The Human Side of Cancer Care: Wisdom from Patients and Families

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Abstract Summary

- In oncology social work, we are with patients at moments when their lives can be profoundly upended by three simple yet powerful words: “you have cancer.” It is in these vulnerable times, from diagnosis through treatment and beyond, that the truths of what it means to live fully often emerge. This presentation explores the human side of cancer care through the lessons patients and families have offered, highlighting fear, resilience, humor, authentic connection, and remarkable strength. Bearing witness to these lived experiences reveals how individuals facing life changing diagnoses often become life’s greatest teachers. Their stories illuminate essential elements of a meaningful life, including courage, genuineness, intentionality, and the ability to find purpose even in moments of uncertainty. Grounded in the psychosocial oncology tradition, this session draws on insights from Jimmie Holland’s The Human Side of Cancer and William Breitbart’s meaning-centered psychotherapy, highlighting how clinicians can learn from patients’ wisdom about living fully and intentionally. By sharing these lessons, this presentation aims to honor the individuals behind the diagnosis and demonstrate the profound impact patient narratives have on the professionals who walk alongside them. Attendees will leave with both reflective insight and practical approaches for integrating these lessons into clinical practice, supporting patients and families through complex emotional and existential challenges.

Body

- In oncology social work, we are with patients at moments when their lives can be profoundly upended by three simple yet powerful words: “you have cancer.” It is in these vulnerable times, from diagnosis through treatment and beyond, that the truths of what it means to live fully often emerge. This presentation explores the human side of cancer care through the lessons patients and families have offered, highlighting fear, resilience, humor, authentic connection, and remarkable strength. Bearing witness to these lived experiences reveals how individuals facing life changing diagnoses often become life’s greatest teachers. Their stories illuminate essential elements of a meaningful life, including courage, genuineness, intentionality, and the ability to find purpose even in moments of uncertainty. Grounded in the psychosocial oncology tradition, this session draws on insights from Jimmie Holland’s The Human Side of Cancer and William Breitbart’s meaning-centered psychotherapy, highlighting how clinicians can learn from patients’ wisdom about living fully and intentionally. By sharing these lessons, this presentation aims to honor the individuals behind the diagnosis and demonstrate the profound impact patient narratives have on the professionals who walk alongside them. Attendees will leave with both reflective insight and practical approaches for integrating these lessons into clinical practice, supporting patients and families through complex emotional and existential challenges. Following this presentation, attendees will: 1. Enhance understanding of the lived experience of patients and families of patients and families to better integrate emotional, social, and cultural needs into cancer care. 2 Strengthen communication and empathy skills by learning from patient and caregiver narratives about what truly supports them throughout the cancer care continuum. 3. Emphasize the importance of frequent check-ins to assess patients' and families' understanding of illness, prognosis and care preferences. In oncology social work, we are with patients at moments when their lives can be profoundly upended by three simple yet powerful words: “you have cancer.” It is in these vulnerable times, from diagnosis through treatment and beyond, that the truths of what it means to live fully often emerge. This presentation explores the human side of cancer care through the lessons patients and families have offered, highlighting fear, resilience, humor, authentic connection, and remarkable strength. Bearing witness to these lived experiences reveals how individuals facing life changing diagnoses often become life’s greatest teachers. Their stories illuminate essential elements of a meaningful life, including courage, genuineness, intentionality, and the ability to find purpose even in moments of uncertainty. Grounded in the psychosocial oncology tradition, this session draws on insights from Jimmie Holland’s The Human Side of Cancer and William Breitbart’s meaning-centered psychotherapy, highlighting how clinicians can learn from patients’ wisdom about living fully and intentionally. By sharing these lessons, this presentation aims to honor the individuals behind the diagnosis and demonstrate the profound impact patient narratives have on the professionals who walk alongside them. Attendees will leave with both reflective insight and practical approaches for integrating these lessons into clinical practice, supporting patients and families through complex emotional and existential challenges.

Learning Objectives

- Enhance understanding of the lived experience of patients and families of patients and families to better integrate emotional, social, and cultural needs into cancer care.
- Strengthen communication and empathy skills by learning from patient and caregiver narratives about what truly supports them throughout the cancer care continuum.
- Emphasize the importance of frequent check-ins to assess patients' and families' understanding of illness, prognosis and care preferences.

Lesson: Financial toxicity goes well beyond assessing tumor burden.

- “The longer I am alive, the more I am putting my family in debt.” – 49 year old male diagnosed with rare form of stomach cancer with significant concerns about medical debt he would leave his family after his passing.
    - Diving deeper: The financial impacts of having a cancer diagnosis is not just about “high medical bills.” Instead it, is the ***cumulative strain***: insurance costs, lost wages, caregiver burden, copays, transportation/lodging costs, medication costs and so much more. Financial strain may lead to delayed refills, skipping medications, avoiding recommended imaging or supportive cares because of ***cost concerns***; all of which may be done ***without consulting with the medical team***.
        - Challenge: Having a ***cancer diagnosis is a chronic condition*** which can result in reaching your deductible early on in the year; year after year.
        - Opportunity: Have conversations with patients and their loved ones about the financial impacts ***early on*** and ***throughout treatment*** helps to encourage conversations with health care providers and seek resources to help aid them in making decisions about their care.

Lesson: Cancer Care Decisions Deeply Rooted in Relationships

- “If it wasn’t for her [referring to his wife], I would have never done any of this.” -40 year old male with esophageal cancer who had esophagectomy and lasting side effects.
- Diving Deeper: There are many factors that influence the decisions people make about their cancer care. Patients may choose to ***pursue, continue*** and perhaps even ***escalate*** their ***treatment because of their roles*** as parents or caregivers. Some patients will endure significant side effects, prolonged hospitalizations, or diminished quality of life because even the idea of stopping treatments would be considered giving up on their loved ones, or not fighting hard enough to be with their loved ones.
- Challenge: People’s roles in their families are often ***complex, powerful and intertwined*** with their sense of who they are and how they fit into this world.
- Opportunity: In oncology care, it is essential to recognize that **decisions are often relational** and to make space for patients to navigate their reality with honesty and support. ***Open the door*** to have conversations about values, fears, and expectations- not just for the ***patient but their loved ones as well.***

Lesson: End-of-Life Conversations Are Often Left Unspoken or Delayed

- "I am doing treatment because I don't want to have him [referring to her husband] lose another wife to cancer." – 65 year old female diagnosed with stage IV colon cancer.
- Diving Deeper: Often times, patients don't discuss end-of-life matters and their preferences/values about the care they want and don't want with their loved ones until ***later on in the disease process or when a crisis arises***. Sometimes, the avoidance isn't because of fear of death but instead stems from how individuals define hope. For some, defining hope is connected to continuing with treatment, maintaining a sense of "normalcy" or "keeping all options on the table." When the conversation focuses on end-of-life, it ***may feel restrictive*** without the ability to "explore all options."
- Challenge: ***Family dynamics*** can significantly ***impact*** how ***end-of-life conversations*** are addressed. Caregivers and loved ones may ask providers "not to tell the patient" about their prognosis which can create ethical dilemmas.
- Opportunity: As workers in the field, it is essential to open the door for end-of-life conversations with ***compassion and curiosity early on in the disease process***. By providing patients [and their loved ones] with informed and accurate information, it ***empowers individuals*** to make decisions that align with their goals, dreams, trade-offs and medical preferences.

Lesson: Caregivers Deserve a Spot at the Table

- "He had been healthy his whole life, rarely went to the hospital and then all of a sudden it all changed overnight. – 67 year old female caring for her 76 year old husband with Multiple Myeloma.
- Diving Deeper: Often overnight, with ***little to no training***, people become caregivers to a spouse, sibling, child, parent, or close friend with a complex medical diagnosis. This circumstance often distinctly divides your life into two halves; before cancer and after diagnosis. ***Caregivers wear many "hats"*** and serve as the patient's care coordinator, hands-on provider [i.e. helping with bathing, wound care, feeding, medication administration], emotional supporter, medical interpreter, advocate, surrogate decision maker, financial coordinator and so much more. Bottom line, when supporting the caregivers patients have better outcomes, improved quality of life and fewer unexpected hospitalizations/emergency room visits, etc.
- Challenges: ***Patient autonomy*** and ***privacy*** are paramount in the health care setting. A patient may choose not to have their loved one included in the appointments for various reasons. ***Role ambiguity*** can lead to confusion about authority; especially true if patient and caregiver disagree about goals of care. In addition, ***time constraints*** may make it impossible for a caregiver to attend a loved ones appointments and speak directly with the medical team.
- Opportunity: Cancer treatment and care isn't confined to the four walls of an infusion room or operating table. It extends much further into the homes where the patients reside, day in and day out. Take time to sit down with caregivers to show your ***appreciation and value*** what they bring to the table. With patient consent, provide caregivers with the supports and resources they need to be successful in their roles; ***individualized support*** is key.

Lesson: Dealing with a Cancer Diagnosis Often Involves Navigating Complex Systems

- Diving Deeper: When patients are diagnosed with cancer, they are often ***thrust into a medical world*** that may be ***unfamiliar*** to them. Patients have ongoing appointments where they are provided insight on their disease and treatment plans using terms and words that are ***overwhelming***. In addition, patients may have to deal with insurance denials, delays and billing disputes. Having to navigate these complex systems is incredibly challenging especially when the ***physical effects of treatment*** [i.e. nausea, chemo brain, fatigue, pain, etc.] are ***added in***.
- Challenge: Cancer patients often have to weave their way through different domains of care to get their needs met. Care may be ***disjointed*** where a patient meets with several providers perhaps at different facilities which can easily become frustrating. Different hospitals and clinics may have ***different electronic record software systems*** causing patients to ***repeat their history*** and be the messenger between the two entities.
- Opportunity: As healthcare professionals, take time to ***be pre-emptive*** for your patients. This may include: proactively reaching out to different disciplines to ***ensure continuity of care***, ensure the patient understands their plan of care and contacts on who they should reach out to with questions or urgent concerns, ***close the loop*** on referrals/tests/orders to make sure it has been completed, and incorporate supportive care resources [I.e. palliative care, nutrition, chaplain, pain management, etc.] early on during treatment. With effective care coordination, it can lead to higher levels of patient trust and satisfaction, smoother transitions and long-term follow-up, improved access to the ***right services at the right time***, reduced emotional stress and more.

Lesson: Conflicting Emotions Can & Do Exist

- Diving Deeper: Having a cancer diagnosis can threaten the very foundation you walk on. During one’s journey, people may feel a ***range of emotions*** from anger to gratitude, happiness to sadness, guilty to relief, uncertainty to hopeful. Emotions ***may not occur in a linear fashion*** and can be best described as emotional layering. For example, a patient may be relieved treatment is working, worried about the disease spreading [or recurring] and exhaustion when thinking about how hard treatment has been.
- Challenge: ***Societal expectations*** on how people should feel and think during treatment which adds an extra layer of pressure. One such norm is the idea of “staying positive”, or other variations such as “stay strong”, “you got this” has a way of demeaning what someone is really experiencing. ***Gender differences and cultural values*** also can shape how people feel and express their emotions.
- Opportunity: As providers in the field, it is important to validate “both/and thinking” [I feel hopeful and am anxious]; create opportunities for ***meaning making*** without forcing one emotion over the other; ask ***open-ended questions*** to allow for in-depth answers and utilize supportive resources proactively instead of reactive.

Lesson: Serious Illness Can Impact Sense of Meaning or Purpose

- Diving Deeper: With a cancer diagnosis, there are many factors that are beyond your control. ***Feeling out of control*** can lead to feelings of hopelessness, discord, and detachment from people and things that bring us meaning and purpose. Meaning-Centered Psychotherapy, developed by William S. Breitbart, reinforces that ***meaning is not dependent on health, outcomes or control***. Instead, it shifts the focus to find ***purpose, peace and connection*** with others despite living with a serious illness.
- Challenge: Having a sense of purpose or meaning can be closely connected with one's ***spiritual, religious and/or cultural beliefs and values***. Finding ***meaning is deeply personal*** and some patients may choose to focus on symptom management alone.
- Opportunity: ***Assess*** in the beginning what is ***important to a patient*** and what helps them get through challenging days [or what has helped them in the past]. Aim to clarify and ***understand patients' values in the present moment***. Avoid trying to bypass distress and be willing to ***sit in silence and discomfort***. Provide reassurance that meaning is not static and can change over time. Incorporate legacy making activities for patients and their loved ones, when appropriate.

Lesson: The Power of True Human Connection Cannot Be Underestimated

- Diving Deeper: Human connection plays a significant role in helping patients to navigate the complexities of a cancer diagnosis. Cancer can ***both strengthen and strain a relationship***. Some relationships/friendships may experience connections on a deeper level through vulnerability. Other relationships/friendships may experience tension due to discomfort, avoidance or lack of understanding.
- Challenge: ***Not all patients*** who are impacted by cancer have a ***reliable support system***. Cancer can intensify existing family conflict or unresolved trauma.
- Opportunity: As professionals in the field, we serve as key facilitators ***linking patients*** to community resources, peer groups, organizations to foster connection. ***Don't assume*** that all individuals have a healthy support system or one at all. When patients do have a healthy support system, name and validate what support is helping.

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