moment in which participating general practitioners inform their patients about advance directives. Therefore their patients often receive little information about advance directives until symptoms occur that make a conversation about an advance directive inevitable. This may lead to advance directives that only represent a form of written consent to withhold certain treatments or a downgraded advance directives that only reflects another version of DNR orders (do not resuscitate orders) as seen in the study from Burchardi et al. [31]. For this reason it is necessary to emphasize that advance directives are an opportunity to extensively describe the patient's preferences concerning different life-sustaining technologies for distinct states of health [31]. Furthermore, from an ethical perspective, advance directives are designed to be completed as an extensive precautionary measure which implies continuously refinement and modification via updates [31].

Another aspect that was mentioned by our interviewees and that needs consideration is that due to the sometimes rapid progress of diseases, the time between the occurrence of symptoms and the patient's inability to communicate might be too short for the

patients to make reasoned decisions. As a result, patients might actually miss the opportunity to make their own decision and convey their preferences [31].

An important point stated by general practitioners was that they are doubtful whether advance directives forms contain enough information to enable them to make a justified treatment decision. Interviewed general practitioners mentioned that especially in difficult situations, medical decision-making can only be guided by advance directives which are specific and as concrete as possible.

However, the ethical ideal that the completion of advance directives should be embedded in discussions between physicians and patients [31] may turn out to be problematic in practice. Limited time resources or timing pressures during consultations [33] in combination with our respondents stating that the available advance directive forms are too short and/or too hypothetical may fail to provide enough room for a broad and comprehensive discussion about advance directives. Since literature shows that patients who are facing a severe illness also find it acceptable to be informed by admitting physicians, oncologists or other health care professionals, even if they are meeting for the first time [34], the outsourcing of advance directives consultations to avoid timing pressures might be a possible solution.

Approach (c) as part of organizational and administrative requirements

The third approach included the moment when advance directives are drafted because the patient wants or has to be moved to a nursing home. A few general practitioners mentioned that they have to draw up an advance directive before they are able to transfer a patient to a nursing home, due to their institutional requirements. However, in this case the requirements of advance directives seem to be more present than the wish to understand the patients' values regarding medical decisions in the future. Furthermore, making an advance directive an institutional requirement can be ethically problematic, since it should be drawn up without pressure and based on the free will of the patient. Therefore a discussion of advance directives should not be confused with coercion to fill out documents, especially if the goals of the document do not coincide with the goals of the resident. If a resident is not ready to make decisions at the time of

admission, the topic of advance directives and advance care planning should be raised at a later date [35].

For this reason, we conclude the approach to make advance directives a mandatory requirement to have the same disadvantages as seen above because the advance directive often needs to be drafted in a short amount of time (to meet the administrative requirement in order to become a resident), and is often based on hypothetical forms. This combination has the risk of drawing up a biased and incomplete advance directive that fails to provide a basis for a justified medical decision making.

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 how they integrate advance directives in their practice. However, due to the qualitative design, representative conclusions cannot be drawn.

Furthermore, the study sample may not have represented the full range of general practitioners' views on this topic, since it was limited in regards to geographical and cultural variation. Also other selection biases due to the recruitment process are possible, since the study was announced under the title of "conditions and quality of end-of-life care in Switzerland – the role of general practitioners". This announcement could have selected especially physicians who feel confident regarding palliative care and/or advance care planning.

Furthermore, because our results rely on only one data source, triangulation from other methods of data collection such as group discussion or a survey may increase the validity of the results. For this reason, the next step of our study is to design a large-scale questionnaire to quantify the results that we obtained from the interviews.

Therefore, we are convinced, that even despite these limitations; the obtained findings already show a variety of well-differentiated attitudes which add significant knowledge about how advance directives are implemented in general practice.

Conclusions/Implications for Practice

The general practitioners interviewed in our study expressed three main approaches to the discussion of advance directives: (1) when the patient is still healthy, (2) when illness becomes predominant and (3) systematically when a certain event occurs (such as the first consultation, the transfer to another institution or the patient reaching a certain age). Some of the participants mentioned that the current forms used to create advanced directives utilized questions and scenarios that are too vague to properly convey patient's wishes. Updates of advance directives were only rarely mentioned by participating general practitioners (3/17).

We as authors therefore reach the conclusion that, in line with our results and the existing literature, GPs preferably

(a) initiate the first conversation about ADs early enough, when the patient is still healthy, to gain a clear understanding of a patient's desires in terms of their medical care

(b) update advance directives regularly since it is known that treatment preferences can change with the time

(c) reaffirm a patients' wishes as their illness and medical care progress.

We also conclude that GPs should refrain from drafting advance directives to meet institutional or organizational requirements because it offers the risk of compromising the free will of the patient. This could lead to the drawing up of a biased and incomplete advance directive that fails to provide a basis for a justified medical decision making.

Acknowledgements

The authors thank the general practitioners who participated, for their time and thoughtful input. Furthermore, the authors express their gratitude to the colleagues who are part of the research team in this study and especially Dr. David Shaw for his thoughtful comments.

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2.3 The utility of standardized advance directives: the general practitioners' perspective

Ina Carola Otte, Bernice Elger, Corinna Jung, Klaus Bally

Introduction

Advance directives (AD) are written documents that give patients the opportunity to communicate their preferences regarding treatments they do or do not want to receive in case they become unable to make decisions. ADs also often offer space for patients to (a) appoint a surrogate decision maker, (b) determine future medical treatments and/or (c) give a personal statement. ADs are most useful for treating physicians, patients, and their relatives when they are drafted in a clear, understandable, and not too broad manner, simultaneously covering all important and relevant medical information (1).

The process to draft such an AD can be very time-consuming, especially for older patients (2). Nevertheless, general practitioners (GPs) are good candidates to achieve the desired level of quality in ADs since they often treat their patients in a holistic way and for an extended period of time (3, 4). In practice however, studies show that GPs often use standardized forms assisting patients in drawing up an AD. Unfortunately, individual statements of any given patient rarely are added to these forms (4, 5). The existing body of literature highlights several limitations of ADs that are linked to this phenomenon. Short forms (often used only to appoint a surrogate decision maker) increase the likelihood of excluding patients' wishes to prolong or determine therapy (6, 7). Furthermore, Pautex et al. (8) found, that patients expect their relatives to play an active role in future medical decision making, but often do not share specific wishes and preferences with them.

Also, the accuracy of healthy patients' stated preferences regarding future treatment choices varies (5, 6). The content, structure, and underlying attitude of standard forms can influence patients, depending on their source; for example, forms provided by the Catholic Church as compared to those from 'right-to-die' organizations (5, 9).

Studies also show that the practical use of these templates is often limited by various factors, such as the usage of statements that are too general in nature (10-13).

In Switzerland, the 2013 adult protection law strengthens the legal status of ADs. Different organisations [for example the Swiss Medical Association FMH, Caritas, ethics consultation services (Dialog Ethik) as well as right-to-die- organizations (Exit)] offer pre-printed templates to facilitate the process of generating an AD. In general, three different types of templates are currently in use. The shortest version of the available templates only allows patients to appoint a person as a surrogate decision maker (14, 15). The version of medium length uses checkboxes to assess patients' values with a special focus on life-sustaining treatments and the discontinuation of therapy. The longest version offers additional space to write individual statements.

GPs often emphasize the importance of individual anamneses of a patient's values (16) and patients often come to their GP to draft an AD (17). We therefore seek to better understand the process of drawing up ADs in general practice. Up until now, no qualitative data exists, explaining which standardized templates GPs use and for what reasons.

Our qualitative study is the first to elaborate on whether GPs use standardized templates, and if so, which version, why, and whether they change/add a patient's individual explanations to the forms. Our study also sheds light on potential concerns and shortcomings related to the use of templates as well as barriers GPs encounter when assisting their patients in drawing up ADs.

Methods

This paper references results from a nation-wide study entitled "Conditions and Quality of End-of-Life Care in Switzerland—the role of general practitioners," which was funded by the Swiss National Science Foundation. The aim of this study is to conduct a detailed exploration of the functions of general practitioners, who administer palliative care in primary practice. Twenty-three qualitative interviews with general practitioners were conducted and analysed.

Sampling and data collection

To obtain a diverse selection of physicians working in different practice settings (group versus single), regions (different cantons, rural versus urban region etc.), gender, age, and professional experience, 30 general practitioners were purposively selected from the FMH (Swiss Medical Association) list (proportional quota sampling). Participants were contacted via e-mail outlining the research. Of this sample, 23 physicians agreed to participate (positive response rate of 76 %). In a 1 h face-to-face interview in their practices, participants answered questions about administering palliative care in a primary care setting. No one other than the interviewers and the interviewee was present during the interview. The qualitative semi-structured interview guideline consisted of 20 questions. The interviewer started with a broader question about the importance of ADs in GPs daily work. Then the GP was asked, which patients are usually interested in drafting an AD and about GPs experiences how ADs are usually drafted? If a GP mentioned the use of a template he was asked which template and why. Also the GP was asked, who (the patient or the GP) usually starts a conversation about ADs and what GPs feel to be the best moment to start talking about the topic of ADs. The interviews were recorded from December 2012 to February 2013. Participants were asked about administering palliative care, their networking with other institutions and stakeholders, and the meaning of ADs for their work. Additional questions explored when and how they approached this latter topic with their patients. The interview guide was pilot tested and subsequently adapted during the first interviews. Either IO or CJ conducted the interviews in German. Both are sociologists who have long term experience with qualitative methods. An additional interviewer (with training in qualitative methods) was hired to conduct the French interviews. All interviews were transcribed verbatim in the original language of the interviewees (French and several Swiss German dialects) and were analysed with the support of the analysis programme atlas.ti, Version 7.0. Participants were given the opportunity to review their interview transcripts. However, no participant made use of this option.

Analysis

All four authors (of varying disciplinary background: sociology, general practice, palliative care) analysed the anonymised transcripts. Everyone followed Mayring's nine steps of content analysis: (1) relevant data was defined, (2) context and appearance of the data was registered, (3) a formal characterization of the data material was described, (4) course of analysis was specified, (5) a theory-lead differentiation was checked, (6) technique of analysis was defined (summarization, explication, structuring), (7) unit of analysis was defined, (8) data material was analysed, and (9) finally interpreted. The data was repeatedly coded, moving from concrete passages to a more abstract level of coding. Themes were derived from the data found in repeating concepts. In team meetings, all findings were critically tested and discussed by all coders. Any disagreements were solved by discussion. Theoretical saturation was reached when interviewees repeated prior findings and did not add anything of new significance.

The study was approved by Basel Ethics Committee (Nr. EK 248/12) prior to its initiation. All participants provided their informed consent.

Results

When questioned about the role of ADs in their daily work, the great majority of those interviewed in our study agree that an AD is of high importance and very useful for their work. According to them, more and more patients ask for assistance in making an AD. GPs frequently report finding ADs to be important because they make it possible to start a conversation about end of life (EOL) issues with their patients. Interviewees often use standardized AD forms that vary in length. The shortest form offers the possibility to appoint a surrogate decision maker while the longest form, additionally offers space for an individual statement from the patient. Templates are mainly completed by the patient at home, without the GP.

Why do Swiss GPs use standardized AD forms?

The long duration of time with which Swiss GPs see their patients not only serves as the foundation of trust in the relationship, but can at times be a communication barrier. Some interviewees found it difficult to initiate conversations about emotional and sensitive topics with their patients, especially when the patients already suffer from a severe illness:

[GP2]: The patient was mentally always very fit and I knew him for quite a while. I really had some doubts and constraints talking to him about ADs.

[GP7]: So, to me it [the AD] is basically a starter and a reminder that we have discussed this topic with the patients. It gives me a frame and room to talk about it; it (the template) is something official that I can use to talk about these topics.

[GP6]: So, I use it to verbally explore patients' wishes and having a short template makes leading such a conversation much easier for me.

[GP8]: Advance directives are helpful to start a conversation not only between doctor and patient but also between patient and involved relatives. It is also easier for me to assess a patient's values during the conversation where the patient has the possibility to ask questions, so I can get a feeling for a patient's values. So I think I actually use it more as an instrument to verbally assess patient's future treatment wishes. For me, having a template for advance directives makes the start of this conversation much easier.

How begins a conversation about ADs und what kinds of templates are used?

The way a GP starts a conversation on the topic of ADs can influence the quality of it. Some GPs hand out one or more templates and ask their patients to read and think about them at home with the option to talk to them about it later on, while others prefer their patients to fill them out alone at home. Other GPs assess and document patients' preferences in more than one consultation, sometimes even together with a patient's relatives.

[GP 5]: Patients sometimes ask me, "Do you have an AD that I can sign?" and I do have different templates, which I hand out in this case. I tell them to think about the content, do they feel that it covers all important topics? Or do they disagree with some parts? And if they feel the template suits them, we usually sign it together the next time we see each other

[GP 1]: I cannot tell my patients what to do or what not to do, I tell them their possibilities and options and then I tell them to discuss it with their family and to document it as good as possible, what they would want later on and what not.

Short standardized AD forms are mainly used to appoint a surrogate decision maker.

Some of the interviewees use the shortest version of the available templates mainly to name a surrogate decision maker, since they find it difficult for patients to anticipate future hypothetical scenarios. Another reason participants choose to use the shortest version is to avoid the burden of talking about “terminal scenarios.”

[GP 8]: My experience is that most of my patients prefer the shortest version possible, where they only name a surrogate decision maker

GP 4]: ...and that is the thing, you cannot cover every eventuality in an AD that is way too complicated and impossible to achieve. And as long as you're healthy you simply don't need a special document, you can simply take the short official version of the Swiss Medical Association FMH. But as soon as things change, you need to reconsider this choice

[GP 9]: So, I use 2 templates, the shorter one (to name a surrogate decision maker) and the longer version, which I only offer if the patients explicitly want it. But these scenarios that the longer version includes are so hypothetical; in my opinion it barely makes sense to use that one

[GP 7]: In general, using an AD with the intent to alleviate pain is in my opinion okay; however, talking about PEG-tubes, enteral nutrition and resuscitation with my patient is difficult for me. I mainly use it to appoint a surrogate decision maker

GP 11 uses the shortest form because the template is only a tool for him to start a conversation in which he can assess a patient's wishes, needs, and values.

[GP 11]: The paper is not important, it is important that you get to know the patient. So I use the shortest version as a starter, but the real assessment of patients' wishes takes place during the conversation we have.

Standardized AD templates, which offer the possibility for the patient to express his/her wishes regarding future life-prolonging treatments.

A few participants use the medium length version in which patients can, in addition to naming a surrogate decision maker, express their wishes regarding life prolonging

treatments by ticking off checkboxes. However, GPs tend to refrain from offering these templates to healthy patients. Instead, GPs mainly offer versions that provide patients the possibility to either accept or decline the use of a PEG tube or antibiotics and/or resuscitation to those with a serious condition.

Their reason for this trend is that GPs often fear that patients cannot realistically imagine future scenarios, such as swallowing inability after a stroke. The more detailed versions allow GPs to address concrete situations and to add changes to the AD if necessary.

[GP 11]: And if I fill in an AD with my patients, I always advise them to make a lot of changes to the form, because especially the medium form includes so many situations that are highly hypothetical and very abstract, it does not make any sense to fill it in

[GP 10]: Well, so there is a form from the FMH, it is very short and here is a longer form. So the medium one, I always use that for the patients, but I find these situations very broad and often too far away from reality, so I see no sense in that

[GP 8]: As long as a patient is still healthy, the short form is sufficient, but as soon as a serious illness progresses it is useful to have a longer version which determines if in case of a pneumonia he/she'd like to receive antibiotics or not.

Standardized templates paired with individual anamneses:

Many GPs emphasize the importance of assessing individual values of their patients in order to correctly ascertain their future treatment wishes. However, participants are not definitive as to whether they also keep a written form of these additional individual anamneses.

[GP 3]: Sometimes patients ask me why they should have an AD. Why is it important to have one? And then I tell them that it is important for me, so we can talk about it and I can understand their thoughts on different things and so I know what they would want in case they cannot express their wishes any longer

[GP 6]: So ADs are a tool for a patient to express his/her wishes in situations where he/she is left unable to communicate them. But they also help me before these situations occur, because I get the possibility to talk about potential questions and therefore assess a patient's values and

wishes. So it is a great tool which makes it easy to start this conversation and to assess his/her values during it

[GP 9]: For me it is important to get to know the thoughts of a patient. What are his/her attitudes regarding different options and how are his/her attitudes/preferences different than mine? So we can find a compromise, something we agree on

[GP 19]: All right, well I am going to be very provocative. Advance directives are very useful when we discuss them with the patient... Advance directives are an issue where I am going to take 1 or 2 h and sometimes more than one conversation, in order to discuss this topic with my patients ... I do it with sick patients in order to find out what are their wishes and in order to try to understand how (.) they imagine future things. However, the problem with advance directives is, when we do it with patients who are still healthy, is that they are not able to imagine future illness

Regardless of the template GPs use, most emphasize that ADs are legally binding documents, which require regular updates.

[GP 3]: I find it important that my patients start thinking about questions related to future treatment decisions and I also have to say since ADs are a legally binding document we have to update them regularly, so they are still valid later on ... but the process of thinking about topics related to ADs is something, that I always support in my patients

[GP 6]: Well, as soon as a patient's situation changes, I mean, maybe a disease that is progressing or cancer and the prognosis changes as well, then we could adapt the existing AD to make it fit the new situation. And that is the main topic to me, as soon as someone becomes seriously ill, ... "We made an AD 2 years ago, what do you think, what would you like in case for example you're suffering from dyspnea? Should we give you antibiotics in case of an pneumonia or just morphine? We need to talk about these things, no?"

Discussion

For most GPs in this study, ADs are an important tool to start a conversation about difficult topics, such as approaching death or death itself. According to the participants of this study, the assessment of the personal values of the patient during this conversation weighs more than the written AD in the end. Often they use either the short (only surrogate decision maker) or the medium length version (surrogate decision maker and check boxes concerning future medical treatment) of the available templates. However, most feel that the situations described in the latter version are highly

hypothetical. Although interviewed GPs mentioned the existence of the longest version, which consists of an individually written statement, they do not actively use it.

For the medium length version, interviewees stated concerns that, in their opinion, pre-printed forms are too hypothetical to cover all important aspects and therefore offer space for misunderstandings and misinterpretation. This fear of misunderstandings is in line with results of a qualitative study by Thompson et al., where participant hospital physicians and nursing professionals note the possible negative effects of advance directives, such as the risk of misinterpretation or general errors in treatment (under- or paradoxical overtreatment) (18). Nevertheless, Harringer's study (4) shows that GPs—despite all concerns—often use short to medium length forms for ADs. Some of our interviewees explicitly claim that it is not the form, but the conversation itself that matters to them. Under this approach, the final document (which they think is too hypothetical anyway) seems to lose some of its importance, while the focus clearly lies on the verbal anamneses of patient's values. Emanuel et al. (19) note the importance of verbal anamneses. Recent studies elaborate on other efforts to further support patients in light of the common issues experienced during end of life scenarios in non-confrontational settings. For example, different approaches can be utilized in conjunction with the go wish card game (20).

Furthermore, the guidelines of the SAMS (Swiss Academy of Medical Sciences) regarding medical communication indicate the low value of short and standardized advance directives. Based on these guidelines, standardized advance directives cannot express individual values because standardized sentences cannot sufficiently illustrate a patient's health and/or biographical background (21). Broad statements such as wanting to "maintain dignity" or be "free from pain", are often too general to provide a basis for individual treatment decisions (22, 23). For example, ADs often refer to forgoing an intervention when the patient's condition is "irreversible" or "terminal". However, determining whether patients are in these states is often very difficult (24).

Additionally, broad statements increase the possibility of contradictions with patients' stated wishes (21). Individuality of an AD is therefore often considered as one of the main indicators of quality (21). Patients' treatment preferences and values change as

their health changes (25-27) at the end of life (28), and even during periods of stable health (28). GPs in this study shared their concern over making ADs with patients who are still healthy because they fear patients would not be able to consistently anticipate future scenarios and treatment preferences. This is in line with the results of Bauer (29).

Since an AD is a legal document, stated wishes must be as authentic as possible and include specific wording to avoid possible misunderstandings. Regular updates are therefore of the utmost importance. The Swiss Academy of Medical Sciences (SAMS) guidelines recommend that ADs should be part of a process, which spans more than one conversation to assess and update values, treatment goals, and possible proxies. However, our interviewees rarely mentioned updates. Interviewees reported offering follow up conversations (as recommended by the SAMS) only when the patient actively asked for it.

Interviewed GPs use the shortest template mainly to start a conversation and appoint surrogate decision makers. However, when the appointment of a surrogate is often the only written document in the end, it is questionable whether the surrogate's decisions are congruent with the patient's wishes. Shalowitz et al. (6) found that patient-designated surrogates incorrectly predict patients' end-of-life treatment preferences in one third of cases. Also patients' fears of abuse by relatives and possible surrogates is a factor that can limit the employment of an AD (30). Following the example set by one of the GPs (GP 8), it can be sufficient to use only the short form to appoint a surrogate decision maker during a patient's healthy days; however, as soon as a serious disease progresses, a more detailed version should be used to offer the patient space to document personal values and preferences as well as anticipated decisions for the future (14).

According to our results, patients often complete an AD template at home, without the support of their GP. This can lead to various difficulties and inaccuracies that can compromise the quality of an AD (5, 31). In order to avoid possible inaccuracies, drafting a useful AD usually takes a few consultations, which also provides the patient time to ask questions.

Further, since there is a pool of different forms for ADs from which to draw (from religious organizations as well as from right-to-die organizations), the one a GP hands out can insinuate certain choices for the patient and therefore influence the patients' follow up decisions. Moreover, while the idea to elaborate patient's values during the conversation could be a good start for assessment, the information a patient receives might not be sufficient for him/her to complete an AD at home. Patients often feel ambivalent about different treatment options and therefore need support and help with their decision making (32). Modifiable factors such as knowledge gaps, uncertainty regarding outcomes, lack of clarity about what matters most, and feeling pressured to choose a particular option may exacerbate the decisional conflict and make the support of the treating GP essential (33).

Conclusions

Standardized advance directives are important tools for GPs and offer a good basis for them to start a conversation about patients' preferences and future treatment wishes. When the patient is still not facing the progression of an already existing disease it could be sufficient to only appoint a surrogate decision maker instead of creating a full AD, since preferences often change during the course of illness.

However, in all other situations, the appointing of a surrogate decision maker should be supported with a written statement of the patient's general values. In order to avoid broad and general statements, tools such as the go wish card game with a variety of pre-formulated value attitudes could be helpful.

Patients and their relatives should always have the opportunity to ask their GP for medical advice when drafting an AD. It is crucial to regularly verify and update existing ADs within the course of a disease.

Strengths and limitations

A clear strength of this study is the use of a qualitative method to explore a multifaceted topic, in which GPs could express how they integrate advance directives in their practice.

Since our study is a qualitative study we are not able to reach a conclusion regarding the quantitative aspects and distributions of opinions among GPs.

Furthermore, because our results rely solely on qualitative data, 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 our interviews.

Authors' contributions

IO and CJ conducted the interviews and performed the analysis of the data together with KB and BE. All authors participated in the design of the study. IO drafted the manuscript with the help of CJ and KB. All authors read and approved the final manuscript.

Acknowledgements

The authors would like to thank Brandon Williams for his thoughtful input.

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2.4 “We need to talk!” Barriers to GPs’ communication about the option of physician-assisted suicide and their ethical implications – results from a qualitative study

Ina Carola Otte, Bernice Elger, Corinna Jung, Klaus Bally

Introduction

When seeking assistance in dying, GPs are often a patient’s first point of contact (1, 2). GPs usually spend extended periods of time caring for their patients, and therefore often know their patients’ preferences and values very well (1, 2). Against this background, a patient’s request for the doctor to not only discontinue treatment, but also to assist him or her to die, is likely to create intensely stressful situations for both patients and physicians (3, 4). In our study and throughout this manuscript we will refer to the act of a physician assisting a patient in dying as physician-assisted suicide (PAS). We define physician-assisted suicide as “a physician providing a prescription of a sufficient dose of drugs to enable a patient with a terminal illness to kill him- or herself”.

Earlier studies have shown that patients and their relatives highly value the opportunity to talk to the treating physician about the option of PAS: Patients state that discussing the option of PAS as a possible “way out” helps them to deal with their situation and can help them to relieve stress (5-7). Furthermore, patients’ requests for PAS can also be an indicator of unmet needs or concerns of patients (8). Therefore, several factors are very important in order to ensure the best possible patient care. These include competent communication about PAS as well as the assessment of its origin, the sincerity of the patients’ wish to die, and other viable alternative treatment options, (7, 9).

From a legal perspective, PAS in Switzerland is not explicitly permitted by legislation; however, assisting in a suicide has not been a prosecutable act for almost a century (10). This is provided that the person seeking assistance is competent and the assister is not motivated by self-interest, pursuant to Article 115 of the Swiss Penal Code. However, even though PAS was not illegal, the code of professional conduct originally did not support the participation of physicians (11). This changed in 2004, when the Swiss

Academy of Medical Sciences (SAMS 2004) published its medical-ethical guidelines on PAS, which state that “it is not part of a physician’s activities because it is contrary to the goals of medicine, but it may be considered by the physician if the person requesting it fulfils certain criteria: is within days or weeks of the end of life, is competent and the wish is well considered and not due to external pressure, and alternative means of assistance have been discussed” (SAMS 2004).

It is therefore the task of GPs receiving requests to establish whether a patient fulfils the listed criteria; this requires the competent and professional handling of this issue (Back et al. 2002). Thus, it is essential to explore how GPs communicate about PAS when receiving requests from patients in practice (7). Understanding their reactions and experiences of PAS queries, and the rationales behind their responses to such requests, is important in order to fully understand any potential shortcomings, barriers or psychological discomfort associated with this issue. However, the available literature is often limited to studies detailing physicians’, patients’, and other stakeholders’ attitudes towards AS in general (e.g.(12)) and arguments pro and against its legalization (e.g. (13-17)). Furthermore, the main approach presented is often aimed at the elaboration of GPs’ attitudes towards PAS in general, but not upon their way of actually communicating or responding to requests for AS (e.g. (18, 19)).

In this study, we chose a qualitative research method (semi-structured interviews) in order to explore in depth this multifaceted, complex topic while enabling general practitioners (GPs) to express possible difficulties they experience when asked to communicate about this matter. The gathered data gave us insight into potential barriers to professional communication about PAS while also giving us rich data with which to ethically analyse GPs communication in practice.

Methods

This paper describes results from a Switzerland-wide study entitled “Conditions and Quality of End-of-Life Care in Switzerland – the Role of General Practitioners” which was funded by the Swiss National Science Foundation. The aim of this study is to conduct a detailed exploration of the attitudes and difficulties of GPs who administer palliative care in primary practice. Therefore, the study design included a qualitative research part

at the beginning of the research project, which is particularly suited to understanding GPs attitudes, values and difficulties when it comes to palliative care and requests for PAS (20). As one of the two steps (focus groups and semi-structured interviews) in the qualitative section of the study, 23 qualitative interviews with general practitioners were conducted and analysed.

Sampling and data collection

A purposive sampling of 30 GPs was chosen from the FMH (Swiss Medical Association) list in order to obtain the maximum variety in terms of practice size (group versus single), location (practices in different cantons and in urban, rural or suburban regions), and doctors' gender and age. Selected GPs were contacted via an e-mail outlining the research. Semi-structured face-to-face interviews, approximately one hour in length, were conducted with the participants. These participants were based in the French, Italian, and German speaking areas of Switzerland. The interviews took place between December 2012 and February 2013. The interviews were conducted by IO and CJ (both authors of this paper). Both interviewers (IO and CJ) are sociologists specializing in qualitative research methods and interviewing techniques. An interview guide was used for all interviews, which evolved as new insights were gained during the data gathering process and led to a more in-depth exploration of this topic. Among the question sets concerning administering palliative care and their networking with other institutions and stakeholders, the participating GPs were asked about their reactions to and handling of requests for assisted suicide. The study was approved by the competent ethics committee (Ethics Committee northwest/central Switzerland "EKNZ") in November 2012 and all participants provided informed consent.

Analysis

The interviews were transcribed verbatim (using the transcription software "F4"). IO and CJ carried out an independent analysis of all transcripts (using Atlas.ti). Additionally, a secondary coding was performed by KB and BE. Critical reviews of each analysis of each interview were performed in order to help us to become aware of our own backgrounds and potential bias (reflexivity) (21, 22). The codings were then reviewed by two independent researchers to ensure inter-rater reliability.

The coders followed Mayring's steps of content analysis. In a first step, the data was coded separately by IO and CJ, moving from concrete passages to more abstract levels of coding including emerging themes. Both coders then discussed their codes and re-coded the data again. After five interviews a preliminary coding guide was developed which was adapted continuously throughout the analysis, adding new codes emerging from the material, if necessary. In team meetings all findings were critically tested and discussed by all coders. Any disagreements were solved by discussion. Since the coding system remained the same for the final interviews and no new codes/themes emerged, we concluded that we had reached saturation.

Results

Of the 23 GPs who participated in this study, three interviewees declined to answer questions about PAS due to personal discomfort. Of the remaining 20 GPs, about two-thirds of the interviewees clearly stated that they would not assist with a patient's wish to proceed with PAS. A few of these interviewees also reported that they discourage patient requests in advance by saying that performing physician assisted suicide is not an option for them. The remainder of the GPs were either supportive of or indifferent to PAS. Those GPs who support PAS stated that they believe it is a compassionate response to a medical need and prescribed the needed medication. Some of them reinforced their position with the rationale that it is good for patients to know about a possible way to end their suffering.

Participants in our study received one to three requests for PAS in their career. The GPs who had chosen to refuse to assist a patient's suicide comprised the largest group in the study and provided the most insight into their handling of requests for PAS. As such, and because we were particularly interested in possible barriers to their patient communication about PAS, this paper mainly focuses on the analysis of their reasons and arguments. We identified three main themes concerning how GPs accounted for their stated refusals to assist a patient's suicide:

Theme 1: Handling of emotional and psychological impact

GPs who stated that they avoid talking about PAS requests emphasized their uncertainty about their ability to cope emotionally with assisting a patient in ending their life. They stated that they fear their own psychological health might be at risk. Instead of PAS, they try to find a way to support the patient without intentionally causing death, for example by giving the patient morphine. Especially in cases where they have a long and well developed patient-physician relationship, the emotional impact of PAS requests increases due to their personal connection to the patient. While they could empathize with terminally ill patients' wishes to die, the feeling of not being able to handle the emotional, ethical, or psychological impact was overwhelming for them. A few physicians reported that they always felt relieved when they did not have to talk about a request for PAS.

GP4, female: I do not feel competent to assist a suicide, and I do not want to either. Especially for my personal psychological health, when I know the patient for a while. I find this legitimate, and I am always relieved when I do not need to think about this topic.

GP19, male: One of the things I try to tell them is that I cannot bear the idea of killing one of my patients. I'm not strong enough for that, I cannot cope with it.

GP23, female: When someone asks for help, I explain that I do not do assisted suicide. It's me, I cannot do it, I feel like I would not be capable - psychologically. So I admit I would never do it. I would give them Dormicum or morphine or something like that.

GP5, male: To me, it is important to clarify the situation as early as possible. I tell them that I could never do it. I say that at the very beginning. This way I can avoid discussing this topic. I guess one consequence of my behaviour is that I choose the easiest patients to treat.

Theme 2: Religious beliefs and moral values

Some of the interviewed GPs who did not want to assist a suicide commented that their opinions are related to their personal values. However, all of them acknowledged that situations may arise in which a request for PAS is quite understandable. While these GPs acknowledge and respect the wishes of their patients, they stated that their own "set of moral values" was the reason for their refusal to assist their patients in ending their lives. They feel committed to relieving a patient's suffering and most agree that physician assisted suicide might, in some cases, be an option for patients. However, they do not want to take an active role in PAS. They would rather search for other options for

their patients, such as improved palliative care, the transferal to another doctor or psychological support. As shown in the following quote, the refusal to assist a patient in dying can also lead to a postponement of the conversation about this option to a later moment “when the time has come”.

GP17, female: Some patients requested it, but I told them: „No, do not rely on me to give you the prescription of this product, no”. I tell them clearly: do not count on me it is (AS) against my beliefs, but I respect your choice, and I’m ready to help you and to accompany you, and we will see when the time has come.

However, as shown in the following quotes, though most participants acknowledge that situations may arise in which a request for PAS is understandable, they still cannot participate in this procedure due to their personal values and beliefs:

GP18, male: I can totally understand why an assisted suicide is meaningful. It simply challenges my beliefs.

Some of them also think that there are other, sufficient options such as palliative care or psychological support:

GP13, male: I had to tell that patient that I am sorry, but that it is not compatible with my own philosophy and that there are other sufficient options.

Theme 3: Conflicts with professional role

Several GPs contend that PAS is not a part of their professional role. They believe their duties are to ensure the patients’ quality of life, to alleviate pain and suffering, and to provide support to patients and their families. They also fear that their involvement with PAS could lead to confusion about their roles as doctors or could make assisted suicide look like a “normal medical procedure”. Some of them underlined that patients’ wishes for an assisted suicide were a psychological issue and possibly avoidable. As soon as the patients received treatment, either from a psychiatrist for their psychological suffering or from a GP who is able to relieve their physical pain, the wish for an assisted suicide, in their opinion, vanishes.

GP23, female: Me, I listen, listen to my patients, but I cannot give them the medication, I cannot see myself doing it. I think it’s not my role. Another aspect is..., it seems clear to me, that we cannot declare assisted suicide as a normal medical procedure, because otherwise the pressure

of our society on aged people might grow to that extent that those people in retirement homes might get the feeling that it is their duty to commit assisted suicide, because they only cost money or because they are “useless”.

GP20, female: It’s quite unusual but when it happens it often demonstrates that they (the patients) feel weakened, they are now in a situation where they feel worse. If you manage to read behind the moral suffering and if you manage to answer to this pain most people forget they talked about suicide because they have their answer.

GP15, male: I don’t talk about it because it is not part of my job, the person needs care I cannot give in my cabinet. Generally, I try to convince the person to see a psychiatrist.

GP12, male: I think if I was promoting suicide, a lot more of my patients would do so. We are really underestimating the influence we have as doctors, especially during end of life care, where people need to give up more responsibilities about themselves. So for me, assisted suicide can never be a part of my professional role.

Discussion

As shown in the introduction, competent communication about PAS is important on different levels: e.g. a patient’s request for PAS can be an indicator for unmet medical needs. Furthermore, talking about AS can give patients the feeling of regaining control about their life and is therefore a possible means of relieving stress in patients (5, 6, 8).

Participants in our study received one to three requests for PAS in their career, which is reflective of the national average of assisted suicide requests experienced by GPs in Switzerland. During the interviews for this study, GPs illustrated possible barriers faced when confronted with requests for PAS; they have to weigh the suffering of a terminally ill patient on the one hand against their own psychological well-being, personal values and understanding of their professional role on the other.

In this section we re-assess these different themes that emerged from the interviews in order to ethically analyse how potential barriers to this kind of communication could be overcome.

Theme 1: expected psychological impact

GPs who addressed this theme based their rejection mainly on their feeling of not being able to handle the emotional impact of PAS. In order to better understand their feelings,

it might be important to acknowledge that although it is legally possible, the handling of requests and the procedure of PAS is still relatively new to GPs. Before 2004, professional guidelines in Switzerland had considered PAS to be incompatible with the aims of medical practice (SAMS 1995). Thereafter, the guidelines of the Swiss Academy of Medical Sciences regarding PAS were broadened (SAMS 2004). This rather recent and still controversial change may therefore leave GPs feeling insecure about the process of PAS, its legal prerequisites and how to proceed professionally.

As a step towards overcoming this barrier, other studies have shown that further education and training can have positive effects on GPs and their capability to deal with the potential psychological impact of PAS (9, 23). Therefore, the topic of PAS and its possible effects on medical professionals should be included in the official vocational training program for general practice. Currently, postgraduate training in Switzerland seldom covers the subject of PAS (24). Additional knowledge concerning PAS and its legal and ethical prerequisites could help to limit the feeling of discomfort expressed by GPs.

Concerning GPs' concerns about the expected psychological impact, Marwijk et al. have shown that ensuring that sufficient time is available for all involved parties to deal with the emotional component of PAS could be another way to reduce potential discomfort (3). Other studies have shown that team consultations and guided group supervisions of all medical professionals involved, paired with a strengthened education, can help GPs to handle the emotional and psychological impact (25). Berghe et al. further report that medical professionals who formerly declined patients' requests for similar reasons found it helpful to accompany a patient undergoing the procedure as a witness, learning that the patient was relieved to gain back control and grateful that his "final days did not have to last any longer", whether or not all medical possibilities had been exhausted (25). As a result, these medical professionals were convinced that the procedure could be part of "genuinely good care" which then minimized their discomfort (25).

Theme 2: Religious beliefs and moral values

Interviewees in this group found PAS to be in direct conflict with their own morals and values. They base their refusal to communicate with their patients about PAS on

personal ethics. They are not against PAS in the context of their profession, but because of their individual opinions. The GPs in our study were aware of their personal struggle with this topic and acknowledged that medical professionalism requires them to be aware that their own personal values might have an impact on offered treatment choices and therefore on patient autonomy.

One possible impact on patient autonomy was apparent when GPs reported their attempt to postpone final decisions with their patients by offering to accompany them and to talk about PAS “when the time has come”. However, by encouraging the postponing of a final decision, GPs risk compromising patients’ autonomy since patients need to fulfil certain criteria for PAS, such as displaying competence and the ability to take the PAS medication by themselves (26). Rather than postponing the decision, a better option to ensure patient autonomy could be the transfer of the patient to a colleague or a right-to-die organisation once a patient’s concrete decision to proceed with assisted suicide has been made. However, in terms of continuity of care, the option of referring a patient to a different colleague or organisation should be thoroughly planned and well considered, since the patient will then be treated outside his or her familiar care environment, which might not be optimal (25).

Nevertheless, it is also important to note that despite all the support that can be offered (e.g. better education on the subject, group consultations, guided team supervision, accompanying of a patient undergoing PAS as a witness etc.), it must be understood that no-one can be compelled to participate in any form of suicide assistance if it is incompatible with their own moral stance or endangers their psychological health (27). This dilemma requires a personal decision of conscience and as such must be respected as long as it does not prevent a GP from offering other options to the patient (e.g. a transfer to a different GP) in order to ensure full patient autonomy.

Theme 3: professional role

Some interviewees stated that their main reason to reject a conversation about PAS is because they see conflicts with their professional role when being asked for their assistance. Their understanding of the medical ethos, with the aim of healing patients while trying to avoid causing additional harm, may contribute to their way of handling

PAS requests. However, some of the GPs acknowledged that there are additional medical goals that physicians have to take into account, e.g. the respecting of patients' personal values and priorities. The Swiss Academy of Medical Sciences has also identified this dilemma. According to their guidelines, PAS cannot be part of a doctor's role because it contradicts the aims of medicine (SAMS 2004). In paragraph 4.1 they state that the proper task of doctors is to relieve patients' suffering, not to offer them assistance in committing suicide (SAMS 2004). However, one could argue that refusing to relieve a patient's suffering by providing PAS amounts to causing harm by omission. Further, the consideration of a patient's wishes is fundamental for a good doctor-patient relationship. Following Andorno (28), the argument against doctor's involvement in their patients' suicide is based on the risk of creating confusion about the proper aim of the medical profession. Some of the participants' responses in this study alluded to the same reasoning: they fear assisted suicide could become a "common and frequent" procedure once they signal their acceptance. According to Martin et al. (29), focusing on healing as the main aim of medicine is potentially ambiguous as this term does not completely subsume medical practice. There are many medical practices that are clearly not specifically healing in nature, but that are still regarded as ethically acceptable and compatible with the medical ethos. Martin et al. state that these measures are accepted because "providing care in accordance with the personal goals and values of the patient is an additional goal of medical practice besides healing" (29). Furthermore, the original definition of the aim of healing might be outdated and not fully apply to newer developments in aging societies (e.g. long term diseases where only palliative and not necessarily curative treatments are possible) (29).

Some of the participants stated that PAS would, in their opinion, not be requested if better palliation of pain and/or methods of decreasing psychological distress were made available. From the literature, it is known that there are three major factors in suffering at the end of life: pain and other physical symptoms, psychological distress, and existential distress (described as the experience of life without meaning) (30). While there is some progress in undergraduate teaching on palliative care, as noted above, postgraduate training in Switzerland seldom covers the topic of PAS. Furthermore, Swiss data from 2008 suggests that physicians are inadequately trained in assessing and

managing the multifactorial symptoms commonly associated with patients' requests for PAS (31). Training in palliative care is an obligatory part of the learning objectives in medical schools but only a few Swiss universities currently offer formal courses (24). The average number of mandatory hours of palliative care education is 10.2 h, which falls significantly short of the 40 hours recommended by the European Palliative Care Association's Education Expert Group (24, 31). An increase in the number of mandatory hours of palliative care education (ideally also covering the topic of PAS) could help to prepare GPs for handling of requests as well as supporting them when it comes to assessing in depth the origin of a patient's wish for PAS. This is especially apparent when it is taken into consideration that other studies have shown that this training has positive effects (9). Perhaps even more so, considering studies have shown that patients' decisions are highly influenced by the actual and perceived belief of pain relief (32, 33). Their consideration of requests for PAS was found to be directly linked with physical or psychological symptoms (34) which were also mentioned by some GPs in this study. It is therefore of utmost importance to handle requests professionally and to evaluate whether an assisted suicide request is made because of suffering that can possibly be alleviated through other methods. However, it is also important to note that more and more patients request PAS not only because of physical or psychological symptoms but because they fear losing their autonomy (35, 36).

Conclusions

Our qualitative study has shown that patients' requests for PAS can create stressful situations for GPs. Participants who reject requests for PAS stated to either feel that (a) they are not able to handle the emotional impact of PAS, (b) PAS to be in direct conflict with their own values or (c) that their assistance would contradict their understanding of the medical profession. Some of the participants also reported to avoid conversations about this topic even though it would be important to assess the origin of a patient's wish for PAS. A possible approach to improve the situation could be the involvement of Swiss right-to-die organisations such as EXIT. That way, GPs would not necessarily be required to participate in the actual procedure of PAS which could partly minimize the discomfort associated with the topic. However, in order to elaborate to what extent this

approach could be useful, further research is required.

Furthermore, an increase in the number of mandatory hours of palliative care education (also covering the topic of PAS) could help to prepare GPs for the handling of requests as well as supporting them when it comes to assessing in depth the origin of a patient's wish for PAS. This could also help physicians in cases in which patients' values differ from their own to have a professional conversation about the topic of PAS. Even in cases of disagreement, the willingness of the treating GP to talk about the option of PAS was shown to be very meaningful, not only to patients but also their families.

Strengths and limitations

A key strength of this study is its use of a qualitative method to explore a multifaceted topic, enabling GPs to express their own attitudes towards PAS. However, the study sample may not have represented the full range of GPs' views on the topic, since it was not specifically chosen to explore the issue of PAS. Other selection biases due to the recruitment process are possible as the study was announced under the title of "conditions and quality of end-of-life care in Switzerland – the role of general practitioners". This announcement could result in a bias towards the participation of physicians who feel confident regarding palliative care and/or advance care planning.

While the topic of PAS is particularly sensitive, and may have legal implications, we recognize that GPs may prefer to avoid portraying a positive attitude towards PAS (social desirability). However, anonymity and congruency with other studies along with additional received statements that are not necessarily socially desirable (e.g. their general positive attitude towards PAS) lead us to conclude that this bias remains small. In order to gain better insight into communication about PAS in practice, we also considered the method of participant observation instead of interviews, as well as a combination of both methods. However, since requests for PAS are very infrequent and rather rare (the participating GPs received one to three requests for PAS during their career which is reflective of the national average), an observation of the conversation between GPs and their patients about PAS was not a feasible option due to the very limited timeframe of this study.

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B: Communication with families and other healthcare professionals

This part consists of research articles concerning GPs' communication with other important stakeholders in the setting, such as the patients' families and other healthcare professionals.

Following research articles can be found in this section:

2.5 Stakeholders and structures in the Swiss ambulant palliative care setting

2.6 When GPs initiate conversation with family caregivers in end-of-life situations - what are their goals?

2.7 Interprofessional silence at the end-of-life: Do Swiss general practitioners and hospital physicians sufficiently share information about their patients?

2.5 Stakeholders and structures in the Swiss ambulant palliative care setting

Ina Carola Otte, Corinna Jung

Introduction

Cases of sudden death are rather rare in Switzerland. In fact, most of the people living there – approximately 80% - die after dealing with a particular illness for a long period of time. However, caring for these patients is often difficult since they often suffer from not only one disease but rather from a combination of diseases. Heart, lung or kidney diseases often occur in combination with chronic diseases of the nervous system or cancer. The co-existence of two or more chronic conditions is often subsumed under the term multimorbidity.

In contrast to patients with tumours, who are mainly treated by a specialist such as an oncologist, patients in the state of multimorbidity are usually cared for by their general practitioner. However, their care often requires more than just the medical attendance of symptoms. It is also the task of the treating physician to not only properly communicate with patients about their condition and prognosis, but also to emotionally support the patient and his/her family, to assist with the medical decision making process and to manage the effectiveness of the team consisting of the GP and other involved stakeholders. The outpatient care for these patients is therefore often a very complex task which lacks formal structure and well established patient pathways.

Against the background of the demographical development, which was recently announced by the Bundesamt for Statistics, an increase from 60.000 cases of death per year to 90.000 cases by the year 2050 is expected. The need for action in this setting is inevitable. One of the core research questions of the SNF project is therefore: “How is outpatient care for end-of-life patients in Switzerland presently structured?”

Methods

The SNF research project consists of four research phases which builds off of one another. During the first four months, a literature review will be conducted with the aim of identifying relevant literature concerning the role of general practitioners in end of life care, the situation of informal carers (family members or friends who care for a beloved person at home), as well as the structures of care in Switzerland and in other countries.

In phase II, 30 semi-structured Swiss-wide interviews with general practitioners will be conducted (until we reach theoretical saturation) as well as seven interviews with so-called informal carers and three interviews with patients who are near the end of life. Subsequently, three focus groups with other health care professionals (e.g oncologists, Spitex nurses, etc.) will be performed. All qualitative data will be transcribed verbatim and analysed (following the code paradigm of Anselm Strauss. [4]).

In Phase III, a large-scale questionnaire will be designed and based on the results of the qualitative data analysis from phase II. The survey will be sent out to 2000 Swiss general practitioners. The design of the survey and analysis of the quantitative data will take approximately 12 months.

In phase IV (which lasts 8 months) all results will be published and presented at conferences.

Involved Stakeholders

Based on the literature review from phase I and from the preliminary results of the interviews with general practitioners, we were able to identify the following stakeholders which are involved with outpatient palliative care:

General practitioners (GPs)

In Switzerland, general practitioners are often the first point of contact for patients. Even when a disease requires the attendance of a specialist, it is the task of the general

practitioner to first see the patient and then to transfer him/her to the correct specialist. Due to general practitioners' long relationships with their patients, they are also often the first source of information for end of life patients when they wish to be cared for at home.

Informal carers

Nowadays, there are approximately 250.000 individuals who care for sick relatives or friends who are in need of support. This informal work was estimated to be worth 1.2 billion CHF [2]. The tremendous benefits of said work cannot be overstated as it provides substantial relief to the Swiss health care system since the same work done by professional nurses would be unaffordable, both economically as well as from a human resources perspective.

Outpatient nursing services (Spitex)

Outpatient nursing services (so-called Spitex) labels a service, which supports the caring for patients at home. According to the Bundesamt for Sozialversicherung, 95% of all Spitex organisations are not-for-profit. They are non-profit organisations which often receive grants from cantons and municipalities. There are also smaller Spitex organisations, such as self-employed nurses. Overall, according to the Bundesamt for statistics, approximately 2.1 full-time positions are available per 1000 inhabitants. However, this number varies based on cantonal and regional differences. Further, so-called specialized Spitex-services are available. In particular, Onco-Spitex-services which are for patients with tumors.

Medical specialists

Depending on the disease, different medical specialists are involved in the care of the patient. In most cases these specialists are oncologists or pneumologists, who specialize in cancer and lung diseases respectively.

Pharmacists

Depending on whether or not the treating general practitioner is also allowed to sell or distribute medications, the more or less the collaboration with a pharmacist is

necessary. However, the disposal of prescription medications is strictly regulated in Switzerland. The prescription of a drug always needs to be issued by a physician. However, in Switzerland, 13 cantons allow physicians to sell the drug directly to the patient. This so-called self-dispensation is strictly forbidden in nine cantons, while four cantons offer a mixed system of both, depending on the location of the surgery. Swiss-wide, almost one third of all prescription drugs is sold by physicians and not via pharmacies. In cantons where self-dispensation is allowed, this number increases to 90% [3].

Spiritual and pastoral caregivers (CGs)

Spiritual and pastoral caregivers are rather seldomly involved in the care for a patient and are, in most cases, not part of the network of carers. Therefore, even though they are very important to the patient at times, they only play a minor role in the analysis conducted within this study.

Hospitals (Spital)

Switzerland has 295 hospitals (according to the BFS [1]) which can then be divided into 119 general hospitals and 176 special clinics. In end of life care, hospitals are often involved when emergencies occur. For patients, proper teamwork between specialist and general practitioner is often an essential element which strongly influences the quality of care received.

Nursing homes

Nursing homes offer the option to either partly or fully take care of the patient in cases where informal carers can no longer care for him/her themselves. Sometimes patients or their families consider the move to a nursing home for safety reasons. This, naturally, causes changes in the existing network of carers. For example, it has to be decided whether or not the general practitioner should still look after the patient or if this should be the task of the nursing home physician. These changes also introduce the potential for conflict as well. For instance, changes made to the treatment plan or discontinuity in the trust relationship with the general practitioner could negatively affect the situation as a whole.

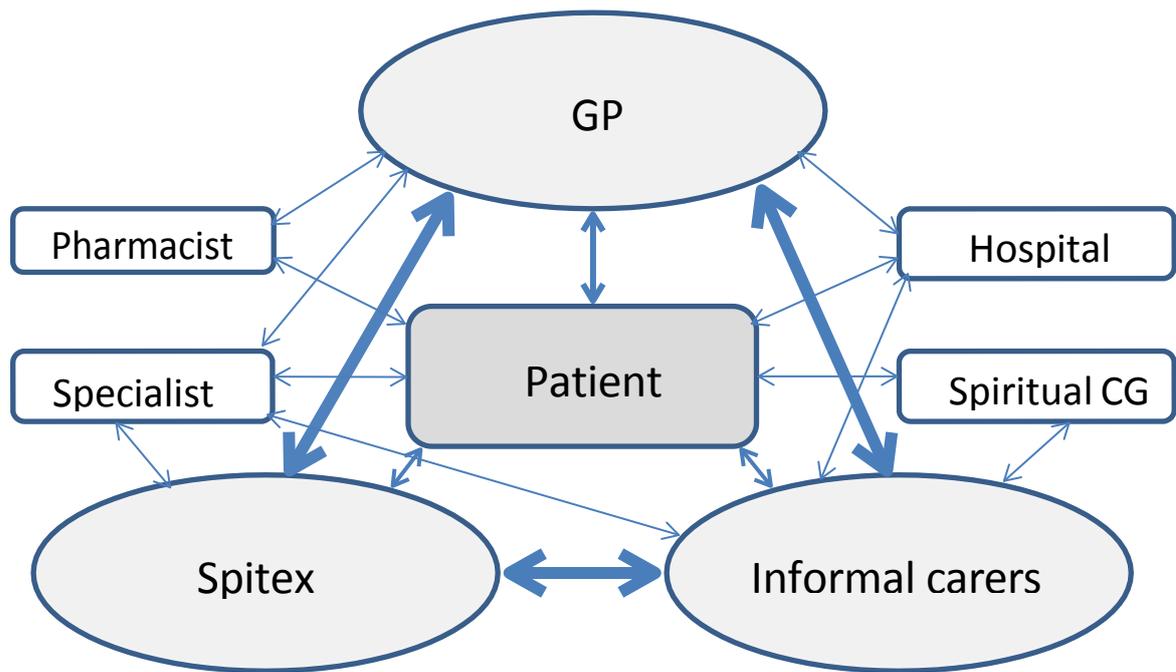


Figure: Stakeholders in end-of-life care (author's own illustration)

Conclusions

Our analysis shows a complex care network of stakeholders who are involved in end of life care as well as links between them that require interaction and communication (figure 1). These interfaces are sensitive to conflicts and interferences due to scarce resources, time constraints or the lack of information. The well-structured and transparent management of these interfaces is therefore essential.

Optimised end of life care is important for all involved stakeholders since it ensures the best patient care possible. The avoidance of organisational intricacies is also in regards to demographic changes and already existing shortage of staff and health care professionals is crucial. This would ensure the best allocation of resources to the patients and their families. On the other hand, optimised structures of care are also desirable for patients and „informal carers“: as to a) not further burden the patient and b) for the informal cares, to not make an already stressful situation even worse by adding avoidable organisational tasks.

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2.6 When GPs initiate conversation with family caregivers in end-of-life situations - what are their goals?

Ina Carola Otte, Corinna Jung, Klaus Bally

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].

To enable an effective communication between physician, patient and family members, it is important to take into account that family caregivers often have their own information needs that differ from the needs of the patient [4-6]. At the moment, the first attempts to create guidelines detailing how doctors should ideally communicate with patients and their caregivers to meet their unique needs are still ongoing [6] [7, 8]. Since structured guidelines for communication with patients and relatives are not yet available in Switzerland, our study aims to further elaborate GPs rationales and goals when initiating communication with family caregivers in ambulant end-of-life care settings.

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. 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 Mayrings' steps of content analysis [9]: (a) the relevant data was defined, (b) the context of appearance of the data registered, (c) a formal characterisation of the data material described, (d) the course of analysis specified, (e) a theory-lead differentiation checked, (f) technique of analysis defined (summarisation, 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 and Discussion

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).

1. 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.

Most patients want information about their illness fully disclosed to their relatives [7]. In addition, family caregivers are often involved in critical medical decisions and even more so when the patient is no longer capable [10]. Also, patients often take factors such as future consequences for relatives into account when making important decisions [11]. As a result, higher levels of shared decision-making between patients and family caregivers often lead to a greater family satisfaction [12]. In our study, GPs pointed out that conversations with patients and their relatives can help to strengthen their communication and mutual decision-making process. They consider initiating conversation with family caregivers as an important element in the advance care planning process.

2. 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.

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 [13]. 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 [14]. However, it should be also taken into consideration that the patient and family relationship is often a dynamic system which is subject to entering into a stage of crisis [15]. Therefore, personality characteristics as

well as family structures play a crucial role in determining the information strategy and the way family should be approached [15].

In our study, GPs mention that the achievement of the same information state may be helpful for the family caregivers who are dealing with the impending death of a relative. Having the same level of information is also necessary to have a mutual basis for an open conversation about approaching death between e.g patient and spouse [16]. Dying patients face complex and unique challenges during their disease that threaten their physical, emotional, and spiritual integrity [17]. According to the participants of this study, open communication is necessary 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 [17].

3. Integrating relatives in the caregiver network

Conversations with involved family members can be helpful in order to integrate these relatives 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.

Without the support of family and friends, it often would be impossible for many terminally ill patients to stay at home [18, 19]. 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 [20, 21]. 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 [20, 22]. Furthermore it is known that relatives often feel overwhelmed by their tasks, since the majority of them never received any medical training [22]. 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 [22]. 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.

4. 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.

Especially in end-of-life situations, GPs often provide practical assistance not only for the care recipient but also for the caregiver [23, 24]. However, the GP's 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 [24]. 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 assess 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 [25].

Conclusions

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 used in Switzerland, our study aimed to further elaborate on the rationales and purposes 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.

Acknowledgements: The authors would to thank Alex Mettraux for his contributions.

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Interprofessional silence at the end of life: Do Swiss general practitioners and hospital physicians sufficiently share information about their patients?

Ina C. Otte, Corinna Jung, Klaus Bally, Bernice S Elger, Jan Schildmann

Introduction

The professional collaboration between general practitioners (GPs) and hospital physicians (HPs) is crucial for referral-based health services. This is true in particular for the care of patients with chronic and/or advanced diseases who receive both inpatient and outpatient treatment. In Switzerland GPs traditionally play a significant role in the management of these patients, including palliative care. The Swiss Medical Association (FMH) however does not offer certifications in this field of medicine. Further, the training of palliative medicine at Swiss medical faculties is substantially below the 40 hours recommended by the European Association of Palliative Care (EAPC)(1).

Research shows Swiss GPs commonly provide medical care for their patients over a period of several years (2, 3). This longstanding relationship means that Swiss GPs often have detailed information on the patients' health status and healthcare preferences. Such knowledge has been shown to have a measurable impact on the quality of end of life care (4). Furthermore, research suggests that the quality of patient care is linked to the quality of the collaboration between GPs and HPs (5-7). A failure of co-ordinated actions between GPs and HPs was shown to result in poorer health outcomes for patients (8, 9) and unhealthy work environments for the physicians themselves (10). It was further shown that delayed or inaccurate communication can have substantial implications for continuity of care, patient safety and patient/clinician satisfaction (10).

The weak collaboration between GPs and HPs has been the focus of several studies (10-18). This research however has mainly been conducted in the United Kingdom and Australia (11-15) (13-19). In addition there is scarcity of in-depth exploration of the reasons for these difficulties as well as interdisciplinary analysis to explore what level of

collaboration is considered appropriate by GPs with HPs. This paper seeks to add relevant data to this area of clinical practice. It presents findings from a qualitative interview study with Swiss GPs about their perceptions on end of life patient care managed in collaboration with HPs. The empirical data is used as starting point for an interdisciplinary clinical-ethical analysis to identify strategies of improvement for collaboration between GPs and HPs.

Methods

Purposive sampling was chosen in order to obtain a diverse selection of physicians to represent a range of practice types, regions, professional experience, age and gender. 30 general practitioners were selected from the FMH list²², in order to represent the major characteristics of the Swiss population of GPs (proportional quota sampling). 23 physicians representing the French, Italian or German speaking regions in Switzerland agreed to participate. In semi-structured face-to-face interviews in their surgeries, participants were asked about palliative care and the level of co-operation with other institutions. All interviews were audio-taped and transcribed verbatim

The analysis was conducted by four members of the research team with different disciplinary backgrounds (sociology, general practice and palliative care experts). The coder followed Mayring's content analysis, a method that provides useful access to the data by preserving the advantages of quantitative content analysis and complementing them with qualitative-interpretative steps of analysis (20, 21). During the analysis, the data was repeatedly coded, moving from concrete passages to more abstract level of coding, deriving themes from the data and searching for repeating concepts. All findings were critically tested and discussed. Any disagreements were resolved by discussion.

²² Swiss wide catalogue of physicians, available on the website <http://www.doctorfmh.ch/> contains 30'000 entries.

Results

All interviewees provided detailed accounts of patient management strategies for patients in the last phase of life. GPs emphasized their unique role in end of life care because their knowledge and longstanding relationship with the patient. This relationship often extended to include the patient's family (see table for example quotes).

When interviewees were asked about the quality of care at the end of life, a common theme was fear of overtreatment within hospitals. GPs expressed concerns with the level of contact initiated and maintained by their hospital colleagues during their patients' hospital stays. Of particular concern to the GPs was their lack of involvement in discussions that related to the patients' treatment preferences, especially at end of life.

The GPs also expressed frustration that they do not receive sufficient information following the discharge of their patients from the hospital. The narratives suggest that GPs do not feel adequately included in cases of difficult decision-making about their own patients.

GPs described the possible negative effects on their patients' health caused by the lack of exchange and collaboration with HPs. For some GPs, this perceived negative consequence had even led to a reluctance to transfer their patient's to hospital care.

Table: Themes and quotes from GPs' responses

theme	related quotes (examples)
<p>GPs feel they have an unique role in EOL care because of their longstanding relationship</p>	<p>GP12: We know exactly what kind of people our patients are, their values and their personality, what they would want and what they wouldn't want. There are patients that we know and accompany for decades, we know how they're like, it is almost family, we are family doctors.</p>
<p>GPs criticize lack of communication with HPs/ GPs fear overtreatment in hospitals</p>	<p>GP12: In the hospital they [physicians] do what they want, I see it on a daily basis in the discharge summaries, they don't ask the patient, or the relatives, they always do the full program, no matter if it is useful or not. (...)to me that is a bad joke, they should just have called us and asked us about the patient's chances.</p> <p>Interviewer: But they never call you?</p> <p>GP12: Very rarely.</p>
<p>GPs feel they receive insufficient information when patients are discharged from hospitals / GPs do not feel adequately included in cases of difficult decision making</p>	<p>GP5: There is no institutionalised communication, so specialists do not talk about important decisions with us. And then, there is also the situation that you only hear from your own patient that he/she was transferred to the hospital due to an emergency. These situations are common. You only get information if you actively call them.</p>

<p>Negative effects on patients' health caused by the relative lack of exchange and collaboration / reluctance to transfer patients to hospital care</p>	<p>GP10: I think it is too bad. The patient should be in the focus. And if I can treat him better than the physicians in the hospital, I mean, if I can also take care of him at night which the hospital can't, then they should inform me. We should work together.</p>

Discussion

Our results add to existing research (6, 22-27) by detailing the underlying reasons why GPs' have concerns with the quality of collaboration with HPs. GPs criticized the lack of collaboration for two main reasons. Firstly, they worried that infrequent communication with HPs negatively affects the care of their patients. Secondly, given the longstanding relationship of care for their patient, GPs described their frustration that they are neither informed nor involved in end of life decision-making when it takes place, as it often does, in the hospital setting.

GPs concerns over the quality of their patients' end of life care is not without foundation when successful GP/ HP collaborations in other countries have been shown to have beneficial health impacts (24, 28). However, it should be taken into account that the available data which have been gathered in different healthcare systems can not necessarily be transferred from one healthcare system to another. As a consequence a needs assessment and intervention study would be necessary to determine positive outcomes of collaboration between GPs and specialists, in Switzerland.

The appeal from GPs to be involved more in end of life care (EOL) due to their longstanding relationship with their patients should be evaluated more critically. One reading of the GPs narrative is that it is desirable for them if they are informed and involved in decision-making. While such feelings seem understandable, we argue that GPs do not have a moral or legal right to such information and participation regarding

hospital care of “their” patients for their benefit alone. A line of argument which would support GPs involvement in decision-making in end of life care, including within the hospital setting, would be to assume that GPs have indeed detailed knowledge of the value related aspects of their patients’ care. This information could be communicated with hospitals with the use of a structured information template on value related aspects at the end of life. There are some barriers to such process, although they seem not unsurmountable: (1) the technological prerequisites, (2) overcoming of data protection issues and (3) documenting such data in a manner that is systematic, regular and provides a structured advance care planning process. Moreover, from an ethical and also legal perspective such involvement of GPs in EOL decision-making may give rise to the question of whether GPs could be designated as informal substitute decision-makers or take on more formal decision-making roles. At present GPs in Switzerland do not have a recognized role in this process.

In summary, we argue that changes to current practice to promote the quality of collaboration between GPs and HPs in Switzerland would need to be based on robust evidence. A needs assessments that takes into account the established structures and peculiarities of the local community, in combination with defined interventions and rigorous evaluation of outcomes, would be required. This assessment may be a catalyst to promote a change in the standard of GP/HP collaboration, perhaps even going so far as a professional requirement. A change in the process of information exchange between GPs, HPs and hospitals would be warranted if empirical work illustrated the beneficial effects on the patient experience, better health outcomes and reduced use of resources.

Limitations

Data collection for this study only included interviews with GPs. Our results are therefore limited to their views. In order to complete the data set, interviews with hospital physicians would be needed. Further, the views of other hospital providers, e.g, nurses as well as patients and their families would also significantly add to this area of research.

A further limitation of the sample may come from unavoidable selection biases due to the recruitment process. The study was announced under the title of “Conditions and Quality of End of Life care in Switzerland – the Role of General Practitioners”. This could have led to a sample of physicians who feel confident regarding palliative care and have a different need for collaboration with hospital physicians.

Result bias is also generated by the fact that study participants tend to answer according to social desirability. 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 where any bias remains small.

Implications

Our study adds to the existing research by distinguishing different factors relevant for Swiss GPs’ negative perception of shared patient management with treating hospitals. Future research should include a needs assessment, the development of a theoretical model for more intense collaboration between GPs and HPs and the piloting and evaluation of interventions targeted to GPs and HPs exchange of information. These are important steps for a scientific approach to provide a more substantial basis for the often claimed need for better collaboration during the last phase of life.

Declaration of conflicting interests

The authors declare that there is no conflict of interest.

Acknowledgements

We wish to thank Esther Schmidlin for supporting our team during the data collection by carrying out several interviews with GPs in the French-speaking part of Switzerland.

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Part 3: General Discussion

The following sections will briefly summarize the major findings of each research article in the context of the two main parts: i) findings concerning GPs' communication with patients and ii) findings concerning GPs' communication with relatives and other healthcare professionals. Moreover, supplementary to the discussion sections in the articles, the ethical implications of these findings as well as the potential further research will be addressed.

3.1 Major findings

The results of this study provide insight into the way GPs communicate not only with their patients, but also with the patients' families and other healthcare professionals in ambulant palliative care in Switzerland. As shown in the introduction section of this thesis, even though Switzerland operates under a healthcare system in which patients often address their GP with any kind of health related questions, the actual practice of how GPs communicate with them has not been sufficiently explored yet. This study is one approach to better understand barriers and difficulties within this communication process that also includes multi-stakeholder collaboration and families.

The choice to apply the qualitative research methods from the umbrella project to this PhD project as well as deciding to present the results in a rather narrative structure was the best approach in order to facilitate and support the exploratory aspect of this thesis. Subsequently, many relevant issues, such as the delayed or flawed communication with other stakeholders in hospitals, were identified and addressed. With the granting and preservation of anonymity, sensitive matters along with socially undesirable or unwanted answers could be obtained. The results of the qualitative interviews later laid the foundation for the quantitative investigation of the umbrella project which was based on a large-scale questionnaire with 2000 GPs.

3.2 Part 1: Findings concerning GPs' communication with patients

The research paper **“Advance Care Planning and its importance in general practice – how do Swiss GPs proceed? Results from a qualitative study” (2014)** illustrated that advance care planning - as it was understood by participants of this study - is a voluntary and mutually beneficial process of discussion between patients and their healthcare professionals. This process can – if and only if the patient agrees – also include family members and friends. Results of this communication process should be documented and should be regularly updated in order to validate former statements. Documented and updated statements should then be distributed among the involved healthcare professionals as well as the patient's family.

Recognizing the need for a good documentation of ACP in this setting, we focused in the following analysis of our data on ADs as a tool to communicate and document ACP with patients.

In the paper **“Advance directives and the impact of timing - a qualitative study with Swiss general practitioners” (2014)** we highlighted the fact that when being asked about the “ideal” or “appropriate” moment to start talking to patients about ADs, the majority of the interviewed GPs followed the approach **“sufficiently early (before illness occurs)”**. The practitioners explained to do so in order to avoid biases that can occur when ADs are drafted during an emergency situation. They also stated to choose this moment in order to prevent the patient from additional stress, and to avoid the feeling of discomfort which can arise when discussing impending death with terminally ill patients. Respondents described that the first step towards raising the topic is often still very difficult for many of them, especially when the patient is in need of palliative treatment. They reported feeling a sense of unease and stated to refrain from fully informing already ill patients about their situation because they fear talking about topics such as dying and terminal illness could be a further burden upon them. However, it has to be noted that the desire to shield patients from this topic may create even greater

difficulties or harm for patients, relatives or involved healthcare professionals and is also ethically questionable (67).

The second approach that was mentioned by the interviewees was **“when illness becomes predominant”** based on the fear that patients will record treatment preferences (and refusals) that are not in line with their actual preferences later on. These beliefs were often based on problems with prediction, adaptation, and extrapolation. Participants stated that they have experienced that individuals have difficulty predicting what they would want in future circumstances because these predictions do not reflect their current medical, emotional, or social context. This experience and the following statements can be backed up by findings from other studies (68-71). For example, participating GPs reported changes in patients' treatment preferences as their health changes (72), at the end of life (73, 74), and even during periods of stable health (73). In these cases, adaptability was named to be a major determinant of changing preferences. According to the GPs, patients often cannot envision being able to cope with a certain health status, such as disability and report the desire to forgo aggressive treatments in such states (75). However, as literature also revealed, once patients experience those health states, they are often more willing to accept more invasive treatments often with limited benefits (76, 77). On the other hand, in the same situation, some patients may shift their goals from life preservation to comfort (45, 78).

As a result, patients of GPs that followed the second approach often received little information about ADs until symptoms occurred that made a conversation about it inevitable. As shown in this paper, this may lead to ADs that only represent a form of written consent that withholds certain treatments or a downgraded AD that only reflects another version of DNR (do not resuscitate) orders.

However, we also found that the ethical ideal - that the completion of ADs should be embedded in discussions between physicians and patients (76) - may turn out to be problematic in practice. Limited time resources or time constraints during consultations, especially when the illness has become predominant (77), in combination with our respondents stating that the available AD forms are too hypothetical, may fail to

facilitate a broad and comprehensive discussion about advance directives.

Consequently, in order to thoroughly review their practice with a special focus on their last statement, namely that AD forms are too short or too hypothetical, we further analysed this finding in the research paper **“The utility of standardized advance directives: the general practitioners’ perspective” (2016)**.

In this paper we found that ADs are mainly used as a tool to trigger or to start a conversation about difficult topics, such as impending death or death itself. The assessment of the personal values of the patient during this conversation weighs, according to the participants of this study, more than the written AD in the end. Often participating GPs used either the short (the appointing of a surrogate decision maker) or the medium version (appointing of a surrogate decision maker and check boxes concerning future medical treatment) of the available templates, but most of them felt that the situations described in the second version are highly hypothetical²³. The existence of the longest version, which consists of an individually written statement, was mentioned but was not actively used by the interviewed GPs. Since some of our interviewees explicitly stated that it is not the form, but the conversation itself that matters to them, the final document (which they think is too hypothetical) seems to lose some of its importance as the focus clearly lies on the verbal anamneses of patient’s values.

Participants criticized the pre-formulated templates, stating that they cannot express individual values since standardized sentences cannot sufficiently illustrate a patient’s health and/or biographical background (71). Often these templates contain broad or vague statements such as wanting to “maintain dignity” which participants stated as too general to provide a basis for individual treatment decisions (79).

²³ For an example of a short template see: http://www.fmh.ch/files/pdf11/PV_e_Kurzfassung.pdf (last access April 2015) and for a typical medium version: http://www.fmh.ch/files/pdf11/PV_e_Ausfuhrliche_Version.pdf (last access April 2015)

Assisted suicide as a special case of patient autonomy – An example for the risks of “non”-communication²⁴

In regards to communication with patients, patient wishes concerning treatments that are not in line with physicians’ opinions or - even more concrete the wish for assisted suicide - are likely to cause ethical dilemmas for GPs. Often, these kind of conflicts arise when physicians’ personal values or their understanding of their medical role contradict a patient’s wishes or requests. The choice to also cover situations when patients request their GP to assist them with their suicide was made to illustrate these kinds of dilemmas. Further, the following research article presents the risks of “non”-communication or missing communication.

The findings in the research article named **“We need to talk! Barriers to GPs’ communication about the option of assisted suicide and their ethical implications – results from a qualitative study” (2016)** further lead us to the conclusion that the general attitudes of GPs towards assisted suicide (AS) (which the majority indicated as usually liberal) are not necessarily consistent with their responses to requests in practice. Evidently, GPs willingness to assist a suicide is not influenced solely by their general attitude towards AS: even while generally not being against it, participants rejected requests when being addressed personally. Personal responses to requests therefore seem to be determined by numerous complex factors and not only by the general attitude towards AS. In our study, the following three identified themes were the main ways in which GPs accounted for their rejections of requests for AS: expected psychological impact upon themselves, their personal opinions and values, and their interpretation of their roles as doctors. We have suggested that in cases where the decision to reject a request is made because of personal reasons, a GP should ensure that the assistance-seeking patient is transferred to an appropriate team without postponement or delay to ensure and further foster patient autonomy.

Furthermore, and more importantly for this thesis, we showed that it is crucial that GPs

²⁴ Non-communication in this thesis refers to the avoidance of communication, for example by turning a particular topic in a taboo.

communicate with their patients about AS and avoid treating requests as taboo. Discouraging a patient's wish to communicate about AS was shown to possibly affect the quality of care received for two reasons. First, having the option to talk about assisted suicide was shown to be important for patients, since it provides the feeling of "knowing a possible way out (of the suffering)" (80). Secondly, requests for AS are often an indicator for deficiency in a patient's care (81). As such, a patient's condition and treatment plan always needs to be thoroughly reviewed by the treating physician after receiving such a request. Therefore, the possibility to talk about this topic can help to identify possible shortcomings in the current treatment of the patient. For these reasons, although physicians should remain mindful of their personal concerns regarding their own involvement, their personal position should not override their willingness to communicate with patients about the underlying motives for a request.

3.3 Part 2: Findings concerning GPs' communication with family members and other healthcare professionals

In Switzerland, in most cases, a patient's family greatly contributes to the practical and emotional aspects of a patient's care. In 2012, a Swiss-wide survey showed that 14% of the Swiss population receives support from family caregivers. Most of these patients, approximately one third, were cared for by their spouse, and by their children as a close second; mainly their daughters (31).

As a result of their willingness to care for their family member, these family caregivers often carry additional burdens that add to the emotional strain of the impending loss of a beloved person. Consequently, 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.

In our research paper "**When GPs initiate conversation with family caregivers in end-of-life situations - what are their goals?**" (2015) we showed that extended communication with families is crucial when it comes to providing palliative care in ambulant settings. However, as shown in the two research papers on communication

with the family of a patient, 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 (with the consent of the patient) can be essential to ensure the best provision of care possible. Since Swiss guidelines on communication with family members are not established yet, our study aimed to further elaborate on the rationales, ways and purposes of Swiss GPs and how they communicate with family caregivers.

During our interviews, GPs were reflective and aware that patients and their caregivers have different communication needs since patients need to prepare themselves for their own death while relatives need to prepare for the time after the patient's death and their loss. In our results, GPs' main rationales for initiating conversations with relatives were:

1. to ensure that their patients can rely on the support of their families during challenging decision-making processes
2. to facilitate mutual communication about difficult topics between patients and their beloved
3. 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

The latter was found to be especially important, since the progression of a disease, along with approaching death are moments that evoke fear and emotional pressure in patients and relatives. Participants experienced that families are often rather hesitant to seek the psychological support provided by a psychologist. According to these GPs, families find it easier to accept emotional support from them.

Other specific challenges of palliative care, which were described by participants, include situations such as when a patient's family waits too long to ask for support in order to not bother the health care provider: a phenomenon subsumed under the term "conspiracy of silence". In order to prevent silence or hesitation in communication, family meetings can help to build a relationship between the doctor and the patient's

family which can establish the level of trust needed to address questions and difficulties more openly.

Additionally to the reasons why GPs initiate conversation with family caregivers, we also sought to understand when and how they implement this kind of communication in their practice. As for the how, GPs basically mentioned three main elements (negotiation, counselling and active listening²⁵) which were already known from family meetings held in inpatient settings.

Based on our results, we conclude that it would be helpful to fully implement adapted guidelines for family meetings in ambulant palliative care settings. In order to provide high quality family meetings and to foster appropriate and effective communication, further education could be useful. This could help to ensure that GPs identify appropriate moments when a family meeting would be meaningful and which members of the patient's family to invite. Also, knowledge of the correct application of introduced instruments in relation to family meetings as well as information on how to approach sensitive topics with all parties involved could help to further improve the communication.

In our paper on communication between multi-professional stakeholders **“Interprofessional silence at the end of life: Do Swiss General Practitioners sufficiently share information about their patients? (2016)**, we shed light on two important topics that merit improvement: First, the lack of structured ACP and its possible impact for multi-stakeholder collaboration near the end of life (1). Secondly, we illustrated possible sources which might be responsible for the perceived lack of communication between hospital physicians and GPs (2). A better understanding of these issues is particularly important, as healthcare provider collaboration could be significantly improved after the problems were more explicitly identified.

The criticism of the Swiss GPs in regards to the current lack of communication seems to have two main sources. On the one hand they fear that insufficient communication affects the care of their patient negatively. On the other hand they point out that in light

²⁵ A more detailed explanation of these terms can be found in the research article in chapter 2.7.

of a long standing relationship with their patient, they perceive it to be inappropriate that they are neither informed nor involved in end-of-life decision making that takes place in the hospital setting.

With regards to the worries of GPs that the lack of communication affects the quality of patients' care, we argue that this seems justified given the evidence on beneficial aspects of such collaboration. Documented benefits of collaboration between GPs and hospital physicians were:

- a) for patients: improved access to services, reduced anxiety, and fewer post discharge complications (82, 83)
- b) for GPs increased involvement in acute care and in hospital decision making (84)
- c) for service organisations stronger working relationships, increased capacity, and greater efficiency (83, 85)

Further, our results showed that GPs often have a unique and detailed knowledge of their patients resulting from their long relationship with them. A number of GPs described their relationship with their patients as very close. In some cases GPs described their relationship to their patients resembling those found in „families“. Information gathered by the GPs, therefore, often not only refers to the medical situation, but also to social and value aspects. This suggests that GPs could indeed also be a valuable resource in inpatient palliative care.

Given the fact that the number of palliative care patients is increasing, the complexity and the amount of information needed to be gathered for each patient will grow tremendously. At the moment, as acknowledged by a number of interviewees, knowledge about the patient's situation is gathered more accidentally rather than systematically and often enough is not documented or shared with others (such as hospital physicians). This is alarming, considering that an essential requirement of good quality of palliative care is a well-functioning communication. The practice described by GPs raises the question of whether a more systematic approach, combined with clearly established communication pathways between GP practices and hospitals, could

increase the quality of care received by the patient.

3.4 Ethical approaches and normative implications

From an ethical approach based on our findings and conclusions in the research articles, the following priorities should be set:

1. The flexibility of decision-making strategies used with capable patients should not be limited by short and hypothetical templates but rather supported in order to encompass individual perceptions of autonomy. Furthermore, communication about topics that have the potential to provoke a personal dilemma, such as requests for assisted suicide, needs to be handled in a professional and reflective manner in order to not inadvertently limit a patient's options and care due to a physician's personal conflicts.
2. Communication between physicians and patients' families could benefit from a more structured approach in order to support the installation of a robust network, which is essential when patients lack the capacity to make decisions or when GPs aim to address families' emotional burdens. Both priorities aim to further a) promote the understanding of patients' and families' individual needs and preferences and b) minimize decision-making and care burdens on families.
3. As a third priority, the communication between multi-professional stakeholders needs to be improved, with a special focus on general practitioners and hospital physicians. Our findings suggest that GPs' potential knowledge in regards to patients' wishes is not fully realized yet and that a great amount of information gets lost in the transition of a patient being admitted to a hospital. Decision-making is currently evolving from a document-driven process to a decision-focused event, which further emphasizes and illuminates the importance of well-structured and functioning communication. Well-functioning communication is not only essential in order to support the team work between all parties involved but also to ensure that every stakeholder has access to all

information which patients or alternatively their proxies²⁶ and physicians may need for their decision making.

In addition, palliative care in Switzerland could benefit from **a) extended training** for health care professionals (with a special focus on communication and team work with other stakeholders) as well as **b) distinct guidelines and directions**.

Extended training should be a priority since the feeling of discomfort on side of the GPs was an underlying theme, which not only reoccurred in different contexts but also became a barrier in the communication concerning ADs. In our analysis, discomfort was often caused by the feeling of additionally burdening the patient when addressing the topic of ADs too late or in general when talking about ADs with patients they have known for a long period of time. This discomfort was found to be based on the link between ADs and impending death. A more distinct education regarding patient communication and the implementation of concepts which promote a more holistic approach, could help GPs to focus on ADs as a supporting and valuable tool for the patient instead of a measure to “regulate” death. However, as mentioned in the research articles above, with the growing number of palliative care patients, the importance of rather holistic approaches will increase and individual ADs *solely done by GPs* might be at risk. Again, this emphasizes, in turn, the need for well-structured networks and communication between all stakeholders to allow good quality palliative care to progress.

Improved guidelines and directions should focus on the minimization of obstacles to successful communication and exchange of information between all parties (especially between general practice and hospitals) involved. This requires a more structured and detailed communication path between hospitals and general practices, in order to not only capture disease related information, but also social values and related patients’ preferences assessed by the GP. However, some findings regarding inter-professional communication have shown ethical and moral tensions between different stakeholders (86). Individual dynamics may also influence the amount of information desired by patients and their family. In some cases patients and families may not choose to receive

²⁶ A proxy is a person appointed as an agent to legally make healthcare decisions on behalf of the patient.

prognostic information, which can result in barriers for health professionals to communicate effectively with them (45).

3.5 Implications for future research

The aim of this thesis was to describe the current practice of communication with patients and relevant stakeholders as well as to identify possible barriers. Thus, the qualitative data presented in this work is to a large extent exploratory. Consequently, further questions arose during the analysis process.

Within a relatively adequate sample of 23 interviews with GPs, only a few participants had experienced the use of an electronic discharge summary system. However, the experience of those who did was positive and further research is required in order to determine possible (dis)-advantages and the system's potential to contribute to more effective communication between hospitals and GPs.

Moreover, our findings revealed that AD templates are still an important tool when it comes to starting a conversation about preferences in end of life care. However, these templates were criticized as being very hypothetical and were said to not cover all important aspects. In other countries, such as Germany, a country-wide analysis of all available templates supported the development of more comprehensive and practicable approaches. Research like that could also be important for Switzerland. Nevertheless, these templates also seem to stand in direct contrast to the current development of decision-making which deviates from a rather document-driven process to a more individual approach that allows patients more flexibility and "in the moment" decisions. Therefore, research concerning this topic should also focus on whether templates can remain to be a supportive part in this process.

In regards to the communication with, and the integration of, family members into the caregiver's network, our research has shown that GPs use tools known from inpatient settings but in rather individual and mostly unstructured ways. As seen in the PalliPa project in Germany, research concerning these ambulant family meetings could help to

develop guidelines which ensure that family members receive all the important information and support they need. At the moment, it depends on the individual GP which topics are addressed since Swiss guidelines exclusively focus on the sensitiveness and timing of these conversations but not on the content.

3.6 Conclusions

The main research questions structuring the PhD project were 1) When and how do GPs initiate conversations about ADs? 2) What difficulties have arisen in the context of conversations regarding sensitive topics such as assisted suicide? 3) How and where does communication with the patient's family fit in? 4) How do GPs communicate with other healthcare professionals and what are their perceptions of possible improvement or barriers?

A number of exploratory answers and conclusions regarding these questions were given in this thesis.

As to answer question 1) it was presented that moments as to when communicate about ADs are rather individual, and split into two main categories: before illness and after the illness has become predominant. For 2) we have shown that difficulties in the communication process often occur in relation to disorganization, transparency (especially concerning collaborations with other healthcare professionals) and emotional discomfort not only on side of GPs but also regarding families and patients. The integration of and communication with families, as addressed under 3), is often achieved through individual approaches with GPs falling back on and individually adapting tools they learn from inpatient family meeting settings.

Concerning 4), the missing transparency and timeliness of communication caused tension and barriers between GPs and hospitals. We suggested that stakeholders involved in the advance care planning process of the patient must be informed of the potential for collaboration with GPs. Currently existing infrastructures concerning their mutual communication must be more transparent and should be more structured.

However, this is difficult to accomplish, as it is not the official responsibility of any party. In addition, inter-professional communication at the end of life phase has also been reported to often cause ethical and moral tensions between different stakeholders. Nevertheless, there is cautious optimism that electronic discharge summaries will help to simplify the communication process and information exchange and might – in the future – also help to benefit from GPs' knowledge when it comes to patients' future treatment preferences, is – in the opinion of the author - warranted.

In addition, as for question 1), 2) and 3) we have suggested that the existing guidelines should be completed, which then should also cover important topics and aspects that should be communicated with the patients and their families. Also possible effects of the timing of these conversations should be included. Findings outlined in this thesis could be useful for further efforts to develop these guidelines with the aim to foster effective communication and subsequently allow good ambulant palliative care to progress.

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Part 4: Appendices

4.1 Collaboration

Research is a process that requires team work, especially large research projects like the SNSF project (introduced above) usually rely on a functioning and effective research team. Moreover, it is particularly essential for qualitative research that numerous researchers analyse and discuss the findings. Therefore, even though this thesis is based on my work in my doctoral project, several other individuals contributed to the articles that appear in the main part, as well as to the design and data collection of/for this research.

Klaus Bally, project leader, developed the initial concept for the larger SNSF project together with **Heike Gudat** as well as **Hans-Ruedi Banderet** and designed the hypotheses and the methodological approach. His experience in the field of primary health care enabled key issues to be properly identified and described. Further, his comments allowed the development of the hypotheses for this doctoral project. As a first supervisor, he also contributed to each manuscript used for this thesis.

Corinna Jung, senior researcher at the Institute for Primary Health Care, helped refining the methodological approach of the overall project and wrote the SNF proposal under directions of Klaus Bally. She further worked on the initial research question and hypotheses of this PhD project and took the lead in formulating the interview guide. Together with Ina Otte, she carried out all of the German interviews. She analysed, coded and compared all transcripts together with Ina Otte and partly with other members of the research team. She developed the article describing the situation of palliative care in Switzerland and – as the second supervisor of this thesis – provided input on all other manuscripts below.

Bernice Elger, professor and head of the Institute for Biomedical Ethics, helped formulating the study hypotheses. Together with **Hans-Ruedi Banderet**, **Heike Gudat**

and **Elisabeth Zemp**, she gave input on article manuscripts and contributed to the development of the overall results analysis.

Jan Schildmann, senior researcher at the Institute for Medical Ethics and Medical History, RUB, played a key role in developing the article on intersectional collaboration. For the article, he discussed parts of the interview transcripts and codes related to the topic with Ina Otte and helped with the drafting of the manuscript.

Esther Schmidlin, as a native speaker and experienced interviewer, carried out all interviews in the French part of Switzerland.

4.2 Semi-structured interview guideline used for the interviews with the GPs (in French):

Conditions and quality of community-based end-of-life care - the view of Swiss general practitioners

Fonds national – Projet 139341

Directeur: Dr. med. Klaus Bally, Institut für Hausarztmedizin Basel (IHAMB)

Équipe: Dr. med. Hans-Ruedi Banderet, Institut für Hausarztmedizin der Universität Basel (IHAMB)

Prof. Dr. med. Bernice Elger, Institut für Bio- und Medizinethik (IBMB), Universität Basel

Dr. med. Heike Gudat Keller, HOSPIZ IM PARK, Klinik für Palliative Care, Arlesheim

Dagmar Haller-Hesters, MD PhD, Primary Care Research and Teaching Unit, Univ. of Geneva

Prof. Dr. phil. Brigitte Liebig, Hochschule für Angewandte Psychologie, FHNW

Prof. Dr. med. Thomas Rosemann, Institut für Hausarztmedizin, Universität Zürich

Prof. Dr. med. Peter Tschudi, Institut für Hausarztmedizin, Universität Basel (IHAMB)

Prof. Dr.med. Elisabeth Zemp, Swiss Tropical and Public Health Institute, Basel

Vade-mecum des entretiens avec les médecins généralistes/ médecins de famille

Remarques préalables

Ceci est un entretien qualitatif semi structuré. Les questions y seront formulées de manière la plus ouverte possible, afin d'éviter les réponses par Oui et Non. Si l'interviewé a déjà fourni des réponses satisfaisantes grâce à de précédentes questions, certaines des suivantes pourront être laissées de côté. Le questionnaire ne sera pas remis aux interviewés. Si le questionnaire s'avère être trop long en phase pilote, des questions seront alors retirées par la suite.

Ce qui nous intéresse ici est principalement d'analyser les perspectives et approches des personnes interrogées, mais nous ne visons en aucun cas à porter de jugement sur leurs décisions personnelles ou opinions. Ceci sera expliqué en détail aux participants à l'entretien.

L'analyse des interviews commencera – conformément aux méthodes qualitatives reconnues – dès la fin du premier entretien et se poursuivra parallèlement aux entretiens suivants. Le questionnaire pourra (et devra) être modifié au fur et à mesure en fonction des interviews ; et ceci pour préciser le contenu des questions ou améliorer les modèles théoriques qui se dégagent.

Les présentes formulations ne sont que des pistes pour les intervieweur(-euse)s. Leur tâche consiste à présenter de manière compréhensible aux interviewés le contenu des questions, et le cas échéant à les leur expliquer.

Un entretien dure environ une heure. Avant l'interview, tous les médecins participants seront bien informés qu'ils peuvent à tout moment, sans conséquences ni justifications, interrompre ou suspendre l'entretien. On leur demandera s'ils ont bien compris et s'ils acceptent toujours l'entretien. Leur participation à l'interview sera considérée un consentement.

Interview des médecins généralistes

Numéro d'interview :

Médecin généraliste :

Intervieweur/euse :

Date :

Il y a consentement écrit à la participation à l'étude.

L'entretien ne doit pas durer plus d'une heure.

Le médecin peut interrompre ou suspendre l'entretien à tout moment.

Vade-mecum des entretiens avec les médecins généralistes

Remarques générales

Nous travaillons sur un projet qui étudie le rôle des médecins généralistes dans les soins de fin de vie. Nous vous adressons tous nos remerciements pour avoir accepté de participer à cette étude.

Nous attirons votre attention sur le fait que vous puissiez évidemment interrompre ou suspendre l'entretien à tout moment sans avoir à vous justifier. Ceci n'aura strictement aucune conséquence pour vous. Avez-vous compris cela ?

Nous considérons votre participation à cet entretien comme un consentement.

Veuillez nous rapporter vos réflexions de préférence de manière la plus détaillées possible, pour que nous puissions recenser autant d'aspects importants que possible.

Nous allons naturellement traiter toutes les données de manière confidentielle et rendront les entretiens anonymes via leur transcription. Après cela il ne sera pas possible de remonter jusqu'à vous. À la clôture du projet, les enregistrements seront détruits.

Vous avez le droit de retirer vos données à tout moment.

Sincères remerciements pour votre participation !

Médecine générale et accompagnement en fin de vie.

- 1. Veuillez me décrire votre travail en cabinet de médecine générale. Pouvez-vous résumer brièvement ce qui est représentatif de votre travail ?**

Laisser parler librement.

Sont recherchés des renseignements sur :

- La patientèle
- L'attitude
- La manière dont le médecin s'organise, est-il(elle) surchargé(e) ?

2. Pouvez-vous me parler de la dernière personne dont vous vous êtes occupé(e) et qui est décédée chez elle suite à une longue maladie (et non une mort cardiaque subite ou un suicide) ?

Laisser parler librement.

Si nécessaire, 5 questions-clés :

- **Quel** était le problème ? – Diagnostic, besoins du patient / de ses proches
- **Qui** était impliqué ? –médecin généraliste, spécialiste, Spitex (éventuellement spécialisé), hôpital, maison de retraite/résidence médicalisée, proches
- Quel trajectoire a eu ce patient ? ou bien : Pouvez vous me raconter plus sur la trajectoire des soins de ce patient ? au domicile, à l'hôpital, maison de retraite/résidence médicalisée
- **A quel moment avez vous été impliqué ?** Dans quelles phase de maladie le médecin généraliste a-t-il été impliqué ?
- À quels moments de la journée, le week-end ? Comment s'est-il organisé ?

- Comment ça c'est passé ? (
- Dans votre avis, comment été la qualité des soins ?,
- Comment étaient l'interface avec les autres intervenants ? (Schnittstellen), travail d'équipe (Comment a été la coopération avec les autres intervenants ?)
- Quel était votre implication affective et au niveau du temps ? (implication affective et dans le temps pour le médecin généraliste).

- Qu'est-ce qu'on aurait éventuellement pu améliorer ? (Demander éventuellement ce qui aurait pu être amélioré.)

Questions relatives aux relations des différents acteurs entre eux

2b. Quelles ont été vos expériences du contact ou de la relation médecin / patient ?

- Ouverture / réserve
- le patient ose-t-il aborder tous les sujets ?
- peur de devenir une charge

Qu'en est-il de la relation entre le patient et ses proches ?

- Relation plutôt difficile ou détendue ?
- Problèmes de violences corporelles ou psychiques ? Si c'est le cas, à quelle fréquence ?
- Thème de la peur de devenir une charge (si c'est le cas, à quelle fréquence ?)

Qu'en est-il de la relation entre le patient et le personnel soignant ?

Qu'en est-il de la relation entre le médecin et les proches du patient ?

Soins palliatifs (définition et accès)

3. Qu'entendez-vous par « Soins palliatifs » ?

Laisser le (la) développer/refléchir librement.

Ce qui nous intéresse ici est l'étendue de la définition :

- Les soins palliatifs correspondent-ils principalement au traitement des symptômes ?
- Y inclut-il aussi les domaines de la communication, l'éthique (Prise de décision, souhait de mourir), spiritualité, relation avec les proches?
- Y inclut-il (elle) aussi des patients avec des maladies cardiaques, pulmonaires, rénales et neurologiques, ou des enfants ?

4. Selon vous, à partir de quand commencent les soins palliatifs ?

Laisser développer/réfléchir. Éventuellement passer à la question 5.

5. Parfois on parle aussi de „médecine de fin de vie“. Qu'entendez-vous par là ?

Ce qui nous intéresse ici est de savoir si le médecin assimile soins palliatifs et soins de fin de vie.

6. Précédemment dans le récit du parcours de vos patients vous nous avez parlé d'un patient avec (/sans) tumeur. Avez-vous également suivi un patient sans (/avec) tumeur ?

Comment ou bien où voyez-vous des différences ou points communs dans le traitement de patients en fin de vie, avec et sans tumeur ?

Pourriez-vous peut-être illustrer d'un exemple ?

Ce qui nous intéresse

- Avis sur le fait que des patients sans tumeur aient besoin de soins palliatifs

- Avis sur le fait que le traitement des symptômes soit plus délicat avec des patients sans tumeur
- Avis sur le fait que l'accès aux soins palliatifs en résidence médicalisée soit particulièrement difficile.

Nous arrivons maintenant à une nouvelle thématique :

Décision en fin de vie

7. Revenons au parcours du patient dont vous m'avez parlé. De quelle manière avez-vous été impliqué dans la prise de décision ?

Laisser d'abord parler librement.

Les informations suivantes sont recherchées :

- Quand le médecin généraliste a-t-il été impliqué ? Au début, en cours ou en fin de vie ?
- A-t-il/elle pris le leadership de la situation ?

8. De manière générale, quand il s'agit de décisions difficiles dans la dernière phase de la vie, comme par exemple celle d'arrêter le traitement d'une personne gravement malade : comment vous y prenez-vous avec le patient / la patiente ?

Pouvez-vous nous décrire une telle conversation ? (Structure et contenu)

9. Comment avez-vous vécu (ressenti) la situation?

Les informations suivantes sont recherchées.

- Quel rôle le médecin s'est-il lui-même accordé ?

- A-t-il/elle considéré que la prise de décision n'était pas de son ressort ?

Aurait-il volontiers été interlocuteur(-trice), mais sans avoir été pris en compte ?

Y a-t-il eu un manque de temps, une incapacité de jugement du patient / de la patiente, des conflits avec les proches, ou autres ?

10. Quel rôle jouent pour vous les directives anticipées chez vos patients?

Laisser parler librement.

Le cas échéant, à quel moment et à quel endroit le sujet est-il abordé ?

Qui aborde le sujet ? Le médecin ou le patient ?

11. Je peux m'imaginer qu'il y a toujours des patient(e)s qui expriment leur envie de suicide. Comment vous y prenez-vous ?

Laisser parler librement.

Éventuellement préciser :

- À quelle fréquence ces questions se posent-elles ?

- Quelle attitude le médecin généraliste adopte-t-il/elle ?

- Quels sont les aspects qui posent problème au médecin ?

- Un / une collègue est-il/elle impliqué(e) dans la prise de décision ?

Perspective du patient

12. (falls vorne bereits beantwortet, weglassen) En relation avec l'exemple précédent de votre patient(e) décédé(e), qu'est-ce qui était selon vous important pour lui / elle à la fin de sa vie ?

13. Je cite ici quelques paramètres relatifs à l'offre de soins palliatifs. Quel rôle jouent ces derniers dans votre quotidien professionnel ?

- Quelle est selon vous l'importance de la formation (de base (initiale) en continue, et post gradue) dans le domaine des soins palliatifs ?
- Êtes-vous satisfait de la configuration de l'exercice en groupe, de la densité des cabinets médicaux et de l'offre de soins d'urgence dans votre région ?
- Institutions hospitalières pour des patients en fin de vie : Comment évaluez-vous les établissements d'hospitalisation de patients en fin de vie ? (p.e. hôpitaux, unités de soins palliatifs ou institutions spécialisées en soins palliatifs)
- Êtes-vous satisfait des institutions (de prise en charge ambulatoire de patients en fin de vie par les soins à domiciles / CMS (Spitex) ?
- Dans quelle mesure êtes-vous affecté par le manque imminent de médecins généralistes ?
- Comment évaluez-vous le système de santé suisse en matière de soins palliatifs
- Êtes-vous satisfait du remboursement Tarmed de vos frais liés aux soins palliatifs
- Qu'entendez-vous par qualité de la médecine palliative ?

Collaboration avec d'autres groupes de professionnels

15. À propos de votre patient(e) décédé(e), comment avez-vous vécu la collaboration avec les autres groupes de professionnels ?

Laisser parler librement. Éventuellement, poser des questions sur les soins à domiciles, (CMS, Spitex), le médecin spécialiste, le pasteur/curé, la pharmacie, physiologiste, ligues, autres...

16. Qui a eu la coordination en main ?

Laisser parler librement

La situation en a-t-elle été facilitée ou compliquée ?

17. Il peut parfois arriver d'être obligé d'envoyer les patient(e)s incurables chez le spécialiste ou à l'hôpital : comment le vivez-vous ?

Laisser parler librement

Quelles sont les raisons (plus fréquents) qui nécessite une hospitalisation?

Qu'est-ce que vous en penser? Quel sont vos reflexions par rapport ces raisons?

Varia

18. Selon vous, qu'est-ce qui devrait ou pourrait concrètement être amélioré en matière de soins en fin de vie ?

Laisser parler librement

A votre avis, la spiritualité joue-t-elle un rôle pour ou pendant le suivi ?

19. Y aurait-il un élément que nous aurions peut-être oublié et dont vous voudriez discuter ?

Statistiques

1. Sexe : masculin féminin

2. Age : _____

3. Date de la fin des études : _____

4. En exercice professionnel depuis ? _____
5. Exercice au cabinet individuel ou
 Exercice de groupe en cabinet médical
- Cabinet avec en tout 2 - médecins
- Cabinet avec plus de 3 médecins
- Autres : _____
6. Le cabinet est situé dans un village ou une ville (plus de 20 000 habitants)
 l'agglomération
7. Durée de la formation postgrade : _____ ans
8. Formation de médecin spécialiste en
: _____
9. Avez-vous effectué une partie de votre Oui Non
postgrade en cabinet de
médecine générale ? (assistant)
10. Titre FMH: Oui Non
Quel titre FMH :
(Ne donner que le titre principal)
- médecine générale
- médecin interne
- médecin interne / générale
- Autres _____
11. Titre supplémentaire, attestation d'aptitude : _____
12. Vos revenus sont-ils principalement issus de
votre exercice libéral ? Oui Non
13. Êtes-vous principalement médecin salarié ? Oui Non

14. Avez-vous une activité hospitalière à côté de votre cabinet? Oui Non
15. Êtes-vous rattaché à un système Managed Care ? Oui Non
16. Travaillez-vous à temps plein en tant que médecin généraliste ?
 Oui Non

Combien d'heures ?

17. Participez-vous au services des urgences ? Oui Non
18. Faîtes-vous des visites à domicile ? Oui Non
19. Exercez-vous une activité rémunérée annexe qui est en lien avec votre activité de médecin généraliste (par exemple des enseignements à l'université etc) ?
 Oui Non
20. Exercez-vous une activité annexe ? Oui Non

a. Si oui laquelle ? _____

b. Combien d'heures ? _____

21. Combien de patients (et non de consultations) se sont présentés dans votre cabinet l'année dernière ?
- < 500 500 – 750 750 –1000
- 1000–1250 1250-1500 > 1500

Observations de terrain, commentaires sur l'interview

4.3 Curriculum Vitae: Ina Carola Otte



Professional Career

05/2015 – ongoing	Advanced Research Fellow at the Institute for Medical Ethics & History of Medicine, Ruhr-University Bochum, Germany
05/2012 – 04/2015	Advanced Research Fellow at the Institute for Primary Health Care (IHAMB), University of Basel, Switzerland
08/2011 – 04/2012	Advanced Research Fellow at the Institute of Biomedical Ethics (IBMB), University of Basel, Switzerland
12/2010 – 07/2011	Research Fellow at the Institute of Science and Technology Studies (IWT), University of Bielefeld, Germany
09/2007 – 12/2010	Student Research Fellow at the Institute of Science and Technology Studies (IWT), University of Bielefeld, Germany

Higher Education

- 05/2012 – 05/2015 Doctorate at the Institute for Medical Ethics in Basel, University of Basel, Switzerland (Dr. sc. med.; Ph.D.)
Grade: magna cum laude
- 10/2004 – 12/2010 Diploma in Sociology, University of Bielefeld, Germany.

Grants and Memberships

Ph.D. Fellowship: “TRANSDISS: disciplinary research in transdisciplinarity”
funded by the German Federal Ministry of Education and Research

Freiwillige Akademische Gesellschaft Basel (FAG): Funded Research Project:
Membership rules and organisational frameworks in university ethics committees
and their influence on ethical decision making

Deutsche Gesellschaft für Soziologie (DGS) (German Society for Sociology)

Society for Social Studies of Science (4S)

Academy for Ethics in Medicine (AEM)

Research Awards

Swiss Research Award in Primary Care: KHM Forschungspreis 2016

Award of the German Association for Medical Education (GMA) for “interdisciplinary
advancement and excellence in medical education” 2016

Selected Publications

Otte, Ina; Jung, Corinna; Elger, Bernice; Bally, Klaus (2016): “We need to talk!”
Barriers to GPs’ communication about the option of physician-assisted suicide
and their ethical implications: results from a qualitative study.
Med Health Care and Philos. DOI: 10.1007/s11019-016-9744-z.

Otte, Ina; Jung, Corinna; Bally, Klaus; Elger, Bernice; Schildmann, Jan (2016):
Interprofessional Silence at the End of Life: Do Swiss General Practitioners and

Hospital Physicians Sufficiently Share Information About Their Patients?
Journal of Palliative Medicine. DOI: 10.1089/jpm.2015.0377.

Otte, Ina; Elger, Bernice; Jung, Corinna; Bally, Klaus (2016):
The utility of standardized advance directives: the general practitioners' perspective.
Med Health Care and Philos. DOI 10.1007/s11019-016-9688-3.

Salloch, Sabine; Otte, Ina; Ruiner, Caroline; Vollmann, Jochen (2016):
Medizin trifft Ökonomie. Werkstattbericht zu einem interprofessionellen Lehrprojekt
Ethik Med (2016) 28:67-70

Otte, Ina; Elger, Bernice; Jung, Corinna; Bally, Klaus (2015): When GPs initiate
conversations with family caregivers in end- of-life situations - What are their
goals? Family Medicine and Community Health. 2015(1): 1026.

Otte, Ina; Elger, Bernice; Jung, Corinna; Bally, Klaus (2014): Advanced directives
in general practice: the impact of timing – the perspective of GPs. In: Swiss
Medical Weekly. doi:10.4414/smw.2014.14035.

Otte, Ina; Jung, Corinna (2013): Akteure und Strukturen in der Betreuung von
Patienten am Lebensende in „Vordenken – mitdenken – nachdenken
Technologiefolgenabschätzung im Dienst einer pluralistischen Politik“
in "Gesellschaft-Technik- Umwelt" des Edition Sigma-Verlags (Berlin).

Yeyang, Su; Borry, Pascal; Otte, Ina; Howard, Heidi (2013):
"It's our DNA, we deserve the right to test!" A content analysis of a petition for
the right to access direct-to-consumer genetic testing Vol. 10, No. 7, Pages
729–739

Selected Talks - international

Otte Ina, Jung Corinna, Elger Bernice (2012) 'Conceptualizing Death? Structures
of End- of- Life Care in Switzerland'. TRANSDISS Klausurtagung, München.

Otte Ina, Jung Corinna, Bally Klaus, Gudat Heike, Zemp Elisabeth, Banderet
Hans-Ruedi, Rosemann Thomas, Haller- Hester Dagmar, Elger Bernice (2012)
"Quality and Conditions of End-of-Life Care in Switzer- land- the Role of GPs"
Kick-off- Meeting of the NRP 67, Solothurn.

Otte Ina, Jung Corinna, Elger Bernice (2012) 'Conceptualizing Death?
Structures of End-of-Life Care in Switzerland'. Vordenken-mitdenken-nachdenken:
Technikfolgenab- schätzung im Dienst einer pluralistischen Politik (NTA5). 29.-31.
Oktober 2012, Bern.

Otte Ina, Jung Corinna, Bally Klaus, Gudat Heike, Zemp Elisabeth, Banderet Hans-Ruedi, Rosemann Thomas, Haller- Hester Dagmar, Elger Bernice. (2012) Quality and Conditions of End-of-Life Care in Switzerland- the Role of GPs'. SAKK-Symposium: Versorgungsforschung in der Schweiz: das Beispiel Onkologie, Bern.
Otte Ina, Jung Corinna, Elger Bernice. (2013) 'Dying with Dignity – the Role of GPs'. LUCAS International Graduate Conference: Death, the Cultural Meaning of the End of Life, Leiden, Netherlands.

Otte Ina, Jung Corinna, Bally Klaus (2014): Drafting advance directives in general practice - shortcomings and potential risks. European and Swiss Congress of Internal Medicine (ESCIM 2014), Genf.

Otte Ina, Jung Corinna, Bally Klaus (2014): On the handling requests for assisted suicide in general practice - a qualitative study. Swiss Family Docs Konferenz, Zürich.

Otte, Ina; Gather, Jakov (2016): Auswirkungen des „Konzepts der offenen Türen“ auf die Anwendung und das Erleben von Zwang in der Akutpsychiatrie. Klinik für Psychiatrie, Psychotherapie und Präventivmedizin LWL, Ruhr-Universität Bochum.

Otte, Ina; Salloch, Sabine; Reinacher, Anke; Vollmann, Jochen (2016): Implementing evidence and individual clinical intuition into medical decision making practice – empirical insights on potential tensions and barriers. **13th** World Congress of Bioethics. International Association of Bioethics (IAB). Edinburgh, Scotland.

Conference Organisation

Co-organising of the 27th ESPMH: European Conference on Philosophy of Medicine and Healthcare. 14 – 17 August 2013 in Basel, Switzerland

Teaching

Tutor to three groups of students in the course “Grundlagen der Ethik für Studierende der Biologie und der pharmazeutischen Wissenschaften“, Spring Semester 2012, Institute for Biomedical Ethics, University of Basel.

Lecture for “Psyche-Ethik-Rechtsmedizin“ Spring Semester 2012, Institute for Biomedical Ethics, University of Basel.

Seminar on “Ethics in Biomedical and Public Health Research“, Spring Semester 2012, Institute for Biomedical Ethics, University of Basel.

Seminar on “End-of-Care – the role of GPs.” Bioethics Research: Contemporary Debates, Autumn Semester 2012, Institute for Biomedical Ethics, Universität Basel.

Lecture for “Psyche-Ethik-Rechtsmedizin” Spring Semester 2013, Institute for Biomedical Ethics, University of Basel.

Tutor to six groups of students in the course “Grundlagen der Ethik für Studierende der Biologie und der pharmazeutischen Wissenschaften“, Spring Semester 2013, Institute for Biomedical Ethics, University of Basel.

Seminar on assisted suicide, Spring Semester 2013, Institute for Biomedical Ethics, University of Basel.

Tutor “Ethik für Biologen”, Spring Semester 2014, Institute for Biomedical Ethics, University of Basel.

Lecturer for a training research project “Medicine and Economics, Spring Semester and Autumn Semester 2015/2016, Institute for Medical Ethics and History of Medicine, Ruhr-University Bochum.