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Qual Health Res 2007; 17; 428
DOI: 10.1177/1049732306298806

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Telling Their Stories, Telling Our Stories: Physicians’ Experiences With Patients Who Decide to Forgo or Stop Treatment for Cancer

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There is currently very little research on how physicians respond to patients with cancer who decide to forgo or stop medically recommended “curative” therapy. The purpose of this article is to report on a qualitative study with 12 oncology specialists in Israel and Australia that addresses this question. The findings indicate that physicians tend to construct patients and their decisions in terms of mutually exclusive categories that focus on curability of the disease, rationality of the patient’s decision, and patients’ personal attributes. Physicians’ constructions of their experience focus on uncertainty and concern. Although contextual factors play a role in how physicians act in this situation, Israeli and Australian oncologists are remarkably similar in how they describe their own and their patients’ experiences.

**Keywords:** cancer; treatment decisions; refusal of treatment; doctor-patient interaction; qualitative research

One of the key tenets of modern medical practice is informed consent. The patient comes seeking to consult a person with specialized knowledge and expertise but, in theory at least, remains an autonomous person who is free to accept or decline the advice given. In practice, the majority of patients go to a doctor wanting to be “fixed” and have their worries and uncertainties dispelled. Their tendency is to accept the treatment they are advised to have, although they may seek further information or take time to come to a decision. Understandably, therefore, much of the recent literature on this topic focuses on the nature of treatment-related decision making, the extent to which the decision-making process is shared between patients and their physicians, and the way in which patients’ participation in treatment-related decisions can be facilitated or enhanced (Charles, Gafni, & Whelan, 1999; De Haes & Koedot, 2003; Sainio, Lauri, & Eriksson, 2001).

The underlying assumption in much of the literature is that competent patients will make rational decisions and agree to the treatment they are offered. When they do so, their decisions and their rationality are seldom called into question. It is when patients choose to decline medical treatments that their decisions and their capacity to make them are likely to be questioned (Brock & Wartman, 1990; Kacen, Madjar, Denham, Ackland, & Ariad, 2005; van Kleffens, van Baarsen, & van Leeuwen, 2004). The ethical-legal aspects of this phenomenon are particularly challenging and are made more difficult when decision making takes place in an emergency situation (Derse, 2005) or when patients do not wish to give a reason for their decisions (Bramstedt & Arroliga, 2004; Layon & Franklin, 2004). Some authors have gone so far as to suggest that although patients who refuse “to give reasons for refusing beneficial treatment” might

**Authors’ Note:** We are grateful to all the participants in this study for willingly sharing their experiences and views. We also acknowledge the support of the Israeli Cancer Association and the Newcastle Mater Hospital Margaret Mitchell Research Fund, Australia, for the research grants that supported the study. A shorter version of this article was presented at the Seventh International Advances in Qualitative Methods Conference, Surfers Paradise, Queensland, Australia, on July 16, 2006.
not be incompetent, “there are reasons to treat them as if they were” (Hurst, 2004, p. 1757). How physicians deal with patients who decide to forgo or stop medically prescribed treatment, and what they experience in the process, are issues that deserve closer examination.

In an earlier publication (Kacen et al., 2005), we have reported some preliminary findings about patients’ experience of deciding not to have treatment for cancer. In this article, we draw on data from interviews with medical and radiation oncologists. The findings provide insight into how physicians perceive patients’ decisions and how they respond to and cope with patients’ decisions that are usually contrary to what they regard to be in the patients’ best interest.

Method

The findings reported here are derived from a larger cross-cultural qualitative study designed to explore how adults with cancer decide to forgo or stop active treatment (i.e., treatment given with curative intent), and how close family members and attending staff construct and respond to the patient’s decision. The cross-cultural comparison is used to explore the extent to which deep-seated cultural values and beliefs influence the views, understandings, and actions of patients, as well as of their families and attending health professionals. For this part of the study, individual semistructured interviews were conducted with 12 medical and radiation oncologists (7 in Israel and 5 in Australia) recruited from two regional oncology centers. The sampling was purposive, with invitations extended to oncologists who had passed on information about the patient-focused part of the project to at least one of their patients or who could recall a recent experience of a patient’s declining treatment. Two of the participants were female, and one was a senior resident training in radiation oncology. They ranged in age from early 30s to mid 60s, and both Israeli and Australian samples included physicians who were born and/or educated elsewhere and had migrated to their respective countries.

The two first-named authors (IM & LK) conducted all research interviews, which lasted from 40 to 90 minutes and were audio-recorded. The key part of each interview was the participants’ description of their interaction with a patient from their recent practice who had declined (or declined to complete) radiotherapy or chemotherapy that was offered with curative intent. Additional questions were asked to clarify issues and elicit more detailed descriptions of the physicians’ responses. Interview recordings were transcribed and analyzed individually by the respective interviewer primarily to identify content categories and define the scope and adequacy of research data. A fuller thematic and comparative narrative analysis was undertaken by IM and LK working jointly during an intensive 2-week residency at the International Institute for Qualitative Methodology, University of Alberta, in July 2005. Further analysis and refinement of the key themes occurred subsequently and included critical reviews by the other authors (SA & JD). All four authors contributed to the final version of the article.

The study was approved by all relevant university and health service human research ethics committees. Potential participants were provided with full information about the study and their rights as research participants, and their written consent was obtained prior to participation. All other requirements related to ethical conduct of research, including confidentiality of data, have been observed.

Findings

In the process of relating specific patients’ stories, the participating physicians also provided rich narratives of their experiences and ways of coming to terms with challenging situations—their own stories. Although these narratives are intertwined, the findings are presented in two main sections: doctors telling patients’ stories, and doctors telling their own stories.

Doctors Telling Patients’ Stories

The physicians we interviewed were asked to describe recent examples of patients who had declined treatment that would have either cured their cancer or controlled it and thus extended their life. Most participants added further stories, sometimes relating to patients who had consulted them many years previously. Like a pebble in a shoe, such stories are uncomfortable and hard to forget. They trouble, irritate, and raise questions about why some patients choose to reject the expert advice they are given and what else might have been done to convince them to accept recommended treatment. Patients’ decisions to forgo or stop active treatment for cancer occur in the context of practice where other patients seek treatment even when their condition is no longer treatable, and where cancers recur and patients die despite physicians’ best
efforts. Patients who “refuse” treatment that is curative in intent are therefore particularly challenging, not least because they disturb the accepted rules of the doctor-patient relationship. Our analysis of research interviews revealed a repeating pattern of narrative construction that physicians used to explain such decisions by their patients. This pattern is characterized by the use of dichotomies, or binary opposites, in relation to what the physicians considered to be salient features of the situation: the nature of the disease, the nature of the patient’s decision, and personal characteristics of the patient.

Nature of the Disease: Curable Versus Incurable

When relating individual patient stories, as well as when commenting on the issues generally, physicians placed great stress on distinguishing between cancers that were operable or able to be eradicated by primary radiation or chemotherapy (or a combination of surgery and adjuvant therapy)—the curable disease—and cancers that held no prospect of remission and where the aim was to palliate symptoms. Treatments given with curative intent were often labeled as “radical” or “aggressive,” and patients with cancer that was deemed curable were expected to go along with medical recommendations for such treatment. These patients were seen as the ones who had most to gain from aggressive therapy and whose refusal was more problematic for the physician than if they had advanced disease that could no longer be controlled. Even when, as in the following interview extract, the physician presents several categories of patient based on the nature of their disease, the dichotomy is still between those in whom cure is a possibility and those for whom it is not.

A less common dichotomy involves consideration of likely benefits of treatment, perceived largely in terms of prolongation of life and relief of physical symptoms. Physicians talk about the trade-off between marginal benefits and negative side effects of treatment, seeing a continuum along which the decision to decline treatment is more or less acceptable. When the impact of treatment is known to be severe and the likely benefits marginal, the patient’s decision is more acceptable and might not be seen as a refusal. Even so, the decision can still be problematic:

I make a distinction between situations where there is a high likelihood of benefit from intervention, be that of a curative benefit or palliative benefit. And patients refuse.

In both above cases, the focus is on the medical evaluation of the situation: whether the disease is curable and whether the patient will derive physical benefit from treatment. Only one of the physicians we interviewed reflected on the possibility that such dichotomies might not matter in the same way to the patient:

When a curative therapy has failed; the patient has developed a recurrent or progressive disease despite that curative therapy. Then you might move from a so-called curative approach to one of, rather than hoping for cure, just hoping for improvement in quality of life... So it’s very different, depending on the disease you are looking at, from the medical point of view. From the patient’s point of view... I don’t think there is any dramatic division between radical and palliative treatment. There possibly is in the physician’s mind, because they’re still hoping to get the best outcome for the particular situation.

On the whole, physicians expect patients to follow their advice when they consider that proposed treatment might be curative, contribute to a longer period of remission, or result in alleviation of physical symptoms. As illustrated in the following extract, however, physicians are accepting of the patient’s right to choose, but, it seems, only when the disease is no longer responding to medical treatment, in other words, when the patient’s decision will not influence the ultimate outcome. When the decision is critical, the physician is likely to persist or use a “different approach,” one more likely to result in the patient’s acceptance of medical advice:

Well, firstly, it [refusal of treatment] seldom ever happens in the context of what we would consider a curative malignancy. Maybe that’s because our
approach...is different where we’re offering chemotherapy with the intention of cure. But generally I guess my view is, to give you an example: some people like Toyotas, and other people like Nissans, and somebody else would rather drive a Mercedes... There’s “horses for courses,” it’s whatever... If there’s a smorgasbord, it’s whatever people feel most comfortable with. And I must say I don’t have a major problem with that, where the intention is palliation, and minimal length of survival. But I guess I’d be quite upset, possibly quite upset, if a patient with a curable malignancy chose not to have it cured.

Thus, although allowing that patients have a right to decide about their treatment, and recognizing that there might be an in-between phase when treatment effects and outcomes are far less predictable, nevertheless, physicians tend to categorize their patients dichotomously: those who can be cured and those for whom that is no longer possible. These categories are likely to influence how information is presented to patients, and how much time and effort might be invested in getting them (and, sometimes, their next of kin) to agree with medical advice. These categories are also used to decide on the rationality, or otherwise, of the patient’s decision to forgo or stop treatment.

Nature of the Patient’s Decision: Rational Versus Irrational

None of the doctors we interviewed shared narratives of patients they considered to have been incompetent to make treatment-related decisions. Yet, they frequently referred to patients’ decisions as “irrational.” The distinction is important and recognizes that legally competent people can make what are (or appear to others to be) irrational choices (Brock & Wartman, 1990; Derse, 2005). However, our interest here is not in the rationality or otherwise of the patients’ decisions, but in how they are evaluated by the physicians.

Patients who accepted treatment where there was potential for remission or cure were invariably seen to be making rational decisions. On the other hand, a patient “with a curable malignancy [who] chose not to have it cured” was seen as making an irrational decision, a decision that justified the physician’s feeling upset and trying to persuade the patient to change his or her mind. The primary consideration for the physician was medical evidence that indicated probability of cure, and the possibility that the patient might have other, more weighty, reasons for declining treatment was seldom explored.

Often, patients’ explanations were given a negative label. They were seen as uninformed, irrational, or based on “fixed beliefs.” One of the consequences of such labeling was the tendency to avoid discussions that would allow patients’ beliefs to be explored and points of common ground identified. Rather, as in the following comments, the physician sees medical knowledge and the patient’s belief system as incompatible. As medical knowledge is, at least in this context, unassailable, the only outcome of a discussion would be to destroy the patient’s belief system. In such a situation, if the physician is right (and rational), and the patient does not see the issues in the same way, then the patient must, by definition, be acting irrationally:

I try and ask them why they don’t want radiation. . . . In that particular case I asked her “why?,” and it was really that she had a fixed belief that [having had surgery] she is now cured, which is actually against medical knowledge, in terms of probability, but I didn’t want to break down her belief system.

On the other hand, when patients were seen to be beyond the curative phase, their decisions were easier to accept, if not as fully rational then, at least, as “reasonable.” Even when treatment is largely palliative in intent, however, the fact that it is offered carries the expectation that it will be accepted. As the following interview excerpt illustrates, the physician is prepared to accept the patient’s decision not to have further treatment, but still not prepared to accept it as a fully rational choice by an autonomous person:

I couldn’t pretend in her case that a cure was going to eventuate, merely I hoped for a prolongation of her life... So when she said she was going to go with her approach [not having treatment]... I felt that a reasoned judgment had taken place, even if I didn’t actually think the reasons were right... To me, it’s reasoned judgment even if the reasoning is askew, or that there is some deep-set problem that makes them take an unreasonable step.

The tendency to deal in terms of binary opposites is again evident. If the physician offers a treatment expecting that it will be accepted, and which is declined, then either the physician’s judgment (to offer the treatment) or that of the patient (to decline it) is problematic. They cannot both be right, and as the physician holds the trump card of medical expertise,
then it must be the patient whose reasoning is in some way flawed. In effect, the patient’s right to decide is conditional. It is respected when the patient accepts medical advice and acts in a “rational” way. It might be more problematic when medical advice is rejected, but the reasons given (e.g., that the disease is no longer curable) are accepted as inadequate but “reasonable.” The patient’s right to decide is seriously questioned when the decision is seen as irrational and when reasons given are seen to come from a belief system deemed incompatible with medical science.

This falls into the basket of fixed irrational beliefs. I liken alternative medicine to magic... This belief, that there are some powers beyond the normal that you can tap into. And the combination of magical thinking and magical beliefs, in combination with sometimes misinformation, and fixed irrational fears, and sometimes exaggerated fears of chemotherapy, surgery, radiotherapy, and their consequences... are things that you occasionally encounter.

So although physicians recognize the patients’ right to make their own decisions about cancer treatment, they are challenged when working with patients who do not accept their (physicians’) expertise as the ultimate arbiter of treatment decisions. There is a tendency to perceive patients’ concerns, hopes, and aspirations that work against acceptance of medical advice as irrational and fixed within the realm of magical thinking. In this sense, the differences between the rationality of medical science and the irrationality of the patients’ belief systems are made evident and are used to stress the “otherness” of the patient; a point to which we will return.

Personal Characteristics of the Patient: Passive Versus Active, Younger Versus Older, “Normal” Versus Deviant

Like their disease and their decisions, patients are categorized in a way that stresses the differences between passive or active, younger or older, and “normal” or deviant or in some way flawed or inadequate human beings. These categories, too, are used in the evaluation of rationality and acceptability of patients’ treatment-related decisions.

Passive versus active patients. When the issues are clear, the physician is certain about what ought to be done, and the patient accepts the advice given, physicians perceive this as a mutually comfortable state. They feel in charge of the situation, but they also feel that their benevolent intentions are appreciated by the patient:

Most patients will go along with the recommended treatment plan and are fairly passive in the decision making process... they are comfortable with the model of benevolent paternalism.

There is a sense in the above statement that, ideally, this is how things ought to be. On the other hand, patients who are perceived to be passive when issues are less clear, or in relation to other people’s opinions about their treatment, are more problematic for the physician. These are patients who do not actively search for information, who do not make autonomous decisions, who are dependent on others, and who expect others to make decisions for them. Therefore, if a husband tells his wife “this treatment is not worth taking [and] the patient will accept his recommendation instead of the physician’s,” the wife’s apparent passivity is seen as less appropriate. Related to that, the husband’s expressed preference is seen not in terms of benevolent paternalism (a stance reserved for the physician) but as a confounding element that brings tension into the physician-patient relationship and the decision-making process.

Active patients are perceived to be different. They collect information from a variety of sources, and they ask many questions and are not always satisfied with the answers given. They demand extra consultation time—time the physicians do not always feel they are able to give them. In Israel, this often involves seeking second or even third opinion before deciding on a course of treatment, and can involve visits to physicians or clinics abroad. Patient-initiated seeking of second opinion was not mentioned by Australian physicians, although they acknowledged that some patients do seek complementary or alternative therapies. In both Israel and Australia, the active patients are perceived as more likely to decide not to accept medically recommended treatment. They are also the ones likely to cause irritation by challenging physicians’ authority and taking extra time. Both passivity and a tendency toward active involvement in decision making are seen as prevailing personality traits that, ultimately, decide how a patient will act:

It varies. I guess it depends upon the person’s position in the family and their interactions with other family members. A passive follower will often accept the
advice of their spouse, or other family members, and go along with it. Somebody who wants to be closely involved with their own decision making, the ones who look after their own tax form, and organize their own Will . . . they will ask all the questions themselves, and will often tell the family members to “shut up, this is my decision, I’m making it,” basically. So it is quite variable. I guess the decision to forgo treatment, where family have an impact on it is . . . again . . . it’s probably that the same weight is placed on the individual and the various family members, in a decision to forgo treatment as is the decision to accept treatment. In other words, if I’m passive and my husband says I shouldn’t have it, then I won’t.

Overwhelmingly, physicians reported feeling that the majority of patients wanted them to make treatment decisions for them. Perhaps that is why physicians feel that in situations where patients welcome benevolent paternalism both their and their patients’ expectations of the consultation are met. When either side comes with a different expectation, the balance within the physician-patient relationship is easily upset, and misunderstandings arise.

There is something of a paradox in this situation, as physicians want patients to be active and take responsibility for decision making in relation to treatment, as long as their decisions are in line with those indicated by the physician. Patients’ questioning is acceptable, if it leads to the “right” (i.e., medically recommended) decision. As is also evident in the next section, patients cannot easily predict when and how decision-making issues will be presented to them and which factors will determine the stance their physicians will take.

Younger versus older patients. Generally, physicians reported that “older” people might gain less benefit from “aggressive” treatment and are more likely to experience severe side effects, although the argument was also made that there might be inappropriate “ageism” in cancer care and that the patient’s physiological status, rather than age per se, is the critical issue. Nevertheless, younger patients are expected to take the risks associated with therapy regardless of how drastic the side effects, and physicians make greater effort to convince them of the benefits of therapy:

Sometimes we say, especially to young women that need to have adjuvant treatment for breast cancer, that their family needs them. Most of them accept treatment but a small percentage do not. For those who decide against treatment, especially when they are young mothers who have a job, we tell them they should have treatment for six months and maybe suffer a little bit so they can be mothers and partners for the rest of their lives.

When medical advice and emotional appeals are insufficient, physicians might resort to putting pressure on family members to help change the patient’s mind. The more “curable” the disease and the younger the patient, the greater the physicians’ need to have patients accept the recommended treatment. In the following example, where a 60-year-old patient had decided, very firmly, against radiation therapy for throat cancer, the oncologist made a number of attempts to convince the patient to change her mind, used other members of the oncology team to reiterate the message, and, finally, resorted to what he called “emotional blackmail” of her adult children, saying to them, “Look! You cannot let her do that [refuse treatment] . . . It’s on your head if you do.” The oncologist described being deeply distressed at his inability to “help” this patient, eventually offering her a compromise by referring her to a famous surgeon, even though he knew that surgery would be a less effective option in her case.

When patients are older (or perceived to be so), we do not find the same amount of effort being exerted by the physicians. They are more likely to accept older patients’ decisions in relation to primary and, especially, to adjuvant therapy. A radiation oncologist, for example, described an 83-year-old patient who underwent surgery but refused follow-up radiation therapy. Even though he tried to convince her that adjuvant therapy would have “given her an extra ten years,” he accepted that “at her age,” other factors might be more relevant and viewed her decision as reasonable.

The dividing line between what individual physicians perceive as “young” and “old” is fluid and might not be clear to individual patients, who might have different perceptions of how young or old they are. Patients might also not be aware that how information is presented to them might vary with their age (or perceived life expectancy) and the unstated expectations of the physician as to how they should respond. In the following example, the physician is describing “an elderly lady who was about 65 year old,” with an inoperable, advanced brain tumor for which she declined radiation therapy. The physician was “not surprised” by her decision, because . . . when you have a bulky tumor that’s not been able to be resected and it’s deep in the brain, and you are an elderly person, and you haven’t [responded
to steroid medication—all of these factors tend to imply that you are going to do poorly no matter what you do with that particular disease. . . . . . given her age and tumor size and location and the fact that it wasn’t receptive, all pointed towards her having an estimated survival [of around] three months. [He did not recall if the patient had her own reasons for declining radiation therapy, assuming that] perhaps she did not have any other things in her life that she had to stick around for.

Describing this patient as elderly and as not having much to live for seemed to help this physician accept the patient’s decision not to have treatment. Yet, had the patient been younger or someone related to him, the physician commented that he “would have been happier if they’d chosen to give it a go . . . there may have been a small benefit.” Had he wanted a different decision from the patient, he “might have tried to encourage her to at least try the treatment.”

It is evident that age is an important factor used by physicians when evaluating patients’ decisions. Age might tip the balance toward a decision being seen as reasonable and so is a mitigating factor. On the other hand, physicians are reluctant to use age as a determining factor when deciding to offer “aggressive” therapy, even when they are personally convinced that the proposed treatment will have serious side effects and little or no therapeutic benefit. The stated intent is to provide therapy regardless of the patient’s age, but the subtext—as in the following example—very clearly indicates that the patient is expected to decline the offer:

The benefits of treatment are likely to be less as you get older, and the side effects are likely to be worse, or less well tolerated. So yeah. Older people . . . more often will make a decision [not to have treatment]. I was surprised today . . . I saw an 84 year old lady, who’s just accepted second line chemotherapy for colorectal cancer, for metastatic colorectal cancer. And I said to her, “I think you’re a lover of life, I think this is the sort of thing you want to do. I’m more than happy for you to withdraw if you find it too toxic, but if it works, you’re gonna be ahead.” She said, “Fine, let’s do it.” So it’s not just age, it’s philosophy, it’s approach to life, it’s co-morbidity and how it’s affecting them. It’s how the patient might perceive that the treatment will affect those around them, and their own quality of life, versus their expectations for longevity, I suppose.

The above interview excerpt illustrates the complex nature of the physician-patient consultation and the imprecise art of decision making on both sides. As did other physicians in the study, this oncologist discussed how challenging it was to balance medical indications for or against particular courses of therapy with patients’ wishes, need for hope, and willingness to take risks against great odds. It seems that knowing how to deal with patients who refuse active treatment for cancer is one side of the coin. The other is knowing when to stop and knowing how to avoid providing futile treatment. Identifying the turning point is not easy.

“Normal” versus deviant persons. In a sociological sense, patients who decide not to have medically recommended treatment are, by definition, deviant and are seen as such by their physicians. These patients fail to adopt the archetypical “good patient” role (Parsons, 1951). By their actions, they make themselves different from the majority of other patients, they challenge the rationality of medical advice, and they use “irrational” reasons to justify their decisions. When acceptance of treatment is the norm, physicians seem to look for some flaw in the patient’s character to explain the deviant, “irrational” nature of the patient’s decision.

The tendency to dichotomize is seen in the acceptance of the “normal” patients as reasonable and responsible, while noting personal inadequacies such as lack of education; low intelligence; family or financial crises; or history of mental illness, alcoholism, or drug abuse in those patients who refuse treatment. Although such characteristics might apply equally to patients who accept recommended treatment, they are raised as in some way explanatory only in relation to patients who refuse treatment. For example, a physician commented that in his experience, the patients who refused treatment “usually were people with a history of mental health problems who did not understand, or did not want to understand, or maybe something very drastic had happened in their lives.”

It is particularly difficult for physicians to accept that some people might choose to live whatever life they have on their own terms and that those terms can be rational, even if they do not appear to be so to the physician. Constructing patients and their situations into binary opposites is one way for physicians to bring order to situations that seem disordered and out of their control. The question of why this is necessary and what purposes it serves is addressed in the next section.

Doctors Telling Their Own Stories

When interviewing physicians, we asked them not only for the “facts” of a situation but also how they
responded to patients’ decisions. Thus, we were given not only patients’ stories—examples of patients choosing to act contrary to their physician’s advice—but also an insight into physicians’ feelings, concerns, and reflections about their role in the situation. Oncology work is challenging enough. When a patient makes a decision that falls outside of the expected range of responses, the physician is faced with a new challenge—a response that is difficult and sometimes impossible to understand, and one that brings up a mix of feelings and concerns.

**Being Uncertain**

The physicians we interviewed dealt with uncertainty on a daily basis, but it was usually their patients’ uncertainty, not their own. Physicians are there to reassure the patient, to provide a name for the disease afflicting the individual, and to provide treatment, and in so doing to provide a sense of predictability and control in a life made unpredictable by cancer. What we found is that the patient’s response—the decision to forgo or stop active treatment—created uncertainty for the physicians. They perceived the patient’s decision as rejection of treatment, a rejection of what they, as highly qualified cancer specialists, had to offer the patient of the value of following medical advice. For the most part, they saw themselves as specialists who are highly trained in the provision of specific interventions, not as counselors with time and skills to delve into deeper recesses of their patients’ emotions or existential concerns. In this context, the consultation with a patient was seen as a means of providing information, answering questions, and obtaining consent, so that treatment could commence. When the consultation did not follow the usual script, physicians reported a sense of uncertainty and helplessness.

**Feelings of Failure and Helplessness**

When their advice was not followed, physicians either rationalized the patient’s actions or had to admit to a failure to understand the patient: “I don’t think I really got to the bottom of the problem... there was clearly something wrong that I didn’t see in that first interview, that I didn’t detect” (a physician commenting on not being able to convince a patient to have radiotherapy). However hard he might try, this physician remains at a loss to understand why a patient would make such a seemingly irrational and “disastrous” decision.

This failure to “get to the bottom of the problem,” to fully understand the patient and his or her motivations, was usually coupled with a sense of failure to convince the patient of the value of following medical advice. Such experiences often left physicians feeling offended and frustrated, particularly when they had put in extra time and effort to be helpful. In the following extract, the sense of irritation is almost palpable as the oncologist tells of a woman in her early 40s, whose breast cancer had gone undiagnosed until some time after metastatic tumors appeared in her bones:

I probably had something in the vicinity of nearly two hours with her, over a couple of appointments. Going through a whole range of different treatment options when quite clearly, in a mechanistic sense, what she needed was some hormone treatment for her breast cancer.../...So we had this paradox right from the word go with this lady who wanted to explore every form of treatment; having it or not having it; what will it do? what it won’t do?... to the nth degree. Very, very difficult series of consultations. And then finally when we laid it on the line that the treatment options for her were absolutely clear—she should have hormone treatment, it was that simple—she still didn’t [accept the advice]. She agreed to have it but then she didn’t come back for it.

The fact that a patient could not be convinced to accept treatment left physicians feeling helpless and frustrated or, months later, still questioning if there “was something that I failed to do to convince [the patient], that she could have taken a course that would have been better.”

However understanding and tolerant they try to be, physicians remain convinced that the treatment option they had recommended would have been better than the no-treatment option chosen by the patient. Constructed in this way, the situation can seldom be seen by physicians as anything other than a
failure: of the physician to convince the patient to make the “right” decision, of the patient to see the benefits of intended treatment, or both. Either way, the patient’s decision is a cause for concern and, sometimes, fear.

**Being Concerned**

Fear of failing to do the best they can for their patients is a strong motivator for the physicians we interviewed. The cases they chose to present were often told in words and tones that showed concern for the patient but also concern for broader implications of the patient’s decision. When courage and activism are highly prized (especially as evident in data from Israeli physicians), then a possibility of failure is particularly uncomfortable and disconcerting. A patient’s death is acceptable if all possible means have been used to avert or defer it. Giving in without a fight is much less acceptable, especially in terms of how others might judge the physician’s actions. The result is persistence in trying to get the patient to accept specific treatment, even when the patient has made a clear decision not to have it:

If she were to say that she didn’t want chemotherapy I would try to encourage her to do it. I would say “you are the boss, and it’s your decision. Understand also though that if I see you doing poorly I will ask you again, if I still think there is a chance this could help you.”

In cases where physicians were confident of cure or prolonged remission, a patient’s determination to forgo treatment raised more personal concerns. In the following extract, an oncologist reflects on a case that has troubled him for some time but which he had not discussed with anyone before the research interview. The case involves a 40-year-old man with Hodgkin’s disease, who has repeatedly refused treatment that the oncologist believes could cure him:

I didn’t feel good [about the situation]. First, I have to stress that I was in fact afraid for myself. I... have treated so many patients in the past that have been cured, and they were glad of our good relationship. I get lots of satisfaction from that. So if one patient doesn’t want [treatment] it’s OK. I personally can go along with that. I don’t want to sound cold, but it happens. So what frightens me is what will happen when, sooner or later, he dies, and the family accuse me of not doing my job properly. Because, at the end of it all, what we physicians have is our good name—as people who can be trusted. I was afraid that it will hurt my credibility. That if he does not accept the treatment... I was afraid of what that would do to me. I was concerned for myself, so in the end what I did was use defensive medicine, “par excellence.”

Physicians are aware that some of the information they provide to facilitate informed consent might influence a patient to not have treatment. The physician quoted above went on to wonder whether he would not have been more persuasive with his patient if he had presented a rosier, less threatening picture of the planned treatment. Not telling the truth, or telling deliberate lies, carries its own risks and concerns, although in this case, the physician is concerned mostly with the futility of such an approach with a patient intent on sticking to the decision he has made:

In retrospect, I wonder if I should have lied to him, and told him that the treatment is not dangerous and that there would have been no risks to his life, or complications. But I am sure I did the right thing, because even if I had lied to him he would have found another excuse not to have treatment. I don’t know; this was the tone of our conversations.

Ultimately, the question is not one of making a decision but of making “the right” decision. It is evident that patients’ decisions to not have medically recommended treatment have consequences not only for themselves but also for their physicians, particularly if the cancer is deemed curable and the patient is young. The “failure” to treat in such situations reflects poorly on the physician and, as shown in the preceding section, might be a source of fear and concern for him or her. The possibility of litigation by a grieving family leads to defensive strategies, including careful and detailed documentation of each consultation, information provided, advice given, assessment of the patient’s cognitive and emotional state, and the patient’s decision.

The reasons for the patient’s decision might be recorded but often are not fully known, sometimes because they are not asked for but often because the reasons given seem inadequate to explain the seriousness of the decision. The decision thus remains a mystery: rationalized, related to various possible influencing factors, but never fully grasped. This failure to understand fully the patient’s lived experience, the existential meaning of the decision, leads some physicians to continue to try to change the patient’s mind.
Although none of the physicians we interviewed reported doing so themselves, they commented that in an attempt to protect themselves, some of their colleagues insisted that patients sign a statement to the effect that they were refusing to have recommended treatment.

There are some people who go through what I call a coercive ritual. Which is, if a patient refuses treatment they’ll ask them to sign a document saying, “I recommended this treatment but you...” essentially, to say that “what you are doing I think is profoundly unreasonable. Can you just confirm this in writing?” You know, the law does not demand that.

Whatever the stance, the outcome for the physicians is an uncomfortable one and requires some form of personal response. To clarify how they live with the clearly uncomfortable decisions some of their patients make, physicians in our study made frequent references to their and their patients’ “philosophy of life” or belief systems. One example was a reference to the Golden Rule, learned in childhood. As long as the physician felt that he had acted in accord with the basic precept to “Do as you would be done by,” he felt that he could sleep easy, knowing he had tried and had done his best, even if that best was rejected by the patient.

Others felt more comfortable if the patient presented his or her decision within a religious or some other system of belief. This seemed to make the decision more acceptable, even if not necessarily any more comprehensible. Lack of information or unfounded fears could be addressed through information giving and the patient “talked round,” but personal belief systems were seen as more difficult to get through. When there was no time to engage the patient in a longer conversation, information that might have helped the physician to feel more comfortable with the patient’s decision was not available:

I think she had already decided that she didn’t want chemotherapy... There wasn’t any obvious background factor that led to her making that decision that I was aware of. And because I had a five to seven minute conversation with her, rather than a one hour conversation, I didn’t get a sense about her religion, her philosophy on life, or other things. [A junior physician who had assessed the patient earlier] clearly got the impression that the patient wasn’t going to have chemotherapy anyway.

Another pattern was that of distancing and detachment. In this case, the emotional response is controlled and “professional”; a nonjudgmental stance is taken, as in the following example:

I don’t get emotional over whether they want treatment or not. . . . I tend to step back and say, “it’s your choice; these are the benefits; these are the potential side effects. Go away and think about it.” . . . Many patients believe in alternative medicines and are paranoid about conventional medicine, and things they don’t understand . . . . Quite entrenched belief systems that are important to the patient, and I am not here to break those down. I guess because I am always wary that science also is only a belief system and that I don’t have the ultimate truth.

More commonly, their own sense of unease with a patient’s decision leads physicians to keep trying to change the patient’s mind, especially when the condition is deemed curable, or the patient is seen as likely to derive some degree of physical benefit from treatment. The hope is that the patient will agree to at least try the recommended therapy and either continue, or be in a position to give a more substantive reason, such as severe side effects, for wishing to stop:

I think if it was a relative of mine I would have been happier if they had chosen to give it a go. And just see how fatigued she was . . . because there are patients who have radiotherapy . . . even if their whole brain is irradiated, they don’t suffer particularly from fatigue. There may have been some small benefit. [He accepted that a particular patient’s decision was “reasonable”] . . . otherwise, I might have tried to encourage her to at least give the treatment a go.

Thus it is the physician’s level of comfort, as well as the concern for the patient that might determine the point at which the physician accepts the patient’s decision or continues to question it and try to change it.

Contextual Factors

Overall, there were many similarities and few differences between Australian and Israeli physicians in the way they responded to patients who declined cancer treatment. There were, however, contextual differences that affected physicians’ interactions with patients. For example, whereas physicians in Australia tended to focus on the individual patient-doctor encounter, physicians in Israel reported greater concern with social and
relational dimensions of the situation. Thus, Israeli physicians reported that most Jewish (although not Arab) patients will seek a second (and possibly a third) opinion, sometimes going abroad to consult with specialists recommended by others before agreeing to specific treatment. At least some of the physicians we interviewed suggested that such actions create feelings of uncertainty for cancer specialists, reminding them that patients see individual doctors as fallible. Nevertheless, Israeli physicians are accommodating of the practice, which is far less common in Australia.

Regardless of their beliefs and place of work, Israeli physicians also appear to be very aware of the emphasis that Jewish religion places on doing whatever one can to prolong life. Religious precepts might be used to justify unfair pressure for treatment being placed on the patient (or by the patient on the physician), even in situations where the condition is terminal and the harm done is greater than any potential benefit.

There is a strong culture of medical activism, to the point that even, some of us would say, that even coercive measures are appropriate. . . . In fact there is no compulsion in Jewish [religious] law in the setting of incurable illness to submit patients to treatments that have a likelihood of undermining their quality of life. But there is often a lack of sophistication, a lack of understanding. People have a fairly superficial understanding of Jewish law and have this impression that you must do everything, and this is just not accurate.

Australian physicians, on the other hand, expressed their primary allegiance to the value of patient autonomy and did not refer to religious laws or precepts for guidance in practice. They often referred to themselves as pragmatists, who might hold personal beliefs but accept their patients’ right to make their own decisions:

It is more a culture now days of presenting the data and allowing patients to choose. We present the indications, or the rationale for offering treatment and then, I suppose, it is really up to the patients if they want to choose it.

Yet despite this somewhat democratic commitment, it is evident that individual physicians (in Australia and Israel) tend to adopt a particular stance to treatment, seeing themselves and/or having a reputation as being particularly “aggressive” in their treatment recommendations, even when the side effects have become severe and distressing to patients. They see themselves as experts who are in the best position to advise patients and find it frustrating dealing with patients who either decide not to have recommended therapy or who seek “overly aggressive treatment” that the physician is reluctant to provide.

In this context, a significant minority of Jewish patients (both religious and secular) are reported to use the services of rabbinical medical brokers (Sapir et al., 2000). It was reported to us that when they are well informed and have credibility within the medical profession, as well as within the wider community, their services are often seen as helpful in facilitating difficult patient and family decisions. At times, they might advise patients not to accept treatments when the harm to the person and his or her quality of life is likely to be greater than any potential benefits. In giving advice, they will give consideration to medical evidence as well as to issues such as the quality of life and the essential meaning of existence as a human. Such a role does not exist within the Australian setting, where treatment decisions are most often a matter between the patient and the treating physician.

Both Australian and Israeli physicians appreciate that some patients struggle with the challenge of making what they (patients) perceive to be medical decisions (e.g., which, if any, adjuvant therapy to have following primary treatment) and therefore tend to ask their physicians to make such decisions for them. Both see the value of exercising “benevolent paternalism” at times, although most are reluctant or refuse to do so in situations where trade-offs between benefits and side effects of therapy are uncertain.

Discussion

Van Kleffens and van Leeuwen (2005), who conducted their study in the Netherlands at the same time as we conducted ours in Israel and Australia, found that physicians are mainly goal oriented when deciding on treatment for cancer, whereas their patients tend to be more reliant on personal values. They also found that an important factor in the physicians’ evaluation of a patient’s “refusal” of treatment is the “curative” versus “noncurative” status of the disease. Our study supports these findings but also sheds more light on how patients’ decisions to forgo or stop treatment for cancer affect physicians at a more personal level. We found that physicians feel uncomfortable, uncertain, frustrated, and concerned when patients
make treatment-related decisions contrary to their (physicians’) advice. They struggle to see such decisions as appropriate, tending to see them as rational or irrational, depending mostly on the assumed curability of the cancer and the patient’s age.

The tendency to use binary opposites as a way of categorizing patients and their decisions might be problematic yet is a common way of thinking, in science as well as everyday life. It might have been particularly evident in this study because of the focus on curative treatment and on the decision to not accept medical advice. As others have suggested,

The order and organization of both the natural world and the human capacity to conceive of it are structured in such a manner that antithesis, the capacity to divide ideas into two groups, may have served as the foundational building block of human experiential knowledge. (Thorne, McPherson, Henderson, & Pesut, 2004, p. 210)

Such dichotomies orientate us to our world and how we comport ourselves within it but can, at the same time, cause us to adopt uncritically one half of the dichotomy or presume a dominance of one over the other.

The most obvious dichotomy we found in this study lies between the expert physician and the lay patient (the other). When the patient who decides not to have treatment is like the physician—younger, educated, intelligent, and articulate—then the decision to forgo or stop treatment is difficult to understand and might be a source of frustration and even anger. Paradoxically, it is because of the similarities between the patient and the physician that “othering,” by dichotomizing, is harder to use as a basis for a response. A decision to forgo treatment might evoke a less emotional response when the otherness of the patient is pronounced in some way: when the patient is older, uneducated, an alcoholic, has a history of mental illness, or is prone to irrational thinking or beliefs. This othering of the patient, through construction of binary categories that exaggerate difference, helps to preserve the sense of the natural order in the physician-patient relationship (Thorne at al., 2004), yet it, too, is problematic.

Human life, especially in the context of cancer, is more likely to be chaotic than ordered into neat categories. It is what lies between the opposites—not just the black and white but all the shades of grey—that is also important and needs to be recognized (Gergen, 2001). Failure to do so leaves many aspects of the patients’, as well as the physicians’, experience poorly understood (Sontag, 1978). For example, our findings indicate that in clinical practice, patients’ autonomy is not an absolute but a finely nuanced concept, respect for which depends on a number of contextual factors, including the perceived curability of the patient’s cancer and the “rationality” of his or her decision about treatment, the patient’s age and family situation, and the stance the patient is prepared to take in relation to treatment. Physicians recognize the patient’s ultimate right to self-determination but might go to great lengths to change a patient’s decision when they consider it “wrong,” although accepting the same decision from another patient as reasonable.

It could be argued that it is because physicians care for their patients that they are reluctant to allow them the autonomy to choose when they perceive the choice as a mistake (van Kellefens, van Baarsen, & van Leeuwen, 2004; Waller, 2001). The liberal notion of individual autonomy (on which the patient’s right to self-determination and the requirement for consent to treatment are based) is in tension with the ethic of care to which some physicians subscribe. The fact that a patient comes to consult a physician means that the physician can inform, advise, recommend, and encourage but cannot insist, demand, or force a patient to accept what medical science has to offer, even when the physician sees the patient’s decision as wrong. As Margalit (2002) suggested in another context, “It is easy to adopt a tolerant attitude toward mistakes made by people to whom we are basically indifferent” (p. 36). Although we would like to think that all actions of cancer specialists are motivated by care and concern for individual patients, the data from our study do not support such a conclusion. Rather, our findings are more in line with Cassell’s (2001) critique of modern medicine generally as increasingly focused on science and technology needed to treat a disease, and its “apparent loss of the ability and desire to care” (p. 104). Oncologists in our study saw patients who declined to follow their advice as a challenge to their scientific authority, expert status, and reputation. Such actions disrupt the expected flow of the physician-patient consultation, demand extra time, and raise questions about the true nature of patients’ autonomy.

When patients accept medical advice, physicians do not question the wisdom of the patients’ decision, nor their competence to make it, but neither do they need to question the wisdom of their own advice or their capacity to provide it. It is only when a patient declines their advice that physicians are made to question patient’s rationality and the fact that factors other than
purely disease-related ones might be at play. Just as important, perhaps, it is that when patients decide not to accept medical advice, physicians might stop to question the appropriateness of the recommendations they had made in a particular case, or their ability to convey essential information in a convincing enough manner. Some, as shown in our findings, might choose detachment as a way of dealing with what they perceive as rejection of their medical expertise. Others might persist, changing strategies and often conscripting family members in their efforts to have the patient accept medical advice. Others still might question their communication and persuasive abilities, feeling that they had failed the patient and that they should have been able to obtain a different outcome.

Perhaps physicians would be less concerned about “failing the patient” if they accepted that failure of the physician to present sufficiently convincing evidence for treatment is seldom the reason patients give for deciding not to have it (Kacen et al., 2005; Verboef & White, 2002). As we have noted in our earlier article (Kacen et al., 2005), patients see their decision as a logical and affirming choice that reflects how they have come to be the people they are at this point in their lives. The decision is not a single cognitive event; rather, it reflects the intentionality of a life that is already living the decision. (p. 114)

This does not negate the need for a careful discussion of medical evidence. Open discussion, during which patients feel free to ask questions and are provided with relevant answers, is essential. However, the patient’s right to decide must be given substance, without the ensuing decision being constructed as irrational or the patient labeled as in some way different or flawed. Accepting that patients make difficult treatment decisions for personally meaningful reasons that go beyond scientific evidence acknowledges them as moral agents. Constructing patients on the basis of difference, and their decisions as irrational refusals of expert medical advice, reduces them to a status of deviants (Sontag, 1978), unable or unwilling to see the benevolent intentions of medical experts. The slowly growing evidence from Australia and Israel (present study), and the Netherlands (van Kleffens & van Leeuwen, 2005) suggests that these issues cross cultural and national boundaries and have obvious implications for clinical practice.

Patients with cancer have to make a series of difficult decisions, including those that relate to treatment. They do so in the light of their life experiences, values and beliefs, priorities, and life goals. Expert information and advice provided by medical specialists is not the only and, sometimes, not the main factor in their decisions. If patients’ treatment decisions are seen in a broader light, as involving more than appraisal of medical evidence, then there is less need to categorize patients and their decisions in black-and-white terms. If there is greater acknowledgement of the patients’ personhood—and the value and belief systems that define the person—then such categorization becomes unnecessary in most cases.

Our findings indicate that physicians recognize the importance of but, for a variety of reasons, find it difficult to engage with the patient’s beliefs or philosophy of life. Time is a crucial factor; physicians’ perceptions of what lies within their legitimate domain of expert practice might be another, yet mutual understanding requires that attentive dialogue include all the factors that are important in the situation. Medical evidence is essential, but so is an understanding of what ultimately matters to a person diagnosed with cancer. Patients who decide to forgo or stop treatment for cancer are making an active decision and are often giving primacy to existential rather than scientific issues (Kacen et al., 2005; van Kleffens & van Leeuwen, 2005). In this context, physicians can help by engaging in broader dialogue with patients and families (or by involving others such as nurses, psychologists, or pastoral workers), and by being prepared to see their expertise and medical evidence not as the whole picture but as one part of a complex and intricate mosaic that is a patient’s life.

References


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