

SOCIAL SCIENCES
REVIEW ARTICLE**Overcoming the stigma of dementia, a challenge to the Cuban society**
Superar el estigma hacia la demencia, un reto para la sociedad cubana

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ABSTRACT

Introduction: Alzheimer's Disease International (ADI) developed a campaign to overcome the stigma of dementia in 2012. Stigma is the greatest obstacle to identify health problems, find their solution, and use the health services the most efficient way.

Objective: To present the effect of the stigma of dementia on the patient, the family, and society.

Material and Methods: A bibliographic review of articles published from July 2010 to March 2016 was carried out. The information was taken in electronic format via INFOMED; and we used databases such as Pubmed, Ebsco, Medline, Sciondirect, Clinicalkey, and Scielo. The data

obtained were analyzed and discussed.

Development: Stigma interferes with a successful social life, opportunities about seeking good jobs, and loss of mental functions in those people suffering from dementia. It is closely related with ageing and loss of mental functions. The areas of the greatest impact of stigma are: work area; driving; and the possibility to give consent for medical procedures, which can have an effect on a premature loss of dignity and autonomy.

Conclusions: To overcome the present stigma of dementia, it is necessary to offer more acceptance and support to patients and families;

increase the quality of the attention to those people with cognitive impairment; educate the population, create favorable environments; implement social networks and social support; and call on the participation of all social sectors.

RESUMEN

Introducción: La Asociación Mundial de Alzheimer en 2012 llevó a cabo una campaña para superar el estigma hacia la demencia. El estigma constituye el mayor obstáculo para identificar los problemas de salud, encontrar sus soluciones y explotar de forma más eficiente los servicios de salud.

Objetivo: Exponer la repercusión del estigma hacia la demencia sobre el paciente, la familia y la sociedad.

Material y Métodos: Se realizó una revisión de la literatura publicada en el período de tiempo de julio de 2010 hasta marzo 2016. La recuperación de la información se llevó a cabo a través de la red de Infomed, utilizamos las siguientes bases de datos, Pubmed, Ebsco, Medline, Sciencedirect, Clinicalkey y Scielo. Se analiza y se comentan los datos obtenidos.

Desarrollo: El estigma interfiere en que las personas con demencias tengan una vida social exitosa, obtengan empleos y puedan vivir cerca

Keywords: social stigma, dementia, social discrimination, health plan, family, society, Cuba.

de otras personas. Está muy relacionado con la edad y la pérdida de las funciones mentales. Las áreas de mayor impacto del estigma son: la esfera laboral, la conducción de vehículos, la posibilidad de dar consentimiento para los procedimientos médicos, lo que puede repercutir en una prematura pérdida de dignidad y autonomía.

Conclusiones: Para superar el estigma que hoy existe hacia la demencia es necesario brindar mayor aceptación y apoyo a los pacientes y familiares, aumentar la calidad de atención a personas con deterioro cognitivo, educar a la población, crear ambientes favorables, crear redes sociales de apoyo y convocar a la participación de todos los sectores sociales.

Palabras clave: estigma social, demencia, discriminación social, plan de salud, familia, sociedad, Cuba.

INTRODUCTION

During the last decades, it has been exhorted to overcome the stigma towards people suffering from mental disorders because it creates enormous barriers that hinder the scientific development and deteriorate patients' quality of life. Alzheimer's Disease International (ADI) developed a campaign to overcome the stigma of dementia.¹ The stigma constitutes the

greatest obstacle to identify health problems, to try to find solutions, and use the health care services the most efficient way.²

In 2005, it was estimated that there were about 46,8 million people with dementia in the world; with a probable increase of 65 million in the year 2030, two-thirds of which will live in developing countries.³ Dementia is the first cause of

disability in older adults, and a health problem that causes greater dependence, need of care, economic overload, and psychological stress in the carers.⁴ Latin America is one of the regions that will be more affected by demographic transition; the cases of dementia will increase from 7,8 million people who suffer from it at present to more than 27 million who will be suffering from it in 2050. In Cuba, 160 thousand people affected by dementia were estimated in 2015, but this number could increase to 421 thousand in the year 2050. The cost of the disease was valued in 512 million dollars annually.⁵⁻⁸

This illness still goes unnoticed⁶, many people consider it a disorder typical of aging, which appears at the end of life when most of the people have already "contributed to society". Dementia is the main health problem that affects older adults and their families, and deteriorates the quality of life of carers. The frequent care of people with this illness conditions that the carer quits the job; therefore, it is necessary to overcome the stigma to guarantee a favorable environment to people with mental disabilities and their families.

OBJECTIVE

The aim of this research is to show the repercussion of stigma of dementia on the patient, the family, and the society.

MATERIAL AND METHODS

A bibliographic review of articles published from July 2010 to March 2016 was carried out. The information was taken in electronic format via INFOMED; and special databases were searched such as Pubmed, Ebsco, Medline, Sciencedirect,

Clinicalkey, and Scielo. Keywords such as dementia, stigma, healthcare, discrimination, and the Boolean operator AND were used for the search of scientific literature in the mentioned databases.

DEVELOPMENT

Definitions of stigma

Goffman (1963) considered stigma for the first time as a cause of fear, low self-esteem, irritability, fury, inability to manage situations, hopelessness, and increase of family load;⁴ However, Thornicroft related stigma with problems of knowledge (ignorance), problems of attitude (prejudices), and problems of behavior (discrimination).⁷⁻⁸ The patients with Alzheimer's Disease are labelled or stereotyped frequently; this act causes negative consequences because

they are excluded or treated in a different way. Evidence suggests that stigma interferes with the possibility of people with dementia to have a social life, get good jobs, and rent or live near other people.

In mental illnesses, stigma corresponds with the affectation they provoke in life relation. In 2003, Schultze and Angermeyer proposed 4 dimensions of stigma of schizophrenia, also applicable to dementia when considered to be a mental disability: The first refers to

discrimination in the context of interpersonal relations; the second is related with the public image of mental disorders; the third is defined as the effect of stigma on social and political structures, legal regulations, and mental health services; and finally, the fourth dimension deals with the performance of social roles.

There are other types of stigma-related behavior which are the stereotypes, prejudices, and discrimination.

Stereotypes are attribute beliefs, attitudes, and behaviors which categorize them as a particular group of the society, as a cognitive construction of stigma in mental disorders; the stereotype is presented as a belief about groups, which is learned during the development of a specific society and through mass media;⁹ for example, people with mental diseases are unpredictable

and potentially violent, and the individual can have his/her own stigma: "... I am a dangerous person, potentially violent".

Prejudice is conditioned by attitudes about specific groups, which include emotional aspects (to feel nervous, annoyed, or fearful in front of a person with a mental disease).¹⁰

Discrimination in the behavioral sphere is based on prejudice and can be manifested as having less opportunities than other people to get a job, to rent; and lack of support from society, or lack of empower.

Corrigan represented a model of the cognitive constructs that emerge from social psychology and impact typology. (Table)¹¹ These constructs for dementia are comparable to the loss of self-esteem, and the social isolation that these people suffer when the illness is evident.

Table. Typology of the impact of stigma on mental illnesses

Construct	Behavior	Public stigma	Self-esteem	Label of Cancelation
cognitive	Prejudice (stereotypes)	"he is dangerous"	"I am unstable"	The diagnosis of mental illness means "crazy".
behavioral	Discrimination	"the owners refuse to hire people with mental illnesses"	The person with a mental illness does not perform new tasks	Individual phrases about going to the clinic to ask for help

What are the consequences of stigma?

The consequences of stigma can be observed in the deciders, the medical personnel, the family (carers), and the society.

In the deciders: 1) Minimizes the health problem which behaves like an ice floe, the greatest part is the one that is not visualized; 2) Produces a delay in taking decisions in order to face dementia; 3) Reduces the quantity of resources

available for the preparation of the personnel that provides health care for people with cognitive impairment; 4) Makes the acquisition of medicines and advanced diagnostic technologies more difficult for the patients suffering from this illness; 5) Delays the offer of accessories and disposable material which is needed for the care of these patients at home.

In the medical personnel: 1) Delays the diagnosis and treatment; 2) Distorts the service offered, as well as the level of the service given; 3) Manifests a tendency to minimize the problem; 4) Favors the violation of the rights of the people with cognitive impairment.

In the patients: 1) Causes that they feel excluded or discriminated; 2) Favors the condition in which they feel that their desires or preferences are not taken into consideration; 3) Limits them to have an active social life and receive visits of friends and relatives; 4) Benefits their own contempt because of having a cognitive impairment; 5) Causes loss of self-confidence, fury feelings or anguish because they cannot remember things.^{13,14,15,16}

In the carers: 1) Limits the act of revealing the diagnosis of dementia when it has been explained to their family member because it could lead to suicide ideas; 2) Limits the possibility to get good jobs because of their classification; 3) Generates nihilism or pessimism about the prognosis; 4) Favors the act of receiving little comprehension in the working area due to the affectations caused by the fact of being a carer.¹⁷

In the society: 1) Generalizes the use of a negative language towards dementia, including the mass media; 2) Produces segregation because they are "mentally ill"; 3) Limits the support given by the social networks to the patients and family members.

Influence of age on the stigma

As the aging process continues, the individual is at a higher risk of suffering from dementia; after retirement, great changes occur in people's lives at an individual and social level; they experience difficulties in adapting to their new condition,

some families do not see the elderlies the same way they used to see them when they were young because, from the economic point of view, they contribute less, but the family support given during all the life is not taken into consideration. Many elderly people report a great imbalance between what they gave and what they receive from society, and the persons with memory impairment suffer from lack of social recognition.¹⁸

In 2008, The World Psychiatric Association Section of old age psychiatry consensus, called upon to promote the highest ethical standards in the psychiatric illness in the medical practice to defend the rights of the people with mental disorders in the world.¹⁹

Influence of gender and stigma

The carers of people with dementia abandon their personal interests to dedicate to the care of these people for an unlimited time; most of them are women (wives or daughters) who, in most of the cases, have to quit their jobs and suffer great affectations in their personal and family lives, as well as in the relations with their couples.²⁰ On the other hand, women represent the highest percent of the medical personnel, and the one that offers institutional care to patients with dementia. The role of the woman in the society has been understood in different ways in the most dissimilar cultures, but generally, they are attributed the role of being the responsible of the home, the feeding of the family, and the care of the ill people.

In Cuba, more than 80% of the carers of patients with Alzheimer's Disease are women. Life expectancy is higher in women than in men, but women are also more exposed to comorbidity, delicacy, and disability, which contributes to an

increase in the overload of the carer and a tendency to depression.²¹ Together with aging, the quantity of elderly women that care for elderly men will be higher. When having excessive workload, women are the ones that suffer from a higher stigma associated with dementia.²²

Social support networks (social groups, mass organizations)

The lack of support networks is one of the main factors that increases stigma of dementia; in Cuba, the existence of elderly people who live alone or accompanied by other older adults with limitations is a concern. The role of principal carer is played by only one person in many families, and the rest of the family has a very passive attitude, which provokes a deterioration of both the quality of life of the carer and family relations.²³ The carers of persons with dementia are likely to have fewer friendships, and receive less visits than those people of their ages who are not ill. The social networks such as elderly groups, mass organizations, and associations of retired people should have a dynamic role in the incorporation of carers into collective activities, the practice of physical exercises²⁴, and healthy lifestyles to prevent the disease and achieve a better quality of life.^{25,26,27}

Needs of people with dementia

The needs expressed by patients with Alzheimer's Disease and carers are related with the information they receive about their illness, the management of their properties, finances, and the communication with the specialists. They also ask for help from social groups; and express the desire to be taken into consideration to maintain their autonomy and dignity; and the need to be cared for trained people with

experience, among other demands.²⁸

In our society

In Cuba, the stigma of dementia affects the recognition of the problem, and some delay in the incorporation of all social sectors to fulfill practical actions that help to fight for the disease. In 2015, it was calculated that 160 thousand people were living with dementia; so if an average of two people suffer the overload for the care of each ill person, then about 480 thousand people could be victims of the stigma of the disease.

In our professionals, the stigma is manifested by the fact that despite dementia is the seventh cause of death in Cuba, when analyzing the results of surveys, many doctors do not consider it as a health problem, there is not a continuous recording of its incidence, and there is a great misdiagnosis because this illness is not customary filled out on the death certificate. In the primary care level, it is necessary to work in the personnel training for the early diagnosis, to promote research on the topic of dementias, and create training programs for both the formal and informal carers of people with cognitive impairment.

Our population is not yet prepared to see that the doctors sit in front of the patients with mild cognitive impairment or mild dementia, and discuss the diagnosis and possible evolution of the disease, establish a life project, and express their willingness in an anticipated way; and this is a consequence of stigma.

In our opinion, the carers suffer the stigma to the extent that they have less resources (generally, they cannot have the possibility to buy disposable diapers, they don't have access to technical help for the people who wonder

around, and they can't maintain a balanced diet according to the conditions of the elderlies); they receive less family and social support; they are victims of unwillingness in their work environment when they have to compete with their colleagues in a level playing field; and have less possibilities to fulfill the tasks advised by social, political, and mass organizations. In Cuba, the elderlies that work and care for other elderlies is increasing daily because of popular ageing and the need to increase the age of retirement; therefore, to develop work policies that protect these people becomes a priority.

On a social level, the media often convey a pessimistic or negative approach when they refer to ageing and dementia; when the doctors sometimes report on this condition, we use to say "the problem of ageing", even when we should be proud of the increase in life expectancy, which is an index that represents an achievement in the Cuban public health. For real success, all the society should assume this task. It is necessary to change the glaze of "pity" towards the persons who work and care for a person with dementia because they really have a double day's work, without even expecting the recognition of the family member who is not in the condition to do it. We should work uninterruptedly for the education of the population with regard to the right of the elderly and people with mental impairment; begin to work in the formation of these values from elementary school, and at home as part of the role of the family. We have to involve much more the radio and the television in the care of people with dementia who have lost their validity because many carers cannot attend to psychoeducational programs for the attention of

the family.

One of the greatest barriers that hinders overcoming stigma is not to consider that "dementia is a problem of all of us". If it is a reality that the Cuban government is worried facing population ageing, which is expressed in the guideline 144 of the social and economic policy of the Cuban state, approved in 2010; then it is necessary to have more participation of the social sectors to create friendly environments for disabled people, eliminate architectural barriers, move homes closer to barber's, hairdresser's, and food services (for the elderly that cannot cook), increase help networks, and tele-assistance services, which make the work of the carer more bearable.

In Cuba, more than the 90 % of people with dementia receive care at home, whereas in the countries with high incomes, most of the care is carried out in institutions at a very high cost; that's why, the carers give an important support to society and the economy of the country, which should be definitely seen from this perspective.

What can be done to reduce the stigma of dementia?

Alzheimer's Disease International (ADI) in 2012, proposes the need to approach the effects on stigma perceived through the education of the people, as well as to increase the quality of sanitary attention by the professionals to the people who has been diagnosed with dementia, and the carers. The ADI has proposed the following guidelines to overcome the stigma of dementia:

1. Communicate each other in an open and direct way.
2. Inform the facts.

3. Ask for help and connect to networks or social groups.

4. Not to be discouraged.

5. Feel that you are part of the solution.

The report also gives 10 recommendations to overcome the stigma of dementia:

1. Educate the people about dementia.

2. Reduce the isolation of people with dementia.

3. Have a say to people with dementia.

4. Recognize the rights of the people with dementia as well as their carers.

5. Integrate people with dementia into their local communities.

6. Provide education about the care and help to formal and informal carers.

7. Improve the quality of care at home, and the care centers.

8. Improve training of health providers in dementia in the Primary Health Care.

9. Encourage the governments to create national plans to face dementia.

10. Carry out research on how to approach

stigma.

The World Health Organization declared dementia in 2012 as a priority of worldwide public health, and also implemented the Mental Health Gap Action Programme (mhGAP) to overcome the gap in Mental Health;^{29,30,31} and its regional office, the PHO, has conceived this illness as a priority in Mental Health. In Cuba, we have been working on the implementation of a National Strategy for the control of Alzheimer's Disease and dementia syndromes, where we state the need of participation of all sectors of the society, and make emphasis on reducing the stigma on dementia, the early diagnosis in the primary health care, and the protection of the rights of the elderlies with cognitive impairment.

The program conceives health promotion and prevention of dementia; and the increase of the quality of medical attention to patients through the training of personnel, the development of research, and the training of carers.

CONCLUSIONS

It is indispensable to reduce the stigma that today exists towards dementia, and give more acceptance and support to people with this illness and their families in order to face the impact of this health problem on society. The increase of quality attention to people with

dementia, the education of the people, the creation of favorable environments, the creation of social networks and social support, and the participation of all social sectors can reduce stigma towards people with cognitive impairment.

RECOMMENDATIONS

We recommend to develop research on mental illness stigma, particularly dementia, to set up strategies to overcome it.

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