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Supported decision-making for older people living with dementia: contributions from bioethics

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Abstract *The significant increase in the elderly population and the high incidence of chronic and degenerative diseases are a matter of concern with regard to issues inherent to promotion of autonomy and preservation of human rights and quality of life in this population group. Exercising the right to make a decision impacts various aspects of human life, such as health care, asset management, relationships, choice of housing, family care, religious activities and even daily routine activities. Supported decision-making (SDM) can be an important tool for promoting autonomy among elderly people living with dementia, as it consists of an approach based on respect for human rights, in which the aim is to establish control over the mechanisms for provision of support so that all people can exercise the right to make decisions inherent to their lives. In order to implement this more robustly in Brazil, it is fundamental to change the culture towards valuing elderly people and implementing the notion that protection involves offering mechanisms for promoting personal autonomy, which is partly achieved through encouragement of social engagement and strengthening community ties. In this regard, the notion of empowerment, based on concepts arising from Intervention Bioethics, is relevant.*

Key words *Aged, Dementia, Personal autonomy, Human rights, Bioethics*

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Introduction

The aging of the population has triggered discussions around the world, with prominence for topics relating to quality of life, healthcare and preservation of decision-making autonomy for elderly people[1]. However, at the same time that life expectancy is increasing, there is also notable presence of discriminatory acts in relation to elderly people[2].

Agism, a term used to describe acts of discrimination, stigmatization and prejudice towards elderly people, results from negative social constructs relating to aging[3]. It is increasingly present in western societies[4], and has been characterized as the third great "ism", after sexism and racism[5]. Age discrimination entails constant limitations and violations of the human rights of elderly people, who are sometimes considered to be "weak", "a social burden" or "unable to make decisions"[6]. Moreover, elderly people are constantly subjected to violations of excising their personal autonomy, especially with regard to decisions in the field of healthcare and asset management[7].

Old age brings greater propensity for chronic diseases that require social and state-led actions aimed at this stage of life. In Brazil, the number of elderly people has grown over the years. It has been estimated that by the year 2025, the elderly population will have tripled in relation to its size in the year 2000 and that by 2045 the number of elderly people will be greater than the number of children[8]. Furthermore, in 2016, Brazil had the second highest age-standardized prevalence of dementia in the world[9], such that from 2007 to 2017, there was a 55.5% increase in the number of deaths due to dementia in this country[10]. This demonstrates the urgency of action towards adoption of social, economic, healthcare and legal mechanisms for promotion and preservation of rights and quality of life in old age.

Dementia affects the elderly population to a greater degree and entails declining cognitive function. At its advanced stage, it may compromise the mental ability to make decisions[11], which has an impact on exercising personal autonomy. This matter is of relevance in that autonomy is an important construct of human dignity[12]. The power to make decisions and have them respected forms part of recognition of an individual as a person within society. Likewise, imposition of limits to this right, especially when supplanted by discriminatory acts, has the power to nullify a person in relation to society. However, even though dementia affects individuals' decision-making abilities, it cannot be considered to be the immediate reason for determining that a person is incapable of making decisions[13]. Thus, studies and actions are required, in order to contribute towards development of mechanisms for providing support for elderly people who wish to make decisions, so that they can do so and have these decisions recognized and respected[14].

Given the complexity of this topic and its individual and social impacts, discussions can take place within different fields of study. Bioethics, understood as applied ethics and as a field of knowledge in which multidisciplinary studies are developed[15], constitutes an important space for discussions regarding promotion of human rights[7,16,17] and care aimed towards elderly people[18], especially those living with dementia.

Supported decision-making (SDM) may be an important instrument for promotion of autonomy among elderly people living with dementia. It consists of an approach based on respect for human rights in which the aim is to institute mechanisms that provide support to enable all individuals to exercise their right to make decisions inherent to their lives. This approach arose as a criticism of the model of substitute decision-making, in which someone is nominated judicially to make decisions in the place of an individual who is considered incapable of making them[19], as occurs in situations of guardianship in Brazil.

The aim of this article was to discuss the approach of SDM and the possibility of applying it for promoting autonomy among elderly people living with dementia in Brazil. For this, theoretical perspectives relating to human rights, from the fields of law and bioethics, were used. This research was both theoretical and document-based, grounded in studies developed by Albuquerque[20], Donnelly[21-23], Shogren *et al.*[19,24] and Sabbata[13], in dialogue with the bioethical contributions brought in by Garrafa[15,25]. It was also based on the Convention on the Rights of Persons with Disabilities (CRPD)[26], on General Comment no. 1 of the Committee on the Rights of Persons with Disabilities[27], on the Interamerican Convention on the Protection of the Human Rights of Elderly People and on the document about Supported Decision-Making and Life Planning, drawn up by the World Health Organization (Quality Rights)[28]. These are internationally recognized documents on the topics of SDM and promotion of autonomy among elderly people living with dementia. In addition, regard-

ing the mechanisms used in applying SDM, this study was based on the document developed in Canada by Bach and Kerzner[29] regarding protection of autonomy and the right to legal capacity; and on the Brazilian legislation on this topic[30,31].

The paradigm of supported decision-making

In the 1960s, movements of greater strength that sought recognition for equality of the rights of people with disabilities started to become better known and more powerful around the world. Criticisms of practices imposed on people with disabilities, such as eugenics and sterilization, limitations on rights, segregation and discriminatory policies, were raised. At that time, people with disabilities were considered incapable of making decisions, especially those involving their health, financial affairs, legal decisions and relationships[19]. In 1982, in Canada, recognition of the right of people with disabilities to make decisions was strengthened through a decision by a Canadian court that recognized the right of Justin Clark, who had been born with cerebral palsy, to make decisions about his life[32], and recognize the importance of placing value on unconventional communication.

A series of events in different countries led to movement towards recognition of the equality of rights of people with disabilities, in relation to other people. Environmental barriers and stereotypes that limit opportunities and rights for people with disabilities were highlighted. Understanding of disability through a social model gained strength[19]. In 2007, the CRPD came into force internationally and expressly introduced the topic of legal capacity and the SDM approach within the sphere of human rights[33].

Article 12 of the CRPD states that for people with disabilities, their right to make decisions about their lives should be recognized, in equality with other people. Likewise, for the signatory countries, it defines the obligation that they should adopt appropriate measures for providing support mechanisms for people with disabilities. In accordance with the interpretation adopted in General Comment No. 1 of the Committee on the Rights of Persons with Disabilities, these mechanisms should include both formal and informal support[27]. This interpretation reinforces the understanding that new comprehension of legal capacity based on the SDM approach should be adopted, to the detriment of the regime of substitute decision-making.

It needs to be emphasized that legal capacity is the guardian of personal autonomy[22]. This refers to legal recognition of the titularity of an individual's rights, while also encompassing legal agency, which refers to capacity to personally exercise these rights[20]. In summary, legal capacity is what makes a person a subject with rights in the eye of the law. This differs from decision-making capacity, which is a matter of having the mental abilities needed for making a decision, and this does not have any direct link with any mental disorder or disease[20]. Decision-making is a process of receiving information and having the ability to comprehend, understand and weight it up and then elaborate and communicate a decision, while taking into consideration the possible consequences of the choice that is made[34]. In summary, decision-making capacity involves the abilities needed to make a decision, which may be influenced by social, environmental and health-related factors[20,22]. The two concepts are related, but cannot be confused. For this reason, a person with reduced decision-making capacity cannot have his or her legal capacity removed.

With regard to elderly people, articles 3 and 7 of the Interamerican Convention on the Protection of the Human Rights of Elderly People prescribe that dignity, independence, protagonism and personal autonomy are human rights belonging to elderly people. Article 30 lays down that elderly people have equal rights to the legal capacity to make decisions regarding all aspects of their lives[35]. This same provision states that countries should adopt measures that provide elderly people with access to the support that they may require in order to exercise their legal capacity. This document reaffirms the importance of legal capacity as a human right that should be recognized especially with regard to elderly people.

The SDM approach is a new paradigm that is consistent with an innovative movement that enables a new view of the legal and social premises that determine what a person is "incapable of doing", such that it becomes a question of "what would be necessary" for that person to be able to make a decision[36]. This change of perspective is in line with respect for dignity and also with promotion of autonomy for elderly people.

The main points from General Comment No. 1 are that support should be made available to all individuals who need it and wish to make use of such support; such that disabilities or illnesses should not be barriers to obtaining support. The forms of support should be governed by the individual's wishes and preferences and not

by what is perceived or interpreted to be in his or her objective best interests. The way in which an individual communicates also cannot form a barrier against obtaining support in making decisions, even if the means of communication is unconventional and the individual is only understood by a few people. Another point is that countries should facilitate creation and availability of distinct support mechanisms, including for people who live in a state of isolation. Thus, lack of financial resources cannot be a barrier against access to support and, for this reason, means that are free of charge should be provided. Furthermore, provision of support cannot affect personal autonomy or limit the rights of people who make use of it, given that such effects would impede them from making decisions. In addition, the support should not be an imposition and, for this reason, the individual must have the right to refuse it. In processes that involve legal capacity, there need to be safeguards to ensure respect for the individual's wishes and preferences. Lastly, provision of support should not be made conditional on an assessment of mental capacity[20,27].

The SDM approach contrasts greatly with the approach of substitute decision-making. In the latter, some people are considered not to possess the decision-making and legal capacity to formulate decisions and exercise their rights and, for this reason, other people should decide things for them. This thinking is based on the paternalistic concept that protection and promotion of the rights of certain individuals, such as elderly people living with dementia, should be done through mechanisms in which a third party will make such decisions in their name, based on the criteria of their objective best interests[20]. However, the SDM approach starts from the concept that protection and promotion of rights takes place through promotion of personal autonomy, among other factors[19,22], governed by respect for the individual's wishes and preferences[20].

In summary, the approach of SDM differs from that of substitute decision-making in its foundations. While the first is governed by the social concept of promoting egalitarian access to rights for all people, through recognizing and respecting their personal autonomy and raising the quality of human rights[19,20], the second is governed by the concept of inequality, in that some people, depending on their illnesses, age or other characteristics, are considered to be legally incapable and cannot exercise their rights. This understanding forms an affront to personal autonomy and consequently to human rights.

In the legal system governed by the approach of substitute decision-making, as is used in Brazil, guardianship processes are commonly used for nominating persons to make decisions on behalf of others[37]. On the other hand, the system governed by the SDM approach starts from the concept that, with adequate support at hand, individuals can exercise their legal capacity and make decisions that are in their own interest. In this approach, substitute decision-making mechanisms serve only for cases in which an individual is unable to manifest his or her wishes in person, such as when an individual is in a state of coma. Even so, such instruments need to be aligned with the SDM approach, in the sense that choices would be made in accordance with what the individual would have decided if he or she had been able to manifest these choices in person[27].

Some countries, such as Germany, Australia, Canada, United States, Ireland, Israel, United Kingdom and Sweden, have moved forward with regard to implementing practical mechanisms for SDM[19]. In a study developed in Canada, for example, seven types of support mechanisms were proposed. These were as follows: a) support for life planning, based on identifying the individual's values and aims; b) independent advocacy, based on aiding the individual towards expressing his or her wishes and exercising his or her rights and duties; c) communicational and interpretive support, with the aim of helping the individual to communicate through alternative routes, which could include signaling, gestural or vocalization systems, etc.; d) representation agreements, based on sharing the individual's biography with other people, through a relationship of trust and comprehension of the individual's means of expression; e) support towards construction of relationships, based on building up connections and support networks for sharing experiences; and f) administrative support, with the aim of helping the individual to bring into reality agreements that were made previously, such as in relation to financing, purchases and sales, etc. These mechanism could be used separately or together, depending on the personality, characteristics and unique needs of each individual[29].

Regarding healthcare, the World Health Organization (WHO) has drawn up a practical guide for implementing SDM mechanisms, especially in relation to their implications for healthcare. This guide states that informal mechanisms are mostly provided by family members and friends and are used by all individuals in their day-to-day lives. The following examples are mentioned:

support circles, as implemented in Australia and the United Kingdom; personal assistance; peer support; support from family members and friends; and community support. Formal support may be necessary for making complex or important decisions, and is more useful when informal support mechanisms are insufficient for supporting individuals with specific needs. The following were cited as examples: personal ombudsman, as implemented in Sweden; independent advocacy, as implemented in England and Scotland; and open dialogue, as implemented in Finland[28].

In addition, the WHO document lists some key principles for implementing SDM mechanisms, including recognition that all individuals have the right to make decisions. Another of these is the principle that individuals should have the opportunity to receive or reject support that is offered for making decisions, and should have the right to learn through experience and to make poor decisions. For cases in which a given individual's real wishes and preferences cannot be identified even after making significant efforts to understand them, the best interpretation of these wishes and preferences should be applied, with the aim of respecting this individual's right to legal capacity and personal autonomy[28]. In these cases, the individual can nominate someone who he or she has lived with and trusts, to represent him or her and make decisions that are needed, if this individual has the ability to express this[29].

Anticipated directives, living wills and advance care plans can be cited as SDM mechanisms that are important within the field of healthcare. These have the objective of making an individual's wishes and preferences explicit for future times when this individual might no longer be able to express them in person. Australia can be cited as an example of a country in which legislation, public policies and broad national incentives regarding support instruments for healthcare decision-making exist, including for elderly people living with dementia[38]. Moreover, through other instruments, wishes relating to other fields of life, such as finances, asset management or childcare, can be recorded.

As can be seen, the SDM approach introduces protection of legal capacity into the scope of huma rights, thus giving rise to the understanding that all individuals have the right to have rights and to exercise them in person, and can count on aid through support mechanisms, if needed[19,20]. This approach inaugurates an important differentiated paradigm with regard to comprehension that all individuals can exercise their personal autonomy and make decisions regarding their lives, including elderly people living with dementia[7,13,23].

Brazilian legal model

With the advent of the Convention on the Rights of Persons with Disabilities (CRPD), part of the Brazilian legislation was altered. The Brazilian law for inclusion of persons with disabilities (LBI) of 2015 instituted a series of rights destined for people with disabilities, including full civil capacity. To this end, the law provides a mechanism for SDM consisting of a legal process for SDM that has been incorporated in the civil code. It enables individuals with disabilities to have the right to nominate people who they trust, to assist these individuals through providing the means and information needed for them to be able to exercise their capacity[30]. This law therefore aids these individuals in making decisions about their lives. It determines that the guardianship process, i.e. the mechanism of substitute decision-making, should only be used as an extraordinary protective measure and should only affect rights relating to assets and business[31].

The civil code was also altered to remove the institution of interdiction, through which a person could be declared to have total legal incapacity and a substitute decision-maker could be nominated to make decisions regarding all aspects of that individual's life. The figure of guardian, instituted through a mechanism of declaration of partial legal incapacity, was maintained for cases in which an individual was unable to express his or her wishes, and for habitual drunks, addicts to toxic substances and profligate individuals[30].

The civil code expressly defines only one formal mechanism for SDM for use in Brazil, which limits its use to people with disabilities and is named "supported decision-making". However, there is an understanding that SDM mechanisms should be made available to all individuals who need them and want to make use of them, independent of their linkage to disability. This therefore encompasses elderly people living with dementia[13,20,23,27]. Although the institution of interdiction was excluded from the civil code, this change was implemented in the civil case code[39]. For example, article 755 of the latter makes mention of the process through which interdiction is decreed. This article is still used as the basis for decisions in which total guardianship of certain persons is determined[40], even if this contradicts the LBI. The statute for elderly persons also does not make reference to the possibility of use of

SDM mechanisms, and there is provision for use of guardianship to supply consent for elderly people who are undergoing healthcare treatments.

Although the alteration to the legislation was implemented in 2015 and laid down that institution of guardianship should only be used in exceptional cases, many guardianship actions have been presented in Brazil courts over the last few years. The SDM mechanism is little known within Brazilian society and its application within the Brazilian legal system remains tentative. In practice, Brazilian courts continue to make use of guardianship as a paternalistic protection mechanism[7,37], with declarations of incapacity to make decisions and nomination of substitute decision-makers who are often alien to the history and life of the elderly person concerned. This shows that the SDM approach has still not been properly implemented in Brazil[41]. For this reason, there is a need to make adaptations to the legislation, so as to harmonizer the legal provisions that deal with this matter, and to include the explicit possibility of use of support instruments for elderly individuals[7,42].

Practical experience from application of SDM in conjunction with the Public Defenders' Office of the Federal District has demonstrated that legal professionals have little knowledge of this subject. Moreover, there is little in the Brazilian literature that connects this approach with the scope of human rights, beyond the need to implement non-legal support aimed at creation of programs to aid people involved in care and support through offering training, guidance and other actions for stimulating use of the SDM approach[43].

Despite the legislative innovations introduced to the Brazilian model, the SDM approach as laid out in General Comment No. 1 can be seen to still be at an embryonic stage in Brazil[41,44]. Actions and public policies of greater robustness are still needed, in order to advance with practical implementation of the SDM approach, such that individuals are regarded as the subjects of their own life processes. Moreover, other support mechanisms based on this approach need to be developed.

SDM for elderly people living with dementia: contributions from bioethics for promotion of autonomy

The significant increase in the elderly population, with accompanying increases in the incidence of chronic and degenerative diseases that are more present in the final stage of life, like dementia, emphasize concerns regarding issues inherent to promotion of autonomy and the decision-making and legal capacity of this population group. Exercising the right to make decisions is reflected in various aspects of human life, such as healthcare, asset management, relationships, choice of housing, family care, religious activities and even day-to-day activities such as choosing clothes and food. Despite the topicality and relevance of this matter, the number of studies developed to cover it, especially in Brazil, remains small[43].

Dementia can be classified as a clinical state in which a decline in cognitive function occurs, involving loss of memory and judgment, limitation of motor movements of greater complexity and limitation of certain intellectual functions[45]. Despite the impact on cognitive functions, mental competence to make decisions about certain areas of life is maintained. For this reason, people living with dementia cannot be automatically considered incapable of making decisions about certain aspects of their lives[13,14].

According to the WHO[11], more than 55 million people live with dementia around the world, and Alzheimer`s disease is its most common manifestation. Every year, the number of new cases increases by around 10 million people. Dementia is the seventh largest cause of death among all diseases and is one of the main causes of dependency among elderly people worldwide[11]. However, although dementia is not an inevitable consequence of aging, elderly people are constantly stigmatized through this lens of incapacity[14] and, thus, suffer marginalization and infringement of their rights, under the aegis of paternalistic "protection" measures[2].

The WHO has fairly frequently published documents that address the need for respect for the human rights of elderly people, especially those living with dementia, and has signaled that a diagnosis of this disease should not cause restriction or loss of rights. Considering that legal provisions are not sufficient for ensuring rights for such individuals, there is a need for action at both social and countrywide level[46] towards developing support mechanisms for elderly people, their caregivers and their family members[47].

Being designated as incapable of making decisions gives rise to a series of negative consequences for elderly people's lives. It reduces self-esteem, trust, desire to live and engagement with one's healthcare[48]. For elderly people with dementia, the most important matter is that they

Ciência & Saúde Coletiva, 28(11):3149-3158, 2023

should be valued[49]. They report that their greatest loss is not in relation to cognition but to how they are valued and their relationships with other people[50]. SDM brings important contributions regarding respect towards elderly people living with dementia, through protecting them and promoting their autonomy[13,20,28,49], and enabling them to exercise contemporaneous relationships[51].

In this regard, in seeking greater effectiveness in applying the current Brazilian legislation regarding how elderly people are treated, it is opportune to introduce into this debate some bioethical, moral and structural propositions. These include the following: links between respect for personal autonomy and its counterpoint of paternalistic protection measures; development of specific mechanisms for providing support for elderly people living with dementia; establishment of family and social support networks; support mechanisms for difficult cases, such as the more advanced stages of dementia; and cultural change regarding discrimination against elderly people[7].

These matters should be addressed not only within the field of law but also through interlocution of different forms of knowledge[14]. Intervention bioethics comes in at this point. This is an antisystemic conceptual line of epistemological reterritorialization of bioethics that was developed in Latin America with the aim of providing understanding for social contexts and their impact on human life[25,52-54]. Through this, applied ethics is proposed as a practical solution for human dilemmas. It presents tools that are pertinent to the present discussion, which involves the perspectives of liberation, emancipation and empowerment of social subjects[15,54]. In this context, intervention bioethics prescribes that human life is permeated by social experience and that individuals are constructed through respect, otherness, valuation and development of the possibilities and abilities of each person, which flow together into the understanding that social connections form part of the exercising of autonomy[15]. At this point, it becomes fundamental to recognize that legal capacity is a human right and that the possibility of exercising this right implies respect for personal autonomy, through participative and supported decision-making[14,19].

Furthermore, starting from the concepts locked in through intervention bioethics, empowerment involves recognition of the power relationships that permeate human relationships, with highlighting of the need to unravel them so that respect for personal autonomy can be promoted, with taking into consideration the existential responsibility between human beings. This process aids in valuation of oneself and the other person, such that the individual figures as the central agent of his or her own history[25].

To implement the SDM approach in Brazil, aimed towards elderly people living with dementia, there is a need to adopt a series of measures at countrywide, social and individual levels[14]. A change of culture is fundamental, so as to place value on elderly people and on the notion that protection involves offering mechanisms for promoting personal autonomy[20]. This is partly achieved through making information available and encouraging social engagement. At this point, discussions coming from intervention bioethics have been shown to be appropriate.

Social inclusion, in the sense developed here, presupposes a collective conscience regarding the need for respect for the dignity of elderly people. It comes from relationships of empathy and solidarity towards other people, especially those who are most vulnerable, with a commitment not to infringe the rights that are inherent to these people[54-57]. It should be emphasized that personal autonomy is an element of fundamental importance regarding respect for human dignity[20] and other basic rights.

The SDM approach indicates that different support mechanisms can be aimed towards a variety of fields of life, which may include asset management, personal care and healthcare, among other matters. In the case of people living with dementia, the possibility of making decisions through support that is made available offers the opportunity to continue making choices and, to some degree, maintain control over important aspects of their lives, based on their own wishes and preferences. With regard to healthcare, for example, having the ability to make choices regarding the course of therapy generates engagement with the care provided and contributes to improvement of the patient's state of health[22]. In this regard, the presence of dementia does not signify the end of moral personality[23].

Even though the Brazilian legislation limits the scope of use of the SDM instrument to people with disabilities, its use may in practice also extend to elderly people living with dementia. Use of this instrument, especially when based on the notions of empowerment, promotion of autonomy and social inclusion among elderly people, can bring in important contributions towards putting these individuals' human rights into effect.

Final remarks

Use of the SDM process in Brazil is still at an embryonic stage. Strategies for refining and improving the process need to be identified, with assessment of the benefits and risks and adaptation of its use for the specific circumstances of elderly people living with dementia.

In this regard, an approach aimed strictly at legal experience has been shown to be insufficient for reaching the objective. Support from the field of bioethics may contribute to moving discussions forward, towards greater social participation among people living with dementia. This may also encourage formulation of public policies aimed towards adoption of a culture of support for elderly people, their caregivers and their families, and for society.

The paradigm implemented through the SDM approach indicates that there is a need for profound change regarding the way in which diseases and disabilities that affect mental abilities for decision-making are understood and dealt with, especially with regard to elderly people. Notions of empowerment and promotion of autonomy bring out the important reflection that strengthening of social ties and the support network are fundamental for development of mechanisms aimed towards changing the scenario of discrimination against people with dementia, starting from the notion that decision-making is a human right and that putting this into practice is an individual-level, country-level, legal, social and, above all, moral duty.

Collaborations

ILOM Cunha worked on the design, research, writing and final review of the article. V Garrafa worked on research orientation, writing and final review of the article.

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