

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Supporting the Patient: Caregiving Takes a Village'

Description:

Caregivers can come from many places in a patient's life. They may be a spouse, family member, neighbor or "chosen family". When caring for a cancer patient takes a village, caregivers come together to do what's best for the patient.

Join us as we sit down with Dr. Iris Cohen Fineberg, an oncology social worker and Assistant Professor at Stony Brook University. In this episode, we discuss planned family meetings, communicating with the treatment team, and how the community can provide supportive care to the patient. We invite caregivers, patients and their treatment teams to listen in on this important discussion.

Transcript:

Elissa: Welcome to *The Bloodline with LLS*. I'm Elissa.

Margie: And I'm Margie. Thank you so much for joining us on this episode.

Elissa: Today, we will be speaking to Dr. Iris Cohen Fineberg, an oncology social worker and associated professor at Stonybrook University's School of Social Welfare in New York.

She began her career as a clinician working with patients and families focusing on patients facing stem cell transplantation and palliative care. She also spent time on faculty at the International Observatory on End-of-Life Care at Lancaster University in England.

As a primary investigator on several studies, Dr. Fineberg's research interests are in oncology and palliative and end of life care with particular attention to communication and family conferencing.

Welcome, Dr. Fineberg.

Iris Cohen Fineberg, PhD, MSW, OSW-C: Thank you. It's a pleasure to be here.

Elissa: So, let's start with the definition of a caregiver. I think that most people assume that it's going to be a spouse or close family member in the household, but that's not always the case. Who is considered a caregiver?

Dr. Fineberg: Well, there's no one correct designation of who a caregiver could be. So, it might be a biological family member, like a child or a parent. It could be someone who is attached, like a spouse. But, it really could be anyone who is providing help to someone to manage their life as they navigate through illness.

Elissa: So, when I was going through treatment for acute myeloid leukemia (AML), I was in my 30's and was living with a roommate, but my parents drove into town from four hours away for the weekdays while I was in the hospital, and then the four rounds of consolidation chemo over the next several months. Otherwise, I essentially took care of myself and would occasionally get rides from friends or other family as needed. Would my parents still have been considered long distance caregivers?

Dr. Fineberg: I would say absolutely, yes. In some ways, I think it's also a matter of how, you as the patient view them and how they view themselves. We want to have the patient really guide us in thinking about, who do they see as a caregiver? And caregiving happens in so many different formats and again, there isn't just one right way to think about caregiving. So, you might have someone providing some of the physical care, some of the in-person care, such as helping someone move around if they have difficulty getting up or getting around in their home. As you mentioned, someone giving you rides. That's absolutely something I would consider caregiving.

But, there are so many other forms of caregiving that can be provided remotely. Emotional support to someone, helping them get through the emotional challenges of an illness is part of caregiving. Helping someone to access resources such as financial

assistance or finding support groups, a lot of that these days, especially, can be done virtually. And so, people far away can be helping with that.

Helping someone to navigate the hospital systems and make appointments; that can be often done over the phone. And helping someone with things like paying their bills and navigating websites. Again, that can be done remotely.

So, caregiving has a lot of different forms.

Elissa: Yeah, that's really interesting. There's so many different people in a person's life, right? It can be neighbors or friends or family. And I'm sure I'm not alone that I went through cancer treatment as an adult, essentially living on my own. So, then you have to rely on those people outside of your household to be able to help you with some of these tasks to just get through cancer treatment.

Dr. Fineberg: Absolutely! And, again, I think, it's you, the patient, that decides how you view people in terms of whether you see them as caregivers or not.

Margie: It's literally gathering, as they say, the village together for the support, so that's always nice to know that it's not just one particular person. It can be many other people as long as we feel close and comfortable with that person.

Dr. Fineberg: That's right.

Margie: And Dr. Fineberg, in your research you studied family conferencing. Could you tell us what is that and how is it beneficial for cancer patients?

Dr. Fineberg: Absolutely. So, family conferences, also sometimes called family meetings, are planned meetings of hopefully, the patient and the family members as defined by the patient, and the set of healthcare providers that fit that particular meeting.

It's not that family conferences can only happen once, but we kind of think of each family conference as its own entity, and we think about a specific focus for that family conference.

Oftentimes a family conference, or a family meeting, will be called if, for example, there's a change in the person's condition, or a treatment decision has to be made and there are several options to consider. The family meeting allows the key people involved in this person's care and life to hear the same information at the same time. And the feedback we've learned is that that's really valuable to people. It's not the same thing to hear about it later from someone as to be at the meeting in some way.

And we think of family conferences, as I mentioned, as something planned. So, it's different than if, for example, the doctor happened to walk into the patient's room in the hospital and some family members were sitting at the bedside, and you had a conversation about care. Those are important conversations, but you wouldn't call that a family conference per se because it didn't have the planned component to it.

Part of the importance of the planned component is that when you know what the conference will be about, such as, for example, care planning, you can think about which people are the right people to have involved in the meeting, and you can do your best to make sure that they can be there. And these days, being there can also happen virtually. We use platforms like Zoom or others to include people who might be farther away or unable to physically attend. So, again, we're thinking of these meetings in very creative ways.

Elissa: Now, when you mentioned, the family of the patient's choosing, that's not necessarily blood relatives, correct? It's not necessarily parents or spouse or children. It could be their chosen family, or maybe, could neighbors come in that are very specifically helping through the patient's care? Is that what the case is?

Dr. Fineberg: That is correct. Now we often have a fairly select set come to any specific meeting. So, you're not going to include your whole circle of caregivers

necessarily but again, the ones that are particularly important or relevant for the discussion that is happening at that family conference. And so, it's a select crowd. Again, hopefully, it's the patient determining who that needs to be. There may be occasions where the healthcare team feels certain people are important to include and will have that conversation with the patient, as well. So, it can sometimes be a bit of a negotiation.

Elissa: So, when does this actually take place? You had mentioned that they're going to be during maybe major changes in the treatment. I assume it might take place at also the beginning, so in the initial stages after diagnosis when you're looking at what the treatment is going to be as well?

Dr. Fineberg: I have to start by saying that not everyone has a family conference. I think of family conferences as wonderful care tools, but they're not a tool that is used everywhere or by everyone. So, we can't assume that everyone will encounter a family conference. I encourage families, and I encourage healthcare providers to use family conferences because I think they're very helpful tools for communication.

In an ideal world, we would have them towards the beginning of care, and then, depending on what is needed over time, you would have them on occasion. So, there's no one right set of timing for them or a correct number of times that you have them. But I do find that if we can incorporate them at least, again, at the beginning of care and then at some of the important transition points in care. They're very useful tools because they allow us to do a few things.

First of all, it allows everyone to hear the same information at the same time, and that gives us a chance to also determine if patients and family and caregivers are understanding the information correctly. Have they all received correct information? How have they understood that information, and do we need to provide some clarification or correction to some of the assumptions perhaps that are made. It gives us a chance to see the dynamic between people, and that is always helpful.

Oftentimes social workers are key members of family conferences. They may be the person that organizes the conference or leads the conference, or co-leads the conference, and even as members of the family conference. Again, the social worker will pay special attention to things like the family dynamic and have a chance to get a better understanding of how the patient and family members and caregivers are all interacting. That's very important information for knowing how to provide the best care back.

Elissa: And when you discuss the major changes, I assume those also would include potentially starting palliative care or end of life care, and just some clarification from you, as well, that those are not the same thing.

Dr. Fineberg: Correct, yes. Palliative care is a much broader umbrella of care than end of life, specifically. We like to think of palliative care as actually being introduced, even at the time of diagnosis. And, being used to the degree needed along the trajectory of care. Palliative care is about addressing symptoms and quality of life and making sure that we're addressing symptoms of all kinds, whether they're pain or other types of suffering, and we certainly want to be doing that while we're providing active oncology care.

So that is, as you pointed out, separate from specifically end of life care, though end of life care is, under that umbrella of palliative care.

Elissa: Right.

Margie: Hearing you speak, doctor, brings me back to what I experienced. My sister and I were the caretakers for my mom. And, unfortunately, we did not have a good experience. The last time that we took my mom to the hospital, they basically were going to discharge her with no services, nothing. They just told us, her time is coming soon, and there's nothing that we can do. And I felt such a desperation, unimaginable. My sister just shut down and I started to physically feel the emotions, like my body was reacting to just having to take her home.

Someone came into the room and saw us in that condition and asked us what was wrong, and we explained to them we don't know what to do. And that's when things started getting in motion, where then someone came in and said, "Okay, so this is what we need to do, this is what we need to prepare. And gave us the guidance.

So having said that, I feel that maybe we didn't ask the proper question. When is it the right time for a relative or a family member to ask for these services because I heard you mention that not all institutions offer this. Is it something that the caretaker has to be aware to ask for?

Dr. Fineberg: That's a wonderful question, and I'm so sorry that your family experience was so difficult. I encourage people to ask if their healthcare team uses family conferences, or if perhaps a family conference could be arranged. I think we can advocate for that, and, in most cases, I think the healthcare team will respond positively.

I always encourage patients and families to make sure they connect with a social worker because a social worker, again, is more likely to be familiar with family conferencing, as well as other forms of support for the patient and family. Most people aren't familiar with what social workers do, and so they don't know to ask for that kind of care. And so, I always encourage people to do so, have a chance to meet the social worker and find out from them the kind of care they can be offering the entire family.

It's very inconsistent, unfortunately, how family conferences are used across healthcare, but that makes it all the more important that families do feel that they can ask for this and say that they'd like to have a family conference.

Margie: Thank you. It's good for our patients to hear that they can ask for these services because it's something that's needed and it's going to benefit the patients.

Dr. Fineberg: Yes. I think all tools that help us communicate in the healthcare setting are positive. Communication is a challenge under the best of circumstances, and these are rarely the best of circumstances.

So, we want to be able to use all the tools that help foster open and transparent communication, and that can include as many of the relevant people in that communication.

Margie: Yes.

Elissa: So, speaking of the relevant people, whether it's in family conferencing or just the multiple people in the patient's life who might be helping them get through this, who they might see as a caregiver. How does that work with multiple caregivers? Are they delegated different tasks to do; we mentioned rides or picking up medications or, helping with bills, things like that. How do they all work together to help the patient?

Dr. Fineberg: That's an important question to be asking. There's no one correct answer to that. I think I always start off thinking from the patient perspective. So, if a patient is someone who actively manages their situation, I would want the patient to maybe determine who they want doing the different components of caregiving in their life. And I think we want to remember every person has their strengths and their talents. We want to optimize those.

Some people might be really great at taking care of tasks like picking up medications and taking care of rides. Other people might be better at providing the emotional support. Someone else might be great at navigating the healthcare system and knowing how to make the appointments and navigate, all of the layers of healthcare.

I first start with the patient. If a patient has the desire and the inclination to decide who's doing what in their life, I want the patient to have that control and be able to provide that guidance to the people who are helping. But that isn't always the situation. There are times where caregivers really need to take some of that decision

making about how to divide the roles and components of caregiving. Maybe the patient is too tired, maybe this is just something that they don't want to deal with at that point. So, you have to kind of read that situation.

And then, the caregivers should have a conversation amongst themselves and just make some decisions about let's think about what the best way is to determine which of us does which part so that, again, we're optimizing people's strengths and, also, honoring that each person will have different roles so that there isn't confusion and there are fewer mistakes in helping the patient.

Margie: What if there's a disagreement amongst the caregivers? Sometimes, they all mean well, but there's disagreement within, what type of services or what they're going to help with, or sometimes a disagreement between the patient and the caregiver. What happens then, how can that be resolved?

Dr. Fineberg: Those are difficult situations, not unusual but those can be difficult. We want to think of this as a range of steps in terms of how you deal with a situation like that. We want to start with the most smooth and, hopefully, effective approach to that, which is, again, communication. So, have people talk to each other, try to be honest about why something is important to you. Why is it important to you to take on this part of caregiving. Or why is it important for you not to take on this part of caregiving? Is it something that causes you distress? Is it something that you just feel you can't manage well, and you really want someone else to do it. Or maybe it's something that you really feel strongly about that is meaningful to you, and that's why you do want to do it.

And so, if people can step into that space of a bit more vulnerability to have a really honest discussion with each other about why they do or don't want to do some component of caregiving, that can be helpful.

That doesn't always work. But it's amazing how far that actually can go when people allow those conversations to happen.

After that you move into the realm of further negotiation and compromise. Let's see how we can find a middle ground. Maybe decide that someone does a certain task part of the time, and then it moves to someone else another part of the time.

I think our creativity is helpful here. If people can realize why something is important to someone, maybe we can then think of creative ways to fulfill that in ways that hadn't been thought of before.

And so, if we're there with good intentions and we ask questions and we really try to figure out what's the best scenario for the patient. What helps this conversation sometimes is to bring us back to the focus of this is about the patient, not about us as caregivers.

And so, sometimes that can help people also refocus and let go of some of the things that they're hanging on to in terms of what they want and focus on what's best for the patient.

Elissa: I think with treatment, in particular, there can be certainly disagreements, with maybe an older parent and an adult child, and they might not want their parent to give up on treatment or do a lesser treatment, or not go into a clinical trial at 90 years old. And, I would think that that would be just kind of difficult with these competing views towards cancer care.

Dr. Fineberg: Absolutely. These are sometimes very nuanced situations, and we know they're emotionally very intense for everyone involved. So that overlay is always difficult.

I do think we need to keep in mind though, we want the patient, whenever possible, to be controlling their situation. And, as caregivers, it can be hard to watch that if you are not in agreement with what the patient wants. But that requires us to take an emotional step back and say, "You know what, this is their life, and they need to have the control," in a situation where there's so often very little control.

And it also begs us to ask questions, be curious, and try to really understand from other people's point of view that may be different than ours. And that's often not easy, but it's amazing how powerful that can be.

Margie: Yeah. I experienced it with the role reversal. It was hard for my mother to accept me as the caretaker, making the decisions, so that became a little bit difficult. But once again, it goes back to what you were saying, that having those conversations, giving the whys and showing how it could be a benefit, and just having that open communication helps smooth out those little rough edges. There's always going to be a little bit disagreements here and there, but as long as there's a conversation and we all have the same wellbeing towards the patient.

Dr. Fineberg: I think it's also important to remember the issue of time. That sometimes we can introduce an idea and the person may not be ready to hear it that moment, but if we give them a bit of time to adjust to this new way of something happening, it's amazing how much that giving of time can be helpful. And so, that requires us to also not be so wound up that we jump as soon as someone disagrees, but to say, for example, as a caregiver, "I think it would be helpful if I could be helping with X or Y." And maybe the patient isn't ready for that, but saying, "Please give that some thought. Maybe we can talk about again tomorrow or in a few days."

And giving people a chance to really think about things to kind of settle in with an idea that's difficult for them to settle into can allow for a whole different kind of conversation a little while later. And so, we need to also be patient both with ourselves and with others.

Margie: So true.

Elissa: Yeah. Now one of the main goals of our podcast is to encourage shared decision making between the cancer patient and their care team to develop the best plan of care for the patient, like we've discussed.

How can caregivers really be involved in that shared decision making throughout the treatment?

Dr. Fineberg: So, I would first say as kind of a consistent mantra, I want it to be up to the patient whenever possible to determine how they want caregivers to be involved in that shared decision making. I think the patient should be determining that for the most part.

If the patient certainly wants that, then having a discussion of how to have consistent communication with the healthcare team, what would be most effective? So, in many places, I think it's advisable to determine one caregiver who will be kind of a point of contact for the healthcare team to connect to in discussions about shared decision making. And you want the patient to be either designating that person as the point of contact, or in some way having designated them in the past through some form of advanced directive if the situation is one in which the patient isn't able to communicate at the time.

It's very helpful for the healthcare team often times to have a single point of contact so that they're not trying to talk to 10 different caregivers on 10 different phone calls. That is not a helpful version.

Elissa: Right,

Dr. Fineberg: Right. And so, if we have someone who's designated as the contact person and there's communication between the patient, the healthcare team, and that person early on saying, "This is someone who wants to be kept in the loop on changes in care, or in decision making, throughout the time." That way you've communicated to the healthcare team what the expectation is and what the desire is. And that way that person can be looped in along the trajectory of care more consistently.

Elissa: That sounds, just really good to have that primary point of contact for the treatment team. And for our final question today, on our patient podcast homepage,



we have a quote that says, "After diagnosis comes hope." What would you say to caregivers to give them hope after a loved one's diagnosis of cancer?

Dr. Fineberg: We know that cancer diagnosis is painful and difficult and, at the same time, what we know is that it is profoundly unpredictable. We don't know what kind of experience with cancer any one individual is going to have. We use statistics and past experiences to guide our thinking about what to expect, but in truth, we don't ever know what one individual's situation is going to be.

First of all, we always want to have hope. And what we want to keep in mind is that what we hope for will change over the course of the illness. Oftentimes, we only think of hope as hoping for a cure, but we can be hoping for lots of other elements, such as someone being pain free or someone being free of suffering of all kinds, whether that's physical or emotional.

Even if someone is at the point where cure is no longer a goal that we know is attainable, that doesn't mean that we can't have hope. But what we do is we adjust what it is that we're hoping for. Things like quality time with family or hoping for an opportunity to do something that's meaningful for that patient, to have an experience or an event that's meaningful and joyful for them. And so, we want to be thinking of hope as something really fluid and flexible.

Elissa: Yeah, I really love that. Well, thank you so much, Dr. Fineberg, for joining us today, and sharing all about family conferencing and all the different types of caregiving that a patient may be able to get for themselves. We hope that our caregivers and patients listening will be able to have better communication with their treatment team, and really have that better experience with their team and their caregivers.

Margie: Yes, thank you, doctor.



Dr. Fineberg: Thank you. It's really been a pleasure and an honor to speak with you today.

Elissa: And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families. Did you know that you can get more involved with *The Bloodline* podcast? Be sure to check out our Subscriber Lounge where you can gain access to exclusive content, discuss episodes with other listeners, make suggestions for future topics, or share your story to potentially be featured as a future guest.

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