

Physical disability in old age: a structural study of social representations

Deficiência física na velhice: um estudo estrutural das representações sociais

Deficiencia física en la vejez: un estudio estructural de las representaciones sociales

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ABSTRACT

Objective: To know the structure of the social representations of older people regarding disability in old age. **Methods:** This is a qualitative, exploratory, and descriptive study based on the theory of social representations. Participants was twenty-two elderly people aged 60 or older, of both sexes, who have some physical disability acquired in adulthood, registered in a center specializing in physical rehabilitation and hearing in Vitória da Conquista/BA. The instruments were a socio-biographic questionnaire and the free association of words test. **Results:** 110 free evocations, processed by EVOC software generating a four houses frame. The structure of social representation revealed that the acquisition of physical disability can produce dependence and sadness, but it must be faced and overcome. **Conclusion:** Knowing these representations is important to develop strategies to improve the quality of life and decrease the stigma of this population.

Keywords: Elderly; Aging; People with Physical Disabilities; Prejudice.

RESUMO

Objetivo: Conhecer a estrutura das representações sociais de pessoas idosas a respeito da deficiência física na velhice. **Métodos:** Estudo qualitativo, exploratório, descritivo, fundamentado na teoria das representações sociais. Participaram 22 pessoas idosas a partir dos 60 anos, de ambos os sexos, com deficiência física adquirida na fase adulta, cadastrados em um centro especializado em reabilitação física e auditiva em Vitória da Conquista/BA. Os instrumentos aplicados foram um questionário sociobiográfico e o teste de associação livre de palavras. **Resultados:** Resultaram 110 evocações livres, processadas pelo software EVOC gerando um quadro de quatro casas. A estrutura da representação social revelou que a aquisição da deficiência física pode produzir dependência e tristeza, mas deve ser enfrentada e superada. **Conclusão:** Conhecer essas representações é importante para o desenvolvimento de estratégias que visem melhorar a qualidade de vida e diminuir o estigma dessa população.

Palavras-chave: Idoso; Envelhecimento; Pessoas com Deficiência Física; Preconceito.

RESUMEN

Objetivo: Conocer la estructura de las representaciones sociales de personas ancianas con respecto a la deficiencia física en la vejez. **Métodos:** Estudio cualitativo, exploratorio, descriptivo, fundamentado en la teoría de las representaciones sociales. Participaron 22 personas ancianas a partir de los 60 años, de ambos sexos, con deficiencia física adquirida en la fase adulta, registrados en un centro especializado en rehabilitación física y auditiva en Vitória da Conquista (BA). Los instrumentos aplicados fueron un cuestionario sociobiográfico y el test de asociación libre de palabras. **Resultados:** Resultaron 110 evocaciones libres, procesadas por el software EVOC generando un cuadro de cuatro casas. La estructura de la representación social reveló que la adquisición de la deficiencia física puede producir dependencia y tristeza, pero debe ser enfrentada y superada. **Conclusión:** Conocer esas representaciones es importante para el desarrollo de estrategias que visen mejorar la calidad de vida y disminuir el estigma de esa población.

Palabras clave: Anciano; Envejecimiento; Personas con Deficiencia Física; Preconceito.

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INTRODUCTION

Population aging presents itself as a worldwide phenomenon today, and Brazil is a country that ages apace. According to the census data of 2010¹ people aged 60 or over account for 23.5 million, more than twice as high as in 1991, when the age group accounted for 10.7 million elderly people. The presentation of this scenario may reflect the combination of several factors, such as the decline in fertility rates, mortality reduction, extension of life expectancy, improved health services, and the use of new technologies in general, among others.¹

Within this increasing group of elderly people in Brazil, it is also possible to detect a large number of people with physical disabilities.² This phenomenon may be associated with the increased incidence of non-curable chronic degenerative diseases, such as *diabetes mellitus*, diseases of the circulatory system, cerebral vascular accident, among others, which have a higher incidence in this age group, and that may result in the amputation of a limb or the installation of a hemiplegia.¹ Moreover, another factor that predisposes the elderly to acquire a physical disability is the very process of human aging, in which several factors are involved, such as biological, physiological and neurological, which can lead to natural and gradual loss of vision, hearing and functional capacity.^{2,3}

Even with this strong presence in terms of demographic and epidemiological percentage, aging and disability still populate the human mind with prejudices and are described as something negative, a period of life dominated by fragility, illness, addiction, disability and unproductivity. Society generally takes a stigmatized position, setting a secondary role in various social contexts, such as work and family for these individuals.⁴ However, it is observed that older people with some kind of physical disability, have in their life history, experiences of adaptation and overcoming challenges arising from the aging and the acquisition of physical disability, thus feeling still able and productive within the social context where they live.⁴

Given this reality, we sought to develop this study by adopting as a theoretical and methodological support the theory of social representations proposed by Moscovici,⁵ which defines the representations as a complex system of opinions, attitudes, beliefs and information relating to a given social object that influences social behaviors, knowledge and communication between people. Social representations comprise a set of concepts, statements and explanations through which the interpretation and even the construction of realities are proceeded.⁶ They encompass thoughts, feelings, emotions, practices, affections and cognitions, which, despite some durability, are presented in constant change in time and history. Thus, it can be considered that the social representations of older people regarding disability can directly influence the way of being, thinking and acting of these people.⁵

One of the social representations study approaches is the structuralist approach or the central nucleus theory developed by Jean-Claude Abric,^{6,7} this being a "complementary approach" to the theory of social representations of Moscovici, from which emanate his most striking features regarding the systematic involvement with experimental practice, thus providing a more fruitful complementarity.⁶ This approach emphasizes the social representations and have contents subject to a hierarchical structure formed by two social cognitive systems: the core (hard, consistent, stable, consensual, which defines the group's homogeneity, linked to the collective) and the peripheral system (flexible, sensitive, integrating individual experiences, where the heterogeneity of the group is expressed).^{6,7}

The core of the representation would be marked by consensual knowledge that is shared by the group, providing homogeneity and ensuring the continuity of the group. It is this central core that provides the meaning and determines the organization of all elements of a representation.^{6,7} The peripheral system is more flexible, allowing the difference and contradictions in the group, adapting to reality and to the differentiation of the representation content and central system protection.^{6,7}

Thus, the social representation is an organization of meaning that operates as a reality interpretation system that governs the relationship of individuals with their physical and social environment, determining their behavior and practices.⁸ This determination is made by the subjects themselves through their history and their experience, or social and ideological system in which they are inserted and the nature of the bonds that will establish this social system.⁸

Thus, the relevance in carrying out this study is based on the fact that the physically disabled elderly individuals represent an increasing segment of the population. After becoming aware of the perception and the meaning attributed to the acquisition of a physical disability by the elderly, it is possible to know in a broader and deeper way the difficulties, challenges and adaptations experienced by these people, and thus deploy and develop actions in the areas of health, welfare, rights, accessibility, among others, which will ensure better living conditions for this segment, which is still seen in a stigmatized way by society.

The aim of this study was to understand the structure of the social representations of older people in terms of the disability and prove that this perception can go beyond the prejudiced view that prevails in the historical and cultural context.

METHODS

This is an exploratory and descriptive study using a qualitative approach that had as theoretical and methodological support the structural approach or central nucleus⁷ of the theory of social representations.⁵ The empirical research field was a center specializing in physical and auditory rehabilitation

located in Vitoria da Conquista/BA. Participants were 22 elderly people of both sexes who had some physical disability acquired in adulthood, and this number was determined by the following inclusion criteria: individuals aged 60 years or older; who had some physical disability acquired from 60 years of age; registered in the rehabilitation center in the period of data collection; with cognitive condition preserved to meet the research instruments. Cognitive status was verified by applying the Mini Mental State Examination (MMSE),⁹ test that provides information about different cognitive parameters, composed of questions grouped into seven categories.

Each category is designed to evaluate specific cognitive "functions" and temporal orientation (5 points), spatial orientation (5 points), three-word record (3 points), attention and calculation (5 points), the three memory words (3 points), language (8 points) and visual constructive capacity (1 point). The MMSE score may range from a minimum of 0 points, which indicate the greatest degree of cognitive impairment of individuals, up to a maximum of 30 points, which, in turn, corresponds to the best cognitive ability.⁸ In this study, the cutoff point was the score \geq to 19 points, which enables participants to take part in the research from the cognitive point of view.

Seventy-six (76) elderly enrolled in the rehabilitation center were identified at the beginning of data collection, and 31 had some type of disability. However, of the 31 elderly only 22 (70.9%) attended the rehabilitation center during the collection period. Despite the small number of participants, the sample was significant (70.9%) compared to the total number of elderly people with physical disabilities registered in the rehabilitation center. It is noteworthy that the said center is a reference in terms of the care provided to the people with disabilities in the public network of the city.

As to the social representation in structural approach, the literature points out that the number of participants must be 100 or more in order to be representative.^{6,8} However, the authors claim to be possible to reach conclusive results even with a smaller group of participants,¹⁰ as it can be observed in some scientific papers published in the scientific literature.^{11,12}

Firstly, the study was presented to the coordination of the rehabilitation center, which requested permission to conduct the survey in such a scenario. Then the participants were selected according to the inclusion criteria, and were contacted when they came to the physical therapy sessions. At that time, they were informed by the researcher about the purpose and methodology of the survey. By agreeing to contribute to the research, day and time was appointed, in a reserved in the very center, place for application of the data collection instruments in an individual manner. Data collection was carried out during the month of August 2015 and all participants signed the Informed Consent following the ethical standards for conducting the study with humans.

As instruments for data collection, we used a socio-biographic questionnaire prepared by the researchers and the Free Word-Association Test (FWAT).^{13,14} First, FWAT was presented and explained to the elder that this is a projective technique that allows access to content that generates social representations and that also allows respondents express themselves freely.¹⁴ This technique also allows the use of explicit or implicit information that could be lost or masked by the use of other methods.¹⁴

Thus, the researcher asked the elders to evoke five words when they heard the inducing stimulus, "physical disability". Shortly after, the researcher asked the elders to establish a hierarchy for the words evoked, which is a fundamental procedure for the establishment of central and peripheral elements of the representation, and those words were recorded by the researcher. For a better application of the technique, a simulation was performed using another inductive stimulus aimed at familiarizing participants with the instrument.

Data were processed by software "*Ensemble de Programmes Permettant l'Analyse evocations*" (EVOG) 2000 version 5¹⁵ This software allows the crossing of quantitative elements - the frequencies of evocations - with qualitative elements - the orders of the evocations - resulting in a contingency table that allows the investigator to approach the elements that structure the organization of a social representation, that is, the central and peripheral elements of the representation.¹⁶ Thus, the implementation of the structural approach to data production and analysis process contributes to the identification of the structure and organization of the representational content of older people regarding the disability in old age.¹⁶

This study was developed from a doctoral thesis, following all ethical guidelines for research with human beings, being submitted to and approved by the Research Ethics Committee of the State University of Southwest Bahia, Protocol 1,251,309 in September 2015.

RESULTS

The results of the implementation of socio-biographic questionnaire showed a higher frequency of elderly males (86.0%). In terms of age, 45.5% of the elderly were aged between 60 and 65 years. As to marital status, 59.1% of older people with physical disabilities were married. When asked about their profession, 27.3% reported working as farmers in the countryside with land cultivation, planting vegetable gardens, and breeding small animal. And 95.5% present as individual income a value between 1 and 5 minimum wages, and most receive only one minimum wage acquired from the social pension benefit from the *Instituto Nacional do Seguro Social* (INSS) (National Social Security Institute). Regarding the level of education, it was possible to detect a predominant formation in elementary school II (between the 6th and 9th grade) in 40.9% of the surveyed elderly.

Regarding the type of disability, 77.3% had amputation of a lower limb, right or left, at different levels. Besides this, 22.7% had a disability characterized by hemiplegia as the result of a stroke. Regarding the causal factor of disability, the data revealed that the thrombosis was responsible for the acquisition of disability in 45.5% of elderly people who participated in the survey. Then there is also *diabetes mellitus* and its effects on blood clotting and peripheral circulation leading to physical disability in 13.6% of participants. Regarding housing conditions, 31.8% live with their spouse, followed by 22.7% who live with their children. When asked who helps them in daily life, 40.9% of participants said that they rely on the help of spouses.

From the analysis of the corpus made by the evocations of the participants, it was verified the recall of 110 words, which, after semantic approach, were summarized in 44 words or phrases among themselves with minimum frequency (cutoff) of 3, frequency average of 4 and evocations average order of 3. According to the analysis, 66 words or expressions were discarded because they were evoked with frequency below the cutoff point. From the semantic aggregation and categorization process, we sought to identify in the remaining 44 expressions mutually exclusive meanings, thus leaving 18 semantic groups, which were mentioned most often in the order of 1 to 5 evocations.¹⁵

From RANGMOT and the TABRGFR report, EVOC12 software presented the four houses frame as the result (Table 1). This table expresses the content and structure of the social representations of older people regarding disability. The method of structural approach⁸ was adopted to realize the description and interpretation of results categorized in Table 1. Thus the words evoked more often and in the first places possibly have higher importance in the cognitive scheme of the elderly, making possible the central nucleus of social representation.¹⁶

In the framework of four houses (Table 1), the vertical and horizontal axes refer, respectively, to the average frequency and the Evocation Average Order (EAO); and the four quadrants represent important elements for the apprehension of the social representations of older people on disability in old age. The upper left quadrant brings the evocations "accustomed", "addiction", "difficulty", "limited", "overcome", "sadness", "living", considered the most important and most frequent in relation to the order of evoked words, and they are more significant for older people, making possible the central nucleus and the likely representation of the study object.

In the upper right quadrant appear the elements "adaptation", "joy", "prejudice" that are part of the first periphery, that is, it brings together the most important peripheral elements that reinforce the elements of the central nucleus, having greater frequency and greater evocation order, however, with lesser importance according to the subjects.

The second periphery or lower right quadrant contains the evocations "care", "lack", "fight", "fear". These are configured

as cognitions that protect the nucleus, exercising regulatory function, translating the knowledge, feelings and attitudes experienced by subjects in everyday social dynamics in which they live.

The lower left quadrant consists of the evocations "disability", "revolt", "suffering", "life", and shows the representation of contrasting elements, which are less common terms, however, referred to as very important for a few participants. These words provide support and strength of the central nucleus.¹³

DISCUSSION

It was observed from the structural analysis, the representation that prevails in terms of disability is that this is a process that brings difficulties for the elderly people, and it may lead to dependence and limitation in performing their daily activities such as hygiene, alimentation, leisure and work, and may cause sorrow to their lives. However, the words that make up the possible central nucleus reveal that a process of acceptance and overcoming the challenges that are presented is required with this acquisition occurred unexpectedly and traumatically.

For the participants, this new situation cannot be regarded as the end of life, of possibilities; rather it should be seen as a new phase of life in which a lot can still be done even with certain limitations and difficulties imposed by physical disability.

Regarding the experiences lived after the acquisition of disability, all interviewed elderly people have described this phase of life as a difficult process to be faced, characterized by changes, challenges and adjustments to be made in various aspects of their lives, and at work and social life. In a study of older people with disabilities,¹⁷ the body was seen by participants as an object of shame. Physical disability is viewed from a negative representation, being described by the participants with expressions that indicate concern, anguish, fear, shame, failure, sadness and prejudice, influencing their self-image. Generally, these feelings are present from the time when these individuals come to present a disability in relation to the current standard of productivity and aesthetic set by the society.¹⁷

In the current social context, aging in physical and social dependence conditions is characterized as difficult to be faced by the individual, the family and society. When the aging context is added to a physical disability, the scenario can become even more complex, since it can bring, in addition to physical disorders, problems of economic, social and behavioral order, which will directly influence the quality of life of these elderly and those who are around.¹⁸

Thus the fact of losing a body part can mean a change in the existence of the elders, as they will have to experience an incompleteness that will influence their way of being and acting. Thus, it is necessary to adapt, readapt, learn to live again, adopting another perspective of the world for themselves and others.¹⁹

Table 1. Four houses table: identification of possible elements of the central core of social representations of disability among elderly people with physical disabilities acquired in Vitória da Conquista municipality, Bahia, 2015

Central Nucleus			1 st Periphery		
Average Frequency ≥ 4		E.A.O. < 3	Average Frequency ≥ 4		E.A.O. ≥ 3
Evoked term	Frequency	E.A.O.	Evoked term	Frequency	E.A.O.
Accustom	5	3.00	Adaptation	8	3.25
Dependency	4	3.00	Joy	4	3.25
Difficulty	5	2.20	Preconception	4	3.75
Limitation	5	2.60			
Overcoming	5	1.80			
Sadness	7	2.86			
Living	5	2.80			
Contrast			2 nd Periphery		
Average Frequency < 4		E.A.O. < 3	Average Frequency < 4		E.A.O. ≥ 3
Evoked term	Frequency	E.A.O.	Evoked term	Frequency	E.A.O.
Inability	3	1.67	Caution	3	4.67
Revolt	3	1.33	Lack	3	3.67
Suffering	3	1.67	Fight	3	4.00
Life	3	1.33	Fear	3	4.00

Source: Research data.

Thus, it is important that older people, even in the presence of physical disability, can balance their limitations with their potentialities and live and age with quality of life. It was observed that some participants sought to understand the world and life with other senses, seeking to develop new skills and overcome the obstacles imposed by a physical disability, seeking to live with joy. In this sense, one can say that men are not passive spectators in the world but they are out in the world, interacting with it, not being attached to any situation, but seeking to become something new.¹⁹ This is evident with the term "overcoming", present in the central nucleus and the word "adaptation", present in the first periphery, which strengthens the central nucleus.

Generally, in the social imaginary, the strong presence of representation and general categorization of people with physical disabilities can still be identified, since this imaginary is impregnated of a prejudiced and stigmatizing view of the elderly and the handicapped. Often, when resorting to their memories, the understanding that people have in terms of disability and aging is pity, strangeness and remoteness of the subject that is different from the others. People with physical disabilities are identified only by their difficulties in the physical, suffering from stigma and prejudice on the part of other individuals in their social relations.²⁰

The first periphery includes the word "prejudice", revealing that the elderly participants of the study are still victims of prejudiced actions. The situation of being an elderly person and physically disabled can worsen, creating a doubly stigmatizing situation, for both the elderly and the physically disabled people

are generally regarded as incapable, dependent and useless by society.

As a result, older people with disabilities can develop feelings of shame and inferiority, since they suffer with segregation performed by others, fueled by concepts of physical decline, of uselessness, of difference and the loss of social role.²¹ In this context, before a newly acquired disability, the moment when the elderly person becomes conscious of also becoming "a disabled person" carries with it the possibility of stigmatization, conflict and suffering.²²

In the case of the individual with a disability, the stigma consists of "body marks" because part of the signs is embodied in appearance, shape, size and functionality, highlighting the difference.²² This perception in terms of the physical appearance can affect the moral status of individuals, deteriorating their identity when they are differentiated in a derogatory manner, which can lead to defensive social behavior (which soften the identification of their condition) or even social isolation. So stigma is one of the great marks of the experiences of the participants of this and another study, presenting itself as a potential generator of social isolation and depression.²²

Therefore, to overcome prejudice it is necessary to adapt to this new condition of life, trying to face it and overcome it. There is growing evidence that stressful events do not always produce negative results and these events cause some people to become more psychologically strong.²³ For some authors, the physically disabled people can become resilient and adapt to their condition,

seeking to strive in order to achieve new personal goals and looking for a positive psychological adjustment.¹⁹ Resilience is here described as an adaptive pattern of functioning before biological, socioeconomic and emotional.²⁴

Therefore, it is understood that the attitudes and beliefs that older people with physical disabilities have about themselves and about their relations with the world, their cognitive integrity and self-regulation mechanisms may enable adaptation mechanisms to address disability and its consequences in their functionality and social relations.⁴ Therefore, age with physical disabilities is a process that requires resilience and adaptive competence to life events and challenges caused by the presence of this condition.⁴

The acquisition of deficiency may cause various feelings in the elderly, and fear is one of the most frequent feeling, as noted in the second periphery. With the arrival of the disability, a new situation is presented in their living, raising many questions regarding their future, their ability to walk, to work, to maintain their livelihood and their families and maintain their social relations.

However, the participants recognize, as was evident in terms of the second periphery, they need to fight the adversities brought about with getting physical disabilities, seeking to overcome and to overcome such difficulties. For this, we need to have the support and care of others, as their family and friends, as reported by the participants. Therefore, social support is an important resource that can benefit older people with disabilities.²⁵

The family assistance and existing social policies in the country must also meet the demands of this population, ensuring the fulfillment of their rights as citizens. Importantly, the Elderly Statute²⁶ places the family as an essential part of the elderly protection. The family is a natural institution and has the protection, affection, food, housing, respect and companionship as principles of subsistence of its own members as well as of particular relevance to the proper development of society. Many of the participants revealed not knowing or not having had access to their rights established by law, relying solely on family support.

Even with the changes in social arrangements occurred in Brazil in recent decades, as the inclusion of women in the labor market, with a reduction in the size of families and the increase in divorce and separations, facts that can weaken family ties, the family system still remains a safe haven for its members when they have changes in their health, such as becoming physically disabled in old age.¹⁸ Thus, the family is considered extremely important in the lives of older people with physical disabilities and it appears as the main source of support for maintaining the quality of life of these individuals.

Such care and the attention of family members other people involved show the importance of the ties and social relations that can be strategic in coping with everyday situations.²⁷ The social support provided to elderly people with physical disabilities may have greater significance because it goes beyond the practical

issues of daily life, since it can give individuals a sense of being loved and a sense of belonging to this group, identifying themselves with it and finding motivation and meaning in life. This is because care is part of the essence of every man, forming the foundation that enables considering the human existence as human. It also represents an attitude of occupation, concern, responsibility and affective involvement with the other.²⁸

Individuals who have high levels of social support and are satisfied with the quality of their network of relationships have a greater sense of well-being.²⁷ In this way, the family social support seems to be essential for the emergence of subjective well-being and quality of life of the elderly with physical disabilities.

According to the evocations present in the contrast area, some participants represent a disability in old age as a synonym for impairment and suffering, and these people have a sense of revolt against the fact of acquiring disability and life style they started to have after such acquisition. When faced with physical the news of physical disabilities some participants asked questions such as "why me?", "Why now?", "How?", seeking an explanation and an understanding of the event. Thus, some elderly people had a sense of rebellion against God and the people who were around at the time, such as family, friends and even health professionals who provided assistance. One of the participants revealed that he would rather lose life than being in that situation, with one leg amputated.

Thus, the impact of the arrival of a physical disability, such as the amputation of a limb, in the experience of the elderly, can be translated into their body image, as well as on their psychological adjustment.²⁹ Many people, after acquiring a disability are faced with a profound sense of estrangement from themselves. They say they do not recognize themselves physically or emotionally. They say they live in a deep distress, which may develop into a depression frame.²⁹

The above central and peripheral structural elements point to important aspects for reflection in terms of the meaning of acquiring and living with a disability in old age from the perception of these individuals who have experienced this fact. According to Moscovici,⁵ representing a something or a state does not mean unfolding, repeating or reproducing it. Thus, when older people with physical disabilities participating in this study developed the social representation of disability, they brought elements that are useful to them in everyday life and that are experienced by them themselves. Social representations are fed not only of scientific theories, but also of great cultural axes of formalized ideologies, experiences and everyday communications.⁵

CONCLUSIONS

The results showed that the structure of social representations of older people, who participated in this study regarding disability, has as its central system the terms to get accustomed, dependence, difficulty, limitation, resilience, sadness, and living. Physical disability was therefore represented as a difficult

situation to be experienced in old age, providing sadness, especially at the initial time of acquisition. This deficiency also caused dependence to perform activities of daily life and the removal of industrial activities. However, participants sought to get used, get adapted and overcome such acquisition, seeking to continue their social relations and hoping for a better quality of life, despite the difficulties acquired with physical disabilities.

The peripheral system presented words such as joy, prejudice, care, lack, struggle and fear, strengthening the representation of older people on disability observed in the central nucleus. The disability acquisition fact requires adaptation, and, even in the face of the existing prejudice in society towards people with disabilities, who are regarded as dependent, useless, and incapable, it is important to seek to live joyfully, overcoming fear, doubt and uncertainty regarding the future.

It is essential for health professionals to understand how elderly people are physically disabled and how this representation can influence the way they think, act and behave in the face of difficulties and challenges before the aging process with a physical disability. This information provides professionals a broader vision that goes beyond the physiological aspect of disability.

The reduced and specific number of participants in the research on social representations is acknowledged as limitations of this study. Given the complexity of the phenomenon investigated, we emphasize the importance of conducting further research on this subject, expanding the number of participants and discussions, the promotion and implementation of social, health and psychological policies, to enable a better quality of life for the elderly people with physical disabilities.

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