

The Politicizing Influence of Caregiving: Making the Micro and Macro Connection in Older Adult Health

Renée J. Cardone

Abstract: I consider the “case” of my mother’s health and social challenges as representative of the urgent need for macro policy changes to support maximal functioning in our increasing older adult population. The “case and cause” gap in social work practice is highlighted. The failure of the medical model to adopt a whole-person approach to healthcare is demonstrated as serving to exacerbate the critical need for comprehensive preventive and ameliorative health and social policies.

Keywords: case and cause, micro and macro social work practice, social work reform

“The personal is political” slogan of the feminist movement of the 60s suddenly came to mind as I began to write this narrative of caring. My mother’s journey from acute illness and emergency surgery to recovery politicized me personally and professionally in a way that I could not have anticipated. Through my parallel journey of providing care for my mother, I was surprised to discover and enlightened about the world of vulnerable older adults. Some of the gaping holes in care and services that are allowed to litter their paths are now visible to me. Gaps in services and access to care block many older adults from maintaining maximal health and wellness and most certainly contribute to health decline in our older adult population. I have come to believe that prevention resources are as vital for thriving in older adulthood as developmental resources are to thriving in infancy and childhood. My caregiving and related advocacy experiences underscore the need for comprehensive policies to address preventive and ameliorative supports for our increasing older adult population here in the U.S. For my profession of social work, this translates to operationalizing the long-standing commitment to the person-in-environment perspective by increasing the capacity of social workers to indelibly link “case and cause” in all the work we do. This can be accomplished in healthcare and related settings by employing a model such as the Consumer Advocacy and Navigational Model (cleverly resulting in the acronym CAN) formulated by Jansson (2011). The CAN model involves identifying, on a case-by-case basis, whenever any of “seven problems commonly encountered by healthcare consumers” (Jansson, p. 2) exist and then applying the CAN framework to deliver both case advocacy and policy advocacy.

This is a story in process, one whose end will not be written here. It illustrates the interconnections of one vulnerable life and macro policies that ignore some of those vulnerabilities. This story serves to underscore the social work profession’s need to discover and operationalize means to make “case and cause” inseparable in practice. Indelibly linking “case and cause” is what the social work profession has long espoused but thus far has been unable to fully achieve. The current state of practice is such that “case and cause” most often run on parallel tracks and operate as practice distractions to one another within the profession. This failure to bridge the micro and macro and apply the integrated whole to our daily practice inhibits social work from accomplishing its mission as stated in the Preamble of the NASW

Code of Ethics (National Association of Social Workers [NASW], 2017).

This story is not a “case” in the traditional case study sense (i.e., it is not drawn from my social work practice; it is from my personal life). Here I relate experiences with my mother’s recent illness and care and the issues raised. The story reveals her experiences with some of the problems Jansson (2011) identified among his seven. My mother’s experiences with healthcare delivery systems serve to illustrate and underscore the gravity and urgency of both professional practice reform and policy change. This is a story about the caregiving relationship between my mother and me. The spirit of it, however, also illuminates the indelible connections between micro and macro social work practice. This story does not have a “resolution.” Just as my mother’s journey continues and the related macro health and social issues remain unresolved, so, too, do social work’s unresolved micro-macro practice dilemmas persist. The specifics of my mother’s illness and recovery and ongoing health and social challenges underscore the urgency with which social work ought to vigorously pursue workable, effective solutions to integrating “case and cause” throughout our work. I use the term “urgent” not because my mother is the subject here, but because her story is like so many others, except that it is less dire than many.

My mother, at 93, is now mostly healthy. She is a first generation Italian-American, born and raised in the U.S. after both her parents immigrated from Sicily. She became a registered nurse as a young woman, toward the end of the Second World War, married my father and practiced briefly while he was in graduate school, then had six children with him and helped raise them as a stay-at-home mother. Later, in her 60s, she began working long hours in a seasonal family business that required her to drive over 20 miles each way, seven days a week, where she performed a variety of administrative and service-related job responsibilities until she was 89. She and several of my siblings then helped care for my father until he died at age 93, about six months before the onset of her acute health crisis.

I became actively involved in supporting my mother and advocating for her when her increasing vulnerability became evident. More than two years ago, she had an acute health crisis which drew me into an intense caregiving and advocacy role in her life. It started the day I learned she was facing a health crisis and left work to fly to the hospital where she was being cared for. Her journey, mine as primary support, and our family’s encompasses the ensuing nine months, during which the doctors and ancillary healthcare personnel (e.g., nurses, physicians assistants, hospice workers), with few exceptions other than her specialist and home health nurse, mostly prepared us for her demise. My involvement included being by her side, often providing direct care, during several hospitalizations and at her home over a nine month period of acute illness and rehabilitation. When she eventually stabilized and was clearly beginning to get stronger, my mother came to live with my husband and me, necessitating a move 250 miles away and across state lines from the communities where she had lived her whole life.

I tell my mother we are a team. She kindly and generously gives me credit for her recovery, but I know that from the beginning we have been in this together, along with substantial support, mostly from my siblings, but also from others. I was able to stay by my mother’s side pretty much 24/7 during the nine months of her illness and recovery, which I point out so as to give credence to the first-hand details of her story.

My presence with her was made possible because of my direct supervisor's commitment to accommodating employees' family needs and because my husband was supportive and tolerant of my absence during those many months of my mother's protracted illness. Toward the middle of those nine months of my mother's intense illness and care, I did need to return briefly to my work in another state so I could finish up a job that had spanned 15 years. Over the previous two years I had already shifted to part-time so that I could spend more time with my husband who had taken a job several hours away. Before my mother became ill, I had arranged to quit the job so that I could embrace a life transition that was clearly presenting itself. That acceptance of transition allowed for serendipity. It created an opening in my life that enabled me to stay by my mother's side when the need arose during the critical periods of her illness and recovery processes, and has extended into the present, now that she is stable. Predictably, of course, the question of whether I have "retired" sometimes surfaces these days. My response that "I am in transition" reflects both my current state of professional development and my concrete status in the work world. As reflected partially through this piece, I find myself most powerfully drawn to musing about my profession and expressing myself through writing and activism on behalf of social work. I have settled into a life-style that for now fits my current need to meet my caregiving, professional, personal and family/social commitments. Throughout each 24-hour day in which my mother's care is necessarily prioritized, I am also reading and thinking about various social work issues, writing most productively in the early mornings, attending to my caregiving responsibilities in a semi-structured way consistent with my mother's stable and largely functional current health status, and improvising most everything else.

My mother's personal circumstances (i.e., health insurance, access to quality care, financial resources and family support) have proved adequate to support her eventual recovery, despite some systemic and institutional deficiencies. Consistent with the strengths orientation in social work, I discovered during her illness that one of the blessings of siblings is that each of us brings our own talents to family crises of this kind. Identifying and drawing from each of our unique talents and skills and applying them to my mother's particular needs has allowed for a smooth recovery period for my mother and the maintenance of good relations among the six of us. We could have adopted instead a model that defined "equal contributions" to her care as "the same" (i.e., "I've spent x amount of time caring for our mother. Now it's your turn to do the same."). I believe, however, that the resulting efforts would have been less targeted to my mother's needs, more frustrating for each of us, and might have engendered a climate of animosity among us, undoubtably despite efforts among us to avoid rancor of any kind.

My siblings and I have been able to bring considerable resources to bear on my mother's particular situation over those many months and now on her continuing care. In the process, however, I also discovered critical unaddressed needs in comprehensive social and health policies that left me shocked and chagrined. These include inadequate public health education for older adults and their families, non-existent to inadequate education of older adult patients and their families by primary care and gerontology medical professionals, and complicated and nonsensical insurance policies that effectively inhibit and even block adequate preventive health practices and recovery. My mother's care was negatively influenced by several of the seven problems Jansson (2011, p. 2) identified as emblematic of navigating the U.S. health system. In my mother's case, these problems definitely include challenges financing her care which has

clearly sometimes not met widely accepted standards and failure to receive needed preventive services. If she had not had the buffering influence of my siblings and me, a case could be made she would have further benefitted from more attention by some medical professionals to their cultural competence (i.e., the influence of her status as a child of the Depression on her reluctance to incur expenses, in this case medical) and to her mental health needs, given that, in the latter case, some cognitive decline contributed to challenging her ability to navigate the complexities of simultaneous experiences with multiple systems of care while also weakened by illness.

I will use the example of the need to address my mother's obvious hearing loss. Over the years, my siblings and I encouraged her many times to get her hearing tested, but she always minimized the extent of her hearing loss and thus rationalized that she really didn't need to get it corrected. Her rationalization is explained, I believe, by a combination of her status as a child of the Depression and thus frugal and (probably related) her own determination to soldier on, even in the face of ameliorative remedies that would ease her burden. As a child of immigrants and of the Depression, she is no stranger to determination. She eventually agreed to a hearing test while recovering from her acute illness, probably because over those previous many months of medical treatment, she had come to accept her growing vulnerability and a role reversal. Increasingly, my siblings and I helped her make (or made for her) critical decisions necessitated by some cognitive decline and the challenges of negotiating simultaneously interfacing multiple systems of healthcare. Throughout and continuing to the present, she has remained in the role of emotionally caring and connected mother. My mother began, with the recovery phase of her illness, to loosen her steadfast resistance to medical care that is anything but absolutely necessary. She has been willing to increasingly trust that my efforts encouraging her to accept care beyond those previous acute needs might actually have merit. She has continued skeptical and concerned about money, but has somewhat reluctantly given herself over to my encouragement to follow through.

Once my mother was recovering and came to live with us, we found our way to the ("specialist") audiologist (i.e., higher co-pay than a primary care visit). The audiologist's testing confirmed that my mother was in need of hearing aids and, in the process of delivering the results of the hearing evaluation, the audiologist delivered critical information that was both sad and enraging. My mother's hearing loss, she said, is of the type that had progressed over many years. Because it went uncorrected too long, her brain permanently lost the ability to distinguish certain consonant sounds. (Because I was in the exam room as my mother was tested, I was able to experience first-hand some of the sound-distinguishing challenges. For example, she might hear "cat" as "cab.") This permanent loss of the ability to distinguish those consonants would extend even to whatever correction hearing aids might have otherwise offered. The audiologist further explained that my mother's experience of understanding oral communication, even with hearing aids, could be likened to trying to read from a text where some of the letters were left out of words; the reader has to figure out what is missing. Of course, there is a critical difference between reading (where one can take time to figure things out from context) and verbal communication. In the latter, while the hearer is working a puzzle to identify from context the right consonants to identify the speaker's intended words, the speaker has gone on with the conversation! The sadness I felt on hearing the results of this evaluation is obvious and

understandable: my mother had moderate to severe hearing loss that was only partially able to be corrected with hearing aids. Even with appropriate hearing aids, she would have to struggle to understand conversation. The enraging part was that, despite having for many years been under the care of a primary care physician with specialty training in geriatrics, the risk of uncorrected hearing loss was never explained to her or to any of us (and I suspect has not been explained to any of his other patients). Had this prospect been explained, the now permanent and uncorrectable might have been prevented. My mother's doctor had been remiss in not helping prevent the extent of her hearing loss. Additionally, my mother's situation highlighted a critical need for public health education to prevent others from suffering the same fate. Over time, I have also learned from the audiologist that wearing hearing aids can also contribute to stability of balance. So my mother wearing her hearing aids from the time she gets up until retiring for the night may also be critical to preventing other health problems, including further cognitive decline (Walling, 2012). Again, this seems like important public health information to which every older person and their families ought to have access.

Moving from health to financial aspects of my mother's care casts light on another dilemma she and millions of other older adults (really, people of all ages) face. The audiology consultation and evaluation are paid for by her insurance, minus a co-pay that is in excess of the co-pay for her primary care physician (i.e., referral to an audiologist is considered a co-pay for a "specialist."). Hearing evaluations are critical for all of us as we age, as my mother's situation illustrates. Yes, administering a hearing evaluation requires specialized training, but assigning a co-pay in excess of that for a primary care visit (in my mother's case, more than twice as much) creates a barrier to care, especially for older adults on fixed incomes. In addition to this and other barriers to preventing health decline that I have referred to here, news delivered by the audiologist that hearing aids are not routinely covered by insurance only added insult to injury, so to speak. I was incredulous, really. It turns out there is no federal mandate requiring that insurance cover hearing aids. It is left to each state to duke it out with insurance companies and, therefore, only a handful have passed legislation requiring insurance to cover hearing aids. In my mother's case, her hearing aids cost \$3,000, and this was only because she was able to use one of my deceased father's hearing aids, which could be re-programmed for her. I set out to learn the story behind the continuing lack of mandate for insurance coverage of hearing aids in the state where my mother lived. An audiologist there told me that the state professional organization for audiologists had repeatedly over many years advocated in the state legislature for coverage, but their efforts continued to fail year after year. It seems obvious to me that it would strain the resources of each state professional organization to have to advocate (let alone repeatedly over many years) for this legislative change; better, a concerted effort by the national association and its allies to effect policy change on the national level. For my part, meanwhile, I have had my consciousness raised about some of the serious barriers faced by elderly individuals to maintain functioning as hearing adults. Obviously, I cannot single-handedly get this policy change. I have, however, told my mother's audiologist that I am available to help with advocacy as this continues to be raised in this state, and I intend to raise the issue with my congressional representative as major changes in health care are being formulated.

My mother has recovered well. Tests show her illness is in remission. At 4 feet, 9 inches, she has gone from 72 to 105 pounds. At 93, she still wants to make a contribution, be useful, and stay

active. She would not want to go to a day program and engage in craft projects or games; she wants to be doing meaningful, useful, real-life work. My mother has taken the initiative to “own” several routine chores at our house (e.g., wiping and putting away dishes, folding laundry, emptying trash baskets, keeping her room “neat as a pin,” etc.). She routinely keeps her eyes open for things that need doing and volunteers to get them done (e.g., she pretty much single-handedly and ecologically rid our front lawn of dandelions this past spring, with the help of tools my husband bought her to ease their removal). The American Academy of Social Work and Social Welfare has identified this common aspiration among older adults to continue to be useful by designating “Advance long and productive lives” as one its twelve Grand Challenges (American Academy of Social Work and Social Welfare, n.d.). The real gap in my mother’s adjustment to her geographic relocation to our community has been finding social outlets for her. She does her best to stay in touch with family and friends back home, including reading the community newspaper online. It is hard to figure out, though, where a newly relocated, healthy, ambulatory, and sociable 93-year-old female can safely find peers with whom to socialize. One option that has presented itself for us is Senior Circle (www.seniorcircle.com), a national organization with local chapters affiliated with hospitals and, in our case, conveniently located within the same office as my mother’s new gerontologist. Still, the challenge in identifying appropriate social opportunities for older adults is not an isolated problem. More likely, many adult children are facing or will face the challenge of making social connections for functional older adult parents who relocate from a distance to reside with them. As the number of older adults increases, and as many of them remain in relatively good health (despite vulnerabilities that may require geographic relocation), the need for naturalistic systems to connect them with each other socially will only increase. The American Academy of Social Work and Social Welfare recognizes this need and the health and societal benefits that accrue from social connection and has included “Eradicate social isolation” among its twelve Grand Challenges (American Academy of Social Work and Social Welfare, n.d.). A dilemma for caregivers is how to effect these social connections for older adults in our care without unduly disrupting the exigencies of our other commitments, both professional and personal.

While the story I have chosen to tell here is not drawn from social work practice, I believe it is representative of the sorts of “cases” my colleagues who work with older adults and their families regularly confront. The needs of frail older adults (with “frail” on a continuum) demand comprehensive health and social policies that address needs often identified in the process of working a “case” but that cannot be ameliorated without action on the level of “cause.”

Returning to “The personal is political” slogan mentioned earlier, two applications seem pertinent here. The first speaks to the fact that the experience of caregiving is also a politicizing activity. One can hardly engage in caregiving without also becoming acutely attuned to the myriad issues raised by the gap between needs and solutions. In other words, we are politicized through the frustration of asking ourselves, “How do I and the person my family and I are caring for deal with the challenges presented by the lack of resources to address our dilemmas?” The second application of “The personal is political” slogan is that this caregiving experience has also further politicized me within my own profession. The National Association of Social Workers identifies its mission, in part, as the aspiration “to enhance the effective functioning and well-being of individuals, families, and communities” (National Association of Social Workers,

2017). My caregiving and advocacy experiences with my mother have served to reinforce my conviction that the social work profession can truly fulfill this mission only if the profession identifies and operationalizes practice strategies that fuel the latent synergistic power that can be unleashed by simultaneously working the micro and macro spheres of influence.

We need to further integrate social work into all forms of medical care for older adults to help rectify the seven problems Jansson identified as confronting consumers of healthcare services. Further, if we are to effectively and indelibly connect “case and cause” as one, social work will need to apply a new practice paradigm, one similar to the CAN model (2011) Jansson has devised for healthcare, but formulated to generalize for most, if not all, practice settings.

One way to effectuate a shift from the current bifurcated specialties of micro and macro practices is to increase the capacity for social work practitioners to access macro interventions within their practice settings, as in the CAN model above. This would shift from the current reality in which direct practice social workers often must to add on to and go beyond routine and expected practice activities in order to try to impact the macro issues related to their practices. Practice settings could integrate the micro and macro by building into the work setting not only the expectation (as in the current state of practice) but also the capacity to influence macro change. Professional standards of practice could call for routinely making explicit the nexus between micro and macro in supervision discussions, in direct practice documentation, and in policies and procedures within agencies. Doing so in agencies is a particular challenge for most social workers today since there are comparatively few actual social work agencies. With the establishment over the past few decades of insurance and managed care-driven policies and reimbursement for direct services, social work has largely ceded its exclusive practice domains, with some notable exceptions—namely child welfare of various sorts—to settings which are no longer administered by social work managers, but often by professionals in medicine or nursing, psychology, education and even by those in the legal profession or business. The impact has been that social workers are being used for their practice skills, but the influence of social work philosophies is absent from the settings in which many social workers work. Unlike, however, the stated intent within the social work profession to effect both the micro and macro, these other professions have no need to recognize, and therefore have no incentive to operationalize, macro aspects of practice. Thus, for social workers in these settings, any macro effort is just that, an “effort” that almost certainly will happen only if a particular social worker takes on the challenge, very likely outside the normal workday and certainly outside the expectation of and without any concrete support from the employer.

The wisdom and power of the person-in-environment perspective in social work must be preserved for social work to be maximally effective. The only way to harness the power of this paradigm is to incorporate into all practice settings the capacity to directly impact both the “case and cause.” To avoid doing so by not making explicit the integration of micro and macro into routine agency work is to maintain the status quo and continue to dilute the social work profession’s contributions to the lives of those we serve and to society generally. The experience of walking alongside my mother on her health journey has helped me see ever more clearly the need for one whole social work.

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About the Author: Renée J. Cardone, MSW, MA, LCSW practices social work part-time at Spring-Ford Counseling Services, a local (western Montgomery County, PA) non-profit agency and continues to support her mother in living a healthy and satisfying life (rjcardone@verizon.net).