




SURROGATE DECISION-MAKING IN OLDER PEOPLE WITH COGNITIVE IMPAIRMENT AND THE DELEGATION OF THEIR AUTONOMY: IS IT REPRESENTED?

**DECISIONES POR SUSTITUCIÓN EN PERSONAS MAYORES CON DETERIORO COGNITIVO Y SU DELEGACIÓN DE AUTONOMÍA
¿REPRESENTADA?**

**AS DECISÕES DE SUBSTITUIÇÃO EM IDOSOS COM DEFICIÊNCIA COGNITIVA E SUA DELEGAÇÃO DE AUTONOMIA
¿REPRESENTADA?**

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ABSTRACT

Objective: To analyze the ethical considerations in situations where older people with cognitive impairment delegate their decisions to third parties. **Development:** Reflective practice based on a narrative review of different sources of information. Population aging is a phenomenon where multiple challenges need to be addressed. Chile is at an advanced stage of population aging, with an estimated life expectancy of over 85 years to be reached by 2050. The World Health Organization (WHO) promotes healthy aging by strengthening functional capacity as an indicator of well-being. There are circumstances in which older people delegate their decision-making capacity to a third party. Surrogate decision-making, with its ethical and legal dimensions, should protect the person's dignity at all times,

regardless of the state of their health, and fully represent their ceded right of autonomy.

Conclusions: The discussion on surrogate decision-making and the protection of autonomy, even in the context of cognitive impairment, highlights the need to treat older people ethically and respectfully, challenging negative stereotypes and avoiding discriminatory and stigmatizing behaviors. Promoting equality, inclusion, information, and respect for the rights of older adults has a direct impact on their well-being and quality of life, which are fundamental elements that public health promotes in the context of active, healthy, and dignified aging.

Keywords: Aging; Cognitive Dysfunction; Decision Making; Personal Autonomy.

RESUMEN

Objetivo: Analizar las consideraciones éticas que surgen en situaciones donde las personas mayores con deterioro cognitivo delegan sus decisiones a terceros. **Desarrollo:** Trabajo de reflexión basado en una revisión narrativa desde diferentes fuentes de información. El envejecimiento de la población es un fenómeno donde se evidencian múltiples desafíos a atender. Chile se encuentra en una etapa de envejecimiento avanzado estimando una esperanza de vida sobre los 85 años para el 2050. La Organización Mundial de la Salud promueve el envejecimiento saludable mediante el fortalecimiento de la capacidad funcional como indicador de bienestar. Existen ocasiones donde las personas mayores delegan a un tercero su capacidad de decidir. Las decisiones por sustitución, que abordan dimensiones éticas y legales deben proteger la dignidad de la persona en todo momento, independientemente de su condición de salud y representar plenamente el derecho de autonomía cedido. **Conclusiones.** La discusión sobre las decisiones por sustitución y la protección de la autonomía, incluso en situaciones de limitaciones cognitivas, subraya la necesidad de tratar a las personas mayores con respeto y ética, desafiando los estereotipos negativos y evitando conductas discriminatorias y estigmatizantes. La importancia de promover la igualdad, inclusión, información y el respeto de los derechos de las personas mayores tiene un impacto directo en el bienestar y calidad de vida, elemento fundamental que la salud pública promueve bajo el contexto del envejecimiento activo, saludable y digno.

Palabras clave: Envejecimiento; Disfunción Cognitiva; Toma de Decisiones; Autonomía Personal.

RESUMO

Objetivo: Analisar as considerações éticas que surgem em situações em que pessoas idosas com deficiência cognitiva delegam as suas decisões a terceiros. **Desenvolvimento:** Trabalho de reflexão baseado numa revisão narrativa a partir de diferentes fontes de informação. O envelhecimento da população é um fenómeno onde existem múltiplos desafios a enfrentar. O Chile encontra-se numa fase avançada de envelhecimento, estimando uma esperança de vida superior a 85 anos até 2050. A Organização Mundial de Saúde promove o envelhecimento saudável através do fortalecimento da capacidade funcional como indicador de bem-estar. Há ocasiões em que os idosos delegam a sua capacidade de decisão a terceiros. As decisões de substituição, que abordam as dimensões éticas e legais, devem proteger a dignidade da pessoa em todos os momentos, independentemente do seu estado de saúde, e representar plenamente o direito concedido à autonomia. **Conclusões:** A discussão sobre as

decisões de substituição e a proteção da autonomia, mesmo em situações de limitações cognitivas, sublinha a necessidade de tratar os idosos com respeito e ética, desafiando estereótipos negativos e evitando comportamentos discriminatórios e estigmatizantes. A importância da promoção da igualdade, da inclusão, da informação e do respeito pelos direitos dos idosos tem impacto direto no bem-estar e na qualidade de vida, elemento fundamental que a saúde pública promove no contexto do envelhecimento ativo, saudável e digno.

Palavras-chave: Envelhecimento; Disfunção Cognitiva; Tomada de Decisões; Autonomia Pessoal.

INTRODUCTION

Chile is going through an accelerated process of population aging, which poses various challenges that need to be addressed. Recent studies indicate that the country is not adequately prepared to face this new reality.^{1,2} One of the imminent issues is long-term care, which is closely related to the growing number of dependent people in Chile. However, cognitive impairment should not be automatically associated with aging.³

Decision-making is an everyday activity for any individual, aimed at foreseeing consequences and achieving the most favorable results within the available options. However, it has been focused mostly on cognitive decline, due to its close association with dementia. Older adults who experience cognitive impairment or dementia are faced with a myriad of crucial decisions related to their hospitalization, institutionalization, or the progress of their medical condition.⁴ These decisions may reduce their autonomy and ability to care for themselves, which in turn leads to delegating their right to decide to other people.

Older adults are not exempt from making decisions permanently. These decisions are often related to medication, treatments, retirement, and domestic or financial matters. Nevertheless, this can become increasingly difficult when cognitive skills are impaired, especially in the case of dementia.⁴ Thus, making decisions on behalf of individuals in the context of loss of functionality raises a series of ethical, social, and clinical questions.

In October 2017, the agreements of the Inter-American Convention on Protecting the Human Rights of Older Persons (IACHR) were implemented in Chile.⁵ This agreement poses a series of legislative challenges for the Chilean state; it urges it to promote, protect, and guarantee the recognition and full exercise of the human rights and fundamental freedoms of older people, aiming for their inclusion, integration, and participation in society. These are complex challenges considering that ageism is rooted in society, and is a pervasive phenomenon, present in institutions, legislation, and policies worldwide.⁶

According to the 2021 Global Report on Ageism by the Pan American Health Organization (PAHO), this phenomenon arises when age is used to categorize and divide people, causing harm, disadvantage, or injustice, and ultimately undermining intergenerational solidarity. Ageism impacts health and well-being and hinders the adoption of effective policies and measures related to healthy aging. This damages people's health and dignity, as well as the economy and society in general, and denies people their human rights, preventing them from

achieving their full potential. In this context, it is the responsibility of the State to take all necessary measures to guarantee the highest possible level of health, by recognizing and respecting old age in a dignified manner.⁶

Decision-making is an everyday activity for any person, aimed at foreseeing consequences and achieving the most favorable results within the available options. Older people who experience cognitive impairment or dementia are faced with a series of crucial decisions such as hospitalization, institutionalization, or the progress of their medical condition. These decisions can result in a decrease in their autonomy and ability to care for themselves, which leads to delegating their right to decide to other people.⁴ These ethical considerations are complex when it is a third party who must make decisions regarding, for example, the health care of a patient or older person. The Chilean state faces a series of legislative challenges to promote, protect, and guarantee the full recognition of human rights.⁵

In response to this, the following question arises: What are the ethical considerations when an older person with cognitive impairment cannot exercise their right to freedom of action and delegates it to a third party? The objective of this article is to analyze these ethical considerations. Another question that emerges is how adequate surrogate decision-makers are to represent the right to autonomy that dependent older people have relinquished.

DEVELOPMENT

This article offers a reflection based on a narrative review, a broad publication that exposes and debates the progress or current state of a specific topic from a theoretical or contextual perspective. The search strategy used for the sources of information is not described, since it is based on an analysis of the literature published in books, print and electronic magazines, or scientific publications, and on the interpretation and personal critical analysis of the author.⁷

Population Aging

The Chilean population is experiencing a rapid aging process in the 21st century. According to the results of the 2017 census, more than 3 million people in Chile were 60 years old or older, representing approximately 17.3% of the total population.⁸ Projections from *Centro Latinoamericano y Caribeño de Demografía* - Economic Commission for Latin America and the Caribbean (CELADE-ECLAC) (2017) indicate that by 2025, nearly 20% of the Chilean population will be over 60 years old, with a notable increase in the group over 80 years old, which will represent around 25% of the total, with a predominance of women.⁹

This aging process is due to the combination of three main factors: a reduction in mortality before the age of 60, a decrease in mortality after the age of 60, and a decrease in birth rate.¹⁰ According to data from the 2017 CASEN survey, around 41.7% of Chilean households are composed of at least one older person, who in 86.6% of those cases is the head of the household. Additionally, the number of older people living alone has also increased, which implies they have less access to caregiving options. Between 2000 and 2017, the percentage of older people living alone in Chile increased from 9% to 18.9%.¹¹

One of the key aspects when it comes to health policies on healthy aging is to view health from a perspective that considers the history and functional capacity of people, which results

from the interaction between the physical and mental capabilities of each individual. This is considered an intrinsic capacity, together with environmental factors, making it the best indicator of health and well-being, beyond the mere presence or absence of disease.¹

Cognitive Impairment in Older People, a Public Health Approach

Due to the increasing nature of average age and longevity rates, a high percentage of patients with mild cognitive impairment is detected, which raises the question of how many will progress to moderate impairment or dementia in subsequent years.⁴

Cognitive Impairment (CI) is considered a pathological condition rather than a normal process associated with aging. It is used to describe people with cognitive deficits who do not meet the criteria for dementia.¹² It is estimated that between 5% and 20 % of people over 65 years of age suffer from CI, which can manifest itself in various ways, with memory being the most affected function in most cases.¹³ Cognitive Impairment is divided into two categories, according to the degree of functional impairment. Mild Cognitive Impairment (MCI) refers to cases in which no compromise is observed in the instrumental activities of daily living (IADL) or in basic activities of daily living (BADL), whereas dementia is characterized by progressive deterioration of IADL and BADL.¹²

The treatment of older people with some degree of CI raises more ethical issues than what can be observed in other age groups, due to their greater vulnerability in terms of disability and dependency.¹³ The quality of the decisions made could magnify this fragility. One of the ethical principles most mentioned in the field of bioethics is respect for autonomy, which is often compromised in older people with CI or dementia. Respecting a person's autonomy involves recognizing their cognitive capacity and preferences, including their right to hold certain points of view, make specific decisions, and carry out actions based on their own values and beliefs.¹⁴

Surrogate Decision-Making

There are certain situations in which people are not in a position to make free or autonomous decisions; due to the decline of their cognitive functions, they delegate their decisions to a third party. According to *Real Academia Española* (RAE), 'representing' means "to substitute for someone and perform their functions." There is an important variable in any representation or substitution that is not mentioned in the definition, since it may imply a voluntary delegation of power by the represented person to their surrogate decision maker so that the latter acts on their behalf in a specific situation. Surrogate decision-making is ethically relevant for the people involved since it directly impacts autonomy.¹⁵

Autonomy, in turn, is a fundamental aspect of personal dignity. Therefore, surrogate decision-making should only be considered in the event that possible aids cannot overpower the limitations.¹⁵ It is observed that the Convention on the Rights of Persons with Disabilities (CRPD) does not establish a clear definition of what is meant by "surrogate decision-making". The law considers the condition of "insanity" as an exceptional situation, in which the person loses all of their right of disposition, including their ability to perform actions related to their possessions. However, civil law in Chile does not adequately address progressive CI, being limited only to preventing the person from managing their assets.¹⁶

The main objective is to protect older people from possible abuse by third parties, thus safeguarding their autonomy, especially in the case of people with cognitive impairment, who are particularly vulnerable.¹⁶ The legal system designates those responsible for making decisions on their behalf, granting them legal representation and the responsibility to manage the limited autonomy of people with intellectual disabilities, seeking maximum benefit.¹⁷ However, the question arises as to whether the designated legal representatives are the most appropriate people to assume that role.

Surrogate decision-making is only ethically valid when it is based on respect for the dignity of the person. This type of decision-making is presented as an option when the person cannot make decisions for themselves, even with adequate support, due to insurmountable limitations in their capacity for self-determination. In these cases, the decision is made looking to significantly benefit the person.¹⁸

Ethical Considerations

It is fundamental to guarantee that older people can exercise their rights, including the right to autonomy. Every decision made by an older person is an exercise of their autonomy.¹⁹ In the field of healthcare, Informed Consent has been implemented to preserve the autonomy and dignity of the patient.²⁰ Nevertheless, complex ethical issues emerge when a decision is made on behalf of a person without their consent, with the argument that it is "for their own good." In these cases, surrogate decision-making may be an expression of dominance rather than supportive interdependence in accordance with the circumstances.¹⁷

The Inter-American Convention on Human Rights (IACHR) has recognized the right of older persons to make decisions, define their life plan, live autonomously and independently in line with their traditions and beliefs under equal conditions, and have mechanisms to exercise their rights, even when assistance is required.⁶

Several models in the field of mental health seek to preserve autonomy, such as shared decision-making, advance directives, and advance decision planning.³⁰ It must be guaranteed that people with disabilities can plan their future decisions under equal conditions. The goal is to respect and promote the autonomy and dignity of older people who have some degree of cognitive impairment. Unfortunately, this is not always clearly specified or defined; under certain circumstances, it is necessary to make prudent decisions that seek to respect the person as much as possible.¹⁶ Thus, standards of action and intervention must be established in order to achieve maximum respect for the vulnerable person.

Standards of Action

In surrogate decision-making, some factors determine the approach to action. There may be explicit information about the person's wishes, limited knowledge of their values and preferences, or even complete ignorance about them. In this context, three approaches to action can be identified: the subjective criterion, in which the person's previous instructions are implemented; the substitute judgment criterion, where a competent person makes decisions on behalf of another who is unfit, taking into account what the person would decide; and the criterion of best interest, used when the person's wishes are not known, in which case the option that would benefit them most is chosen.^{6,21}

Standards of Intervention

Situations arise in which surrogate decision-makers cannot adequately perform their duties, there is no express instruction on the part of the patient, or future decisions may be questionable. These circumstances require standards that seek to identify unqualified families, standards that identify cases in which special vigilance is required during the decision-making process, and standards that identify questionable decisions made by the surrogate.^{6,21}

This article has certain limitations. Being an essay, it may present biases due to the non-systematized inclusion and selection strategy. This can result in some ideas or concepts being too general and others simplified or omitted, depending on the author's criteria. This could lead to a partial representation of the original discussion or central issue. On the other hand, it does not address specific approaches, programs, or interventions that could make a difference in the well-being of older people in light of the aforementioned ethical considerations.

CONCLUSIONS

This article aimed to analyze the ethical considerations that arise when older people with cognitive impairment delegate their decisions to third parties, reflecting on the ethical aspects that guarantee the comprehensive well-being of older people, even when their autonomy is diminished or limited. The fact that Chile faces population aging in the context of socioeconomic, gender, and/or territorial inequality is highlighted, which poses multiple challenges that need to be addressed.

The increase in longevity implies not only a greater prevalence of chronic and degenerative diseases but also an increase in the prevalence of functional disability and cognitive impairment, affecting the degree of autonomy of older people at the personal, family, social, and/or economic levels.

Older people are at risk of being excluded and deprived of exercising their rights. This could lead to considering them as "incompetent"; however, despite losing their autonomy, they still maintain the capacity and mental faculties to make decisions related to their own life. A classic example is "institutionalization", a decision made by family members without consulting the affected person, which reveals ethical dilemmas that violate their fundamental rights.

Surrogate decision-making, defined as decisions made by a person on behalf of another when the latter has voluntarily delegated their ability to decide, must at all times protect the dignity of the person, regardless of the state of their health, and fully represent the transferred right of autonomy.

Accordingly, surrogate decision-making is only ethically valid when it is based on adequate respect for the dignity of the person. These decisions are presented as an option when the person cannot make decisions for themselves, even with the necessary support, due to significant limitations in their capacity for self-determination. In these cases, the decision is made looking to benefit the person.

On the other hand, the general rules that govern this process should be applied to older people who have the full capacity to give consent. These rules focus on ensuring that their wishes, both in their formulation and expression, are conscious and free at the moment of making a decision.

It is not appropriate to automatically assume that people with cognitive impairment cannot make decisions. Sometimes it is necessary to support them in this process, while in other cases it would be responsible to make decisions on their behalf.

In short, this article aims to show, from the perspective of public health, the contribution to promoting the comprehensive well-being of older people and the respect of their rights and autonomy. By addressing the ethical considerations related to the aging population in Chile, with its socioeconomic and health challenges, the need to guarantee the dignity and rights of older people is emphasized. The discussion on surrogate decision-making and protecting autonomy even in cases of cognitive impairment underlines the importance of treating older people respectfully and ethically.

By challenging negative stereotypes and avoiding discriminatory and stigmatizing behavior, this article addresses equality and respect for older people. The importance of promoting equality, inclusion, information, and respect for the rights of this population has a direct impact on their well-being and quality of life, a fundamental aspect promoted by public health in the context of active, healthy, and dignified aging.

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