

Chronic Sorrow in Stage 4 Cancer: A Spiritual Challenge

Journal of Patient Experience
Volume 11: 1-3
© The Author(s) 2024
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/23743735241241953
journals.sagepub.com/home/jpx



Annette M Lane, RN, PhD¹ 

Abstract

Living with Stage 4 cancer impacts how individuals conceptualize themselves and how they conduct their everyday lives. Within this synopsis, I describe my experiences living with progressing Stage 4 breast cancer. The construct of chronic sorrow is applied to my experiences. I suggest that grief and chronic sorrow are largely spiritual issues and give examples of my spiritual practices. Finally, recommendations are offered for healthcare professionals.

Keywords

cancer, clinician–patient relationship, spiritual/integrative care, challenges

Introduction to the Issue

Chronic sorrow, an appropriate response to major changes in life, may be misunderstood or even pathologized.^{1,2} Within this synopsis, I look at chronic sorrow that comes with a life-altering diagnosis; what changes when life is forever altered in unplanned ways? How has chronic sorrow impacted my life and how have I tried to deal with this? Implications for healthcare professionals will be added.

Key Factors for Consideration

Chronic sorrow is an important construct to understand when experiencing significant illness or when helping others who are living with profound life changes related to illness, including when their prognosis is limited. Kaethe Weingarten, a therapist and writer, recognized how the construct of chronic sorrow, initially meant for parents of children with ongoing illnesses, applied to her adult clients with life-changing illnesses. She poignantly described how life can be untenable when changes in health and physical abilities no longer allow individuals to express who they conceptualize themselves to be. Deep sorrow ensues.³ Chronic sorrow is defined as:

A set of pervasive, profound, continuing, and recurring responses resulting from a significant loss or absence of crucial aspects of oneself (self-loss) or another living person (other-loss) to whom there is a deep attachment ... The essence of chronic sorrow is a *painful discrepancy between what is perceived as reality and what continues to be dreamed of*. The loss is ongoing since the source of the

loss continues to be present. The loss is a *living loss*.⁴ (emphases mine).

Put bluntly, individuals lose their expected future, hope, loss of friendships, and sometimes, loss of control of their bodies and loss of dignity.^{5,6} This discrepancy between what once was and is now, is painful. There often are daily reminders of what has changed and what will never be, whether that involved previous circumstances (eg, health) or wished for goals.⁵ The grief is real and painful and often not understood. Chronic sorrow is normal and should not be pathologized.^{2,5}

Since early 2019, I have been living with Stage 4 breast cancer. Breast cancer had spread to my hip. Over time, more metastases occurred in my spine, sternum, and pelvis. I have grieved what the cancer has taken from me. I fought for several years to maintain my career as an academic but noticed that I was no longer mentally agile. I could not quickly pivot conceptually in meetings. The medications were causing brain fog. I then decided to move toward retirement by working 3 years at a significantly reduced workload. I have felt such sorrow—2 major sources of identity—physical abilities (eg, running) and academic acumen were altered. Not only was my identity—how I defined myself—altered,

¹ Faculty of Health Disciplines, Athabasca University, Athabasca, Canada

Corresponding Author:

Annette M. Lane, Faculty of Health Disciplines, Athabasca University, 1 University Drive, Athabasca, Alberta T9S 3A3, Canada.
Email: alane@athabascau.ca



but the structure of my day was changed. How would I fill my days in meaningful ways when I couldn't engage in related activities? Being locked into that reality was difficult when others' lives were much more interesting and goal-oriented than mine. To *be* rather than *do* was not enough. Chronic sorrow permeated my experiences.

Recently, a scan revealed that the cancer had spread to my liver. This is a game changer; the prognosis now is very limited. In the past, the prognosis was limited, but death was still distant. Even when my future looked bleaker than I had counted on, ostensibly, there was a future. Now, this timeframe has narrowed—2 years. The goal now is to live as meaningfully as I can, despite the challenges related to the metastases as well as the side effects of chemotherapy (such as extreme fatigue, pain, nausea, etc). And, to enjoy life as much as possible! However, the unbidden guest, chronic sorrow, lurks in the corner of my heart and mind, as well as in those of my family members. My family asks, "How long will we have Annette?" This time, the living loss of chronic sorrow is the future, or rather, my lack of future on earth.

How am I addressing my new reality with its inherent chronic sorrow? Although my faith has always been important, with the demands of living with a Stage 4 diagnosis, I rely heavily upon faith and spirituality. This makes sense as grief is profoundly spiritual.⁴ The spiritual nature is related to the existential^{5,7}; *who am I now that I cannot exercise hard, function effectively as an academic, commit to volunteer work, etc.* Faith, as part of spirituality, helps me connect to who I am as a person when I cannot define myself solely by activities, and allows me to tap into other activities that express faith and spirituality: praying for others. Another important aspect is being able to work through the sorrow that comes and goes with losing who I was, including self-forgiveness.^{5,6} And my faith assures me of a future, where there will not be sorrow, loss, and pain.

Digging deep into my Christian faith is comforting; eternity is closer now and I am so grateful for this hope. Developing a deeper faith through prayer for others helps me to feel like I still impact the world even though my career, physical stamina, and mental quickness are compromised. Expressing love to family and friends, while always a part of who I was, has greater urgency now. Even colleagues have been recipients of my ill-timed expressions of love! Perhaps embarrassing for others but less so for me, I don't want love to be left unspoken.

Several times a week I walk with my husband and brother, or with my twin sister. My speed and length of walks are reduced. Seven- or 8-mile walks are off the table. Although the thrill of physical accomplishments is gone, the depth of conversation and the meaningfulness of these conversations have heightened. Interestingly, a good walk—albeit reduced—combined with nature and meaningful conversation can produce a "high" that I would have thought only occurred through intensive exercise. Clearly, my spiritual self is strengthening as my physical prowess has declined.

Throughout my Stage 4 breast cancer experience, I have seen a psychologist. When I had mentioned how I was "lost in liminality" (I could not move forward to a better life or go backwards to my former life), she acknowledged how difficult this experience was—both through her words and her tone of voice. When I saw her with my new prognosis related to liver metastases, I mentioned how destabilized I felt. She readily, by her words, gentle tone of voice, and attentive body language normalized my experience. I have progressed from questions of how I could live meaningfully with reduced physical capacity and concentration issues but not having a "deadline" (pun intended), to now needing to balance preparing for the end with living in the present. The ability to discuss death and the afterlife with my psychologist is extremely helpful. While professionals do not need to believe as patients do, they need to support their patients' beliefs, as long as they are not harmful.⁷

Recommendations

Understandably, nurses and physicians often do not have time to address at length the challenges embedded in living with a markedly reduced lifespan. However, they need to recognize the spiritual nature of chronic sorrow and not pathologize patients' responses. Also, the *manner* with which professionals relate to patients such as me, is extremely important. Even if professionals do not have extensive time to discuss how I can navigate chronic sorrow, a gentle, affirming manner communicates that I as a person am worthwhile and that I can still contribute to those around me. In other words, they communicate that my personhood still has meaning.⁵ In that way, professionals can contribute to the spiritual health of their patients or clients.

Conclusion

When professionals recognize that patients with a greatly reduced lifespan are living on the edge, literally (limited time) and figuratively (at the edges of their capacity to cope), and can respond to patients' frustrations, fears, and tears, this is hugely empowering to their patients. If they do not feel adept at addressing spiritual issues, referrals to chaplains or psychologists who feel comfortable addressing dying and death is extremely important. Chronic sorrow is a *normal* response to facing into Stage 4 cancer diagnoses and this should be validated. Also, professionals should recognize that what is considered sorrowful may change over time. Being attentive to ways to address chronic sorrow in patients with Stage 4 cancer will help them cope with the suffering of their illness.


Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Annette M. Lane  <https://orcid.org/0000-0002-1806-0736>

References

1. Lane AM, Reed MB. *Living and losing: a grief primer*. 1st ed. Kendall Hunt; 2023.
2. Wikler L, Wasow M, Hatfield E. Chronic sorrow revisited: parent versus professional depiction of the adjustment of parents of mentally ill children. *Am J Orthopsychiatry*. 1981;51(1):63-70.
3. Weingarten K. Sorrow: a therapist's reflection on the inevitable and unknowable. *Fam Process*. 2012;51(4):440-55. Doi: 10.1177/23743735231154955
4. Roos S. *Chronic sorrow: a living loss*. 1st ed. Routledge; 2002.
5. Isaksson A-K, Gunnarsson L-G, Ahlstrom G. The presence and meaning of chronic sorrow in multiple sclerosis. *J Clin Nurs*. 2007;315-24. Doi: 10.1111/j.1365-2702.2007.01995.x
6. Ahlstrom G. Experiences of loss and sorrow in persons with severe chronic illness. *J Clin Nurs*. 2007;16:76-83. doi: 10.1111/j.1365-2702.2006.01580.x
7. Lane AM, Reed MB. *Older adults: understanding and facilitating transitions*. 3rd ed. Kendall Hunt; 2019.