Initiating palliative care conversations: lessons from Jewish bioethics

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What are the ethical responsibilities of the medical staff (doctors, nurses, social workers, and chaplains) regarding the preservation of meaningful life for their patients who are approaching the end of life (EOL)? In particular, what is the staff's ethical responsibility to initiate a conversation with their patient regarding palliative care? By subjecting traditional Jewish teachings to an ethical analysis and then exploring the underlying universal principles, we will suggest a general ethical duty to inform patients of the different care options, especially in a manner that preserves hope. The principle that we can derive from Jewish bioethics teaches that the medical staff has a responsibility to help our patients live in a way that is consistent with how they understand their task or responsibility in life. For some patients, the best way to preserve a meaningful life in which they can fulfill their sense of purpose in the time that remains is to focus on palliation. For this reason, although palliative and supportive care are provided from the time of diagnosis, it is critical we make sure our patients realize that they have the opportunity to make a decision between either pursuing additional active treatments or choosing to focus primarily on palliative therapies to maximize quality of life. The Jewish tradition and our experience in spiritual care suggest the importance of helping patients preserve hope while, simultaneously, honestly acknowledging their situation. Staff members can play a vital role in helping patients make the most of this new period of their lives.

> he period following several unsuccessful attempts at curing a life-threatening illness such as cancer, in which the patient is still relatively high-functioning, can be a very difficult time for patients, their families, and also for the medical staff (doctors, nurses, social workers, and chaplains). What should happen next should the patient undergo another active treatment in the hopes of either a cure or of significantly extending their life, or should the patient consider palliative care only to maximize their quality of life (QOL)? Patients and their families are often focused on active therapies whose goal is cure or significantly extending life; and physicians are often willing to collude in that hope. Palliative care itself includes "aggressive" treatments such as radiation or chemotherapy as well as purely supportive care, and patients and doctors alike often favor aggressive palliative therapies without giving serious consideration to other palliative approaches which would likely be better for the patient and their QOL. Our focus here is on

palliative treatments that have the primary goal and expected outcome of maximizing QOL. If the staff members do not think that any useful nonpalliative treatments remain, how can we best help patients at this critical time?

In such a case, one key question relates to a particular element of truth-telling - do staff members have a duty to tell patients that they do not think cure-oriented treatments are worth pursuing? Historically, doctors often took a paternalistic approach to truth-telling, ie, withholding information in line with their sense of what was best for patients; however, that attitude has changed over the past 50 years in the United States.² At the same time, while the general, ethical, and legal landscape now demands that doctors engage in these kinds of open conversations with patients, many do not for a variety of reasons.³

There is increasing awareness that there cannot be a monolithic analysis of the ethics of truthtelling. Culture, society, and ethnicity, among other factors, including each individual's web of relationships, play a major role in influencing whether the patient wants to be told the truth,² and whether the doctor is inclined or willing to tell that truth.⁴ For this reason, it is important for the doctor to understand the patient's individual circumstances.² In addition, in order to fully understand their own decision-making process in these

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situations, doctors need to consider the influence of their personal backgrounds and the ethical systems from which they operate. These factors weigh heavily in situations such as end of life (EOL) truth-telling or being asked by patients to "do everything" possible. 4-6

Various philosophical or ethical systems have been used to analyze these situations, from both the patient and staff perspectives, by asking what that system's approach would be to address these particular issues.⁷⁻¹³ However, are these approaches helpful for people who do not follow those precise philosophical or ethical systems? Is it possible to draw out the general principles that underlie these approaches, such that any member of any medical staff could develop their own approach to these kinds of situations? That is the methodology employed by several bioethicists discussing this issue 14-15 and the methodology we will employ.

In addition to questions of truth-telling, the medical staff needs to consider some of the other needs they could help address during this transitional period of a patient's life. One study found that these patients need staff members to acknowledge their fears and find a way to balance hope and honesty. 16 Other studies describe the importance of asking about and relating to the patients' spiritual needs at this time to develop an appropriate plan of care. 17

The medical situation

Case 1. "I don't want to die before I'm dead." With these words, Yoav (the patient's name has been changed), a 31-year old cancer patient with a wife, a 3-year-old son, and a one-month-old baby, encapsulated his situation. "I want to be able to live the rest of my life, and I'm afraid that I'm already dead."

Yoav understood that he was not expected to live more than 6 months (retroperitoneal leiomyosarcoma, being treated with adriamycin/ifosfamide), and he wanted to do whatever could be done to help preserve his QOL as much as possible, so that he could enjoy time with his young children, perhaps take a vacation, and finally move into the house that he and his wife had bought just before he became ill. However, he was afraid that the time remaining would contain nothing but unmitigated, overwhelming suffering that would prevent him from really living out the time he had left.

Yoav's fear is our question: How can we - patients, family members, and medical staff - work together to preserve life and stave off death? Yoav was not talking about life and death in the clinical sense, but he was talking about life and death in the experiential sense; ie, preserving a meaningful life and preventing what we could call "death-in-life".

The medical staff generally has a duty to try and preserve life in the clinical sense, but what are the ethical

responsibilities of everyone involved? From the doctors to the patients themselves, what are the ethical responsibilities regarding preserving meaningful life for someone who is approaching death? The answer to that question will have major ramifications for our issues of patientdoctor communication and truth-telling.

Case 2. Miriam (the patient's name has been changed), a 38-year old mother of four, including a toddler, came to our department after the surgeons discovered that her pancreatic adenocarcinoma was inoperable. After 2 weeks during which Miriam and her husband feared she would die imminently, I met with them as her condition was stabilizing and they were beginning to think about moving forward. A switch had been turned in her life, she said, and she was accepting and looking for the way in which her medical condition could turn out to be a blessing. At the same time, their focus was on a cure, while the doctor's ideal focus of care would have been purely palliative.

Our analysis is focused on terminal patients who are not expected to live more than a year for whom there is no curative treatment, only palliative care. It is quite normal for patients to decide to undergo further active treatments in the hopes of a cure or significantly extending life, despite the fact that they have been warned about the likely side effects and the fact that the medical staff does not think any substantial benefit from the treatment will occur. In fact, the medical staff thinks this patient is extremely likely to suffer more than benefit from the treatment. Why, then, do so many of our patients end up undergoing these treatments? Why do they not choose to focus on palliative care, to maintain the best possible QOL for the time that remains? For some patients, it is very important to feel that they are actively doing something, to feel that they are fighting their illness and not giving up. 18 Other patients may prefer not to acknowledge the medical situation. Too often, though, the decision to continue with another non-palliative treatment is actually a non-decision, where patients do not realize they have different options in front of them. ¹⁹ After a patient completes one unsuccessful treatment, they ask what treatment to do next. Unfortunately, many doctors follow the patient's lead. The possibility of no further treatment and focusing on palliating symptoms to enhance one's QOL is not necessarily brought up for discussion, and so it might not be considered. An in-depth conversation about the patient's goals for the time to come is not always

Is this *status quo* ideal acceptable, or in need of change? To look for guidance, we will analyze this situation through the lens of Jewish bioethics.

Jewish bioethics

The basis for Jewish bioethics is the body of halakhic material (legal rulings in specific cases) and aggadic writings (ethical statements or potentially didactic stories) in the Jewish tradition. Brody¹⁴ outlines a challenge in bringing Jewish bioethics to bear on discussions relevant to a wider audience. When faced with a particular medical-ethical dilemma, a rabbinic decisor looks through the legal material to provide the questioner with binding guidance on how to behave in that situation. However, the use of Jewish bioethics to mandate specific behaviors in specific situations only makes sense when writing for an audience of Jews who feel bound by Jewish law. In order to engage with the general Western world of ethics, the Jewish ethicist must use halakhic material as a source for ideas about medical ethics which can be defended independently of their origins". 13(pp265-267) In other words, our interest is in the concepts and principles that can be derived from the Jewish source material and then applied by anyone to their own practice, not in determining a legal ruling for Jews bound by the halakhic system. We are not writing to suggest how to treat religious Jews; we are offering a general ethical argument based on principles derived from sources in the Jewish tradition. It is important to note that Judaism is not univocal, and we can only offer one voice among many.

An ethic of duty

There are important differences between Western and Jewish ethics. Most significantly, we begin by noting this fundamental difference: "the distinction between an ethics whose foundational language is duty, as is true of the Jewish approach, and contrasting that with our common Western ethical approach, whose basis is rights," as stated by the late Benjamin Freedman, Professor of Bioethics at McGill University. 15(p12) In Judaism, one has a duty at all moments in life - whether to society, to family and friends, or to God. Duties, rather than rights, are the central consideration. These duties devolve upon individuals and the collective, even against their will. In the Bible, they begin with Adam and Eve's duty upon creation "to work the land and protect it" (Genesis 2:15). The collective duties expand with the acceptance of the Ten Commandments and the Torah at Mount Sinai, following the Exodus from Egypt.

Making joint use of Western and Jewish approaches can be productive. "Secular bioethics . . . has a great deal to say about procedural questions - who will decide - but relatively less about substantive questions - how to decide;" yet how and what to decide is the almost exclusive focus of Jewish bioethics. In this way, the 2 fields could be highly complementary. 15(p17)

If we narrow our focus from ethics to bioethics, we can consider what our duties are in relation to the Jewish system regarding questions of health. Judaism teaches that there is an obligation to seek healing. The obligation to seek healing finds its source in one of several possible texts in the Jewish tradition: "Just take care for yourself, and take great care of your soul" (Deuteronomy 4:9); "Yet your blood of your soul shall I require of you" (Genesis 9:5); and "Do not stand idly by the blood of your neighbor" together with the presumption that "a person is his own relative," meaning one must treat oneself at least as well as one treats one's neighbor. 13,15[pp142-145] In Judaism, our bodies are not our own, rather they are objects to be held in trust and used well on behalf of their true owner. (For a discussion of the various Jewish positions on whether God is the sole owner of our bodies or if people can also be considered owners, see Genizi.⁹) God gave us the use of our body, but only on the condition that we care for it and seek medical treatment when necessary so that we can use it to fulfill our other duties, however they may be formulated. Here are 2 traditional Jewish formulations:

- Rabbi Moshe Chaim Luzzatto writes that "this, too, is a commandment upon us, to protect our bodies in a fitting manner to enable us to serve our Creator through
- Maimonides writes that "It is impossible to reach completeness of the soul . . . so long as he has pain or strong hunger or thirst or overheating or fierce cold." Therefore, one must strive to treat pain.²¹

The principle is that however one formulates their ultimate duties in life, we have an obligation to enable the fulfillment of that ultimate duty by seeking healing and never intentionally damaging one's own body.

The principle that one's body is held in trust rather than owned seems to be directly opposed to the value of autonomy which is prominent in Western ethics. Nevertheless, one can accept the application of Western ethics in society without fully agreeing with them internally. A great many cultures, or at least individuals, seem actually to also believe in a sense of self-regarding duty. Many cultures believe in the duty to care for one's health for any of a number of possible reasons; ie, "obligations to those who rely upon you or care about your well-being; a belief that one's body is to some degree held in trust or stewardship, whether this be on behalf of God, some ideal that you hold, or some special mission that is yours to accomplish; a duty to your community or tribe, or any entity larger than yourself." 15(p140) Once broadened in this way, the principles derived from the Jewish approach can be relevant to anyone who feels a sense of responsibility to act to preserve one's health for the sake of another or for the sake of being able to accomplish some larger obligatory purpose.

Finally, Judaism expands the circle of duty to seek healing by taking one further step. Not only does each individual have a duty to preserve their own health in order to be able to perform one's other duties in life, but each individual also has a duty to help preserve the health of others. All people have some sense of duty to help preserve the health of others (in certain situations even against their will), so that they can then fulfill their duties in life; including laymen who can help either their parents and family²² or anyone else ("do not stand idly by when your neighbor's blood is at stake"; Leviticus 19:16) and doctors with respect to their patients ("and you shall return it [his health] to him"; Deuteronomy 22:4).

Different people and different cultures have an entirely different sense of what their duties are in life. The principle that we derive from Jewish ethics teaches that we have a duty to help enable others to fulfill their duty of living in a way that is consistent with how they each understand their task or responsibility in life.

Applied ethics

In a situation where, from the medical staff's perspective, the only remaining beneficial treatments are palliative, Western ethics might not be helpful, since ethically the doctor has the right to bring up all forms of palliative care or the right to wait for the patient to ask about it. (We are not addressing the varying legal requirements to have such a conversation. Recent Israeli law, for one, does mandate that the doctor initiate such a conversation.) But with an approach based on duty, the picture becomes clearer. Let us begin by considering the situation from the patient's point of view. Leading Jewish thinkers, in discussing the process of deciding between curative and palliative plans of treatment in cases like ours, argue that the decision should be left to the patient. 23,24(2:74) (See Bleich's dissenting argument 13 and Brody's rebuttal. ^{14[p223]}) This may seem obvious to today's doctors working on the basis of patient autonomy but, in an ethic of duty, this is very surprising. We expect there to be a clear duty, one way or the other. Why is the decision left to the patient?

To answer this question we must carefully define Judaism's duty of living. The Jewish ethic of the duty of living is not precisely to "extend life as much as possible in order to fulfill their duties in life." If that were the case, we would expect the doctors to decide, not the patient. This definition runs the risk of confusing the means with the ends at the EOL. The purpose of the duty of healing or extending life is a means to enable one to fulfill one's duty in life, but it is not the primary

duty itself. At the EOL, extending life is not always the best way to fulfill one's duty. We would like to suggest that Judaism teaches that we each have a responsibility "to maximize one's ability to fulfill one's duties in life". Maximizing one's ability to live life well can differ from extending life. Sometimes, treatments focused on extending life with no hope of curing or mitigating the illness make it harder to fulfill these life duties because of the difficult side effects. For example, if the focus is on doing good deeds, then one may be able to do more good deeds by taking the palliative route and not having to devote most of one's energy to getting through the pain. In this approach, the decision is left to the patient because he and he alone will know what is best and what will enable him to fulfill his duties.

Rabbi M. Feinstein draws a helpful analogy in addressing whether a patient with a fatal illness should undergo a risky procedure that carries a chance of long-term survival but also a chance of immediate death, or forgo the procedure and definitely live but only for a short time. His approach can serve as our paradigm: "Behold, in monetary matters some people spend what little money they have on the chance of a big windfall, even though in the event that it fails they'll lose what little they had. And some people don't want to spend what little they have when there's a chance of losing it all."25 It is good for people to get to continue living their lives in the way that is true to how they had lived their lives until then, with the values and duties which guided them through life. In Freedman's words, "It is rational for dying patients to live their last days as though they are living, rather than dying, in a manner fully consistent with how they have lived their lives up until this point." 15(p280) For some patients, it makes the most sense to do the treatment, even against the doctor's recommendations, because they see their duty in life as being a fighter or a risk-taker, and undergoing a risky procedure or treatment seems right to them. But for other patients, if they understood the full picture, their consistent understanding of their duty in life might tell them to focus on leaving a message for their loved ones, or healing family rifts, or providing a long-term arrangement for their philanthropic concerns. The patients' job is to decide what to do now, based on their over-arching understanding of how to fulfill their duty in life.

Let us return to our original question – what is the staff's duty in such cases? Our duty is to make sure that the patient, and his/her family, knows that there is a decision to be made, and that focusing on palliation is a possibility. By palliation, we mean focusing on maximizing one's QOL. For some people, the way to maximize their ability to fulfill their duties in life would be not to continue with more active treatments but to focus on

palliation. If we do not ensure that they know that the possibility of palliation exists, we might fail to give them the opportunity to make the decision that is best for them.

Thus, our presentation of Jewish ethics argues in favor of the importance of truth-telling as it relates to the presentation of treatment options, because that enables patients to make an informed decision in determining how best to fulfill their duties.

The duties of the medical staff

In order for a patient to best fulfill their duty when they are approaching the EOL, we know that some will choose not to undergo further active treatments. Our first responsibility is to be sensitive to the patient and provide information about this potential choice in a caring and non-threatening way, guided by the patient's willingness to listen. (An exception to this conclusion would be if one had a specific reason to believe that having such a conversation would harm the patient or otherwise make it harder for them to use their remaining time well.) Additionally, sharing this treatment option does not necessitate providing all the details of the medical situation, if the patient does not wish to hear them. Grunfeld et al and Alesi et al outline some of the best practices for having these honest and compassionate conversations. 18,26 The ability to choose is itself of therapeutic value to a patient who might be suffering from feelings of powerlessness. It is guite common for a patient to have the doctor decide, 1 and can be considered an active decision that may reflect the patient's approach to life. Perhaps the worries and regrets related to having to make further decisions would negatively impact the patient's ability to fulfill their other duties. The medical staff needs to make sure the OOL option is presented as a real option and is given serious weight in the conversation rather than just briefly mentioned, as often happens.¹

In these situations, as in all the care that we provide, it is important to get to know the patient as a whole person. The more we know his values, his needs, and what is most important to him, the better we can work with him to find the care plan best suited to the life he is trying to lead. In addition, it can help care providers become more comfortable with providing care even when they feel it is not indicated - "the providers may have missed a reason why there is compensating value in the life of the patient and may become comfortable with providing the care if they understand these compensating values". 14(p17) At all times, palliative approaches to minimizing pain and suffering should be applied, whether they accompany active treatments or stand alone.

Thinking back to Yoav (Case 1), one could imagine that a primary focus on palliative care with a minimum of

side effects would be beneficial for him as a means of best fulfilling his sense of duty for the time that remained. However, we cannot be certain of that fact in a vacuum. Once the options are clearly presented to the patient and his concerns are heard and acknowledged, he can then make the decision that is right for him. And in fact, although he initially opted for a more aggressive treatment course, the basis for his decision was the hope that overall it would result in a better quality of life with his family. In the end, unfortunately, the combination of illness progression and treatment side effects led Yoav to abruptly cease all treatment. Although we would certainly have preferred to have had the opportunity to provide palliative care rather than no care, we hope that his decision to cease treatment was an empowering and dignifying one that enabled him to be true to himself.

For Miriam (Case 2), there was an initial treatment decision to be made. Should she begin receiving more intensive chemotherapy - a 3-drug combination of oxaliplatin, irinotecan and 5-FU (folfirinox) - with a greater chance of extending life, but also the likelihood of much worse side effects? Or should she receive gemcitabine, a standard chemotherapy in advanced pancreatic carcinoma, also an appropriate palliative treatment in her case, a treatment that her body could much more likely withstand? Her doctor explained both options and shared her opinion that the folfirinox combination would be too much for Miriam, leaving her in great suffering. Miriam and Shaya decided on what felt to them like a compromise approach of gemcitabine together with a biological treatment (erlotinib). They had the need to preserve hope for a cure, but were also intentionally entering on a new path of personal and spiritual growth that would have been impossible when dealing with overwhelming side effects. As she started the treatment, Miriam pursued an internal process of partnering with God and freeing herself from the need to feel in control, as had been predominant her whole life.

Practical challenges

It can be difficult to have these conversations. For a patient to consider not pushing on with every last curative treatment available, because that might not be the best way to use the time that remains, he needs to acknowledge the possibility that he has transitioned from the period of unending life to the period of life that is coming to an end. He needs to acknowledge that there might not be a cure, which is very difficult to do. However, being able to acknowledge that fact is infinitely valuable. The knowledge that we will die and that our time here is limited is one of the most important motivations in helping us to live our lives to the fullest, something we should strive to remember throughout our whole lives.²⁷

It may also be difficult to acknowledge death's approach, especially for family members, for fear of appearing religiously unfaithful. 17,27 In addition, questions of faith are often inextricably linked with questions of guilt and duty – is it really alright for me to start preparing for the possibility that my loved one is in the final stages of life?

Overwhelming levels of fear or anger can make it hard for a patient to maximize his ability to live life well, which can be hard to overcome on one's own. Patients report wanting staff to help out by acknowledging their fears.¹⁶ We should sit down and take the time to encourage patients to articulate their fears which, once stated in words, often are not quite as scary as they had seemed. When we enable our patients to let out the full wrath of their anger, we can help weaken the hold of these emotions on their lives. These emotions are entirely natural, and often need a listening ear for the patient to be able to process them so that they are able to put these emotions into perspective and they no longer dominate the patient's

The staff might be concerned that by initiating conversations about palliative care, a patient's sense of hope will be taken away. Hope is a very positive outlook for our patients.³ Preserving hope is also a crucial factor in patients deciding to undergo more aggressive palliative treatments like chemotherapy. 18 However, in our experience, we have seen that it is possible to preserve hope for a miracle while also acting in accordance with the strong likelihood that our patient is in a new period, the period of dying. We cannot dismiss the possibility of a miracle; there are too many stories of people who survived for years against all the doctors' expectations. The key is to reach a balance of hope and reality, so that one can use the time remaining as best as possible. Patients themselves identify balancing hope and honesty as one of the most important things they need from the medical-care team. ¹⁶ In the words of Rabbi Maurice Lamm, Judaism is "deathdefying," not "death-denying." One must do the utmost to preserve life, but not deny that death lies at the end of the road. In his words, "We struggle to preserve life and, failing that, we struggle to preserve humanity, so long as we live". 28(pp135-139)

Case 2. Miriam and her husband did an amazing job of achieving that balance. While preserving their hope that her treatment would lead to her tumor shrinking, they set about maximizing the 3 months they had while Miriam was feeling relatively good to do the things they now found most valuable. She spent a lot of time with her children, took a painting course, and practiced new techniques for mindfulness. Her

husband joined a men's prayer group and found great release in freeing his unceasing inner prayer voice. In Miriam's words, "If I have the strength for something, then I don't want to miss the opportunity." She knew that her opportunities were likely to be limited, and she made the most of that relatively healthier period in fulfilling her sense of duty to personal spiritual growth and to family.

When tests showed that the tumor was still growing, Miriam and Shaya were badly shaken but were committed to finding the way forward. After two more treatments, Miriam's condition began to deteriorate, and she suffered from liver dysfunction and ascites. When I visited, she was mourning her losses. "If only I could just have a normal life." When I reflected back to her the ways that I saw that she was still growing, she was strengthened spiritually. Perhaps she had begun to fear that the opportunities for really living were ending and was comforted to be reminded that, as one door closed, others had opened. The next day she shared with me her new approach. She would no longer be a big planner. She wanted to live in the moment, and she knew how to enjoy the moment despite the suffering.

The next time they saw Miriam's doctor, she explained to them that the only remaining treatment had not shown success in cases like hers and would likely make things worse for Miriam's dignity and QOL. It was a very difficult conversation for Miriam and her husband, but they decided to enter a home-hospice framework. They have enjoyed unending support from friends and family and continue to make the most of their time together.

The end of life

As with any period of life, there are innumerable meaningful ways to live one's life. The EOL is no time to stop living. Jewish tradition suggests a number of goals for the EOL, many of which may be shared by other traditions. Ultimately, it is up to the patient to make the most of the time that remains, but staff (and family, of course) can also help facilitate making the most of this time. The first step is simply recognizing that, although one's physical limitations might be greater and the distractions of pain and perhaps ongoing treatment are present, good things are still possible, as was the case for Miriam. Some personal goals can still be achieved, life can still be celebrated, and hope for a positive future for one's loved ones and for one's own soul can still be thought of as sources of comfort. One's relationship with the divine can still be strengthened. Judaism emphasizes that more good deeds can always be done, and that it is a wonderful time for spiritual growth. Relationships can still be healed, and the pure act of forgiveness, even without reconciliation, can be deeply powerful. Some people choose to follow the lead of Jacob in the Bible, leaving ethical wills, providing

children, grandchildren, and future generations with guidance on how to live their lives, thereby providing a means for this person's values to live on. This can be a time for love and for giving. As the family draws closer to care for their beloved at the end of his life, the degree of love between them can reach new heights and permanently transform the family's relationships.²⁸

Conclusion

The Babylonian Talmud (Tractate Sotah 46b) tells the story of the city of Luz whose residents lived eternally, until the day came, separately for each resident, when the person felt that the time had come for him to leave the city walls and pass away. What was the secret of their longevity? As Rabbi Yitzchak of Karlin explains, "one who is on the path of life need not fear the angel of death".²⁹ May we all be blessed with staying on the path of living our lives, even and especially at the EOL, so that we will live, and not die, our whole lives.

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