

**SENIORS CARING FOR SENIORS: THEIR PERCEPTIONS FROM
A COMPREHENSIVE POINT OF VIEW.**

MAYORES CUIDANDO MAYORES: SUS PERCEPCIONES DESDE
UNA MIRADA INTEGRAL

ANCIÃOS CUIDANDO ANCIÃOS: SUAS PERCEPÇÕES DE UM
OLHAR COMPLETAMENTE

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Abstract: Aging is a process that involves multiple changes in the human being, forcing some elderly people in a situation of dependency to require a caregiver. This is a qualitative study with a methodological approach of case study, aiming to know the perceptions of older people who are caregivers of another elderly people with severe dependence. In-depth interviews were conducted using content analysis. The following categories were defined: motivations, difficulties, caregiver emotions, self postponement for the sake of the other, family support, emotions associated with the diagnosis, religion, institutionalization, nursing care expectations, access to state benefits, and death. The results show that most caregivers are women, without family support, who have a sentimental bond with the person cared for, and that their motivations to perform this task where affection and obligation. Self postponement was observed; the caregiver devotes completely to this task, abandoning other activities and experiencing burden accompanied by economic limitations due to the low income they receive.

Keywords: Qualitative research, nursing, aged, perception, caregiver, elderly, nursing, dependence.

Resumen: El envejecimiento es un proceso que conlleva múltiples cambios en el ser humano, generando que algunos adultos mayores se encuentren en situación de dependencia y requieran un cuidador. Este estudio cualitativo, con enfoque metodológico de estudio de caso, tiene por objetivo conocer las percepciones de adultos mayores que son cuidadores de otro adulto mayor con dependencia severa. Se realizaron entrevistas en profundidad empleando análisis de contenido y se definieron las siguientes categorías de investigación: motivaciones, dificultades, emociones del cuidador, postergación por el bien del otro, redes de apoyo familiares, emociones asociadas al diagnóstico, religión, institucionalización, expectativas de cuidado de enfermería, acceso a beneficios del estado, y muerte. Los resultados muestran que la mayoría de los cuidadores son mujeres, sin apoyo familiar, que tienen un vínculo sentimental con la persona cuidada, y que sus motivaciones para desempeñar esta labor son el cariño y la obligación. Se observó postergación por parte del cuidador dedicándose por completo a esta labor, abandonando actividades ajenas al cuidado y experimentando sobrecarga acompañada de limitaciones económicas debido a los bajos ingresos que reciben.

Palabras claves: Investigación cualitativa, enfermería, anciano, percepción, cuidadores, dependencia.

Resumo: O envelhecimento é um processo que envolve múltiplas mudanças no ser humano, gerando algumas pessoas idosas em uma situação de dependência, exigindo um cuidador. Este estudo qualitativo, com abordagem metodológica de estudo de caso, visa conhecer as percepções de idosos que são cuidadores de outra pessoa idosa com dependência severa. Foram realizadas entrevistas em profundidade utilizando análise de conteúdo e foram definidas as seguintes categorias de pesquisa: motivações, dificuldades, emoções do cuidador, adiamento para o bem do outro, redes de apoio familiar, emoções associadas ao diagnóstico, religião, institucionalização, expectativas de atendimento de enfermagem, acesso a benefícios estatais e morte. Os resultados mostram que a maioria dos cuidadores são mulheres, sem apoio familiar, que têm vínculo sentimental com a

pessoa atendida e que suas motivações para realizar este trabalho são carinho e obrigação. O adiamento foi observado por parte do cuidador, dedicando-se completamente a essa tarefa, abandonando atividades que não sejam cuidados e experimentando sobrecarga, acompanhada de limitações econômicas devido à baixa renda que recebem.

Palavras-chave: Pesquisa qualitativa, enfermagem, percepção, cuidadores, idosos, enfermagem, dependencia.

INTRODUCTION

The rise of the aging index in Chile in the last decades shows an important social change related to the incorporation of a new age group with roles and characteristics in constant variation due to social restructuring (1). The National Institute of Statistics (INE) shows that, at the national level, in 2014 the number of older adults (people aged 60 and over) was 2.6 million, representing 15% of the total population, while in 2002 this figure was 11% (2). Based on these data, the National Service for the Elderly (SENAMA) points out that Chile has also been part of this demographic change. It is the second country in Latin America with a high percentage of people over 60 years of age (3).

In this context, aging poses challenges for health systems and also the economy and politics, since it brings with it inequities and problems of a population that has suffered the consequences of a harsh life history of work and sacrifice. This has created the need to implement initiatives to benefit this population, establishing national public policies such as the “Chile Cuida” (Chile Cares) Program. The current outlook for older people is linked to chronic noncommunicable diseases and socioeconomic risk; these factors can deteriorate the quality of life of older adults and affect their families (4).

The need of providing a permanent caregiver to meet the needs of the elderly has been studied, and the characteristics of the people who fulfill this role have been described, mainly wives and daughters of the person receiving care. Aging affects all members of each family nucleus. This study points out to the need to study people who, being older, have to take care of older adults, in order to get closer to their day to day experiences, allowing us to know how they perform this task and how it influences their quality of life from their own perception. Our ultimate goal is to contribute to the implementation of strategies that improve the living conditions of the elderly people of this country.

METHODOLOGY

This research corresponds to a qualitative study carried out in a Family Health Center in the northern sector of the city of Santiago. The objective was to know the perceptions of older adults who care for other older adults with severe dependence on their quality of life.

The paradigm used for this research is the post positivist: reality does exist, but it cannot be completely understood with certainty(5). For this research, the criteria of rigor

developed by Guba and Lincoln were used: credibility, transferability, dependence and confirmability (6), fulfilled through the field notes, transcriptions of the interviews with the interviewed person own review and triangulation of researchers.

The theoretical methodological approach used was the case study, used for small-scale researches within a time frame and limited resources, adapting to the context of the study in order to identify unique situations that deserve a special interest, thus allowing a closer look to the day to day routine of the person (7).

The data collection technique used in this study was the in-depth interview. The following units of meaning were previously defined: motivations, difficulties, emotions of the caregiver, self postponement for the sake of the other person and family support networks, considering also the possibility of obtaining other meaningful units through the interviews.

These interviews were transcribed by the authors themselves without editing and later analyzed through the methodology of content analysis. According to Mayring, content analysis allows us to discover the meaning of a message, classifying and / or coding the different elements in predefined units in order to identify their meaning objectively and systematically, thus achieving their interpretation (8).

For the selection of participants the convenience sampling method was used, which allowed selecting those accessible cases that would accept being included in the study. This is based on the convenient accessibility and proximity of the participants (9). Also, for this study, the criterion of theoretical saturation was considered: data collection ends when the information obtained gets repetitive, providing no new findings (10). This was achieved with the stories of six participants.

The participants of this study were selected considering the following inclusion criteria: being a senior citizen (60 years old or older), volunteers, of both genders, with an income of less than USD 412 per month (the minimum monthly income in Chile), who has been at least two years caring for another elderly person in a situation of severe dependence according to the Barthel index (11) and who signed the informed consent. In this research the ethical principles of social or scientific value were adopted: scientific validity, equitable selection of people, favorable risk-benefit ratio, independent evaluation, informed consent and respect for the registered persons (12). Considering that it is a qualitative research, the conditions of authentic dialogue were added to the aforementioned criteria, achieved by means of presenting the results to the participants (13).

This research was approved by the Human Research Ethics Committee of the Faculty of Medicine of the University of Chile with the approval Act of project No. 115- 2017 and by the ethics committee of the Family Health Center. The participants of this research signed the informed consent prior to conducting the interviews.

RESULTS AND ANALYSIS

The following table summarizes some background of the participants in this study.

Table 1: Characterization of the participants

Particip- pant	Age	Gender	Years caring	Age of person cared for	Gender of person cared for	Relation- Ship
LE	78	M	17	78	F	Wife
JV	69	M	4	63	F	Wife
RG	73	F	4	81	M	Partner
IP	68	F	3	68	M	Husband
MF	90	F	2	92	M	Husband
SM	63	F	17	89	F	Wife

Source: Personal Collection (2017)

From the inductive and deductive analysis process the meaning units were constructed: "*Motivations to care*"; "*Difficulties in care*"; "*Caregiver emotions*"; "*Gender*", "*Access to State benefits*", "*Religious beliefs*", "*Postponement as a person*", "*Family support networks*"; "*Expectations of nursing care*"; "*Fear of institutionalization*"; and "*Death*."

The units of meanings mentioned above are as follows: In the unit "*Motivations to care*" the participants state that the reasons that motivate the care are the fulfillment of a duty, plus the lack of options and the love for the family member who is prostrate. They consider care as a continuous struggle due to a lack of options and mainly due to the lack of support networks. Transcripts of their statements in Spanish are followed by an approximate translation to English.

"Yo creo que las dos cosas, porque si no fuera por el amor y el cariño no habría luchado tanto (toma una pausa y se emociona) y bueno, tengo que seguir luchando porque no queda de otra opción, no es que yo quiera porque sí, sino que no me queda de otra opción, es así de simple, es un deber..." (J.V.)

"I believe that both things, because if it were not for love and affection I would not have fought so much (pauses and gets emotional) and well, I have to keep fighting because there is no other option, it's not that I want to without a reason, it's because I have no other option, it's that simple, It's a duty ... "(J.V.)

The category "*Difficulties in care*" refers to the problems and limitations that caregivers face on a day-to-day basis. The participants point out that the main problems are economic and that the most important limitations are associated with the lack of time to perform other activities not related to care. The participants of this study receive two types of pensions: older adults who contributed to a pension program during their work life receive pensions through fund administrators, while those who did not but meet some government requirements receive a basic old age pension. In both cases, their

pensions do not exceed USD 412 per month, not enough to cover their basic needs. With regard to time limitations, caring for another person hinders the development of a normal life, so the caregiver must dedicate himself completely to the other person, postponing his/her personal issues.

"Y a veces nos falla el dinero también, sí... porque también uno saca una miseria de sueldo...que no te dejan desarrollarte como persona, o sea, no puedes hacer nada." (S.M.)

"And sometimes money is also a problem, yes ... because you get a very poor salary ... that does not let you develop as a person, that is, you can not do anything else." (S.M.)

The unit of meaning *"Emotions of the caregiver"* refers to emotions associated with the work performed. Sadness and anguish predominate, frequently expressed through weeping as the interviews develop, mostly related to the physical deterioration experienced by the person being cared for.

He llorado mucho, mucho. De verlo tan flaquito, si está tan flaquito, con los huesitos parados" (M.F.)

"I have cried a lot, a lot. To see him so skinny, he is so skinny, his bones protruding" (M.F.)

The participants highlight that at the time of knowing the diagnosis of their loved one, their first response was the denial.

"Siempre el no creer, no creer el cáncer, yo le decía: no tienes nada, te van a sacar esto (refiriéndose al tumor) y vas a quedar bien" (S.M.)

"Never believing, not believing in the cancer, I told him: you don't have anything, they are going to remove this (referring to the tumor) and you will be all right" (S.M.)

The unit of meaning *"Gender"* shows the view that the participants have regarding the gender roles imposed by the society as caregivers. There is a marked presence of these traditional roles in their discourse: that the woman must be the one in charge of the care and the man is the provider and family supporter.

"Es difícil porque los hombres no estamos preparados para cuidar. O sea, la mujer tiene un don especial porque la mujer desde chiquitita parece, nacen con ese don hasta toda su vida. Ven a los papás, a los hijos, van a trabajar, trabajan en la casa, si uno de repente que viene a hacer eso, cuesta, porque uno, uno va a trabajar, trae la plata, se va a la cancha a jugar fútbol. Ella está en la casa." (J.V.)

"It's difficult because men are not prepared to care. I mean, the woman has a special gift because the woman since she is a little girl seems to be born with that gift lasting her whole life. They look after the parents, the children, they go to work, then they work in the house. If one suddenly has to do that, it is difficult, because one, one goes to work,

brings in the money, then goes to play football . She is in the house. "(J.V.)

When reversing roles, caregivers mention that it was difficult for them to assume this position because the tasks they perform daily are socioculturally associated with the female gender.

"Yo cocino, yo hago todo acá. Tengo que lavar. Como una dueña de casa." (J.V.)

"I cook, I do everything here. I have to wash. Like a housewife."(J.V.)

The category *"Access to State Benefits"* refers to what caregivers think regarding access to state benefits supporting their task. They point out that there is a scarce supply of services at their disposal, which are not well perceived at first, but after knowing them better they value the help received. The initial distrust occurs because they see the helpers as strangers, who are not part of their family nucleus and who enter their home.

"Nos ha pasado con las del Chile Cuida que ella al principio no quería que vinieran a cuidarla, hacer la limpieza de la casa o a cocinar, pero en ese sentido nunca hubo problema porque siempre el almuerzo estaba... más bien llegaban a conversar" (L.E.).

"It's happened to us with the Chile Cuida staff. At first she did not want them to come and take care of her, do the cleaning of the house or cook, but in that sense there was never a problem because lunch was always ready ...mostly they came to chat" (L.E.).

However, the caregivers emphasize that they have benefited from the help provided by the "Chile Cuida" program.

"Felizmente, yo digo felizmente, que hay un programa, no sé si ustedes lo han oído hablar siquiera...Chile Cuida". (S.M.)

"Fortunately, I say fortunately, that there is a program, I do not know if you have even heard about it ... Chile Cuida". (S.M.)

In the unit of meaning *"Religious Beliefs"* it is clear that there is a strong attachment to religion in Chilean society. God is highlighted as an entity that determines their lives, that accompanies them, strengthens and comforts them in difficult moments.

"Sólo Dios va a saber qué es lo que me tiene en el destino, cierto, entonces hay que esperar no más". (J.V.)

" Uno sin fe no se hace nada. Es un apoyo, la fe que uno tiene, porque uno tiene alguien que uno se conversa con alguien y se llena de energía nueva porque si no, uno no sale..." (M.F.)

"Only God knows what will be my destiny, true, then we just have to wait." (J.V.)

*"One without faith does nothing. It is a support, our faith, because one has someone, can talk to someone, gets filled with new energy because otherwise, one does not make it ..."
(M.F.)*

The category *"Postponement as a person"* refers to the activities that they fail to perform, the deterioration of their self-caring and the importance that they place on the person they care for. The priority is to satisfy the basic needs of the loved one which often limits the self-care on the part of the caregiver. Although in some cases there is some adherence to recreational activities, most postpone their own needs and personal development for the benefit of the person cared for.

"Mi prioridad no es mi prioridad en este minuto tampoco, mis prioridades son estar con la mamá, terminar con la mamá". (S.M.)

"De partida, tuve que dejar de trabajar para cuidarla... una de las primeras causas. Y la segunda de que la enfermedad que ella tiene es progresiva, no tiene remedio, entonces me tuve que quedar con cuidarla no más." (J.V.)

"My priority is not my priority at this minute either, my priorities are to be with mother, to finish with mother". (YE.)

"Initially, I had to stop working to take care of her ... one of the first causes. And the second one is that her disease is progressive, it has no cure, so I had to choose to take care of her and nothing else." (J.V.)

Regarding the *"Family support networks"*, the opinions of the caregivers regarding the support received by their family is mainly to highlight its absence. The reports show that there is a separation of the members of the family nucleus regarding the job of caring. The responsibility falls completely on the older adult who exercises the role of primary caregiver, who must fulfill this task since there is no other person who wants to assume it.

"Tú sabes que en estas situaciones siempre hay uno que se hace más cargo que todos los demás, que todos los demás hacen vista gorda de todo y todos se olvidan de que fuimos cuatro, o sea que fuimos cinco, sin contar mi hermana que falleció, ellos se olvidaron de que también fueron criados por una mamá, no tan solo uno". (R.G.)

"You know that in these situations there is always one that takes more responsibility than everyone else, that they turn a blind eye to everything and that everyone forgets that we were four. We were five counting my sister who died; they also forgot that they were also raised by a mother, not just one." (R.G.)

In the category "*Expectations of nursing care*" caregivers talk about what they expect from the care provided by Nursing professionals. In their testimonies it is emphasized that what is expected is mainly a pleasant, affectionate and respectful relationship, hoping that the Nursing professionals will be vocational, always looking for the well-being of the elderly.

"Con cariño, no con que "ah, este viejo", siempre que sea con un cariño, con un don que tengan de cuidar. No faltando el respeto, tener respeto con todo." (I.P.)

"With love, not "ah, this old man", must always be with love, with a gift that they must have for this task. Not lacking respect, respecting everything." (I.P.)

The category "*Fear of Institutionalization*" shows a marked opposition on the part of the older adults interviewed to let the person being cared for to be institutionalized, preferring to exercise the care themselves even though the other members of the family are not present.

"No, no, no, no, eso sí que no, no. Nunca he pensado en eso, ni nadie de mi familia ha pensado "lo vamos a llevar, porque no te deja tranquila", no. Déjenme a mí, si ellos no quieren estar, pero yo estoy aquí." (J.V.)

"No, no, no, no, not that. I've never thought about that, nor has anyone in my family thought "we're going to take him, because he does not leave you in peace", no. Leave me, if they do not want to be, but I'm here." (J.V.)

In the category "*Death*" caregivers point out their concept of death and the emotions that emanate when thinking about the end of life. As old age is the culmination of the human being, death becomes a latent element in the stories of all the participants. It highlights the strong impact that this issue generates emotionally, causing them anguish and fear.

"Sé que la tengo que dejar partir con mi dolor fuerte que siento, sé que la tengo que dejar partir, tal vez yo soy egoísta en llorar, pero es algo de uno, tú no puedes evitarlo. Es un proceso demasiado fuerte, es un proceso demasiado duro". (I.P.)

I know that I have to let her go with the strong pain that I feel, I know that I have to let her go, maybe I am selfish in crying, but it is something that one feels, you cannot help it. It is too strong a process, it is too hard a process ". (I.P.)

DISCUSSION

The discourses of the participants show stereotypes of care traditionally associated with the female gender, which is consistent with the research carried out by Flores, showing that there is a marked social construct that associates the female gender with caregiving (14). When men assume this role they face the gender inequalities constructed by society, which are reversed in these situations and impact their perception, who state in their

stories that it has been complex to fulfill this role when not being prepared to assume it in a "natural" way. In the case of the men interviewed in this study there is a lack of expression of emotions which may be associated with gender stereotypes, which push men to stay stoic in the face of adversity, while women are allowed to openly express their emotions (15).

In some international studies it is pointed out that caregivers play a double role, since they are dedicated to the care of a dependent person and also perform a remunerated job (16). However, this trend is not maintained in the ones interviewed, who due to their age do not work any more and are dedicated exclusively to caring, meaning that the income they receive comes exclusively from their pensions. This is worrisome, considering the precariousness of the pension system in Chile, which does not protect the interests of the elderly and provides insufficient income to cover their basic needs. It also must be considered that the severe dependency of the person receiving care increases their daily economic expenses. The lack of economic resources is perceived by the caregivers as the main difficulty in their work, which prevents them from allocating income to other activities that are beneficial for their quality of life. This, added to the long hours devoted to care, the difficult access to health services and the absence of family support makes them feel overloaded. This is felt by all the participants in this research and is consistent with the reviewed studies (17). It is important to point out that in the literature reviewed it is clearly stated that in order for the caregiver to be able to cope, the work in the family must be distributed in an "equitable manner" so the task does not fall on just one person (14). However, the participants state that the care task falls solely on them, which aggravates the overload condition they experience.

Several studies indicate that the care of a person with dependence is associated with negative effects for the health of the caregiver, generally linked to the psycho-affective area such as depression. Likewise, the results of this investigation show that this situation is repeated among the participants; most of them indicated that they perceive a deterioration in their health after caring, especially in the area of mental health. Although it is not possible to establish a causal relationship between caring for someone and suffering alterations in health, it is important to consider that given the context in which care is exercised this could be stressed also by the fact that there is a sentimental bond with the recipient of care and who is assuming this responsibility without counting on the help of third parties (18).

Regarding institutionalization, it should be noted that studies conducted in Sweden show that the overload and the feeling of unmet personal needs in caregivers are associated with their desire to institutionalize the person they care for. This is contrasted with the findings of this research, which show a marked opposition on the part of the older adults interviewed to let the loved one to be institutionalized, preferring to exercise the care themselves, even though the other members of the family do not help (19).

Regarding the link that can be established between this study and Duvall's theory of the Family Life Cycle, it is possible to show that most families are in the eighth stage of this cycle, where the family nucleuses acquire the denomination of "elderly families",

concluding this stage with the death of both spouses. According to this phase, the goal is the exercise of mutual care in old age, which is not reflected in this study, since care is performed unilaterally. In relation to the tasks that must be fulfilled in this phase, the breach of the regulation between dependency and independence stands out, since there is no balance between these topics in the lives of the interviewed older adults. On the contrary, it is possible to appreciate how the caregivers fulfill the task of facing the illness and the near death of their loved one, making this topic latent in their stories (20).

Finally, according to the Theory of Orem, two types of care can be distinguished: the one exercised by the person on himself, called self-care, and the care that is given to another person who is not able to satisfy his/her basic needs on his own (21). In this study it stands out how self-care is affected in the health of the caregiver, not only in the physical aspect but also in the emotional and psychological aspect, impacting on their mental health.

CONCLUSION

Among the findings of this research are the sadness felt by the caregivers for the physical and mental deterioration experienced by their loved one, manifesting it through weeping throughout their stories. Caregivers are self postponed for the benefit of their loved one, abandoning activities outside the care and dedicating their time completely to meet the needs of the person cared for, experiencing an overload that impacts all areas of the human being. Regarding the difficulties, economic limitations predominate, where older adults receive income through their pensions that do not exceed USD 412 per month, not enough to meet their basic needs. This gets worse due to the lack of family support networks; the caregiver performs his work alone, without receiving help from third parties belonging to his family.

It is extremely worrisome that, despite the fact that the population is aging, there is little research regarding the care provided by older adults to contemporaries in a dependent condition. This is a pioneering study in this field. We hope this work could be the beginning of more studies deepening on this issue and that we can actively work on initiatives that contribute to improving the quality of life of this population.

Nursing participation is suggested in government support programs for the caregiver, such as the Chile Cuida program. Nursing is an art and discipline dedicated to the care of the human being and therefore should be the one who leads this type of initiatives, being the one that has more knowledge in the subject. Along with this, increasing knowledge on this subject will allow Nursing professionals to provide comprehensive and personalized care, according to the context that encompasses the daily life of caregivers.

This study provides a new vision, from the qualitative research angle, which allows to enrich the scarce information that we have on this subject, obtained so far through quantitative research.

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