

“What the patient wants...”: Lay attitudes towards end-of-life decisions in Germany and Israel

Julia Inthorn · Silke Schicktanz ·
Nitzan Rimon-Zarfaty · Aviad Raz

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Abstract National legislation, as well as arguments of experts, in Germany and Israel represent opposite regulatory approaches and positions in bioethical debates concerning end-of-life care. This study analyzes how these positions are mirrored in the attitudes of laypeople and influenced by the religious views and personal experiences of those affected. We qualitatively analyzed eight focus groups in Germany and Israel in which laypeople (religious, secular, affected, and non-affected) were asked to discuss similar scenarios involving the withholding or withdrawing of treatment, physician-assisted suicide, and euthanasia. In both countries, respect for patient autonomy and patients’ wishes to die with dignity found broad consent. Laypeople argued in favor of accepting such wishes when they were put down in an advance directive. Laypeople in non-religious groups in both countries argued on the basis of a respect for autonomy for the possibility of euthanasia in severe cases but, at the same time, cautioned against its possible misuse. National contrast was apparent in the moral reasoning of lay respondents concerning the distinction between withholding and withdrawing treatment. The modern religious laypeople in Israel,

especially, argued strongly, on the basis of the *halakhic* tradition, against allowing the withdrawal of treatment in accord with a patient’s wish. We conclude by discussing the emergent notion of shared responsibility and views of professional responsibility, which we connect through relevant cultural themes such as religion and national culture.

Keywords End-of-life care · Euthanasia · Lay perspectives · Responsibility · Israel · Germany · Advance directive · Decision-making process

Introduction

In 2006, the former Israeli Prime Minister Ariel Sharon suffered a massive stroke and fell into a coma. Subsequently, he received life-sustaining treatment for almost a decade and was kept in a pervasive vegetative state until his death in January 2014. The media coverage of his case illustrated the impressive possibilities as well as the open debates concerning life-saving and life-prolonging treatments for patients who remain unconscious for years. A report from Germany included voices accusing his sons of selfishness in keeping their father alive (Inbari and Gil 2013). NBC news quoted the medical ethicist Arthur Caplan, who claimed that “[k]eeping Sharon or others like him alive in a very damaged, extremely limited state with no hope of recovery is not something that the government should pay for without some support from those who want life to go on” (Caplan 2013). In Israel, where the withdrawal of artificial nutrition is legally prohibited, media comments on the comatose Prime Minister were relatively non-controversial, and included some newspaper coverage of the excitement caused by alleged brain activity. In a 2010 art exhibition in Tel-Aviv, a life-sized sculpture of Sharon lying in a hospital bed was put on

J. Inthorn (✉) · S. Schicktanz
Department of Medical Ethics and History of Medicine,
University Medical Center Goettingen, Humboldtallee 36,
37073 Goettingen, Germany
e-mail: julia.inthorn@medizin.uni-goettingen.de

S. Schicktanz
e-mail: silke.schicktanz@medizin.uni-goettingen.de

N. Rimon-Zarfaty · A. Raz
Department of Sociology and Anthropology, Ben-Gurion
University, 84105 Be’er-Sheva, Israel
e-mail: rimonn@post.bgu.ac.il

A. Raz
e-mail: aviadraz@bgu.ac.il

display. The gallery curator described the exhibit as “an allegory for the Israeli political body—a dependent and mediated existence, self-perpetuated artificially and out of inertia, with open eyes that cannot see” (Simon 2010). Such end-of-life dilemmas are becoming more widespread and common for laypeople. They are influenced by cultural and religious factors and take place within different national and medico-legal frameworks. In this study, we compare Israel and Germany, both at the cutting edge of Western medical progress, in order to highlight the role of cultural variation and pluralism in the recognition and moral assessment of the bioethical dilemmas of laypeople. Germany and Israel are paradigmatic examples of two opposite regulatory approaches to end-of-life decisions and constitute different religious and cultural backgrounds. They also represent opposite positions in the bioethical discourse of experts. While the medico-legal policies and institutional responsibilities for end-of-life care and advance directives have been thoroughly discussed (Schicktanz et al. 2010a, b), less attention has been given to how laypeople—and particularly those who are affected by end-of-life care issues—perceive and frame such responsibilities. Therefore, we examine the attitudes of German and Israeli laypeople, including modern religious people and those (e.g., relatives of patients) directly affected by issues of withholding and withdrawing treatment, physician-assisted suicide, and euthanasia.¹ The different national backgrounds serve as a starting point on the macro-level and facilitate the micro-analysis of the perspectives of laypeople on end-of-life decisions. By means of this interplay between macro- and micro-structures we want to elucidate how broader cultural and religious factors and professional bioethical arguments in public debates influence lay morality.

Background: the regulation of end-of-life decisions in Israel and Germany

The governments of both countries commissioned interdisciplinary expert committees—the German National Ethics Council and the Public Committee on the Care of the Dying Patient in Israel—to make recommendations for the regulation of end-of-life decisions. The reports of both committees paved the way for ensuing legislation on

advance directives (Ethikrat 2006; Public Committee on “The Care of Dying Patients” 2006). A comparison of these two documents shows a consensus about the framework within which end-of-life decisions should take place. Both reports advocate providing basic care for all patients, on the one hand, and restricting patient self-determination to the limiting of treatment, on the other hand (Schicktanz et al. 2010a). Besides these similarities, the reports also reveal significant differences in religious and cultural factors (see below) that are mirrored in the legislation. (For an in-depth comparison, see Schicktanz et al. 2010b)

In both Israel and Germany, the voices of religious groups play an important role in the debate on end-of-life decisions (Shapira 2006). In Germany, these include the Roman Catholic Church (Kongregation für die Glaubenslehre 1980) and Protestant churches (Frieß 2008; Schardien 2007). The churches agree that euthanasia should not be legal but have positive attitudes towards pain relief and all forms of withholding and withdrawing treatment in accordance with a patient’s will. The Orthodox Jewish (*halakhic*) tradition, in contrast, gives absolute priority to the sanctity of life. Hence, this value trumps self-determination. Withdrawing treatment is considered to be an active and, thus, unacceptable life-shortening intervention. Withholding treatment (for example by not resuming it after a necessary pause), however, is viewed as passive and, thus, considered acceptable under certain circumstances (Barilan 2003, 2012; Schicktanz et al. 2010b).

These differences are mirrored in the legal situations in both countries. In Germany, the law on advance directives (2009), which is part of the guardianship legislation (BGBI 2009 I 2286), emphasizes the plurality and individuality of attitudes towards death and end-of-life decisions. The law permits a broad variety of advance directives as expressions of patient autonomy (Jacobi et al. 2005; Wiesing et al. 2010). In Israel, the Dying Patient Act (2006) is a stand-alone law dealing with advance directives. It frames death and end-of-life care primarily as social events that are defined by Jewish *halakhic* restrictions on autonomy. Advance directives are allowed but only on a very restrictive and bureaucratic basis (Barilan 2003, 2012; Jotkowitz and Glick 2009; Shalev 2009, 2010). Overall, the Israeli law has two major unique attributes. First, the execution of advance directives is limited to terminally-ill patients in the last 6 months of their lives. Second, it allows only the withholding of treatment. In Israel, an advance directive requires that a long, jargon-loaded form issued by the Ministry of Health be filed. The German legal position is, in contrast, rather liberal. Any decision concerning medical treatment, regardless of the stage of illness, must respect an advance directive. Different forms of advance directives are promoted by various organizations, such as the Ministry of Health, medical associations, social

¹ We differentiate between withholding of treatment (not administering it when indicated) and withdrawing treatment (stopping already started treatment; e.g. stopping artificial ventilation), which are summarized under the German term “passive Sterbehilfe” (passive euthanasia) as two ways of letting a patient die. Furthermore, we discuss physician-assisted suicide and euthanasia as two acts that aim at deliberately ending a person’s life. In the first case the act is done by the patient himself (e.g. applying a deadly dose of treatment); in the second case the application is administered by a physician.

movements, patient advocacy groups, and the Churches, and all are legally binding.

Another issue—sometimes raised explicitly, sometimes implicitly—affecting deliberations in Germany and Israel is the Holocaust and the role of Nazi doctors in non-voluntary euthanasia. The experience of the political instrumentalization of medical experts frequently arises in the German discourse. It is used as historical evidence in support of slippery-slope arguments and against any form of physician-assisted suicide or euthanasia, a practice now legal in Belgium, Switzerland, and the Netherlands. Interestingly, the attitudes of Israeli Holocaust survivors concerning euthanasia (which play only a minor role, if any, in the emerging legal policy) are found to be opposed to those of German professionals (Leichtentritt and Rettig 1999). Israeli Holocaust survivors argue that profound differences exist between Nazi practices of non-voluntary euthanasia and physician-assisted dying upon a patient's wish. Therefore, they caution against comparisons between the Holocaust and other practices. Cultural factors, such as religion and the lessons of the Holocaust, influence not only the process of legislation but also the attitudes of health professionals (Pelleg and Leichtentritt 2009; Sprung et al. 2007; Wenger and Carmel 2004) and the role played by patient-support groups (Raz et al. 2012).

Recent studies have highlighted the importance of cultural factors for end-of-life decisions (Gysels et al. 2012) and especially for the relationship between health professionals and family members in joint decision-making in the sensitive context of end-of-life care, withdrawing or withholding treatment and euthanasia. Some of these have recommended that especially patients' and their families' cultural background and position between individualism and collectivism be taken into account (Searight and Gafford 2005). The emerging bioethical debate on so called 'shared decision making' at the end of life reflects on this tension between individualism and collectivism and is taken up in both frameworks. In Israel, the legal framework strengthens patient autonomy and involvement in decisions, but there is a relative lack of shared decision-making in current practice in the context of the end of life (Miron-Shatz et al. 2011). For Germany, Härter et al. (2011) show that, despite the variety of activities and training programs for shared decision-making, work needs to be done to make shared decision processes at the end of life a matter of routine.

In this study, we augmented the comparison of legal situations and expert discourse by considering lay moralities. We examined the attitudes and arguments of laypeople towards the distinction between withdrawing and withholding treatment, the execution of advance directives, and physician-assisted suicide and euthanasia. The study

sought to assess the differences and similarities between lay attitudes in Israel and Germany in terms of religious background, national culture, and personal experience. In particular, we focused on the plausibility of explaining differences between public/legal policy and personal opinions in terms of underlying moral contentions.

Methodology

The study is situated at the interface of ethics and sociology, with empirical research providing a description of attitudes towards end-of-life questions that can then be analyzed in their social context and from an ethical perspective (Horn 2013; Rehmman-Sutter et al. 2012). Studying the perspectives of lay people towards end-of-life decisions by comparing Germany and Israel contributes to the current debate among experts by identifying conflicts and problems experienced on a daily basis. Furthermore, the comparison enables us to critically assess the plausibility and practicability of abstract moral arguments, and it confronts the moral views of experts with the public's understanding of ethics (Schicktanz et al. 2012). Sociological research allows for the construction of a database of arguments voiced by lay people. Though usually not informed by theory and often informal, they nevertheless reveal which ethical questions lay people see as relevant and the circumstances in which they find them so. Lay morality thus adds to the expert discourse by showing how moral dilemmas are lived out in the complexity of everyday life and how responsibilities are actually distributed among agents in decision-situations. How is shared responsibility conceptualized and who should be heard in decision-making processes? Do Israeli respondents draw a line between withholding and withdrawing treatment that corresponds to Israeli law and *halakhic* tradition, while German respondents emphasize the individualistic and self-determined features of end-of-life care (Shalev 2009; Horn 2013)? By means of this 'reality-check', abstract ethical argumentation can be tested for its pragmatic applicability, and one can critically assess whether theory has an expert bias about what counts as an ethical problem. Most importantly, the experiences and moral views of affected people, who have already found themselves in end-of-life decision-situations, can help us to understand the priorities and perceptions of patients (Abma et al. 2012)—a paradigmatic requirement for all ethical positions that call for the strengthening of patient autonomy. Such results can then inform the debate in Germany and Israel. Finally, the comparative approach allows the connecting of findings to broader cultural scripts and thereby contributes to the self-reflective localisation of bioethical debates (Leget et al. 2009).

Juxtaposing the two countries highlights the contexts of national variation and pluralism, and it offers a more fine-tuned examination of group diversity and similarity within the contexts of being affected and of religiosity (Raz and Schicktanz 2009a, b). Our study was designed to examine the ways in which cultural (i.e., national and religious) differences exist alongside shared positions in order to determine whether such ways reflect a common sense of being affected by disease.

Since medical care in both countries provides technologically advanced intensive care and life-prolonging measures, we assumed that the broader context of end-of-life care and of decisions about end-of-life treatment are similar. We chose participants in the focus groups in a way that reflects different backgrounds with regard to 'being affected'. We defined 'being affected' as having cared for a terminally ill person compared to 'non-affected' persons who had had no such experience (see Schicktanz et al. 2008).² We conducted two focus groups of affected people and two groups of non-affected people in each country. In order to be able to assess the relevance of religion and religious arguments, one non-affected group was composed of participants with a religious background and contrasted with a group of secular participants. (The division was based on the self-ascriptions of participants.) The participants in the 'modern religious' groups were recruited from Christian parishes in Germany and Jewish communities in Israel. We were especially interested in the degree to which modern religious participants referred to arguments used by religious leaders in the public debate on end-of-life legislation. All participants were recruited by information sheets, flyers, and posters distributed and displayed in public places.

Focus groups had between 5 and 9 participants with 59 participants (25 male and 34 female) in total, 29 in Germany and 30 in Israel. Participants' ages were between 20 and 80 years old, and different age groups were represented in all focus groups. Participants differed in their educational backgrounds, but self-recruitment resulted in a slightly higher proportion of people with a university education. Focus groups were conducted as part of an exploratory pilot study to map out major differences and similarities between Israel and Germany with regard to issues of end-of-life care.

Focus groups took place between December 2010 and December 2011 and were conducted by the research team assisted by other researchers who were all experienced in facilitating focus-group discussions. Sessions lasted between 1 and 2 h. The same scenarios and questions were

used in all of the groups. After presentation of the end-of-life scenarios, participants were asked to discuss arguments for or against the withholding or withdrawal of a suggested treatment. The first scenario involved an elderly woman (89 years old) who is unconscious and has been hospitalized for some time. The relatives present an advance directive, which instructs physicians not to use life-sustaining measures, such as machine support of heart- and lung-function (withholding). The attending physicians are unsure if they should follow the advance directive in the case of heart or lung failure. In the second scenario, the 89-year-old woman is already connected to a respirator after having been admitted to the hospital because of a heart attack, and, after seeing the advance directive, her doctors wonder if they should disconnect the respirator (withdrawing). Finally, the participants were confronted with a third scenario in which a patient who suffers from untreatable pain asks a doctor to help her end her futile suffering.

Focus group discussions were audio recorded and afterwards transcribed and anonymized. The methodology was approved of by the ethics council. The transcripts from each country were translated from Hebrew and German into English to allow for comparison. The translations were produced by professional translation offices in both countries and validated by the research team with regard to scientific terminology, content, and the order of speakers. The translated transcripts were then analyzed thematically and compared cross-nationally in order to uncover discursive themes and categories of themes recurring within and across groups of respondents (Denzin and Lincoln 1994). Following a review of the relevant literature and our hypotheses, preliminary codes included two main categories: bioethical codes (e.g., formal principles such as autonomy, beneficence, non-maleficence, and justice as well as informal moral constructs such as types of responsibility and mis/trust) and cultural codes (e.g., relationship to medicine and doctors, religion/secularism, regulation, and so on). Following the cross-analysis of the transcripts, for which the teams in both Germany and Israel used Atlas.ti software, the teams discussed the preliminary coding, and cases of interpretive disagreement were clarified with additional codes and sub-codes as needed. For the purpose of juxtaposing 'lay moralities' and 'expert discourse,' emergent topics identified through inductive coding were further compared with the general categories of bioethical discourse gleaned from public policies and interviews with experts.

Results

The main theme in all of the discussions was patient autonomy and its relevance in the different scenarios.

² We did not ask terminally ill patients themselves to participate since discussing end-of-life decisions might have been too tiring, stressful and disturbing for them.

Therefore, this section starts with participants' views on withholding treatment and the conditions under which participants gave patient autonomy absolute priority. It continues by presenting the results of the discussion of the withholding scenario in which the participants discuss a serious conflict between patient autonomy and the duty of doctors not to harm. This conflict was regarded as even more serious in cases of physician-assisted suicide and euthanasia. Finally, participants' ideas on how these conflicts should be addressed through a more deliberative, shared decision-making process and their related views on particular forms of advance directive and the need for a legal framework are summarized.

Patient autonomy as the leading principle for withholding end-of-life medical treatment

Participants in all of the groups of both countries agreed that treatment should only be started if it is in accordance with the patient's will. If a patient has, as in the first scenario, an advance directive that does not allow life-sustaining treatment, the artificial ventilation should not be started. All of the participants judged unanimously that it is the responsibility of the patient's doctor as well as her family to adhere to her wish:

Yes, do it! Because doctors should respect the request of a dying patient, who knows what is best for her.
(*Israeli female, affected group 1*)

The advance directive was seen as an expression of one's will which should be as respected as direct communication with a doctor.

Physicians have to implement the written instructions because it is the same as asking the woman herself, she has written down in advance whether she wants to get help from machinery, CPR or anything like that, when she still [has] the ability to decide about her own life. She asks not to go against the natural process of dying and not to interfere deliberately, intervention is not natural. It is the duty of doctors to implement her request. (*Israeli female, affected group 2*)

In order to strengthen their views on respecting the advance directive and patient autonomy, participants referred to a patient's dignity. Dying with dignity was described as an integral part of the dignity of life and as implying the ability to act autonomously and that others ought to respect one's wishes.

Discussions of 'dying with dignity' were connected to images of old age in all groups with slight national differences. In the Israeli groups, old age was seen as a good reason for respecting a person's decision. In the German

groups, old age was regarded as an indicator of a life fully lived and as calling for reflection on the value of successfully finishing a life course. Discussions of the desire for the withholding of treatment were embedded with images of a good death, and participants claimed that this desire should be respected, as the following quote shows.

And I think, at a very old age, sometimes it is somehow ... One has likewise to see that one dies in dignity. If someone says: 'I want that with 85 years of age my life is concluded. I had a beautiful life.' And then one should, the way I see it respect this wish. (*German female, modern religious, non-affected group*)

However, the German groups also discussed the notion of a life fully lived critically as something subjective that can be assessed only by the patient herself and not from a third party's perspective. Otherwise, there might be the risk that elderly people are seen generally as dispensable and become victimized by age rationing:

Stop! Age does not matter at all. Age plays here ... Then we could simply put our old people down ...
(*German female, secular, non-affected group*)

A few participants in both countries wanted to restrict the scope of self-determination for withholding treatment. They voted for allowing the withholding of treatment only in cases where there is no hope of a cure. So, the patient's wish not to receive treatment should be followed only when the dying process has already started. For this minority, the autonomy of the patient remained an important principle, but the impossibility of recovery was introduced as a restricting criterion.

But if it is simply the case that she remains confined to bed for a week and the doctors say, 'Well, let's see, there exists the possibility that she will become independent again and can live somewhere in a retirement home or her private apartment,' then it is certainly clear that one must perhaps do much more. But if the only concern is life support, then it is the age on the one hand, and, of course, dignity on the other hand. (*German male, affected group 2*)

I agree that the question here is, if this is final? For the patient I mean. If the situation is final and she was asking for it, then they [doctors] should comply.
(*Israeli male, modern religious, non-affected group*)

Withdrawing treatment: between patient autonomy and doctors' duty 'not to harm'

While discussions of withholding treatment were rather uncontroversial the idea of withdrawing a treatment, like

artificial ventilation, that has already been started caused more debate. The fact that withdrawing treatment necessarily involves the active intervention of doctors received special attention in the reflections of participants. When discussing the second scenario, in which artificial ventilation was already in use and doctors learned only later about the advance directive and the patient's decision against life-sustaining treatment, more diverse positions evolved in both countries.

In the Israeli focus groups, there was a general tendency against withdrawing treatment. The main reason given was that withdrawal requires the active intervention of doctors and that was seen as morally different from passively withholding treatment.

There is no justification to disconnect the patient if the connection to the machine is already made and is planned as a short-range intervention. (*Israeli male, affected group 1*)

Participants did not regard the patient as a person dying but connected her death to the action of the doctor. Therefore, withdrawing treatment was not considered ethically equivalent to withholding it:

This question is more difficult because it is like killing her. (*Israeli female, secular, non-affected group*)

Participants in the modern religious group in Israel especially emphasized that withdrawing treatment is more problematic than withholding it. They referred to Judaism in general and Jewish law in particular.

The law in *Shulchan Aruch* states that you may not even move a pillow from underneath the head of a dying person in order to hasten his death. (*Israeli male, modern religious, non-affected group*)

Among the German groups, positions were not as clear-cut. Although there was a general tendency to see withholding and withdrawing treatment as similar moral predicaments, as both lead to the patient's death, the second scenario induced more controversy. Participants in the modern religious group, especially, saw a morally relevant difference between withdrawing and withholding treatment.

Well, I see a great difference there [between withholding and withdrawing]. [...] here we have the concrete case where an apparatus is connected, and—that when it is disconnected—the patient will die. That does not have to be the case. There is no guarantee that the person will indeed not continue breathing. But as long as the machine is connected, the person will breathe. (*German male, modern religious, non-affected group*)

Furthermore, members of the German focus groups discussed the individual situation and, especially, the chances of recovery in it intensively.

I would say that the question is: 'Who is the patient? What are the chances of recovery?' Not the age is crucial, but what the doctors think. One has to somewhat rely on the doctors. (*German female, secular, non-affected group*)

When there was no chance of recovery, there were strong votes in both countries—though not an overall consensus—in favor of respect for the patient's self-determination and the withdrawal of treatment. The timing of the decision played a crucial role here:

These interventions have been made, nothing can be done. But if it lasts for a long time—I estimate around two weeks—or three, I think you must disconnect according to the request of the patient. (*Israeli male, affected group 1*)

In both Israeli and German groups, the process of decision-making and the distinction between long-term and short-term interventions were raised in attempts to resolve such a dilemma. There was overall agreement that in an emergency any treatment to help the patient should be given immediately. Participants in all of the groups, however, were concerned that such cases can lead to the dilemma of withdrawing treatment later on if the emergency intervention does not restore the patient. Preferably, such situations should be avoided by prior extensive communication between patients, relatives and doctors about treatment plans and advance directives. Ideally, the question of withdrawing treatment will not arise when treatment is started only if it is effective and accords with the patient's wish. Given the complex chain of decisions that end-of-life care requires, participants in all groups agreed in rejecting automatic emergency treatment. There was also strong support in both countries for respecting patient autonomy even in cases of withdrawing treatment.

On my part, I would say, that first of all, the apparatus should be turned off because this is what the patient wanted. (*German male, modern religious non-affected group*)

However, even when participants argued in favor of withdrawing treatment, they raised concerns about the appropriateness of requesting this of doctors. Participants in both countries who followed this line of argument expressed empathy with the doctor who might find withdrawing treatment morally problematic.

If the situation deteriorates and there are no chances for recovery, the advance directives should come into

effect, within the framework of the Israeli law. However, I cannot imagine the possibility that someone takes responsibility for another's life, I mean actually disconnecting the patient from the life-support machines. (*Israeli female, modern religious, non-affected group*)

Therefore, the law should protect doctors.

It has to be clearly regulated that if it is on the paper there are no legal consequences for the person who pulled the plug. (*German female, modern religious, non-affected group*)

While the law cannot free doctors from the responsibility for withdrawing treatment, it should at least provide a clear framework in which to make decisions. Participants were not always familiar with their countries' current legal framework.

Physician-assisted suicide and euthanasia: unsolvable dilemmas and the advice to be cautious

The third scenario involves an everyday language plea for assisted suicide or euthanasia. Participants in all groups found it important to express their acknowledgment of the difficulty of the ensuing moral dilemma. Overall, they were very sympathetic with patients who wanted to end their suffering. Affected and secular laypeople in both countries openly discussed ways of relieving the patient's pain. The reasons given dealt primarily with the individual case presented, and participants found it difficult to provide clear-cut suggestions for regulations applicable to the case.

My opinion on that is a bit paradox. In this concrete example, I would be in favor of the doctor following it. But I would likewise be for if, given that it is illegal, that [he] is prosecuted for it. Naturally, I also don't want a legal vacuum in this situation, for one thing, and secondly, I don't want it to be legalized in Germany. For the simple reason that this leads to a slippery slope, as one says in English; where one would quickly start drifting off. (*German male, affected group 2*)

This moral dilemma is very heavy. I'm all in favor of helping—not to continue agony for days and months. I cannot morally oblige the doctors to give him something to hasten the death, and for some reason I cannot explain, something inside my feeling, I think that refraining from treatment that preserves the life is preferred in this case. To do an act of active killing is morally difficult for me, though both options are similar in terms of the end results. (*Israeli male, affected group 1*)

The heterogeneous suggestions ranged from options within the current legal framework, like additional palliative care,

palliative sedation, and stopping treatment, to physician-assisted suicide including travel to countries that allow it. Participants who had experienced a close relative's suffering and death recounted stories that were similar to the scenario, as in the following example:

And there were moments of weakness where he [the father] said: 'Just take a stick and kill me.' Then as a relative you are standing at the bedside and say [to yourself]: 'What does he tell now?' But he is completely lucid. But not in a way that [hesitates] all is still intact. Simply, that he could not take the suffering anymore. (*German male, affected group 1*)

However, the experience didn't make it any easier for participants to come up with solutions. Answers were often openly paradoxical. On the one hand, participants saw that the relief of suffering was an important aim; on the other hand, they raised serious concerns about legalizing physician-assisted suicide or even euthanasia. They were especially concerned about possible abuses of liberal euthanasia regulations:

But if I find myself in the position where the person in front of me tells me faithfully: 'That is different for me, and I really want that,' then I am not the one who has to make the decision. Insofar, I think, I would be ready to give her these drugs. Precisely because the decision does not lie with me. Whereby—since it actually concerns euthanasia—I have to remark that I nevertheless find that is should be forbidden since the danger of abuse is far too high. (*German male, modern religious, non-affected group*)

All of the groups discussed different types of social pressure, from family members as well as the broader society, coercing patients to hasten their death against their will as a serious risk; the main concern was that relatives might want to get rid of the elderly for financial reasons:

Unfortunately, in some cases we heard that family members take advantage of an incurable illness of a family member to get money, and their decision to disconnect him from life support, for example, does not seek to benefit the patient. (*Israeli male, affected group 1*)

It is also a problem if, for example, in a nursing home relatives would say: 'We don't want that anymore.'—Do you now act by thinking of the resident, who perhaps does not have an advance directive, or are there some among them who would like to save on the EUR 1500 nursing home costs per month or get the inheritance. (*German female, affected group 2*)

To contrast the more individual case-centered perspective, participants were also asked to comment on the legalizing

of physician-assisted suicide and euthanasia. Overall, participants in both countries, except for the modern religious Jewish groups, were in favor of changing current law and allowing these actions. They advocated clear regulation and effective controls to prevent abuse but stressed that new permissive legislation should apply only to terminally ill patients with unalleviable suffering.

... yes, not just one and very quickly, but two doctors and perhaps yet another person. Well—caution!(*German female, affected group 2*)

In contrast to the other groups, modern religious participants from Israel unanimously opposed assisted suicide and any liberal regulation of euthanasia.

Yeah, that is a problem. I don't think that Judaism teaches in favor of prolonging the dying process. But you certainly cannot hasten death. (*Israeli male, modern religious non-affected group*)

They explained their straightforward position in terms of religious values, such as the sanctity of life.

I think the doctors should not help him with this because God gave him his life and is the only one who can finish them. (*Israeli female, modern religious, non-affected group*)

Who should decide? Shared decision-making as a challenge

There was general agreement in all of the groups that an advance directive does not automatically lead to a clear decision with which everyone can agree. Advance directives need to be executed, and this can result in new ethical dilemmas. There was an overall consensus that decisions on behalf of patients are difficult to make and that responsibility for them is a burden that causes anxiety.

Participants were asked which additional procedures should be in place in case of conflict over the execution of an advance directive. Overall, opinion was equally divided between giving family and doctor's final authority. Most importantly, though, the decision should reflect the patient's will and take the advance directive as a guideline. While the German groups tended to trust family members more than doctors, many Israeli participants strongly advocated for doctors, pointing out that they are experts and have the most experience with end-of-life decisions. Arguments in favor of doctors as final decision-makers were that they have a better clinical understanding of the case, can better assess what is in the patient's interest, and are not emotionally involved.

The doctors are the most professional and they really know the situation—if there is a chance, what are the

chances, these are things that the family or the court cannot know without the doctors. (*Israeli male, modern religious, non-affected group*)

Since doctors are bound by the ethos of their profession to cure, most German participants favored giving family members the authority to make decisions. Their arguments were that they know the patient best and therefore understand what he would want in a specific situation. As two participants put it:

The relatives.—Of course, always on the basis of the advance directive. (*German female, affected group 2*)

[R]elatives should have the final say, since these are the persons who know the patient best and for whom the patient's life means most. (*German female, modern religious, non-affected group*)

Some participants in both Germany and Israel who had had no experience with making end-of-life decisions mentioned the problem that family members are emotionally involved and would find it difficult to decide for their loved ones.

Well, the difficulty that I see is that if the responsibility to decide lies with the relatives, due to the closeness of the relationship, anxieties and the inability to say goodbye of relatives will perhaps be an important issue. (*German female, modern religious, non-affected group*)

The relatives are very involved emotionally and it's also not very fair to put them in this situation where they should choose. The doctors can make a rational decision, according to the specific therapeutic risks and benefits, but for that—so they can really make a balanced decision and not be afraid that somebody would sue them, the law should be on their side. (*Israeli male, secular, non-affected group*)

Interestingly, participants in the affected groups had no such doubts, and this strengthened their desire to be involved in decision-making regardless of the burden. There was overall agreement that a shared decision process, in which different perspectives are heard and a solution is found together, is best. Related to this attitude is the belief that only those involved in the situation should participate in decisions. Thus, the court as impartial party was seen as a last resort which should have no authority of decision making but which could be appealed to in cases of disagreement.

In case of disagreement between the doctors and the relatives—the court should decide. (*Israeli male, modern religious, non-affected group*)

Formal or informal advance directives?

Throughout all of the discussions, participants talked about the ambiguity of an advance directive that results when the patient's wishes are not expressed clearly. Participants in all groups agreed that advance directives should meet formal requirements, which one participant summarized as follows:

They must fully accept the request of the woman, but only if she wrote the directives in clear and sound mind and with full understanding of the issue, in case she has no medical background regarding the implications of her request. (*Israeli female, secular non-affected group*)

Participants were also asked about the advantages and disadvantages of formal and informal advance directives. Among the Israeli groups, there was agreement that the formal form mandated in Israel is preferable to the informal form. They argued that a precise advance directive based on the mandated form is the most helpful sort in decision-making.

The benefits of the formal form—it is very clear. Not too many gray areas. (*Israeli male, secular, non-affected group*)

The form's complexity (and the legal regulations) forces people to seek out advice and inform themselves about all of the options and their consequences. Patients' thorough understanding of the matter due to that was seen as a safeguard.

German participants were less clear about the form that advance directives should take. While many also argued that a precise advance directive has the advantage of clearly communicating the patient's wishes to doctors, some supported the informal form. According to them, an advance directive that provides information about the kind of person a patient is rather than just ticking boxes about which treatments are declined under which medical conditions provides a better guarantee that treatment accords with the patient's wishes.

Well, I rather would like to write down my own thoughts. What I think of life; what my values are and how I would imagine it to be then. (*German female, secular non-affected group*)

Furthermore, German participants thought that the large number of templates for advance directives is more confusing than helpful.

Discussion and conclusion

End-of-life decisions and the problems related to them are intensively discussed in societies with advanced medical

systems. Thus, in the beginning of the twenty-first century dying is no longer the taboo that, in the 1980s, the social historian P. Ariès claimed it to be (Ariès 1981). Instead, the public discussion of difficult cases, such as Sharon's, and of the process of shaping a legal framework for advance directives has transformed the previous silence over dying in a hospital into a public awareness of the difficulties and dilemmas involved. The results presented here provide insights into the complex ways that cultural factors and experience with the end of life influence how laypeople perceive end-of-life decisions.

Being affected is regarded as an important influencing factor in many fields of medicine (Raz and Schicktanz 2009a; Schicktanz et al. 2008). It has been argued that the influence of culture can be moderated by the lived experience of being affected, overruling particular cultural perspective, is a universal factor (Kleinman 1999). Several, including our own, studies have shown that in cases involving biotechnologies, such as genetic testing or organ transplantation, affected and non-affected laypeople often differ strongly in their attitudes towards those technologies (Raz and Schicktanz 2009a; Wöhlke 2013).

Our study, however, shows no such strong differences of attitude between affected and non-affected persons in the respective context of end-of-life issues. There was overall consensus, cutting across affected and non-affected groups, regarding general issues such as supporting the development of institutions for palliative care, respecting patient autonomy, and defending patients' decisions to limit treatment. Participants also agreed that it is necessary to proceed with caution in end-of-life situations and strive for shared decision-making involving all stakeholders. One possible explanation for this is that the media discourse on demographic change and end-of-life dilemmas has increasingly influenced the general public in many Western, industrialized countries. In contrast to other medical settings involving life-planning, such as genetic testing or organ transplantation, advance directives are relevant to everyone, and, consequently, the issues connected to end-of-life decisions are well-known to the public. Thus, participants stressed the importance of autonomy as much as experts (Gedge et al. 2007). The most significant argument reflecting the unifying perspective of being affected was the support for euthanasia in extreme cases where the risk of losing one's autonomy and dignity overruled the perceived responsibility of society to regulate end-of-life care. The unanimous claim for more self-determination and professional respect for patients' (and citizens') autonomy is a result of the shared belief that everyone is capable of her own end-of-life decisions.

As our findings show, the main difference among experts, doctors, ethicists, and our lay participants is in conceptualizing end-of-life decisions. Focus-group

discussions were initiated with a binary question, e.g., withholding treatment or not, which, later in the discussion, respondents framed in terms of a longer process, involving a series of decisions, through which they accompany (or would have liked to accompany) their relatives. This is in contrast to the acontextual framework of end-of-life decisions as unitary dilemmas, which is often used in ethical deliberations and empirical research, such as the EURELD study (van der Heide et al. 2003). Advance-care planning shows parallels to this procedural understanding (In der Schmitzen and Marckmann 2011), for, in this conception, the patient, as well as her relatives, are in continuous communication with doctors.

Shared deliberation about palliative and curative therapy options and values should be the basis of decision-making. In shared deliberation, as the participants in our focus groups regarded it, advance directives, as the voice of the patient himself, are essential because family members or third parties do not always properly take their position into account. This is in contrast to the opinions of some experts who defend the power of attorney as the more powerful instrument for guaranteeing patient autonomy (Fagerlin and Schneider 2004). In the light of their experiences of family struggles, our participants criticized the claim that a power of attorney is an adequate substitute for an advance directive.

Our study indicates the need for critical reflection of the classical model of doctor-patient communication (Emanuel 2008; Hanson 2008). Shared decision-making in different fields of medicine has already been thoroughly discussed, and various studies have shown its positive effect on decision outcomes (see overview in Scheibler et al. 2003). However the participants in our study conceptualize this complex communication in terms of shared responsibility. They extend the classical model by explicitly integrating normative aspects of the process into decision-making. As they understand it, the decision-making process should be a complex deliberation among moral agents about questions of dying with dignity and the quality of life in which doctors are stakeholders with a professional ethos. They regarded the ethos of doctors to cure and to save life as the source of their expertise and authority, but that authority, they also thought, needs to be counterbalanced in the context of the end of life to prevent the prolonging of life by any means. Respondents in the German focus groups, especially, stressed this. They claimed that medical authorities are too biased (in favor of life) to make objective end-of-life decisions but that they nevertheless constitute a morally important perspective, though one that should be complemented by the perspective of family members. Those lay perspectives have equal standing with medical ones when it comes to determining what constitutes living and dying with dignity.

The concept of shared responsibility can be translated into the role assigned to the family in such a decision process. Differences with regard to the cultural scripts of families thereby became apparent. While laypeople in both countries generally expressed a desire that relatives be involved in the decision-making process, German participants were concerned about the social challenge for those patients who have no family or are not on good terms with the family. In Israel, a more traditional image of the family prevailed in which family, as omnipotent source of support, is always there (see Birenbaum-Carmeli 2010; Hashiloni-Dolev and Shkedi 2007).

Our design also gave us a more nuanced insight into the interdependency of culture and religion. While the difference between the Christian, German and Jewish, Israeli religious groups was relatively small, the difference between religious and secular groups was more apparent. Respondents in the religious groups in both countries tended to regard the difference between withholding and (actively) withdrawing treatment as more ethically problematic than participants from the secular groups. Our findings support some of the results of the quantitative ETHICUS study (Sprung et al. 2007), which emphasized the differences between religious and secular individuals. The ETHICUS study found strong effects of enculturation for Protestant/Catholic doctors depending on whether they were working in Southern, Central, or Northern Europe. These results are similar to our findings that religious denomination needs to be studied in its enculturated form and local context. Differences in, e.g., legal contexts, cannot be explained solely by the influence of different religious backgrounds or of different religious leaders, despite their prominent roles in national debates. The group of non-religious persons that is not represented in the same way like religious groups in the public debate and their negotiation with religious position needs to be further investigated.

Interestingly, drawing a line between actively and passively intervening at the end of life remains a challenging question. In all of the groups in both countries, participants raised the problem that doctors hesitate to withdraw treatment, e.g., switch a machine off, because it feels like an active intervention that leads to a patient's death. Surveys and qualitative studies of German doctors have shown that doctors, despite professional training, still differentiate between withdrawing and withholding treatment. Therefore, they tend to misjudge which forms of refraining from treatment are in accordance with German law and which are prohibited (Borasio et al. 2004; Van Oorschot et al. 2005; Beck et al. 2008). In theory, most ethicists and lawyers favor treating both withdrawing and withholding treatment as equivalent decisions to limit therapy. Distinguishing active and passive intervention does not

necessarily lead to different judgments about the kinds of end-of-life actions that are ethically justifiable. Our participants voted qualitatively for allowing both by giving priority to the patient's desire. As an input for ethical theory, we suggest that acknowledging the moral psychological challenge of withdrawing treatment should be further considered. Instead of insisting on a formalistic theoretical approach, one informed mainly by the analytical and consequentialist tradition, which equates both actions, addressing this difference from a moral psychological point can help to improve real-life conversations.

Limitations

Qualitative studies are by nature limited in their generalizability and representativeness, as their value is in hypothesis- and theory-building (Whittemore et al. 2001). Furthermore, only a few scenarios can be discussed in depth in a single study. The selection of our discussion scenarios was inspired by controversial issues in the academic debate, such as the relevance of old age, clear-mindedness, suffering, and untreatable pain for end-of-life decisions.

In our scenarios, the decision was first framed as one for doctors to make. We asked about the possible contributions of family members to the decision-making process only later on. This may have produced a bias regarding the roles of family and experts in end-of-life deliberation. The clear preference for shared responsibility in end-of-life decisions, however, shows the importance of family members participating in decision-making from the perspective of laypeople. Affected laypeople, especially, stressed the need to involve family members in end-of-life deliberations.

Furthermore, the diversity of participants in the focus groups in terms of age, religious convictions, and being affected was intentional, as we were more interested in the diversity of opinions than in finding homogeneity or even general consensus. The focus groups in this exploratory qualitative study were neither representative nor exhaustive but shared a socio-economical and educational bias, which is typical for qualitative studies using self-recruited samples. Our findings, however, complement and extend the accepted view that Germany and Israel are bioethical cultures opposed in their attitudes toward end-of-life care. Hence, our study contributes to a more nuanced view of the differences, beyond such broad generalizations as Christianity versus Judaism, between Germany and Israel. In the future, we intend to complement these qualitative findings with the results of more representative, quantitative research.

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