Grief as a Fundamental Aspect of the Human Condition: Making Space For Loss in Disability and Rehabilitation

By Sarah M. Schwab-Farrell, PT, DPT, PhD

"I have concerns for dysplasia. Do you know what that is?"

Those were the words that froze my world in the summer of 2025. I was at a routine ultrasound visit, nearly 6 months pregnant with my first child. It was an appointment that my partner and I had looked forward to for weeks, only to have it bring oceans of uncertainty and worry.

We were initially (perhaps naively) optimistic. As a disability scholar and physical therapist who is married to a pediatric occupational therapist, I felt like we were uniquely prepared—or as prepared as we could be—to raise a child with a disability. We knew that there would undoubtedly be challenges, but we were determined to give our child the best life possible and cultivate an environment full of disability pride.

After multiple maternal-fetal medicine appointments and laboratory tests, my husband and I learned that our daughter had a fatal form of osteogenesis imperfecta (OI), and she would not survive birth. OI is a rare group of genetic disorders affecting the production of collagen. It is characterized by bone fragility, growth deficiency, and other connective-tissue symptoms.[1] There are various classes of OI, most of which have minimal impact on life-expectancy. Medical management, including rehabilitation, facilitates function for many people with OI. In more severe forms of OI, however, symptoms commonly manifest in utero, and complications (eg, arterial dissection, distortion of ribcage) can be perinatally lethal[1]—as was the case in our situation.

In the weeks and months that followed the loss of our daughter, I was confronted with an indescribable and profound grief. It was a sadness I never knew possible. I immersed myself in familiar habits, which for a researcher, involves a lot of reading. Except instead of reading literature within my area of expertise (I lacked the focus), I devoured grief literature. I wanted to understand and put words to my feelings. While learning about the grieving process, I began to critically reflect on some of my own work related to disability and disability acceptance in rehabilitation.

The Role of Grief in Rehabilitation

So much of my career as an early-stage researcher has focused on reconceptualizing the disability construct, fostering disability acceptance, and celebrating diverse movement patterns in disability.[2–5] Through a new lens shaped by my personal experience with grief, I was reminded of the value and meaning of this work. However, I also realized that the role of grief in disability and rehabilitation—while perhaps implicitly underlying those messages—was not explicitly stated or properly emphasized. For instance, in a paper I co-wrote about disability acceptance post-stroke—published just a couple months before the loss of my daughter—we wrote, "It is important to note that many people with stroke who demonstrate acceptance still experience loss (eg, loss of freedom, independence, spontaneity), and they miss some activities."[4] Implicitly, we also said "…and that is okay," but further elaboration on grief and how grief can exist concurrently with acceptance was not offered.

The losses that often accompany the onset of disability (eg, loss of identity, relationships, bodily autonomy) are analogous to other sources of grief.[6] For instance, several studies have characterized the experiences of stroke survivors as a form of grief and loss.[7,8] An autoethnographic account from an individual after spinal cord injury offers additional perspective on the losses that go along with disability: "What is being faced up to from the moment a spinal cord injury is incurred, and every day thereafter, is a loss so personal, and consequences so utterly life changing…to experience spinal cord injury is almost certainly to grieve."[6] The uncertainty associated with chronic disability can also contribute to grief.[9]

Grief as Integral to Lived Experience

While it is positive that the disability and rehabilitation literature often highlights resiliency, optimism, and hope following the onset of disability, there is also a broad under-recognition of the contribution of grief as an integral part of this lived experience. There is limited understanding of how we make space for grief in a clinical encounter (from both the clinician and client perspective) and how that can influence outcomes. Further, it is poorly understood how grief may be embodied; expressed through an individual's movement patterns, and thus, may change how we evaluate an individual's movement.[10]

Recent work in physical therapy education calls for expanding grief and loss education in the curriculum, with the acknowledgement that many healthcare providers have poor grief literacy—which impacts their ability to provide support to grieving clients.[11] Appeals for increased disability advocacy and anti-ableism in the rehabilitation professions and in professional education are consistent with the previously-described notions of grief as a critical part of lived disability experience.[12]

GRIEF AND CONCURRENT ACCEPTANCE

While I have strived in my research to be an advocate for fostering disability acceptance (and wholeheartedly stand by that work), what I have come to recognize is that grief and acceptance can coexist and there is not a strict dichotomy between the two. If we acknowledge acceptance, we must also acknowledge grief.

I have learned that loss is not something that we must "move on" from in order to accept and adjust to our current life situation. We can find our current life meaningful—a hallmark characteristic of acceptance—but still grieve what has been lost. Grief does not need to disappear or fade, but rather, we get stronger and are able to carry the same grief better. Fundamentally, hope and determination are critical components of the grieving process.

In Clifton's account of grief following spinal cord injury, they write: "This is not to say, however, that life is over, or that resiliency and grief are opposed to one another."[6] Perhaps feeling and carrying the weight of grief (with appropriate supports) may even lead to greater resilience.

MAKING SPACE FOR GRIEF

For disability and rehabilitation researchers and clinicians like myself who seek to foster disability acceptance, we should continue to promote acceptance strategies and help people with disability discover what is gained from loss.[4,13] However, we should also acknowledge and make space for grief and its function as a process of personal integration and expansion (recognizing, too, that grief is not homogenously experienced by everyone).

The Humanities as Entry Point

Grief is a fundamental part of the human experience, and thus, the humanities are an excellent entry point for learning to discuss, hold space for, and live with grief. It is an area that we, as rehabilitation clinicians working with people experiencing grief and loss from disability, ought to consider more deeply.

Art, poetry, and writing are all vectors by which one can make meaning from complex lived experiences, and can be helpful for navigating emotional processes such as grief.[14,15] In fact, the current narrative reflection began as a means to process my own grief.

An additional interesting area for rehabilitation clinicians to consider with respect to grief is dance/movement therapy. Dance and movement therapy is increasingly being studied as a creative approach for managing complex grief and loss, with the recognition that grief often includes embodied effects.[16–18]

REHABILITATION PROFESSIONALS AS KEY

As movement is largely acknowledged as the professional expertise of physical therapists,[19] rehabilitation clinicians have the opportunity play a unique role in the grieving process for people with disability by facilitating movement with specificity and intentionality. Importantly, rehabilitation clinicians have opportunities to encourage creative movement for people with disability, drawing upon examples and strategies that promote and celebrate any movement strategy (not just movement that is biomechanically "correct") as meaningful."[2–5]

In closing, I want to emphasize that I am by no means an expert on grief; I am simply sharing reflections from my own experiences as a bereaved mother with the hope that these lessons can be usefully applied to

rehabilitation to better support people with disability as they navigate their own personal uncertainty and loss.

Conclusion

A couple months after I returned to work (still in the throes of grief), I was talking to a stroke survivor—a stroke survivor who has very much accepted her current life situation and is a strong disability advocate in the community. I asked her, "What is something you want people without disability to understand about your disability?" She responded pointedly and with a response illustrating that acceptance and grief can coexist: "I didn't choose this."

There is much we can do in rehabilitation to facilitate disability acceptance;[4] we should do all those things. However, we can do those things while also creating the space for grief to be fully present. We must recognize the complexity of grief and that individuals who are grieving do not get a choice in how they grieve or why they grieve. Likewise, families and communities who support individuals grieving also do not get a choice, and they also are likely experiencing different levels of grief. When we interact with people with disability and their families, it is critical to remain mindful of their losses and help empower and support recipients of care in their grief process.

Dedication

This work is dedicated to Maeve "Mae" Marie Farrell—a beautiful life so loved and lost far too soon. My greatest hope was that you would get a chance to do great things in the world. The world didn't get a chance to know you. But I did, and you forever changed my world.

And to Patrick: when gravity was not enough, you held me up.

References

1. Rauch F, Glorieux FH. Osteogenesis imperfecta. *Lancet*. 2004;363(9418):1377-1385. doi:10.1016/S0140-6736(04)16051-0
2. Schwab SM, Silva PL. Intellectual Humility: How recognizing the fallibility of our beliefs and owning our limits may create a better relationship between the physical therapy profession and disability. *Phys Ther*. 2023;103(8): pzad056. Accessed October 20, 2025. https://doi.org/10.1093/ptj/pzad056
3. Silva PL, Schwab SM. Disability through the lens of affordances: a promising pathway for transforming physical therapy practice. In: *The Modern Legacy of Gibson's Affordances for the Sciences of Organisms*. Routledge; 2024.
4. Schwab-Farrell SM, Whalen Smith CN, Dunning K. Deconstructing the role of the physical therapy profession in disability acceptance for people with stroke. *Phys Ther*. 2025;105(7):pzaf064. Accessed October 20, 2025 . https://doi.org/10.1093/ptj/pzaf064
5. Schwab-Farrell SM, Mayr R, Davis TJ, Riley MA, Silva PL. Destabilising the norm: a critical experimental approach to move physiotherapy beyond movement "normalisation." In: P. Thille, C. Hebron, R. Galvaan, & K. S. Groven (Eds.), *Inviting Movements in Physiotherapy: An Anthology of Critical Scholarship*. In: Critical Physiotherapy Network and College of Rehabilitation Sciences, University of Manitoba. 2025:90-112. doi:10.82231/S8HA-YK54
6. Clifton S. Grieving my broken body: an autoethnographic account of spinal cord injury as an experience of grief. *Disabil Rehabi*. 2014;36(21):1823-1829. doi:10.3109/09638288.2013.872202
7. Alaszewski A, Alaszewski H, Potter J. The bereavement model, stroke and rehabilitation: a critical analysis of the use of a psychological model in professional practice. *Disabil Rehabil*. 2004;26(18):1067-1078. doi:10.1080/09638280410001703521
8. Hughes AK, Cummings CE. Grief and loss associated with stroke recovery: a qualitative study of stroke survivors and their spousal caregivers. *J Patient Exper*. 2020;7(6):1219-1226. doi:10.1177/2374373520967796
9. Reenen EC van, Nistelrooij IAM van, Visser LH, Beukelaar JWK de, Frequin STFM, Niemeijer AR. The liminal space between hope and grief: the phenomenon of uncertainty as experienced by people living with relapsing-remitting

multiple sclerosis. *Plos One*. 2025;20(1):e0315501. doi:10.1371/journal.pone.0315501
10. Schwab SM, Spencer C, Carver NS, et al. Personal factors understood through the Ecological-Enactive Model of Disability and implications for rehabilitation research. *Front Rehabil Sci*. 2022;3. https://doi.org/10.3389/fresc.2022.954061
11. Marengo J, Donlan P. Beyond acceptance: the importance of expanding on grief and loss education in physical therapy curricula. *J Phys Ther Educ*. 2023; 39(4):309-313. DOI: 10.1097/JTE.0000000000000412
12. Whalen Smith CN, Havercamp SM, Tosun L, et al. Training an anti-ableist physical therapist workforce: critical perspectives of health care education that contribute to health inequities for people with disabilities. *Phys Ther*. 2024:pzae092. DOI: 10.1093/ptj/pzae092
13. duChemin D. We Are All Missing Something: A Meditation on Amputation, Constraints, and Creativity. *J Humani Rehabi*. 2025;Fall. Available at: https://www.jhrehab.org/2025/09/23/we-are-all-missing-something-a-meditation-on-amputation-constraints-and-creativity-2/. Accessed October 20, 2025.
14. Beaumont SL. Art therapy for complicated grief: a focus on meaning-making approaches. *Canadian Art Ther Assoc J*. 2013;26(2):1-7.
15. Thompson BE, Berger JS. Grief and expressive arts therapy. In: *Grief and Bereavement in Contemporary Society*. Routledge; 2011:303-313.
16. Philpott E. Moving grief: exploring dance/movement therapists' experiences and applications with grieving children. *Am J Dance Ther*. 2013;35(2):142-168.
17. Dominguez KM. Encountering disenfranchised grief: an investigation of the clinical lived experiences in dance/movement therapy. *Am J Dance Ther*. 2018;40(2):254-276.
18. Callahan AB. The parent should go first: a dance/movement therapy exploration in child loss. *Am J Dance Ther*. 2011;33(2):182-195.
19. Sahrmann S. The how and why of the movement system as the identity of physical therapy. *Int J Sports Phys Ther*. 2017;12(6):862.

About the Author

Sarah M. Schwab-Farrell, PT, DPT, PhD is an Assistant Professor in the Department of Rehabilitation, Exercise, & Nutrition Sciences at the University of Cincinnati. She earned her DPT from the University of Cincinnati (2018) and MA (2020) and PhD (2022) in Experimental Psychology from the University of Cincinnati. She also completed post-doctoral training in the Neurorecovery Lab at the University of Cincinnati. Sarah's empirical and theoretical work merge rehabilitation, disability studies, and ecological psychology to understand the creative and adaptable movement strategies people with disability use to engage with their environments. Sarah's research seeks to re-conceptualize disability as a complex construct that is inherently shaped by and given meaning through context. In doing so, her research challenges medicalized/biomedical assumptions commonly made in rehabilitation and works to empower people with disability. She was awarded the 2024 Ohio Physical Therapy Association Emerging Leader Award. Her research has been funded by the Foundation for Physical Therapy Research and the Ohio Physical Therapy Association.