KOMMunikation und ENTscheidungsfindung bei lebensbedrohlichen Erkrankungen und deren Repräsentanz in Patientenverfügungen

COMMunication and decision-making in cases of life-threatening illness and their represENTation in “living wills”...

A study conducted in a rural, primary-care hospital in German-speaking Switzerland using in-depth interviews with patients, their relatives and the healthcare professionals involved.

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Summary

Aims of the Study

Successful communication of therapy objectives and options is essential for decision-making in life-threatening illness. Poor understanding of and diverse attitudes to medical interventions can complicate decision-making. This study investigated the patients’ perspectives, those of relatives, doctors and nurses regarding quality of life, planned limitation of medical intervention and the role of “living wills” in facilitating decision-making in cases of life-threatening illness.

Methods

We conducted structured in-depth interviews with 57 participants from five relevant study groups between September 2014 and October 2015 at a primary-care hospital in a rural region. Of these interviews, 4 were with expert physicians in order to develop the standardised interview structure subsequently applied, 15 were with patients who were or had been seriously ill, 5 relatives were interviewed, 13 interviews were with doctors, 12 with nursing staff and 8 with referring general physicians. The analysis occurred using the documentary method. In addition group discussions with doctors and nurses were carried out, whilst non-participative observation of daily working activity in various settings in the study hospital was conducted. Following the period of collection of data preliminary findings were discussed in workshops. The results of the group discussions, from the non-participative observation of daily working activity, as well as those from the workshops were channelled using triangulation[1] into the overall analysis.

Results

When deciding about medical intervention in cases of life-threatening illness, individual quality of life is the central consideration for all study participants. Views on how quality of life of the sick individual should be measured and, which degree of suffering might still be personally tolerable, are widely divergent. There are clear differences between the professional groups of doctors and nurses. In line with their professional role hospital doctors want to intervene for longer and more intensively than nursing staff, who frequently feel “closer” to patients and their suffering. Relatives of patients suffer greatly as a result of the life-threatening illness of the persons for whom they care, whilst patients themselves often hold a much more abstract view of their illness.

Regarding the function of “living wills” in guiding decision-making, all the participating groups have the following five stances in common: decision-making in patients with life-threatening illness requires on-going communication with all affected parties throughout the course of treatment. In instances of patients being unable to decide for themselves, a “living will” can contribute to the chosen course of action, is however frequently imprecise or not applicable to the current situation. Many medical professionals expect a “living will” to confirm a “do not resuscitate” order. Particularly in a crisis “living wills” can facilitate initiation of discussions regarding treatment preferences. There is no ideally formulated or perfect “living will”.

[1] Triangulation is a methodological approach in qualitative social research. Through intentionally combining different methods during processing and study of a given phenomenon, advantageous insights should lead to a situation in which insights gained may be consolidated.

Conclusion

Owing to the very broad differences in opinion regarding quality of life and choice of medical interventions in life-threatening illness between the participating groups, all affected persons must be included in the decision-making process. Insight into identity of role amongst the affected parties can be particularly helpful.
"Living wills" can help initiate the process of discussion of and approach to end of life issues, nevertheless in given difficult situations they can be found wanting. The most important measure towards inclusive decision-making is the continued, candid communication regarding the current situation, whilst taking individual preferences, the possibilities and role identities into account.

Keywords: end-of-life decision making, living will, Erwachsenenschutzrecht, shared decision-making, patient-physician relationship,
Keywords: end-of-life decision-making, living will, adult protection law, shared decision making, patient-physician relationship

Synonyms
"living will", advance directive

The study „Communication and decision-making" was approved by the Northwest and Central Swiss Ethics Commission, EKNZ 2014-202

Introduction

Even before implementation of the new Adult Protection Law on January 1st 2013 numerous publications on the topic of patient autonomy, living wills (advance health directives) and power of attorney have appeared. As part of the National Research Programme (NFP) 67 "End of Life" between 2012 and 2017 33 project groups have conducted research on different aspects of end of life in Switzerland. One of the modules in NFP67 focussed on decisions, motives and attitudes relating to the process of dying. This module addressed a similar question to our study but focussed not merely on dying, rather on how decisions regarding medical and care interventions in cases of life-threatening illness are reached. Medical and care interventions in life-threatening illness harbour far-reaching consequences for patients, carers and relatives. Deciding which interventions should form part of a plan of treatment and which should be dispensed with results from an interaction of various factors among which basic attitudes of the parties involved, ethical considerations, standard medical procedure, applicability of interventions, professional common sense, professional judgement of the situation in question but particularly depend on the wishes of the affected individuals. Many of these factors are neither explicit nor are they apparent to all affected parties. The primary objective of our study was to investigate these implicit and explicit factors with a view to improving mutual understanding in any given case.
An advance health directive (living will) is a legal document, which at the time of formulation lays down the wishes regarding medical treatment of an individual (still in possession of his or her mental faculties) in the event of them losing their ability to make decisions for themselves through illness or incapacity. Discussion leading up to revision of the outgoing Guardianship Act before the Protection of Child and Adult Rights Act 2013 took force focussed on reinforcing patient rights and curtailing heteronomous medical decision-making. The legally binding nature of an advance health directive is for many an important step towards enhancing patient autonomy. The personal reasons for formulating a living will do not need to be entirely consistent with the expectations attached to the document's legally binding nature. The reasons for and against formulating an advance health directive emerging from studies on the subject are not that diverse. The main reasons for writing a living will are fear of loss of autonomy and of over-treatment. Among the reasons for not choosing to make a living will are young age, good health and the conviction that relatives or doctors will without doubt make the right decisions on a person's behalf.
The number of advance health directives among in-patients has marginally increased in recent years. This does not necessarily mean that the documents are brought to or available in hospital, neither that they are read by treating physicians or discussed with the patient. In studies on advance health directives a question frequently posed is how prevalent are living wills and to what extent do they affect day-to-day activities [7]. There is little awareness of the fundamental factors, which motivate people to make an advance health directive, which hopes or fears are linked to doing so and, what role living wills play in decision-making. The second objective of this study was to examine communication in decision-making and the contributory role of advance health directives in this process.

Methods

Study design and participants

Owing to the complex nature of our study objectives, focussing as they do on personal and professional attitudes, social processes and communication, we applied qualitative sociological research methods (see data analysis). Four initial interviews with experts formed the basis of the structure subsequently applied to the in-depth interviews. These open interviews were evaluated on-goingly. Two video-recorded group discussions, non-participative observational protocols of everyday work and the protocols of workshops on advance directives supplemented the statements of the various participants in the interviews (see Table 3).

Five categories of participants were selected: patients, their relatives, doctors from the study hospital, referring general practitioners (GPs = family doctors), and nursing staff from the study hospital. In-patients were invited to participate by treating physicians or nursing personnel. Adult patients, who were currently suffering, or had previously suffered, from a life-threatening illness and were fit enough to participate in the interview, were included. Hospital employees irrespective of hierarchy and from all departments were invited to participate by E-mail and Intranet. GPs were recruited by E-mail or direct invitation by their hospital colleagues (for details of the study participants, see Table 1). Study participation was voluntary. All participants received detailed information, gave their consent in writing and were permitted to pull out of the study without having to cite reasons. The study was approved by the Ethics Commission of Northwest and Central Switzerland (EKNZ).

Table 1

Interviews carried out in the KOMMENT-Study

Group	Number	Specification
Experts	4	Senior doctors from the steering committee
Nursing staff	12	3 x intensive care unit 3 x accident and emergency room 2 x nurse instructors 2 x acute geriatrics 1 x medicine 1 x surgery
Doctors	13	4 x physicians 3 x surgeons 2 x gynaecologist 2 x orthopaedic surgeons 1 x anaesthetist 1 x acute geriatrician
General practitioners	8	Referring physicians (general practitioners) from the region
Patients	15	8 discharged patients, 7 in-patients aged between 49 and 101 years, mean age: 69.2 years, median: 78 years
Relatives	5	
Total interviews	**57**	

Data analysis

The interviews were audio-recorded, transcribed and evaluated using the documentary method of Bohnsack and Nohl. The recorded statements were sorted into subject groups and ordered by “type” using text analysis of the communication context. These types could thus be more precisely analysed for similarities and differences based on their intrinsic implications [8]. Definition of types and determination of similarities and differences was done by the interviewer UA and this process was checked and commented upon by an experienced psychologist conversant with the methods used. Evaluation of the interview transcripts occurred on-goingly. Insights arising from the early interviews could be incorporated in subsequent interviews. The video-recorded group discussions were transcribed. These video-recordings and observational protocols served the purpose of being able to compare the statements made in the interviews regarding communication and decision-making with the everyday reality. Participants at the workshops on advance directives were asked to make notes directly afterwards, the content of which was also compared with the statements arising from the in-depth interviews and the group discussions [9].

Results

A total of 57 structured interviews of roughly 1-hour duration were conducted with the study participants: 4 interviews with experts, 15 interviews with patients from the study hospital ranging from 48 to 101 years of age, 13 interviews with doctors and 12 with nurses from different departments of the study hospital; 8 interviews were conducted with referring GPs and 5 with relatives of patients (see table 1).

In this phase of data collection and evaluation we conducted two video-recorded group discussions and six non-participative observational sessions in different departments of the study hospital. These sessions were recorded with observational protocols. The results arising from workshops with "health professionals" and patients regarding use and application of living wills were also incorporated into the overall analysis (documentary and memory aids are summarised in Table 2).

Table 2

Overview of data collection instruments

Number	Type	Details	Recording / Documentation
57	Structured interviews	Carried out in hospital rooms, with patients in the nursing institution or at home, in the family doctor's surgery	Audio, complete transcription
6	Non-participative observation	Accompaniment for a whole shift of individual staff in differing departments of the study hospital	Hand-written structured observational protocols
2	Group discussion on advance health directives	Carried out in the study hospital, one group discussion with 10 doctors, one with 11 nurses	Video, partially transcribed
2	Workshops on advance health directives	Workshop 1: 40 participants from the study hospital and referring general practitioners Workshop 2: patients participating in ambulatory cardiac rehabilitation (Kardiofit)	Memory log

The doctor-patient relationship

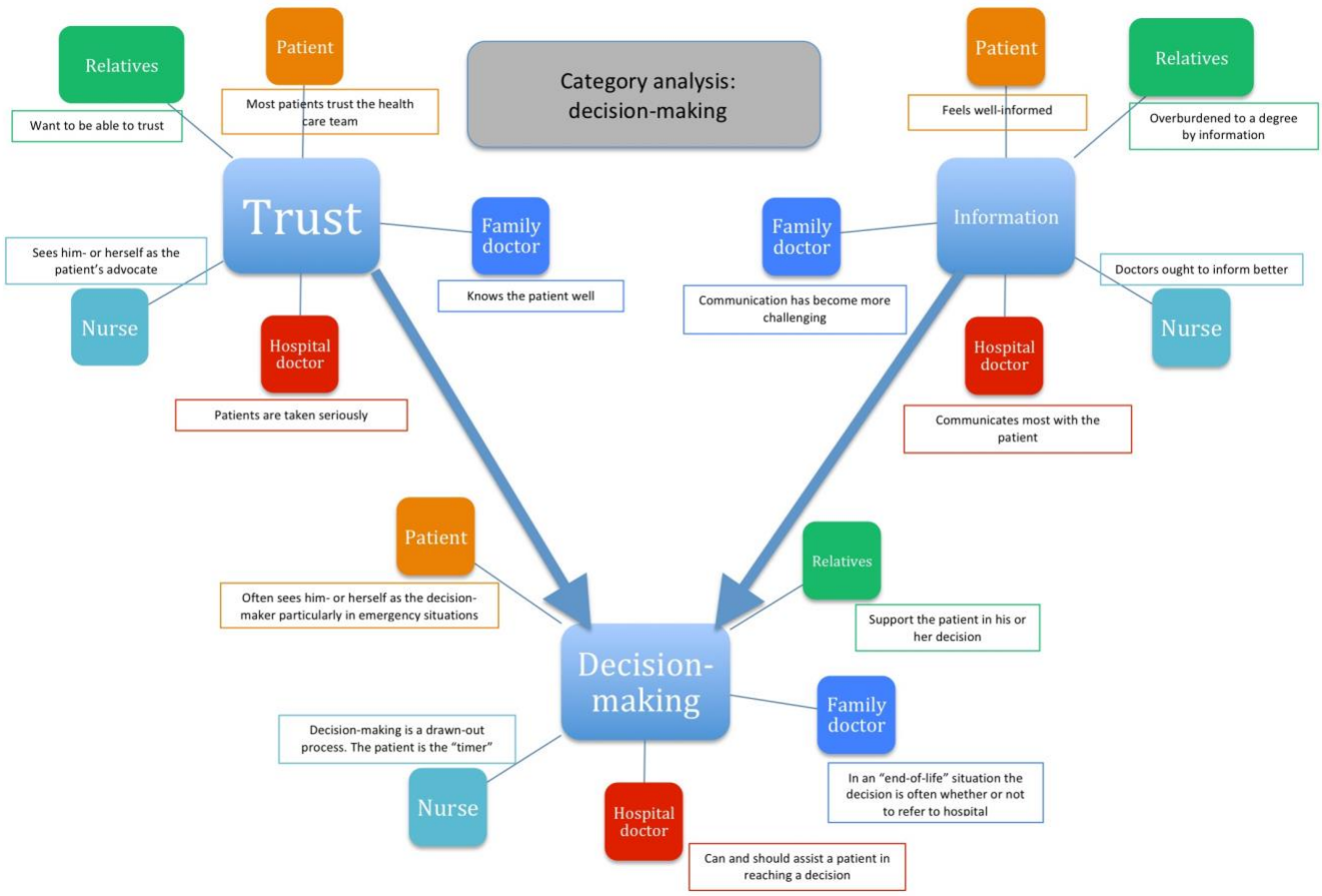
Hospital and community doctors are seeing a paradigm shift in the doctor-patient relationship with patients being increasingly autonomous and informed. Patients and their relatives generally want to be informed and participate in decision-making. Despite this the majority of patients emphasise how important trust in the treating physician is, for example: "[…] I was actually so confident, I had complete trust in the doctors, in this doctor, I felt, yes, he knows what he's doing" (P15010).

Most patients felt adequately informed by the treating physician, for example: "Yes. Hey, they sat there next to me so long and took their time. And I really appreciate that. They honestly sat there by my bed and, yes, took time to talk, to explain, and if I didn't know something then they explained it again. Yeah. Mega, excellent" (P15002).

Numerous patients described how they barely considered themselves to be an active agent in a crisis and that decisions regarding medical interventions in life-threatening situations seem to follow a predetermined scheme, for example: "… and then I, I couldn't have said yes or no. I was thrown into the situation. And then I thought, yes, I've no other choice" (P15003).

Despite most of the interviewees being over 60 years of age and that younger patients might interact with more self-assurance with their treating physician, there are indicators that the capacity of patients to actively participate in decision-making in crisis situations in an informed fashion might be over-estimated. "At the end of the day you've got to decide" might be synonymous with a call for help, "what do you think, doctor?". Decision-making is in most cases a process with several steps occurring over the whole period of treatment. Information regarding the involved parties is as relevant as the mutual trust of the involved parties with open communication (see Diagram 1).

Diagram 1: Category of decision-making and influencing factors



Quality of life, tolerable suffering and limitation of medical interventions

Alongside interpersonal differences regarding definition of quality of life, what constitutes tolerable suffering as well as limitation of medical intervention, there are conspicuous differences between the different study groups, particularly between doctors and nurses (see Table 3). Many of the nursing staff described uneasiness at the doctors' rather invasive approach with patients, who "have run out of strength and energy". Members of both professions agree that "nurses" see themselves as being generally more directly exposed to the patients' situation and suffering. This is due on the one hand to their more frequent and prolonged contact with patients and on the other hand due to the very differing training, professional self-perception and assignment of doctors and nursing staff: nurses are expected to be more empathic and to provide devoted care, whilst doctors are expected to provide analytical diagnosis and rational provision of treatment. Good communication is the deciding factor, in making transparent decisions and thereby being able to stick to a common objective in the treating team.

Table 3
Correlation and differences in attitudes between doctors and nurses

Issue	Attitudes of doctors	Attitudes of nursing staff
The medically possible	Basic stance on the medically possible is predominantly positive; limitations should be applied to far-reaching end of life interventions.	Basic stance on the medically possible is predominantly positive; limitations should be applied to far-reaching end of life interventions.
Decision-making	… is generally regarded as being manageable without difficulty; the healthcare team can and should lead patients towards a decision.	... is generally seen as a prolonged and individual process; the healthcare team can and should lead patients towards a decision.

Quality of life and bearable suffering for me	A somewhat diffuse issue. The perception of what constitutes quality of life is crucial, when deciding to limit medical intervention in critical situations.	Poor quality of life is almost always understood as being a loss of autonomy because of loss of mental faculties; it is the crucial factor in deciding to limit medical intervention in critical situations.
Quality of life and bearable suffering for patients	Quality of life of patients is the crucial limiting factor. As decision-makers doctors can and should be able to achieve an acceptable course of action.	Quality of life of patients is the crucial limiting factor. Quality of life can only be judged individually and in the specific context.
Favouring advance health directive	... taking an advance health directive into account is already a mandatory part of in-hospital procedure (despite this in practice seldom available); can serve as useful starting point for communication in end-of-life situations.	... taking an advance health directive into account is already a mandatory part of in-hospital procedure (despite this in practice seldom available); can serve as useful starting point for communication in end-of-life situations.
Dismissive towards advance health directive	... because only a confidential discussion can clarify the current situation and wishes of the patient.	... because the advance health directive is either insufficiently precise or too detailed it leaves too much room for interpretation. The discussion on the subject of personal expectations and wishes to facilitate the decision-making process is much more important.
Relationship between advance health directive and resuscitation-status	Up to a point an advance health directive is assumed to mean "Do Not Resuscitate (DNR)"	Up to a point an advance health directive is assumed to mean "Do Not Resuscitate (DNR)"

There are also large differences in the perception of illness and suffering between patients and their relatives. Relatives have greater difficulty dealing with the situation than their sick loved-ones. Helplessness and fear of loss of a sick relative are the predominant feelings. This already became apparent during the interview, where all relatives were compelled at some stage to weep as they recalled their experiences.

This did not occur with any of the interviewed patients. Almost all participants were unable to provide a definitive answer to the question, whether a potential future state could be defined, which would be regarded as no longer worth living for. Mental derangement, uncontrolled pain, and complete dependency on nursing care, were named as unbearable states by a small number of participants. A further criterion, which influences the decision to dispense with life-prolonging interventions, is a poor prognosis. In this regard medical professionals have difficulty defining concrete circumstances, which they would no longer regard as being compatible with individual quality of life, for example: "[…] then I would have reached the point, where I would say, here's no quality of life, but on reaching such a point not able to look after oneself, I don't then know, whether I would say, no, this is no longer bearable, or whether I would 'down-size' my expectations and still be able to feel something good" (A15007).

Communication in the decision-making process

There is a general consensus among the study participants that comprehensive and open communication amongst all involved parties should steer the decision-making process. The opinion of one of the nursing staff on communication: "That's the crux. How one communicates things. I mean, how open too, how openly the doctors say, here we could run into difficulties." (S15001).

Nevertheless, time and again there are communication problems in the decision-making process, where lack of time in everyday dealings is cited as a hindrance, also individual differences in attitudes to communication or the differing professional stance of doctors and nurses. As a rule, it is not sufficient to merely communicate decisions made for medical reasons. For a decision to be acceptable to all affected parties it must not only be informed but also collectively reached [10]. Despite all this available information many patients still do not see themselves as participants in decision-making in critical situations but see the decision as ultimately lying with the treating physicians. Genuine "shared decision-making" represents an ambitious goal, not easily reached [11].

End of life planning should be orientated towards the objectives and preferences of a patient, whilst circumstantially appropriate interventions should, where possible, be acceptable to patients and relatives [12]. A communal decision needs to take into account the expectations of all parties, the patient and his relatives, the GP, the hospital doctor, the nursing team. In the study hospital there is no fixed guideline regarding communication of the decision-making process. The health-carers have faith in the good atmosphere in the workplace, in the prevalent organisational culture and the flat hierarchy of the small teams. Patients and their relatives come to the hospital with considerable goodwill and trust. Questionnaires on patient satisfaction regularly score well above the national average [13].

Significance and limitations of advance health directives

The minority of interviewed participants had completed a "living will" for themselves (10 of 57 = 18%), whereby several participants had considered doing so based on personal experiences. Of 21 of the group-discussion participants merely four had an advance health directive. These low quotas are surprising, particularly owing to the recruitment brochure specifically drawing attention to "living wills" as being a point of discussion. One might conclude that interest in the topic of advance planning, quality of life and end of life issues is big enough to motivate participation in our study. Debating the issue, however, does not automatically lead people to make a living will. More significantly the interviews and discussions show that there are no simple answers to existential questions.

Attitudes to quality of life, bearable suffering as well as personal life circumstances and identification with one's professional role significantly influences the very diverse attitudes to living wills. The overwhelming majority of study participants emphasised the personal discussion with relatives and/or carers regarding personal preferences in relation to quality of life and life support as being more important than recording these opinions in an advance health directive, for example: "… one can discuss the matter, […] but not afterwards (in the event of a loss of mental faculties…). And this cannot be adequately recorded in a living will. One can discuss it. With one's representative" (S15006).

It is, however, not a given that this exchange of ideas will or would have taken place explicitly between persons in a position of trust. This becomes apparent in numerous interview and discussion passages, for example: "[…] thus one should […] accordingly include one's person of trust [in the living will], and there already was my problem, I'd never discussed these issues with a person close to me. I mean, it's clear, one might well discuss cases one has experienced in general, but for oneself (.) That I do find remarkable." (A9 in a group discussion).

There are numerous different versions of advance health directives in circulation. What an ideal advance directive should look like is a question, which cannot be answered conclusively. The perceptions as to the ideal form and content of a living will are almost too diverse (see Table 4). A positive aspect for both medical and nursing staff is that an advance health directive is a suitable means with which to initiate discussions into treatment preferences and limitation of medical interventions.

Table 4

Opinions regarding advance health directives

Opinions regarding the advance health directive, opposite attitudes of patients and relatives, doctors and nursing staff; summary from the interviews	
An advance health directive (AHD) should be like this or should fulfil this purpose:	
Either *	**Or***
AHD should be short and formulated with simple words	AHD should extensive and detailed
AHD only as a standardised form	AHD should definitely be handwritten
AHD is a purely legal document	AHD can help link discussions
AHD is a practicable instrument, since it is possible to anticipate future attitudes regarding quality of life	AHD does not work for judging what constitutes quality of life, a judgement which can only occur in the moment, not in advance
AHD offers protection from prolonged suffering in hospital	Having an AHD can carry the risk of being 'written off' in hospital

AHD can unburden relatives	AHD can overburden relatives
AHD is favourable for patients and processes in the acute hospital	Health care professionals see the AHD for themselves as superfluous/irrelevant
AHD documents the actual wishes of the patient	Patients wishes can only be ascertained in real-time discussion during a course of treatment
Patient's wishes must direct the decision-making process	AHDs are applicable to a limited degree because patients are neither conversant with medical possibilities nor familiar with the limits of feasibility

* *There were frequently stances among those presented, which lay between the extremes cited here.*

Discussion

Advance health directives and allocation of power of attorney should strengthen patient autonomy and assist the decision-making process in treating patients, who are no longer able to make decisions for themselves. An advance health directive enables a person in possession of their mental faculties to define in advance, which medical measures should or should not be implemented in the event of them losing their power of self-determination. It is evident based on the results of our research that defining such a course of action in advance is not sensibly applicable in a majority of cases. This is true for laypersons and health care professionals alike. An advance health directive implies several assumptions, which we investigated in the interviews, group discussions and workshops. A patient may use the advance directive to determine, depending on a given illness and or prognosis, how medical and care processes should be applied. In order to declare such intentions in advance, one should be able to predict what kind of quality of life is to be expected for a given illness or prognostic situation. The perception of how quality of life is to be judged in a given circumstance, fundamentally influences the decision to limit medical interventions. Virtually all study participants shared this opinion.

To judge quality of life in a life-threatening situation two factors are of particular importance: on the one hand, one's own well-being or by contrast, one's perception of a state of unbearable suffering, must be definable in advance. As we were able to show, even health care professionals tend to be vague on this point. Perhaps imagining a state of extreme limitation of powers of reasoning or complete dependency on nursing care by unfamiliar persons represents a limit of "the bearable". Such a definition in advance in a state of good health is barely possible. On the other hand medical and nursing staff consider judging what represents quality of life for an individual in a concrete crisis to be possible, however frequently reach differing conclusions. Quality of life may, in a given situation, be judged from a number of standpoints, particularly if a patient can communicate his or her own perceptions. An accurate predetermination, the way advance health directives would have it, still seems unrealistic.

The role identity of the various participating groups strongly influences judgement of quality of life and the interpretation a given living will in a particular healthcare situation. Opinions on judging quality of life, on limitation of medical intervention and on the usefulness of living wills are conspicuous in their differences among the healthcare professions (see Table 3). Particularly the observation that nursing staff, "see themselves more directly exposed to the suffering of their patients" and through personal dismay at this suffering more readily favour limitation of healthcare interventions for very sick patients than the treating physicians, is echoed mutually by interviewees from both professional groups. The opinions expressed by patients, relatives, and GPs clearly reflect the differing perceptions of role identity. The good decision-making process needs to incorporate all the statements arising from the different professional groups.

The validity of advance health directives in assisting the decision-making process on the whole is subject to very critical appraisal. The opinions on their form and content are too divergent. Partially contradictory positions are reflected in nine fundamental points (see Table 4). Neither a revision of existing documents nor the decision to select a limited number of versions would redress this problem [15]. The living will is not a substitute for discussion of the presumed wishes of a patient in a given clinical situation. Even greater caution is called for when dealing with living wills and applies to all parties involved. Before an advance health directive is drafted the content should be discussed in detail with patient and relatives. In hospital advance health directives should not only be registered but also read and discussed with patients. Only in this manner can a consensus between individual preferences and options of treatment be reached.

Strengths and limitations

Our study has several limitations. Only 57 interviews were conducted with individuals from the five categories planned for. The limited number of study participants in each group was mainly the result of finite resources. Nonetheless the material gleaned was sufficient to achieve theoretical saturation in each of the study groups.
Recruitment of participants was mainly done by the study doctors, who addressed potential candidates directly. This process was neither representative nor random and one must hence assume that there was a selection bias in all the target groups (patients, relatives, GPs and hospital staff). We speculate therefore, that disgruntled patients, relatives, GPs and hospital staff are underrepresented in the study.
All interviews were conducted by the study agent (UA), who also led the group discussions and recorded in writing the content of the non-participative observational sessions. As a result data collection was very homogenous. In order to avoid one-sided data interpretation there was scientific supervision by an experienced psychologist conversant with the methods used. Additionally there were regular discussions in the steering committee pertaining to preliminary results.
Strengths of the study were the great openness with which the discussions were marked. The study hospital is popular in the community and embedded in the region. The hospital employees enjoy considerable trust. Hospital employees appreciate the excellent atmosphere at the workplace. For this reason recruiting study participants was possible without major encumbrances.
Triangulation of the interviews with the group-discussions, the non-participative observational sessions and the workshops on living wills were designed to complement the interview material.
Our study was independent, was conducted without external support and executed using our own financial resources.

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6. Eine im Auftrag von Pro Senectute Schweiz 2017 durchgeführte quantitative Befragung von 1200 erwachsenen Schweizern ergab, dass knapp zwei Drittel (65%) aller Befragten die Patientenverfügung (PV) kennen, 22% hatten demnach eine PV verfasst, wobei dieser Anteil mit zunehmendem Alter steigt, von 5% im Alter von 18-39 Jahren bis auf 47% bei den über 65-Jährigen.
https://www.prosenectute.ch/dam/jcr:fd964281-c806-4bed-a0b7-3481087fb5b8/Omnibus-gfs-zh-Befragung-zur-pers&ouml%3Bnlichen-Vorsorge.pdf
Eine Studie am Universitätsklinikum Hamburg Eppendorf (UKE) in Deutschland zeigte, dass von über 50% der Patienten auf der Intensivstation, die angaben, eine Patientenverfügung oder eine Vorsorgevollmacht

verfasst zu haben, lediglich 23% auch tatsächlich in einer Krankenakte auftauchten. Geraldine de Heer et al.: Patientenverfügungen und Vorsorgevollmachten bei Intensivpatienten, Deutsches Ärzteblatt Jg. 114 Heft 21

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