

The Giving Caregivers

Resilience as a Double-Edged Sword in the Context of Healthcare

JULIANA SALDARRIAGA, *A Piece of Pie*

In this paper we challenge an assumption about caregivers of chronic patients that we've repeatedly encountered in our ethnographic fieldwork: that of the inherently and permanently resilient caregiver, or a person that, driven by feelings of affection for the chronic patient, will remain strong regardless of the challenges posed by the healthcare system or the disease itself. We describe three deeply rooted beliefs that explain why this assumption is still widespread within healthcare systems: the belief in caregiving as female calling, or the fact that women are assumed to have not just a biological advantage, but an interest in caregiving, the belief in individuality, or the fact that individuals are thought to have a preexisting and inalterable identity, and the belief in the pathological origin of mental illness, or the fact that we tend to ignore structural causes and social determinants of mental and emotional distress. We provide theoretical and practical evidence to support each belief and suggest tangible ways in which ethnographers and research teams working in healthcare can start to challenge said beliefs—and, as a result, transcend the assumption of the inherently resilient caregiver.

Caregiver resilience, feminization of caregiving, individuality vs. collectivity, social determinants of mental illness

INTRODUCTION

As ethnographers working in healthcare, we have witnessed an interesting shift: healthcare providers, pharmaceutical companies and other actors have started to move from a patient-centric to a more systemic approach, one in which the entire healthcare ecosystem acquires as much relevance as the patient. Due to this change in perspective, at *A Piece of Pie* we are pushing our very own relational-patient centric model, to observe the connections that exist between players and how these become a potential area of intervention (Camargo and Saldarriaga, 2021). It is by applying this model that we've had the pleasure of getting to know and working with the central subject of this paper, which is the caregiver, an actor that lives the patient's chronic illness in their own way.

It isn't radical to say the experience and the needs of caregivers must be considered. This is something that, even if not done on purpose, has still occurred spontaneously, considering caregivers sometimes accompany chronic patients during ethnographic interviews. What is different is that we argue there are assumptions about caregivers and caregiving that limit our capacity to genuinely understand and collaborate with this actor. A strong assumption, and one that we will question throughout this paper, is that of the inherently and permanently resilient caregiver, or a person that, driven by feelings of affection for the chronic patient, will remain strong regardless of the challenges posed by the healthcare system or the disease itself.

This romantic assumption of the caregiver is widespread, at least so in Latin America, where we've conducted most of our ethnographic fieldwork. There are several reasons why it is an assumption that must be critically approached to make way for more novel understandings of resilience. First, the imaginary of the inherently resilient caregiver allows budget-restrained healthcare systems to assume a passive role when it comes to supporting caregivers. It is common for healthcare providers, patient associations, among other actors to admire and praise caregivers, but such appreciations haven't been translated into concrete and permanent efforts. Second, a more genuine and holistic understanding of caregivers is essential to understand what "caregiver burnout", a concept that has become somewhat

generic, actually looks like: “The vagueness derived from the various ‘caregiver burden’ definitions limit the term’s relevance to policy-making and clinical practice.” (Bastawrous 2013, 431).

In this paper, we will describe three deeply rooted beliefs that reinforce the assumption of the inherently resilient caregiver and limit the capacity of healthcare systems not just to understand, but to support caregivers in ways that respect their agency. These are: the belief in caregiving as female calling, or the fact that women are assumed to have not just a biological advantage, but an interest in caregiving, the belief in individuality, or the fact that individuals are thought to have a preexisting and inalterable identity, and the belief in the pathological origin of mental illness, or the fact that we tend to ignore structural causes and social determinants of mental and emotional distress. We provide theoretical and practical evidence to show how deeply engraved these beliefs are in Western societies, but we also suggest tangible ways in which ethnographers and research teams working in healthcare can start to challenge said beliefs—and, as a result, transcend the assumption of the inherently resilient caregiver. This so as to not draw an entirely hopeless picture of the caregiver situation and to emphasize the importance of ethnography, the social sciences, and design to critically approach widespread and taken-for-granted assumptions.

THE BELIEF IN CAREGIVING AS FEMALE CALLING

As COVID-19 began to spread in 2020, the president of Mexico Andrés Manuel López Obrador addressed the nation and suggested that the women of each household would be the primary caregivers of infected patients: “Although women want to change their role, the tradition in Mexico has always been that the daughter takes care of the father. We men are more unattached, so daughters must be responsible for fathers and mothers.” (Sanabria 2020). This rather explicit affirmation perfectly illustrates our first belief, which is the belief in caregiving as female calling.

It is not a coincidence that the caregivers of chronic patients are usually the female relatives. This is what we’ve seen conducting fieldwork in Latin America, but the literature suggests it’s what happens in other regions as well. We don’t mean to say there are no male caregivers, this is starting to change and even more so in high-income countries (Lorenz-Dant 2021). Our point here is that, whenever a woman assumes the role of caregiver, it is regarded as normal and even expected, almost as if she had a biological advantage for this task. This normalization has several implications: the first is that caregiving is not regarded as work, but rather as an extension or a practical application of what we assume it is to be a woman: a loving, affectionate, and unselfish being that easily disregards their self-interest to support others (De los Santos and Carmona 2012). This happens to the point that caregiving is seen not just as possible for women, but pleasurable and fulfilling too—even in defying and challenging contexts such as Latin American healthcare systems. We have seen in our fieldwork and in the literature that caregivers of chronic patients might even say they “don’t work”, not because they’re not investing time and energy, but because they’re not receiving any compensation (Valderrama 2006). A second implication of this normalization is society and healthcare systems have, somewhat unconsciously, over-relied on these female caregivers. Caregiving is not a priority in the public agenda or in state-led initiatives, and yet maintaining the health of the population just wouldn’t be possible without them (Valderrama 2006). De los Santos and Carmona (2012) make a similar point when suggesting there are three agents that are responsible for providing care to the elder population (the state, the market, and the families), but that the reality—at least so in Latin American societies—is that the family will be the only source of caregiving an elder will receive.

We've seen a third implication in the field: female caregivers feel guilty whenever they don't perform their expected role properly. When conducting social media scans, we have come across female caregivers asking for advice on how to "remain strong". Comments such as these seem more common than comments admitting a lack of resilience, and thus it is only until a crisis—a dramatic manifestation of the burden of caregiving—that caregivers will challenge or reflect upon their normalized role. We once met a caregiver who suffered from face paralysis and didn't immediately understand why this had happened to her; it was only in retrospective that she realized it was a dramatic expression of the extreme stress and pressure she permanently felt. On another occasion, a divorced caregiver once told us she "finally snapped" when her two teenage sons were reluctant to visit and take care of their father, an Alzheimer's patient, for a single day. They told her they had already made plans because "they assumed" she would take care of him, a seemingly inoffensive remark that deeply struck her and made her, from that day onwards, more aware of her own needs. It is due to testimonies such as these that we've understood it is a revolutionary act for the caregiver to challenge her expected role and to understand that acknowledging her self-interest doesn't mean she has failed.

We recognize healthcare systems and actors such as pharmaceutical companies and patient associations are aware and have even addressed the caregivers' situation in many ways. In our fieldwork, it is not uncommon to come across brochures and other printed material, as well as online and onsite events, in which caregivers are given recommendations on how to take care not just of the chronic patient, but of themselves too. However, we argue these efforts are limited for several reasons: first, whenever Latin American patient associations address the caregivers' situation, they do so sporadically and tend to concentrate only on the caregivers that look after the patients with that specific chronic illness. We've rarely seen initiatives between association to focus on common ground and cross-pathology aspects of the caregiver experience. Second, these efforts can go by unnoticed by caregivers. For example, pharmaceutical companies, and specifically their patient support programs teams, have realized that women that have been caregivers for a significant time do not need information about the chronic illness, considering they have already gained empirical know-how on how to best manage the patient. Third, and related to what we just mentioned, it's important these efforts do not patronize caregivers. A geriatrician once told us he learned something new and significant whenever he interacted with caregivers during conferences and other events—and that this disposition to learn from (rather than just instruct) caregivers was unfortunately rare among healthcare professionals (HCPs). Lorenz-Dant (2021) even suggests caregivers must be recognized as "partners" in the care of people with dementia.

This disregard for the knowledge accumulated by caregivers can be explained on a more conceptual level: Colombian anthropologist Arturo Escobar suggests Western society became pervaded by expert and scientific knowledge in the nineteenth century, to the point that other knowledges became secondary and perceived as less objective and reliable (Escobar 2018). Since women healers have historically represented a more empirical approach to healing, the displacement of knowledges has a gender dimension to it: "The suppression of women health workers and the rise to dominance of male professionals was not a "natural" process, resulting automatically from changes in medical science, nor was it the result of women's failure to take on healing work. It was an active takeover by male professionals." (Ehrenreich and English 2010, 28).

As we already mentioned, besides describing each of our deeply rooted beliefs, we will also provide practical ways from ethnographers and research teams to challenge each belief. First, whenever the sample for qualitative or quantitative research is defined, the gender of

the caregiver must not be taken for granted or considered just for the sake of diversity. It must become a variable that is subject to analysis, so that research teams may observe how the belief in caregiving as female calling manifests itself and implies practical differences in the female and male caregivers' experience. For example: is society more permissive or more reprehensive of the male caregiver, in the sense he is seen as a man that is performing a female task? Second, a feminist or a gender-sensitive approach (also known as the gender lens) should be applied whenever caregivers are involved. This will enable research teams to map broader cultural dynamics and gender roles in which female caregivers are embedded. For instance, many Latin American women that become caregivers of chronic patients are already burdened with caregiving in general (of the household, of young children, etc.) and it is essential to acknowledge this. As stated by a caregiver interviewed by Valderrama: "First I took care of my children and when I turned 50, when I thought I could end my dedication towards others and take care of myself, I had to take care of my parents and now I take care of my grandchildren." (Valderrama 2006, 375). A gender lens must be adopted not just during fieldwork, but when designing questions guide and conducting analysis as well.

Third, research teams should take advantage of participatory design methods whenever interacting with caregivers. Following Ezio Manzini's "everybody designs" (Manzini 2015), respecting the agency and recognizing the know-how of female caregivers enables us to challenge reductionist conceptions of this actor. It is by applying these methods that we've realized, for example, caregivers are more interested in having moments of leisure or finding ways to make an income while taking care of the patient than in receiving what they regard as repetitive or superficial information on the patient's chronic disease. Finally, research teams should realize the benefits of the focus group for research on caregiving; an empathetic and genuine conversation between female caregivers is ideal to understand their experience is more complex than a test on their supposedly inherent resilience. In this sense, we believe patient associations and patient support programs, besides offering education on chronic illnesses, should look for ways to bring caregivers together. Providing them with this support network implies a more relational understanding of resilience, one in which resilience is not an inherent trait but a result of how supportive and enabling the caregiver's context is.

THE BELIEF IN INDIVIDUALITY

This second belief that prevents us from challenging the assumption of the inherently resilient caregiver has been widely explored in academic literature and can be summarized as follows: Western society is based on the modern idea of the autonomous and self-sufficient individual, or the individual as an atomic entity separated from its surroundings (Soares 2018). Escobar argues that "...the notion that we exist as separate individuals continues to be one of the most enduring, naturalized and deleterious fictions in Western modernity," (Escobar 2018, 83-84) and that we should look at non-Western cultures to understand there are more relational notions of personhood, such as the Buddhist idea of interbeing. It is also important to recognize the historicity of this belief: first, it was modernization and globalization that replaced communal forms of relating in Western societies (Esteva and Prakash 1998). Second, Western scholars have been able to theorize collectively, and this has enabled them to produce paradigms that determine how we understand reality; the individualism-collectivism duality is an example of this (Rautakivi et al. 2022).

Let's look at how this belief directly impacts our perception of caregivers. First, this belief suggests that, as human beings, we must be able to distance ourselves from our immediate context to understand ourselves in neutral and pure terms (Gordon 1988). Thus

the skills with which caregivers perform their role, including resilience, are considered preexisting and totally independent from their situation. Second, it is due to this belief that the individual becomes the obvious basic unit of analysis, and that society is reduced to a collection of individuals. This has led research teams in healthcare to map and address “patient needs”, almost as if patients existed in a void (although we recognize this is changing due to the growing awareness of the healthcare “ecosystem”), and to perceive “patient empowerment” as a phenomenon that occurs within patients—when in fact there could be an over-burdened caregiver that is sustaining this empowerment (Stajduhar et al. 2010). Third, the dominant theory of responsibility in the West is that of individual responsibility (Soares 2018); I am in charge of what happens to me, so if I don’t perform my role as caregiver properly, it’s because I just wasn’t resilient enough—not because my context was severe and challenging. This idea of individual responsibility is implicit whenever patient associations and other actors talk about caregiver burnout and how to prevent it: they always address the caregiver, as if it were solely up to them to avoid feelings of distress. We argue caregiver burnout should always be conceived in terms of its structural causes, not in terms of a caregiver’s inherent personality traits.

Finally, in a society where individuality is the norm, our understanding of collectivity is quite simplistic. We reduce collectivity to a concrete group of related or like-minded individuals (family and friends); we cannot see it as a broader and more abstract phenomenon, and this limits our capacity for collective action (Rautakivi et al. 2022). When we apply this to caregivers, patient associations in Latin America have told us they have a hard time engaging caregivers; they argue it isn’t uncommon for a caregiver to attend events once or twice and to then “get lost”. We believe it’s because caregivers would rather look for support within their families and immediate social circle, which is how collectivity is understood in Western societies. This implies that each caregiver’s experience will depend on their social capital, and we’ve certainly seen in the field: due to digital savviness, it is easier for younger caregivers to connect with other caregivers via social media. Another example, of course, is the fact that higher-income caregivers can afford a professional caregiver and access the HCPs of their choice.

To tackle this belief, the conversation should become less about the resilient caregiver and more about the contextual factors that enable or hinder that resilience. For this, we invite research teams to apply what American sociologist Matthew Desmond calls relational ethnography (Desmond, 2010). Desmond suggests we choose our ethnographic object carefully and encourages us to let go of categories, taking them as “curious somethings” rather than absolute truths. This way, he speaks of boundaries rather than bounded groups, and processes rather than processed people. What if our object of study is not the caregiver, but the relations and connections of this caregiver to other actors and their surroundings (Camargo and Saldarriaga 2021)? It is certainly an approach that enables us to challenge the belief in atomic individuals and atomic patients and to rethink resilience as something more contextual than an inherent and preexisting trait.

Additionally, research teams can overcome this belief by proposing collective solutions to the challenges identified in the field. Can we push those initiatives that could benefit more than one caregiver? An HCP we once interviewed thinks so. She argued healthcare providers, despite their limited budget, should contemplate how to intervene public spaces to promote inclusion of patients with physical and mental disabilities (certainly, a cross-pathology and collective approach) instead of solely focusing on providing access to pharmacological treatment. By collective solutions, we also mean solutions that involve the broader community, including actors that one would not contemplate when addressing challenges related to health. Consider how supermarkets, banks and public transportation

can become quite relevant when it comes to patients with Alzheimer's and other dementias. For example, Santander Bank is interested in offering dementia-friendly banking services in the UK. Activating these kinds of support networks for patients and caregivers is precisely what will enable the caregiver's resilience.

Another way to challenge the belief in the individual is to incorporate differential frameworks to analyze and process the information obtained in the field. In 2014, Native American writer Karen Lincoln Michel revisited Maslow's well-known hierarchy of needs, in which "self-actualization" stands at the top of the need pyramid and is thus understood as the ultimate goal. Michel argues that Maslow based his pyramid on the Blackfeet Indian Nation, but that he was selective and prioritized individual needs such as self-actualization, and left out "communal actualization" and "cultural perpetuity", which can be understood as collective needs (Michel 2014). This is an example of a framework in which how we relate to others and to our surroundings is perhaps more important than how we achieve our individual potential, as if we existed in a void. Finally, another interesting framework is that of the "saturated self" (Gergel, 1991): globalization, communication technologies and current social dynamics have led individuals to take on the personas and values of the people they interact with. Applying refreshing ideas of the self-concept gives us a better understanding of caregivers and of identity in general in contemporary societies.

THE BELIEF IN THE PATHOLOGICAL (AND NOT SOCIAL) ORIGIN OF MENTAL ILLNESS

In our fieldwork, we've encountered psychiatrists and psychologists that, during their appointments with chronic patients, also try to ask caregivers how they're feeling with their role and responsibilities. This suggests certain actors are already acknowledging caregivers require emotional support, however, we argue this has occurred organically and spontaneously, as the result of HCPs' own initiative and not of state-led initiatives or public policy. The result is that feelings of stress, anxiety and depression among caregivers are being treated only when they've reached a dramatic level rather than prevented. Scholars argue caregiving has all the features of a chronic stress experience: "...it creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance." (Schulz and Sherwood 2008, 23). It is so illustrative of this experience that it has even been used as model for studying the health effects of chronic stress (Vitaliano et al. 2003). Most HCPs we've interviewed are aware of this; a geriatrician once told us caregiving should be understood as a risk factor for the development of chronic illness later in life. We argue that our third belief, which is the belief in the strictly pathological origin of mental illness, explains why other actors besides HCPs, such as healthcare providers, payers, and the pharmaceutical industry, have not taken decisive steps to address the caregivers' emotional state and its structural causes.

There is an evident connection between this belief and the belief in individuality: individualization is precisely what leads us to see mental illness as an individual, chemico-biological problem: "We blame suffering on faulty minds and brains rather than on harmful social, political and work environments". (Davies 2021, 2). In this scenario, changing from one mental or emotional state to another solely depends on the individual. This is implicit in Western self-help discourses and life-coaching techniques and became widespread during the COVID-19 pandemic (in Colombia, for example, both leaders and word-of-mouth encouraged unemployed or struggling citizens to "reinvent themselves"). English theorist

and writer Mark Fischer describes this belief as “the privatization of mental illness” and suggests it has benefits for capitalism: first, it creates a demand for pharmaceuticals and leaves the structural causes of mental distress aside: “...by privatizing these problems [...] any question of social systemic causation is ruled out.” (Fischer 2009, 21). Second, individuals are taught to aspire to a reductive and hedonic model of mental health, one centered around healthy habits that are aesthetical. For example, is not uncommon for patient associations and patient support programs to offer yoga and mindfulness workshops to patient and caregivers alike. Not addressing the structural causes of mental illness explains why suicide rates haven’t been significantly reduced, despite a significant investment in psychiatric and neurobiological research (Davies 2021).

We need more studies that shine light on the social determinants of mental illness—and ethnographers and social scientists working in healthcare are essential for this. We also think research teams should always include family physicians—a primary care physician that practices family medicine—in qualitative and quantitative studies. We’ve had positive experiences with this HCP in Latin America (known as *médico familiar*) and argue their background enables them to identify contextual and household dynamics that may represent a threat to caregivers’ mental health. We also need diagnostic and screening tools that properly identify social (and not just pathological) risk of mental illness in a more formal way and apply them to caregivers of chronic patients (Andermann 2018). These screening processes could be incorporated into protocols and guides to map impaired health behaviors in caregivers (skipping their own medical appoints, poor eating habits, etc.) (Schulz and Sherwood 2008). Finally, we must acknowledge “treating” these social determinants of mental health means advancing in public policy rather than individualized pharmacological treatments and therapies (Shim 2018). This suggests the kinds of actors we should work with besides healthcare providers: public officers, NGOs, etc.

CONCLUSION

Critically approaching the assumption of the inherently resilient caregiver is a challenging task, one that requires we recognize deeply rooted beliefs about caregiving, such as the ones we’ve described in this paper. To not take for granted the belief in caregiving as female calling, the belief in individuality, or the belief in the pathological origin of mental illness, we argue research teams in healthcare must be interdisciplinary; an interdisciplinary team has a higher capacity of coming across analytical frameworks that can be applied to recognize deeply rooted beliefs. For example, a team member with a background in gender studies will be more attentive to the gender roles that are at play in the experience of caregivers, or a team member with a background in psychology can be more critical of well-known frameworks, such as Maslow’s rather individualistic understanding of human needs. We also insist on the presence of ethnographers within these interdisciplinary research teams; ethnographers possess not only the theoretical knowledge and the practical tools, but also the sensibility to spot cultural, contextual, and structural dynamics that affect how people behave and relate to each other—and this is essential to rethink what resilience is in caregiving. Applying ethnography to understand and work with caregivers becomes even more urgent when we consider population aging is a demographic “megatrend”. According to the World Health Organization, the proportion of the world’s population over 60 years nearly doubled between 2015 to 2020. An increase in older people also implies an increase in caregivers, so addressing our assumptions about caregivers should happen sooner rather than later. The United Nations General Assembly even declared 2021-2030 the Decade of Healthy Ageing, something that could actually be used as platform to generate awareness

about the caregiver's situation and specifically about the assumption of resilience as inherent trait.

We wish to conclude this paper with a reflection on the different types of evidence obtained healthcare research: the establishment of evidence-based medicine (EBM), which prioritizes techniques from biostatistics, engineering, and epidemiology, raises a question on the role of qualitative evidence in healthcare. Adams (2013) suggests the reliability and truthfulness of different types of evidence is codified in EBM: "In this approach to health care, the type of evidence that counts the "least", if at all, derives from what gets called "anecdotal" information [...] studies that foreground the individual speaking subject as the primary source of truth have virtually no purchase, nor do those additional truths garnered from the families, communities, or relationships that help form that speech." (Adams 2013, 56). As we've shown in this paper, the deeply rooted beliefs that must be challenged to adequately work with caregivers are more easily detectable by ethnographic means. This means ethnographers working in healthcare must insist on the differential value of their approach and also encourage discussions on the importance of caregiver's anecdotes and experiences in this new era of EBM. These are thought-provoking questions for ethnographers working in healthcare.

Juliana Saldarriaga is a Colombian anthropologist with comprehensive experience in healthcare consulting and a growing interest in medical anthropology and global health. As innovation manager at A Piece of Pie, she enjoys bringing ethnographic methods, as well as anthropological and feminist frameworks, into the pharmaceutical industry and its internal and external stakeholders.

REFERENCES CITED

- Adams, Vincanne. 2013. "Evidence-Based Global Public Health." In *When People Come First: Critical Studies in Global Health*, edited by J. Biehl and A. Petryna, 54-90. Princeton: Princeton University Press.
- Andermann, Anne. 2018. "Screening for social determinants of health in clinical care: moving from the margins to the mainstream." *Public Health Reviews* 39 (19). <https://doi.org/10.1186/s40985-018-0094-7>
- Arroyo, María Concepción and Verónica Montes de Oca. 2020. "Entre el deber y el querer: el proceso y las motivaciones del cuidado femenino en la vejez." *Revista Latinoamericana de Población* 15 (28): 30-62. <https://doi.org/10.31406/relap2020.v15.i1.n28.1>
- Bastawrous, Marina. 2013. "Caregiver burden—A critical discussion." *International Journal of Nursing Studies* 50 (3): 431-441. <https://doi.org/10.1016/j.ijnurstu.2012.10.005>
- Camargo, Selene and Juliana Saldarriaga. 2021. "Recalibrating a Patient-Centric Perspective in Healthcare Today". *EPIC* website. Accessed [July 3, 2022]. <https://www.epicpeople.org/recalibrating-patient-centric-perspective-healthcare-today/>
- Davies, James. 2021. *Sedated: How Modern Capitalism Created our Mental Health Crisis*. London: Atlantic Books.
- De los Santos, Perla Vanessa and Sandra Emma Carmona. 2012. "Cuidado informal: una mirada desde la perspectiva de género." *Revista Latinoamericana de Estudios de Familia* 4: 138-146.

- Ehrenreich, Barbara and Deirdre English. 2010. *Witches, Midwives and Nurses: A History of Human Healers*. New York: The Feminist Press.
- Escobar, Arturo. 2018. *Designs for the Pluriverse: Radical Interdependence, Autonomy, and the Making of Worlds*. Durham: Duke University Press.
- Esteva, Gustavo and Madhu Suri Prakash. 1998. "Beyond development, what?" *Development in Practice* 3(8): 280-296. <http://www.jstor.org/stable/4028743>.
- Fischer, Mark. 2009. *Capitalist Realism: Is There No Alternative?* Winchester: Zero Books.
- Gergen, Kenneth J. 1991. *The Saturated Self: Dilemmas of Identity in Contemporary Life*. New York: Basic Books.
- Gordon, Deborah H. 1988. "Tenacious Assumptions in Western Medicine." In *Biomedicine Examined*, edited by M. Lock and D. H. Gordon, 19-56. Dordrecht: Kluwer Academic Publishers.
- Lorenz-Dant, Klara and Mary Mittelman. 2021. "Sex and gender differences in caregiving patterns and caregivers' needs." In *Sex and Gender Differences in Alzheimer's Disease*, edited by M. T. Ferretti, A. Schumacher and A. Santuccione, 393-419. <https://doi.org/10.1016/B978-0-12-819344-0.00015-6>
- Manzini, Ezio. 2015. *Design, When Everybody Designs: An Introduction to Design for Social Innovation*. Cambridge: MIT Press.
- Michel, Karen Lincoln. 2014. "Maslow's hierarchy connected to Blackfoot beliefs." *A Digital Native American* website, April 19. Accessed [July 3, 2022]. <https://lincolnmichel.wordpress.com/2014/04/19/maslows-hierarchy-connected-to-blackfoot-beliefs/>
- Rautakivi, Tuomo, Ritthikorn Siriprasertchok and Harri Melin. 2022. *A critical evaluation of individualism, collectivism and collective action*. Tampere: Tampere University Press.
- Sanabria, Lucy. 2020. "Sigue la mata dando: AMLO vuelve a asegurar que por tradición las mujeres cuidan más a sus papás." *Sopitas.com* website, June 25. Accessed [August 14, 2020]. <https://www.sopitas.com/noticias/amlo-mujeres-mexicanas-tradicion-familiar-cuidar-papas-coronavirus/>
- Schulz, Richard and Paula R. Sherwood. 2008. "Physical and Mental Health Effects of Family Caregiving." *American Journal of Nursing* 108 (9): 23-27. 10.1097/01.NAJ.0000336406.45248.4c.
- Shim, Ruth S. 2018. "Addressing the Social Determinants of Mental Health: If Not Now, When? If Not Us, Who?" *Psychiatric Services* 69 (8). <https://doi.org/10.1176/appi.ps.201800060>
- Soares, Conceição. 2018. "The Philosophy of Individualism: A Critical Perspective." *International Journal of Philosophy and Social Values* 1. 10.34632/philosophyandsocialvalues.2018.2664.
- Stajduhar, Kelli, Laura Funk, Eva Jakobsson and Joakim Öhlén. 2010. "A critical analysis of health promotion and 'empowerment' in the context of palliative family care-giving." *Nursing Inquiry* 17 (3). <https://doi.org/10.1111/j.1440-1800.2009.00483.x>
- Tronto, Joan. 2006. "Vicious circles of privatized caring." In *Socializing Care: Feminist Ethics and Public Issues*, edited by M. Hamington and D. Miller, 3-26. Maryland: Lanham, Rowman and Littlefield Publishers.

Valderrama, María José. 2006. "El cuidado, ¿una tarea de mujeres?" *Vasconia: Cuadernos de historia – geografía* (35): 373-385.

Vitaliano, Peter P., Jianping Zhang and James M. Scanlan. 2003. "Is caregiving hazardous to one's physical health? A meta-analysis." *Psychological Bulletin* 129 (6): 946-972. 10.1037/0033-2909.129.6.946.

World Health Organization. 2021. "Ageing and health." *World Health Organization* website, October 4. Accessed [July 3, 2022]. <https://www.who.int/news-room/fact-sheets/detail/ageing-and-health>