BOOK REVIEW

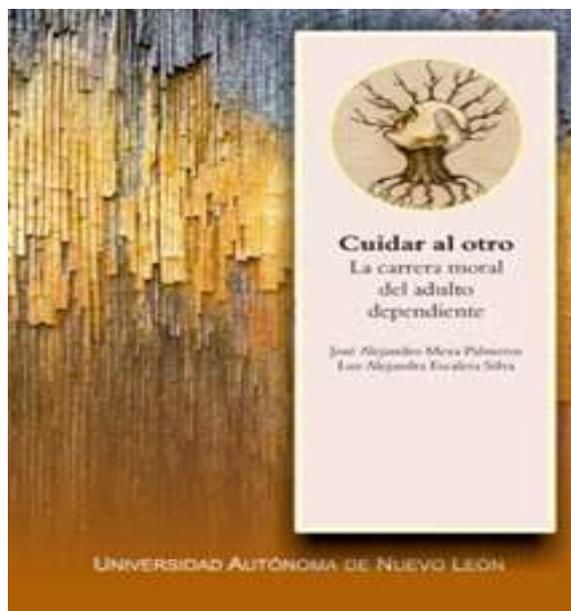# Caring for the other: The moral career of the dependent adult

Georgina Sánchez Ramírez

The fields of demography and global economics have been concerned with population ageing for more than four decades. Their view has been linked to the "burden" attributed by the neoliberal model to the ageing society. Regardless, the last 25 years have seen an emphasis on comprehensive care for a sector of the population that has been growing due to increased life expectancy. Such emphasis derives, in great measure, from the United Nations' (UN) Principles for Older Persons. However, international agreements that stress the need for nation states to respect the dignity, independence, participation, self-fulfillment and care of the elderly, are ultimately subject to the social policies, intentions and resources of each country involved. In the United Kingdom, a Ministry of Loneliness has been created at the express request of its First Minister, Theresa May. The ministry, which began operations in 2018, has as its main purpose the generation of social policies that promote greater interpersonal contact among the lonely population. It is estimated that in the UK, around 200,000 elderly people may spend up to a month without any kind of communication with another human being, a fact that seriously compromises their mental and physical health.

Although this phenomenon is of a global nature, we are concerned mainly with its manifestations in Mexico. Although the country is

Georgina Sánchez Ramírez. Expert in gender and health. Full time professor, *El Colegio de la Frontera Sur*, Mexico, San Cristóbal de Las Casas Campus, Chiapas, México. Correo-e: gsanchez@ecosur.mx

Source: ditorialuniversitaria.uanl.mx

ageing at a considerable rhythm, the landscape is rather confusing, as there are no clear budgets or public policies that stipulate how to meet the demands of the elderly. This results in abysmal gaps in the transit from old age to dependency and death, requiring the support of other social networks. In general, these are family members who must care for those who can no longer care for themselves due to old age.

However, this taking care of "otherness" does not happen automatically, as a promised gift of life. In most cases, it generates tensions, decisions, and measures that depend, not only on the degree of affection or availability, but on the economic, symbolic, moral and ethical resources of each human being involved in caring for the dependent person. Such is the focus of this book, in which Meza and Escalera present, in five chapters, a Medical Anthropological approach, framed within Human Rights discourse, to the dilemma faced by

all Mexicans when family elders become dependent on others to continue existing and living with dignity the last moments of their life.

Loss of independence is a feature of disability. Rather than being a guide to elderly care, this book provides a deep, serious and direct account of what happens when the dependency of the elderly becomes unmanageable for their families. This may be due to various reasons: the need for specialized medical care, a state of mental health that entails a risk to the person and other family members, or the lack of a strong emotional bond that would lead a family member to care for the person. These are decisive factors in the decision to relocate the elder into a family setting, or into an institution (such as a nursing home, charity house, or day center, among others).

Divided into 5 sections, the work is based on the Goffmanian methodological paradigm of *the moral career* (in this case, of dependent adults). In the first chapter, the authors offer a brief overview of the contemporary history of elderly people's rights, framing their research within a Human Rights paradigm centered on procuring dignity for the old of age. In Chapter 2, they give a historical context, problematizing the issue through a discussion of available figures. In Chapter 3, they develop a very clear theoretical framework, based on a Medical Anthropological approach, which is highly recommended for those interested in the study of ailments throughout the patient's career. In the fourth and last chapter, they provide a reading of the results through their scrupulous theoretical framework, arriving at conclusions and lines to follow within this emerging theme in the country's demographic, social and human agenda.

To further endorse this book, I would say that Chapter 1 is a valuable piece that can serve as a very useful reference for the new generation of studies on the elderly in Mexico and, I would dare say, in Latin America. The authors successfully establish the normative international context of elders' rights, recalling the UN's 1991 adoption of principles favoring the wellbeing of the elderly, as well as the creation of Pan-American instruments (without Mexico's ratification) in the 2015 Inter-American Convention on Protecting the Human Rights of Older Persons. This information is presented in a schematic and pedagogical manner, allowing us to grasp the magnitude of the issue of non-compliance with pro-human dignity laws, starting with a Kantian discussion of the subject and culminating in an analysis of current Mexican legislation.

In the second chapter, they present hard data on the situation of asylums, as well as a brief but substantial historical journey from the origins of elderly housing to the establishment of asylums in Mexico and, in particular, in Nuevo Leon province. They focus on two recurrent problems of such spaces: the permanent lack of trained care-taking personnel in all asylums, and the loneliness that must be endured by the people who are housed there. In such spaces, the lack of communication, a vital substance for the social beings that humans are, leads to a marked increase in health issues in the elderly.

Meza and Escalera make one of their greatest contributions in the third chapter, where they present the conceptual framework based on Goffman's patient's career, in a step by step manner that reads almost like a beginner's guide. They lucidly show how an individual's categorization within a social group - in this case, the permanently disabled - implies their redefinition in terms of cultural norms. Furthermore, they explain how this becomes possible through interaction with the environment, mentioning how "when we enter a hospital no more than a superficial glance is needed to distinguish the healthy from the sick". Through this approach, we come to understand a social category as a "definition given to an individual {sic] that has the capacity to alter their social destiny" (p.55).

Social labels operate as immutable tattoos that mark people's destinies, exerting a huge weight over the future of those who have an ailment that causes permanent dependence. Following this Ariadne's thread, the authors take up the issue from the perspective of Medical Anthropology, and the three levels of categorization that make up the event of illness: 1) Illness, which is the technical definition given by professional personnel, 2) Suffering, which implies the experience of suffering through illness, and 3) Malaise, which is the social perspective towards the behavior of those who "suffer" the illness. It is through the lens of Malaise that society deploys the guidelines for treatment:

rights, behaviors, therapeutic interventions, dignity or disrespect, mediated by the power exerted over the person labeled as ill.

Subsequently, Meza and Escalera give a more concrete example of the categories that derive in social labeling. In their mention of Waxler's work with infants cataloged with learning problems, they discuss how the way in which families were notified was mediated by their social class - rich or poor - and their power relations with the school institution. Such differentiation directly impacts the minors labeled with disability, becoming a social determinant of their eventual well-being as adults by affecting their career options and social relationships through their categorization as different and, therefore, unequal.

In addition to this conceptual classification, the authors fully engage with the moral question of who has the real, symbolic and decisive power of labeling. They indicate that morality is not always an element in the evaluation of professionals who diagnose, prescribe, treat, limit or accompany the "sick", "disabled" or "different" person. Since a diagnosis may have powerful repercussions on the destiny of the diagnosed person, one made erroneously - for diverse reasons, ranging from technical incompetence, to academic ignorance, to discriminatory social values such as racism, classicism, sexism, etc - entails a crueler future for the labeled person, as well as for their social milieu.

This theoretical background gives way to a discussion of the career of those who become ill. Splendidly honoring Goffman, Meza and Escalera define the patient's moral career [sic] as the changes over time experienced by all people belonging to the same social category, in this case dependent adults (and their relatives) situated within the institutionalization process. The authors gracefully guide the reader by the hand, making clear what they mean by career: a series of linked events that lead to an outcome that is not necessarily agreeable (dependency, to the degree that the person is admitted into an institution). The context of dependent persons will permeate their individual decisions, which become mixed up with the opinions of family members, friends, professionals and the people who surround them. Furthermore, the moral career of dependent persons is influenced by the power of professionals, in relation to which they become disabled beings.

The authors also explain elements of social assessment and standardization. They provide, as an example, the role that is expected of the patient and which, if transgressed, justifies the exercise of power over them, such as the sedation and/or confinement of people with mental illnesses considered unpredictable. They hasten to explain that, while the "role of patient" is not usual, in the case of chronic degenerative diseases, its use is pertinent to this book since it applies to dependent adults who suffer considerable social refusal when they transgress the behavior that is expected of them - that of manageable, obedient, submissive babies, with an almost inexistent presence that does not disturb -.

The above situation is compounded by the dominant economic system's disqualification of people who are no longer productive, although it may be more nuanced in alternative social contexts (as in, for example, rural and indigenous communities where treatment of elders is more linked to their effect and prestige within the social group). However, in both cases, the authors warn about the risks entailed by the fact that dependent people are at the mercy of their environment (impersonal, in institutions, and emotional, in their social group), which is marked by the historical moment's social values. It is essential to consider that older and dependent people's autonomy will wane throughout their moral career; thus, their self will be defined by those who accompany them in such career (caretakers, family members, and professionals, among others).

Meza and Escalera's fieldwork took place in an old people's home (casa de asistencia) in Monterrey (Nuevo León). They reconstructed narratives by interviewing family members of interned older adults, since most of the latter were diagnosed with severe cognitive dependency. Through a masterful methodological narrative, they trace the steps through which they were able to to compile the information and carry out the ensuing processing of qualitative data, captured with great clarity in the results chapter.

The presentation of the research results starts from the begging of the career: the moment when the status changes, the event that triggers a loss of autonomy in old age. They go on to focus on the

career's contingencies: What drives the train of our life to a specific station? What situations operate as determinants? The authors point, first of all, towards emotional bonds, guilt, and the acceptance of the dependent person's limited strength. This leads to difficulties in giving more attention to the dependent person and, ultimately, to the need for institutionalization. The closeness or aloofness of family members will depend on the affective and emotional bonds that have been previously established - or not - during the life of the dependent person. The decision to institutionalize will be defined by the "conscience" of the person who takes it, who must face dilemmas related to how they would like to be treated in such a situation, or what they would like to be done for them. It is a kind of human compassion that transcends the familial bond and is decided in the private realm.

Meza and Escalera also mention the legal mandate, which corresponds to the public arena. The obligation to take charge of the dependent family member is naturalized through the intermediation of third parties, under the safeguard of the law. The compiled narratives give an account of the complexities of being implicated all day and all night - under legal enforceability - in the care of someone who can no longer care for themselves, especially if that person is a family member two generations removed, without any kind of emotional relationship.

This is linked to other elements of conflict mentioned by the authors. If cognitive dependency is compounded by physical and economic dependency, the outlook is bleak, especially in a country such as Mexico, where the state increasingly cuts back on social welfare, leaving the full weight of the dependent person to the family.

The most heartrending narratives are seen in the cases where there is no minimum bond of affection or compassion with the dependent person, leading to inhumane treatment. Others are experiences of transgression, through which the bearable becomes impossible, and in which love is no longer sufficient because resources - physical, emotional, financial, among others - are no longer enough to allow for continued care of the dependent person. It is possible that isolation (caused by dependence) may make us unbearable,

putting us into a situation of greater isolation, which may in turn be exacerbated by difficult contexts such as small, isolated, or poorly articulated families, which is quite common in the modern world.

In this sense, I allow myself to make a comparison with Laura Gutman's (2009) argument that the solitary upbringing of small children is extremely exhausting and, in many cases, violent, isolating and depressing. She juxtaposes this to something she calls "tribe" children, a situation in which many other people support and interact in the care of minors, which results in more loving and humane parenting. In the case of the elderly, caring for dependent adults in solitary conditions can be exasperating and feel impossible. This could change if dependent adults were served by more extensive family and social networks, as the elders of urban tribes. Canada and Japan are successfully experimenting with social programs where they favor the interaction of different generations to tackle the loneliness and lack of love faced both by infants and the elderly population. The costs pay off when there is a real concern for citizens throughout the life cycle.

But the crude reality of this country is different and, in the face of the impossibility of taking care of otherness in isolation, arises what Meza and Escalera call the moral dilemma. This term alludes to the fact that whether the caretaker is transitional or definitive, involving a system of agents and agencies, will depend on the personal situation of the caretaker (health, support networks, financial resources), as well as on the exhaustion of the care-taking relationship since, in many cases, the caretaker's stress propitiates the transition to another caretaker in order to avoid ill-treatment.

Notwithstanding, the authors make reference to the fact that it is not always the family alone that makes the decision to institutionalize. It can happen through the intermediation of medical personnel or social workers who confirm the stress that is experienced in the care of the dependent person in question.

They also mention how, on occasion, third parties report the abuse or abandonment of the dependent person. In Mexico, if those complaints are made before an agency - of which the most appropriate is the DIF (System for the Integral

Development of the Family) - this may lead to a scenario colloquially referred to as "winning the raffle of the tiger". In this scenario, the Mexican State, via the DIF, adjudicates the responsibility of caring for the dependent adult alluding to questions of kinship (for example, a second-degree uncle with whom no contact has been had for decades, but with whom kinship can be proven, can become responsible after abandonment of the dependent person by closer family members). This means that a person can suddenly be faced with an unexpected responsibility, regardless of their readiness to take on this burden. Thus, the State disguises its incapacity and disinterest in the older adult population and the social policies regarding them, by transferring the care of the dependent person to the next available family member.

However, while taking charge of a dependent adult in a voluntary manner may generate the conflicts aforementioned by Meza and Escalera, having to do so under "legal enforceability" touches the central node in the contemporary issue of who will care for otherness. Thus, this situation brings together three elements of modernity: a greater life expectancy (older population with more dependencies and disabilities), the shrinking of State resources in terms of security, and the transition to institutionalization on behalf of the family, for which taking care of elders is no longer a moral imperative.

An even more serious case, reminiscent of the documented nightmares of most confinement institutions of earlier centuries - boarding schools, jails, mental asylums, convents, orphanages, and reformatory institutions -, is that of non-governmental agencies. In some of these, belonging to the Catholic Church, the institutionalized person is isolated from their family members "for ever" without any possibility of contact with the outside world. Thus (and this is one of the last sections of the book) emerges the question: where is the dignity of people throughout their lives, including old age?

The authors emphatically make the distinction that, unlike psychiatric patients, institutionalized elders can, according to the conditions of the space where they are interned, improve their situation. This may happen if, while interned, their health problems are better served,

they find themselves in cleaner and more harmonious spaces than their own homes of origin, or if they are provided with more affection and communication than in their previous living space.

It is possible that the outcome of this work will be a letter dedicated to the Mexican State, (and possibly to other Nation-States that are dismantling social welfare) and its social policies for the elderly. As has already been said, these are insufficient, lacking in dignity, as well as in economic, ethical and creative resources. The rise in the elderly population above 70 is one of the indicators of the development of a country, a situation before which it is critical and urgent to seek measures of protection and wellbeing.

In addition to the message directed at the State, this book is a whisper in the ear about what we as citizens refuse to recognize: old age - our own, close, distant or foreign. We live in a world where marketing advertises youth as the only valuable asset of the human species. This comes at the expense of the physical, mental, financial and emotional health of a population duped into the belief that tomorrow will not come, and that by not thinking about it, we can eschew the consequences of having a long life

Thinking about old age, dependence, and precariousness depresses us, anguishes us, turns us into unpleasant beings, doomsayers who question something that seems too far away. However, as this book points out, our biography marks and defines the conditions to which we will be subjected to at the end of our lives. Meza and Escalera's work fulfills its commitment to make us reflect on the present and the future, so as to fulfill our life journey with dignity. In thinking about our futures, we can feel solidarity with those who currently need us, while taking care of others. This also affords us the possibility to learn, to develop our humanity, and to conjure up the demons of our conscience with which we do not want to deal in our old age.

References

Gutman, Laura (2009) *The revolution of mothers: The challenge of nurturing our children*. Barcelona, Integral.