

Palliative Social Work: Caring for Seriously Ill Persons

Transcript of Video



Video

https://youtu.be/Y7ltLsmRt_k



Resource Guide

<https://tinyurl.com/rhw5v5p>

0:00 Dana Ribeiro Miller My name is Dana Ribeiro Miller. I'm an inpatient palliative care social worker. We created this video in the hopes of helping students become exposed to palliative care and understand the many ways in which they can intersect with the field and join this ever-growing opportunity in social work to impact change. Thank you for watching.

I think that palliative care is a fast growing subspecialty of social work that is really at the forefront of the intersection between health care and social work and there are more opportunities for social workers in this moment to work in palliative care in a variety of settings. Palliative care is changing the way that medicine looks at and handles patients and their families. At the same time as the technological abilities of healthcare are expanding and changing and people are able to live longer than ever before and we're able to sustain life longer than ever before. And that comes with many benefits, but it also causes many hard decisions or potentially difficult choices for patients and families. And palliative social workers have the opportunity to impact those choices and help advocate and create change.

1:24 Jim Palmer: I'm Jim Palmer. I'm a licensed clinical social worker. I currently work in a hospital-based palliative care program. To me, we are not simply invited to care for the patient's physical body, and not strictly asked to care for their medical issues. We are being invited potentially to care for the total person and the total essence and being of who they are. And to me that necessitates full disciplinary, interdisciplinary, care and support and expertise.

2:02 Lilian Espinoza: My name is Lillian Espinoza. I am a licensed clinical social worker. I have an advanced certificate in hospice and palliative care. I am also the co-founder of the Palliative Care Service at a community hospital that services adults and mostly geriatric population. The community hospital that I work in is very culturally diverse. We service adults and mostly geriatric population. I provide psychosocial assessments. I provide education for patients about their

treatment options. I am an advocate for them, advocating ensuring that they understand that the right for treatment, that they understand the treatment options. I am an advocate ensuring that they have the right for self-autonomy, the right for self-determination. I am a member of the Ethics Committee as well.

3:02 Marianne Muzic-Lucenti: My name is Marianne Muzic-Lucenti. I'm a licensed clinical social worker and an advanced palliative hospice social worker. I work in a pediatric skilled nursing facility that provides medical management, skilled nursing services, rehab services, and also provides long-term care to our medically-complex and medically-fragile children in the Tri-State area. My specific role at this facility is to manage the Palliative Care Program. As manager of the Palliative Care Program, I'm responsible for working with families, providing them ongoing support for family and child, working with the interdisciplinary team, providing them with the education support they need to do best practice.

3:50 Michelle Charles: So, I'm Michelle Charles. I am a licensed Master's level social worker, and I am an oncology social worker in an inpatient hospital setting. And with that comes quite a bit of palliative and end-of-life care. I work with individuals who have cancer and they are all across the spectrum, really, with their disease trajectories. So, some people are at diagnosis, some people are kind of somewhere in the middle and expecting cure, and then some folks tend to be at end of life.

4:24 Jeanine Sanderoff: My name is Jeanine Sanderoff. I am a LMSW in the State of New York, and I have a post-master's certificate in palliative and end-of-life care. I work in a hospital setting. I work in a department of home care where we have begun a palliative care initiative. I'm part of a team. A team that consists of nurses, physical therapists, occupational therapists, speech therapists, sometimes nutritional counseling is also available, and of course I'm the social worker on the team.

4:57 Adam Schoenfarber: My name is Adam Schoenfarber. I'm a social work team manager and I work in hospice and palliative care, specifically in home-based hospice programs. The majority of my work is with people that are really in the last six months of their life, but often the last days or hours of their life.

5:13 Nicole Harrison: I'm Nicole Harrison. I'm a licensed social worker and administrator at a dialysis center here in Manhattan. I work with patients who have end-stage renal disease. Some have acute kidney failure. Essentially their kidneys have failed and they have to come to treatment three times a week. So a huge part of what we have is management skills for these patients, it's a lot of empathy, trying to be where they're at, helping them through the process. We do individual counselling and support groups. The most rewarding thing about palliative care is the richness that it brings to your life. You have an opportunity to be there at a very critical moment in a patient's life.

5:55 Terry Altilio: I'm Terry Altilio and I am a palliative social worker currently working in a hospital. On a day-to-day basis I work with patients and families who are in hospital. We work with

patients and families who are outpatient. I'm a teacher and I'm the co-editor of The Oxford Textbook of Palliative Social Work. So I have a lot of different ways that I interface with social work and palliative care. The most rewarding part of the setting that I work in has to do with meeting patients and families of all different cultures with all different diagnoses, all different ages, who bring to the circumstance of illness enormous strength, as well as enormous challenges and ways of viewing the world that you wouldn't necessarily be privileged to hear about.

6:42 Dana Ribeiro Miller: health care social workers, the possibilities for where you intersect with patients and families are endless. But as patients and families live longer lives, as medicine becomes more complex, it is not uncommon for social workers in a variety of settings to encounter somebody who is living with serious or life-limiting illness or maybe approaching the end of their life. And it's really important to have an understanding of primary palliative care skills, what palliative care is, and how you as a social worker can adapt change and help those patients and families.

7:12 Lilian Espinoza: Because palliative care is not only for end of life, it can be at the beginning of a diagnosis, during the middle of diagnosis, during a person that has a life-threatening illness. We may be able to see this patient in an inpatient setting, and their families, at any point in their illness.

7:31 Dana Ribeiro Miller: In social work we talk a lot about intersections or the spaces where the micro and the macro meet, and healthcare really sits at that nexus. You have all of the macro level systems and issues that affect people's lives from policy, from how we get access to healthcare, from who gets access to healthcare. And you have all of the personal things we see in clinical social work, in terms of real time impacts of behaviors and experiences on patients and families. And so anywhere you work in healthcare social work, anywhere you work in social work, having a general understanding of palliative care and how it can help your patients and families is incredibly important.

8:08 Michelle Charles: I find it really rewarding because you tend to find people who are just really at the worst part of their lives, you know, and to be able to support someone who is really just like totally thrown by their diagnosis, totally thrown by all these strange things that are happening to them, all these medical interventions that are happening to them, is really kind of like of gift. You get to meet people who are really in quite a reflective space in their lives and they tend to be a lot more insightful than they ever imagined. I think one of the most rewarding things for me is like meeting someone who says to me that they've never been to therapy before or they were never interested in any kind of counseling and they're able to kind of just really open up quite beautifully about what their life has meant to them and you know what the people around them mean to them.

9:04 Dana Ribeiro Miller: The three big things I think palliative care is helpful with, and I think healthcare in general, can open up the conversations around, is: 1) pain and symptom management. While you walk this journey of illness, and all of the poking and prodding that comes with it, how can we keep you as comfortable as you can be. 2) Is thinking about the potential

decisions that may be coming down the road, thinking about where your illness intersects with your life, where the medical possibilities intersect with your life, and helping you make decisions that make sense, both medically possible and personally possible. Because a lot of times in healthcare we talk about what's medically possible but that's not what's possible for every person. And the last thing we do is try to help shape and put together for patients and families those plans in a way that everyone on their team, both in their life and in their healthcare life, knows and understands, so you don't get asked repeatedly the same questions over and over. The opportunity to advocate as a palliative care social worker is everywhere in healthcare. You don't have to be on a specialty-trained team I think to impact patient care.

10:07 Terry Altilio: What I have learned is that the way we guide patients, the words we use, sometimes it can be a conversation of 30 seconds and you have said something that touches the heart and mind of a person in a way that you would not do if you spent hours with him. And that has to do with listening, the ability to have long-term relationships with some of our patients and families, first of all points to the fact that we're not taking care of patients who are always dying. Some of these patients are living for years with life-threatening illness. We know that's going to be the circumstance of many people and families in the future.

10:45 Dana Ribeiro Miller: So I work on a large inpatient palliative care team. I work with doctors, nurse practitioners, other social workers, chaplains. Every day is different and exciting. We work in different dyads and triads. Sometimes with a doctor, sometimes with a nurse practitioner, sometimes just by myself. We're meeting families, assessing patients for pain and symptoms, we're counseling them, we're guiding them through decision making. Sometimes, I'm not even working with the patients and families and we're working with medical teams and doctors to help shape what's important in conversations and decision making, to help them understand the humanity behind the medicine, the humanity behind the person in the bed, and why we need to make decisions or have conversations differently.

11:30 Marianne Muzic-Lucenti: Palliative care cannot consist of only one practitioner. It is formulated from a multidisciplinary perspective and each discipline brings their own gifts and values and skill sets to the program and enriches the experience the family is going to have. Sometimes the family may come up with a decision that they feel is appropriate, but the medical team may think otherwise. So trying to navigate between both systems as a social worker can be challenging but rewarding at the same time when the communication is successful and the outcome is one that is beneficial to the patient and family.

12:17 Nicole Harrison: What really helps us do the job better is working with the team, is being able to see it from different points of view. What a patient may tell me, it's maybe something that's different than what they tell the patient care technician or they just may be comfortable with someone else, and really just seeing it and tackling their needs from different angles.

12:36 Jim Palmer: So the benefits of working with an interdisciplinary team are incredibly rewarding and satisfying in that we are able to treat the totality of the person who has the serious illness. Everything from the physical manifestation of their symptoms and their pain, to the

existential pain and suffering that they potentially are dealing with, as they journey with serious illness with both the diagnosis and the prognosis of serious illness.

13:03 Lilian Espinoza: As a social worker, my work is very impactful. I am able to use all the skills that I went to school for. Ensuring that their wishes are heard. Ensuring that their care is holistic, meaning that I am the person that makes sure that I am the bridge between them and their family, the bridge and facilitator in communication between them, their family, and the bigger interdisciplinary team.

13:34 Adam Schoenfarber The work is enormously intellectually challenging. It requires that you think on your feet. It requires that you are creative. It requires that you are optimistic and that you're excited about all those things.

13:48 Nicole Harrison I never go in knowing what my day is going to bring. One day I can have a crisis another day it can be completely mundane, but I just never know and it always keeps me guessing. There are some ethical dilemmas, especially when it comes to end of life with our patients, whether or not they even need to continue to be on dialysis, and that's a huge decision that we work through as a team and with the patient to figure out what is in their best need. In dialysis, we're fortunate enough to be able to sometimes form long-term relationships with our patients.

14:18 Michelle Charles: I think what's great about palliative care is that it really calls on all of your skills as a social worker, so you get to be a counselor, right, because so much of what the need is going to be for people is this opportunity to reflect, this opportunity to, you know sometimes they can't talk to their families about the extent of their pain, because they're afraid of scaring them. So, yeah, you get to do the counselling bit. And then there's just so many concrete needs that come up for people, both at end of life and while they're going through chronic illness. So you've got to really be a resource for people and, yeah, you get to just wear so many hats at the same time.

15:05 Jeanine Sanderoff: What I find rewarding in my care setting is that I am never bored and that I love going to people's houses. I love meeting people on their own turf. I love learning about families and people and who they are. What is happening to them at this point. And, basically trying to be of assistance. Because when I meet people on home care, it's not the highlight of their life. They're usually very, very sick. And it's an honor to be invited into their home. Most people have never met a social worker before. They think I'm either going to put them in a nursing home or take away their kids. And I get to show them that there's a whole dynamic use of social work practice out there to assist people with whatever their situations are at the moment. I talk with people, "What do you see for yourself down the road? Has a doctor spoken to you about anything? Is there anything you want to ask the doctor that you haven't asked?"

16:15 Marianne Muzic-Lucenti: The most rewarding aspects of this work that I do as a pediatric social worker is making, developing, that connection with the family and nurturing that bond. For some of our families it could be a two-week relationship. For some of our other families, it could take years. And working with the family and understanding what their wishes are specifically for

their child. So, as a pediatric palliative social worker, my scope of practice varies from management skills to also clinical skills working with families and patients on a daily basis. So, from a managerial perspective, that involves policy revisions, involvement in different communities, committees. From a clinical perspective that work varies from day to day. We deal with a lot of anticipatory grief responses, families in state of crisis, how to work with a family at end of life, what are their expectations of that.

17:29 Jim Palmer: To me the reward of being a palliative care social worker is that I am meeting fellow human beings in some of their greatest moments of need. Times when they are at their most vulnerable. They are their most shaken to their core and I am there with them, journeying with them to the best of my ability to support them through some of the most difficult moments in their life.

17:57 Terry Altilio: It's amazingly profound to be able to walk that journey with a family and a patient as they work with serious illness, as they get better, as they get worse. What that all means to them. Palliative care is about continuity through transitions and trying to build with families and patients what we sometimes call non-abandonment. That we stay with them, or somebody stays with them, throughout the journey of the illness rather than having consistently new beginnings. I would tell them to listen and discover what makes this person a person. Listen and discover their personhood, because after all is said and done, that's what illness is, is in a person. And sometimes what happens is we get so lost in the illness, and the pain, and all different aspects of the illness, that we forget to discover who the person is in the bed. So that's what I would suggest to them. That they listen and look, look around the room. See what you see that helps you to know what this person has brought to this experience. So listening is really, really important. And listening on many levels. The ability to have long-term relationships with some of our patients and families, first of all points to the fact that we're not taking care of patients who are always dying. Some of these patients are living for years with life-threatening illness. We know that's going to be the circumstance of many people and families in the future.

19:30 Adam Schoenfarber: I get to see these professionals just work magic with families. Just create these moments of compassion and empathy and healing that I I didn't know that that existed.

19:42 Marianne Muzic-Lucenti: There's a lot of people who still think that the field is taboo or they have a lot of trepidation about palliative care and my mission in life is really to demystify that and have families understand that palliative care is not for children that are actively dying, but it's for children with any kind of chronically medically complex condition to ensure that they live each day to the fullest.

20:10 Jim Palmer: That future I believe is to move palliative care further and further upstream, as we describe it, in the medical system. Currently, at my place of employment, we now have a social worker who is embedded in the primary medicine department and the beautiful opportunities with that position is that patients and families are being exposed to palliative care earlier and earlier in

their trajectory of illness so that they are more and more familiar with all the benefits and rewards of palliative care.

20:44 Nicole Harrison: A way to start in palliative care is to really think outside the box. I think there are a lot of different opportunities out there that just aren't in hospital settings. Seek out internships and mentors and other people in the field. I think that's the best way to get into this type of work.

21:04 Jim Palmer My advice would be to take heed of what I was offered when I was an MSW student and that was to expand my vision of who I wanted to be as a social worker and to consider other opportunities. And that might include taking coursework that is related to palliative care, that might include volunteering in hospice agencies. Volunteers are crucial to hospice care and there are so many opportunities to step into this work early. If you have an interest in healthcare-related social work, I think that palliative care is the most rich and rewarding and challenging areas of health-care related social work.

21:54 Adam Schoenfarber: There are always conversations on Twitter happening around this, so you can use the hashtag HPM or end-of-life care. And “Ask Me Anything” on Reddit around providers and patients just exposing yourself to this.

22:11 Dana Ribeiro Miller: Palliative care as a field is not brand new. However, the need for palliative care is growing and changing every single day. Healthcare is pushing outside the walls of the hospital into the community. We are meeting patients and families with serious illness, in ideal times, at the time of diagnosis. And so that creates a need for a much larger body of people who are trained to do this work. And so, there's become a need to have everyone in healthcare social work have primary palliative social work skills, and then for those who have a passion beyond that, to develop subspecialty training in palliative care. I think it would be important to utilize your field education time as a time of experimentation to work in different settings and see what that feels like. There's a variety of professional organizations, like the Social Work Hospice and Palliative Care Network, where you can attend conferences and join message boards and talk to other social workers who are doing this work and get a sense of the richness of it, and if that feels like something you could do in your daily life.

I worried when I chose healthcare social work or that I was neglecting some core social work values that were important to me about larger social change, about helping people at the margins, about being an advocate. And, when I look at palliative social work I'm constantly amazed every single day. You know I started the field hoping I could change one patient or one family's experience. But by being present, by participating, by working in an interdisciplinary way with doctors, I get to help change the way medical professionals think about patients and families and that creates larger social change and culture change, and that has the larger impact I went in the field to hope to achieve.