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Advance directives and the impact of timing

A qualitative study with Swiss general practitioners

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Summary

PRINCIPLES: Advance directives are seen as an important tool for documenting the wishes of patients who are no longer competent to make decisions in regards to their medical care. Due to their nature, approaching the subject of advance directives with a patient can be difficult for both the medical care provider and the patient. This paper focuses on general practitioners' perspectives regarding the timing at which this discussion should take place, as well as the advantages and disadvantages of the different moments.

METHODS: In 2013, 23 semi-structured face-to-face interviews were performed with Swiss general practitioners. Interviews were analysed using qualitative content analysis.

RESULTS: In our sample, 23 general practitioners provided different options that they felt were appropriate moments: either (a) when the patient is still healthy, (b) when illness becomes predominant, or (c) when a patient has been transferred to a long-term care facility. Furthermore, general practitioners reported uncertainty and discomfort regarding initiating the discussion.

CONCLUSION: The distinct approaches, perspectives and rationales show that there is no well-defined or "right" moment. However, participants often associated advance directives with death. This link caused discomfort and uncertainty, which led to hesitation and delay on the part of general practitioners. Therefore we recommend further training on how to professionally initiate a conversation about advance directives. Furthermore, based on our results and experience, we recommend an early approach with healthy patients paired with later regular updates as it seems to be the most effective way to inform patients about their end-of-life care options.

Key words: *advance directives; general practice; decision making; advance care planning; patient-centred care; primary health care*

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 regarding their medical care [1, 2] (for an example of an advance directive form see: http://www.fmh.ch/files/pdf11/PV_e_Ausfuehrliche_Version.pdf [last access: March 2014]). 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 have been discussed [11].

Several qualitative studies have shown that most general practitioners (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, see http://www.admin.ch/ch/d/as/2011/725.pdf). 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 whoever 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 minimised. 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 regarding how advance directives should be facilitated and implemented. Based on the insights given during these interviews, we hypothesise 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 about 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 was funded by the Swiss National Science Foundation (additional papers from this research study are currently under review and not published yet). 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. A total of 30 general practitioners were purposively selected from the FMH (Swiss Medical Association) list (Swiss wide catalogue of physicians, available on the website http://www.doctorfmh.ch/ contains 30000 entries), 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 about the foundation which financed the study and information about 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 (audacity software is a free audio editor and recorder, more information available on the website http://audacity.sourceforge.net/about/). 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 and German speaking regions in Switzerland agreed to participate (positive respond 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 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). 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. A total of 17 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 (AD) is the main focus of this research paper.

Different "right" timings of an advance directive

Through the interviews, we identified three main trends regarding how general practitioners determine the appropriate moment to discuss an advance directive 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 utilised (c) systematic approaches, such as age or during the first consultation with 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:

– **GP 11:** "When I fill in an advance directive 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."
– **GP 10:** "Well, so there is a form from the FMH (Swiss Medical Association), 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 (the form which GP10 is referring to is accessible through www.fmh.ch/services/patientenverfuegung.html).

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 an additional source of discomfort:

– **GP 13:***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 emphasised 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:

– **GP 4:** *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.*
– **GP 2:** 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:

–**GP 17:** 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.
– **GP 9:** 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 [19, 21, 22].

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 imaging what their decisions will be when a disease becomes predominant [25–27]. 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 given 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 minimised, 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 directive that only reflects another version of DNR orders as seen in the study from Burchardi et al. [31]. For this reason it is necessary to emphasise 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 organisational 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 (this is also noted in the guidelines of the Swiss Academies of Medical Sciences (SAMS): http://www.samw.ch/en/Ethics/Guidelines/Currently-valid-guidelines.html). 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 that the approach to make advance directives a mandatory requirement has 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

One 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 especially selected 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. (The results of the large-scale questionnaire will be available in summer 2014.)

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 utilised 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 organisational 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.

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