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Guest Editorial

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We are currently facing a national caregiving crisis. I am one of the 53 million Americans providing unpaid care to a family member with a chronic or life-limiting illness (NAC 2020a). Research typically examines older adults caring for their spouse or partner; however, illness, thus caregiving, occurs at all stages in the lifespan. More than one-third of young adults aged 18–39 years are caregivers (AP-NORC 2018), yet they are underrepresented in caregiving scholarship. Young adult caregivers (YAC) in non-normative patient–caregiver relationships (e.g., siblings) are often left out of literature completely. Despite comprising 17% of caregivers of young adult patients (NAC 2020b) and 7% of caregivers overall (NAC 2020a), sibling caregivers are grouped into the vague “Other” category with friends, in-laws, etc. (Lai et al. 2022; Litwin et al. 2014). Baby boomer trends and increased life expectancy among individuals with disabilities are contributing to a rise in sibling caregivers (Namkung et al. 2017), yet little is known about their unique experience. As such, resources are not typically designed for their needs.

At 23, I experienced this first hand, professionally and personally, as a research coordinator supporting patients undergoing a hematopoietic cell transplantation (HCT) and their caregivers, while simultaneously caring for my brother receiving the same treatment for leukemia. As a sibling caregiver, I experienced a unique sense of isolation, an Otherness, compared to more common patient–caregiver relationships. I needed support and found resources geared toward parents, spouses, adult children, or nonspecific Others – few included siblings’ perspectives. I quickly discovered we typically do not qualify for caregiver aid; notably, siblings are excluded from federal policy altogether and not entitled to benefits allotted by the Family Medical Leave Act (FMLA) (Wage and Hour Division 2023b). As an Other, I was not eligible for FMLA when I became my brother’s full-time caregiver during his HCT.

Consequently, I continued working full time throughout his 5-week hospital stay and subsequent 2-month recovery in hospital housing. I hoped it would serve as a distraction, but my work directly reflected my life – there was no distracting from my reality. I faced challenges attempting to balance my professional, personal, and caregiving responsibilities, all while feeling excluded from not only my peers but also current caregiving research, resources, and policies. In this editorial, I aim to highlight the unique challenges I and other sibling caregivers face, our exclusion from research and policy, and the need for resources that are intended to support *all* caregivers.

Caregivers almost always find themselves juggling work and caregiving responsibilities. Specifically, 6 out of 10 caregivers report impacts on their employment due to caregiving (NAC 2020a). Unsurprisingly, these caregivers also report struggling with higher levels of stress (Longacre et al. 2017). My work performance declined as compared to pre-diagnosis. This is common; many caregivers receive warnings about performance or attendance (NAC 2020a). Like so many (NAC 2020a), I also declined a promotion just prior to my brother’s HCT. Already feeling overwhelmed with work and aware that my caregiving responsibilities would increase as the transplant process began, the idea of taking on more work was distressing. One-third of caregivers even report leaving their jobs due to difficulty meeting work demands (Lerner 2022). Furthermore, YACs report the highest financial strain and are more likely to say a paid leave of absence from work would be helpful (NAC 2020a). Caregivers should not have to choose between working or caregiving and should not have to worry about negative impacts on performance. A paid leave of absence is crucial to caregiver well-being, and federal programs that alleviate employment pressures on caregivers are a lifeline.

FMLA, a federal policy, allows employees to take unpaid, protected leave to care for a spouse, child, or parent with a serious health condition (Wage and Hour Division 2023a). Caregivers categorized as Others, like siblings, are not eligible for FMLA and must find alternative ways to balance caregiving and work. Some states have begun to recognize this critical gap in resources for Other caregivers, such as New York (NY State Senate 2023), California (Employment Development Department 2023), and New Jersey (Department of Labor and Workforce Development 2023a), defining family member as “any individual that you consider to be family” (Department of Labor and Workforce Development 2023b). Expanding the definition of family is critical not only to sibling caregivers but also to the well-being of sexual and gender minority individuals who rely heavily on chosen families (Rosa et al. 2022).

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Federally, however, siblings and Others are not considered family, leaving us vulnerable and uncertain of our job security.

Caregivers, especially YACs, tend to not recognize themselves as caregivers (Charles et al. 2017; D'Amen et al. 2021), making us a difficult population to identify and recruit into research. Grouping siblings along with other less-prevalent caregivers rather than in our own distinct and identifiable groups perpetuates feelings of otherness, leading us to believe we are not “true” caregivers, like spouses or parents. If siblings do not see ourselves identified as caregivers, we aren't as likely to self-identify and seek support. In fact, in exploring caregiving literature as part of my work, I felt like an imposter in some ways not seeing myself represented as a caregiver. My otherness left me feeling unworthy of identifying as a caregiver. Given that caregivers are already vulnerable to feelings of isolation and seclusion (Gray et al. 2020; Lee et al. 2021), this language exacerbates feelings of loneliness among sibling caregivers. This is especially pertinent to YACs, who feel removed from our peers as caregiving responsibilities interrupt typical young adult developmental experiences (Bolas et al. 2007; Granek 2014). As our understanding of these caregivers' unique experiences evolves, the words we use to describe them should as well. Just as we no longer call family and friend caregivers “informal” caregivers (Applebaum 2022), the use of Other further invalidates sibling caregivers who just want to feel seen but are ignored even by scholars and policymakers. Caregivers should be identified for who we are, whoever we are, no matter how much of the population we represent. If a research sample is primarily composed of parents and partners, the few siblings enrolled should not be grouped together with any other smaller group. We should be made visible, distinctly identified as our own groups, and not lost in the vagueness of Other. This will help other researchers see siblings as valid caregivers, as well as aid in self-identification. Moreover, further research needs to be conducted examining sibling caregivers' unique experiences. That way, resources can be developed and tailored to our needs.

I am not only a caregiving researcher but a sibling caregiver myself – a sister, an Other. My brother was only 33 when he underwent an HCT, a physically and psychologically intense treatment that left him severely immunocompromised. Per his oncologist, I could not leave him alone for more than 2 hours, a challenge even for someone not juggling full-time employment. Ironically, I was already working directly with patients who received an HCT and their caregivers, making my “work-life balance” virtually non-existent. Luckily, I could work remotely during this time or else I may have had to resign, devastating my financial and personal well-being, and likely my ability to properly care for my brother. I was “lucky,” yet still found it difficult to balance caregiving and work. I struggled to fit caregiving into the workday, once delaying cooking his meal because of a meeting, afterwards feeling shameful that I prioritized work over his needs. There were times I wasn't fully present in the moment to support my brother, like when I sat beside him in hospital rooms answering emails while he anxiously awaited lab results to see if his blood cell counts were recovering post-transplant. I wish I spent more time talking to him during those moments, instead of being preoccupied by work. I felt incredibly guilty when I did not dedicate myself 100% to caregiving, as well as when I struggled to meet the demands of my job. At work, I felt like I couldn't fully support the patients and caregivers I spoke to because of my own ongoing experience. It was hard to maintain composure as they recounted their struggles during HCT, struggles I was currently facing. At home, I felt burnt out, distracted, and unable to fully support my brother, much less myself.

Caring for my brother is the most meaningful part of my life, and I am so grateful for the cherished memories we are making together during his ongoing recovery. However, FMLA or paid leave would have drastically reduced my caregiver burden by allowing me to focus solely on my brother's health and well-being, while maintaining my own. Caregivers should never have to choose between caregiving and making a living, and *all* caregivers deserve to be included in policy, especially paid leave. Furthermore, researchers need to use inclusive language in their work. Although a smaller amount of the population, sibling caregivers exist; we are our own entity. We should be made visible. Research and policy go together, and as the experts continue to ignore us, so will policymakers.

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