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There is nothing informal about caregiving

Allison J. Applebaum, PH.D.

Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, NY

Editorial

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Author for correspondence:
Allison J. Applebaum,
Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, 641 Lexington Avenue, 7th Floor, New York, NY 10022, USA.
E-mail: applebaa@mskcc.org

Words matter. The language we use to describe the human experience is essential to understanding individuals' lived experiences and how we can best care for their well-being. Take the words *formal* and *informal*, for example. The word *formal* suggests official, proper, qualified, while *informal* suggests casual, unofficial, easy. Imagine then describing a group of individuals as unofficial, that is, as an unofficial person involved in the daily intense work of taking care of a loved one with a chronic or life-limiting illness. Then imagine trying to course correct a linguistic norm. This is the tipping point that I, as a caregiving scientist, am now trying to influence.

I wrote my first scholarly article on the topic of caregiving in 2013 (Applebaum and Breitbart, 2013), a systematic review published in this journal summarizing the state of intervention research for caregivers of patients with cancer. In that paper and in many subsequent works through 2020, I repeatedly made a significant error. This error was a disservice to the field of cancer caregiving, to caregiving science more generally, but most importantly, to caregivers themselves. I referred to family caregivers — the friends and family members who are so intimately involved in the care of patients — as *informal caregivers*. It was an error of language, but more importantly, it was an oversight of the essence of human identity.

Back in 2013, I had seen the phrase used in a handful of oncology publications written on the topic of caregiving, and in many more coming from the literature on dementia caregiving. The word *informal* was used, I believe, to differentiate family and friend caregivers from *formal* caregivers, that is, healthcare professionals who provide care to patients as part of their paid employment. The intended use of the word was to highlight the element of caregiving that is inherent in our work as healthcare professionals, and the fact that we are, in effect, employed (i.e., paid) to take care of others. We are, formally, caregivers. Yet, like many words being deeply examined today, *informal* calls for reflection.

There is nothing *informal* about caregiving. There is nothing *informal* about the care provided by the thousands of caregivers who have now received support in the Caregivers, Couple and Family, and Bereavement Clinics at Memorial Sloan Kettering Cancer Center (MSK) since our programs began, or through the many clinical trials coming out of these clinical services. There is nothing *informal* about the care that at least 53 million Americans (AARP National Alliance for Caregiving, 2020) are currently providing to loved ones with chronic and/or life-limiting illnesses, care that involves significant physical, emotional, spiritual, existential, and financial costs. And there was nothing *informal* about the decade that I stood by my Dad and gave every ounce of my soul to taking care of him, supporting him, and honoring his wishes.

My Dad was Stanley Applebaum, the world-renowned composer, orchestrator, and arranger who is perhaps best known for his arrangement for Ben E. King's "Stand By Me." The memorable string line in the middle of "Stand By Me" that gives the song its orchestral feel was my father's creation, as were thousands of other arrangements he did for all of the top artists of the 50 and 60s. My Dad had Lewy Body Disease, a progressive neurodegenerative disease that can lead to fluctuations in consciousness. For him, these fluctuations meant visual and auditory hallucinations that were disturbing and often accompanied by life-threatening autonomic changes, like sudden drops in blood pressure or temperature. One moment we would be discussing a piece of classical music and the next, he would be unable to focus, distracted by a false perception of three men standing by his bed about to attack.

During the decade that I took care of him, I served as his eyes, ears, and often, voice while he lay in stretchers, frequently for days in cold hospital hallways (Applebaum, 2022). I realized during the first or second of what was eventually thirty-something ER visits, that without me by his side, when my Dad was having an LBD fluctuation and was not oriented, there would have been no way for any of his "formal" caregivers — that is, his healthcare providers — to *know* my Dad, to know anything more than what they could see in front of them with their eyes and in the medical record. I knew in those moments that without my conveying to the healthcare team who my Dad was in terms of his personality, his drive for life and desire to continue to be productive in all ways possible for as long as possible (he continued to write music until his last weeks), that he would be at risk for being labeled as another ninety-something-year-old man with multiple comorbidities and a likely poor prognosis, and that this label could significantly shape the care he would receive and the trajectory for his life. And so, I stood by him and was his fiercest advocate, formally so.

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When he was not in the hospital, and during the periods when his disease was well controlled, my caregiving responsibilities remained significant. While I earned by doctorate in clinical psychology the old-fashioned way, I eventually earned my honorary degree as a seasoned social worker, collecting expertise in medical, nursing, legal, and financial aspects of care in the context of my caregiving journey. I had become a sensitive diagnostician, could identify the early signs of UTI or dehydration, could stage a bed sore and implement the proper wound care routine, and knew all the drug and food interactions for my Dad's medication regimen. I had a keen understanding of the risks of IV fluids on my Dad's cardiac functioning and knew to watch for swelling of his legs as signs of heart failure. I could interpret basic blood panels and advise on which antibiotics worked best for the type of bacteria that showed up in his urine cultures. I had taken an ad hoc course in internal medicine and seemed to have passed the final exam.

But that wasn't all. In addition to serving as his stand in nurse, physician, and constant aide, I was also his case manager; I coordinated care among his various medical providers and navigated the financial side of his receipt of healthcare, such as figuring out how to pay for care received by his actual home health aides. This included the extraordinarily complicated (and almost prohibitively so) process of getting my Dad onto Medicaid, which eventually required my bringing his case to Medicaid court and subsequently seemingly running my own home healthcare agency with aides that I found, interviewed, and subsequently trained. This, of course, was *formal* caregiving, pro bono.

The enormous responsibilities placed upon caregivers were well documented in the scientific literature long before my caregiving journey began, though they were thoroughly brought to life for me through my lived experiences. I realized early on that the challenges I was facing were in many ways universal to caregivers. And yet, I also knew that I came to the role with many gifts, including a higher education, professional experience in healthcare, a supportive employer, and deeply caring friends, gifts that would mitigate some of the distress I was experiencing. Nonetheless, as if in slow motion, I watched as my caregiving responsibilities deeply impacted every area of my life, from my relationships to financial security, to my own physical and mental health. In my repeated measures single case study design in which I served as both investigator and participant, I collected rich mixed-method data that touched upon many of the key themes that I am now addressing in my research, including multifaceted caregiver distress, unmet needs, invisibility, uncertainty, and financial toxicity. I look back at my journey and see how my experiences served as a microcosm of much larger issues faced by caregivers in the United States (US) and how these challenges — and their enduring impact long after active caregiving journeys have ended — formally and officially represent a national healthcare crisis.

There are many steps that we can take to begin to address this crisis, including implementing clinical services for caregivers like the ones I and colleagues have developed at MSK in hospitals across the country, formally recognizing caregivers as members of the healthcare team, and documenting caregiver data as a standard of care (Applebaum et al., 2021). An additional step is for us to forgo the use of the word *informal* when describing caregivers and the significant responsibilities they shoulder. Other, more accurate ways to refer to caregivers include *family and friend caregivers*, *care partners*, *partners in care*, *care advocates*, or simply *caregivers*. We need to use language that honors the work that caregivers do, and in no way detracts from the importance of every aspect of this role.

Our choice of language is critical for so many reasons. To start, we are currently witnessing the ways our public policy landscape in the US deeply and negatively impacts the experiences of family caregivers. Our public policy colleagues are increasingly looking to us, the caregiving science community, for data to support the arguments they are bringing to Congress (e.g., around a robust national paid family medical leave policy). The inclusion of the phrase *informal caregiver* undermines the countless ways that caregivers are the backbone of our healthcare system and require support to carry out their responsibilities. Our scientific literature sets a standard for how the foci of our work is addressed outside of academia, and we need to be cognizant of how the language we use can not only be offensive to caregivers but can detract from the messaging being put forth beyond our academic walls.

I cannot re-do a decade's worth of writing and replace each instance of the phrase *informal caregiver*, but I can make a commitment to shift my language moving forward, and I encourage all caregiving scientists to do the same. I know that I am not alone in being a clinician and researcher who also has had an intimate, personal experience with caregiving. All of us were, are, or will be caregivers, often repeatedly through our lives. And so, all of us know that our caregiving journeys — for ill or disabled family members, for children, for anyone in our lives — are anything but *informal*.

References

AARP National Alliance for Caregiving. (2020) Caregiving in the United States 2020. AARP. doi:10.26419/ppi.00103.001.

Applebaum AJ (2022) I was never "just" a visitor. *Hastings Bioethics Forum*. Available at: https://www.thehastingscenter.org/i-was-never-just-a-visitor/.

Applebaum AJ and Breitbart W (2013) Care for the cancer caregiver: A systematic review. *Palliative and Supportive Care* **11**(3), 231–252. doi:10.1017/s1478951512000594

Applebaum AJ, Kent EE and Lichtenthal WG (2021) Documentation of caregivers as a standard of care. *Journal of Clinical Oncology* **39**(18), 1955–1958. doi:10.1200/jco.21.00402

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