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Is there interest of Mexican adults in being prepared should they develop Alzheimer's or other dementia?

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ABSTRACT

Introduction. Alzheimer's disease, as well as other dementias, cause a progressive deterioration of cognitive functions, preventing patients from making decisions and having control over themselves in an advanced stage of the disease. **Objective.** To explore some expectations, wishes and preferences in a sample of mature adults should they develop Alzheimer or other dementia. **Method.** We surveyed 368 mature Mexican adults without dementia using a large survey created by the authors and used in a previous study; data were collected in some public places where mature people were invited to participate. The survey was completed from July 2019 to August 2020. **Results.** Although most participants had considered they might suffer from dementia in the future, less than half had communicated their wishes to their relatives about future medical treatments in case they could no longer decide for themselves; very few had prepared a written advance directive. Most participants agreed that patients should know their initial diagnosis, mainly to be able to prepare themselves. The main reason given by those who would prefer to hide the diagnosis was to avoid suffering. **Discussion and conclusion.** Our results highlight the need for health professionals to promote discussion with people about the possibility of suffering from dementia, as well as the importance of making decisions in advance, and letting their relatives know about them.

Keywords: Alzheimer's disease, Mexican adults, dementia, communication, advance directives.

RESUMEN

Introducción. La enfermedad de Alzheimer, así como las otras demencias, causan un deterioro progresivo de las funciones cognitivas, evitando que en una etapa avanzada de la enfermedad los pacientes puedan tomar decisiones y tener control sobre sí mismos. **Objetivo.** Explorar algunas expectativas, deseos y preferencias en una muestra de adultos maduros en caso de que llegaran a desarrollar Alzheimer u otra demencia. **Método.** Encuestamos a 368 adultos mexicanos maduros sin demencia usando una encuesta creada por los autores y utilizada en un estudio anterior; los datos se recopilaron en algunos lugares públicos donde se invitó a las personas a participar. La encuesta se aplicó de julio de 2019 a agosto de 2020. **Resultados.** Aunque la mayoría de los participantes había considerado que podría sufrir demencia en el futuro, menos de la mitad había comunicado sus deseos a sus familiares sobre futuros tratamientos médicos en caso de que ya no pudieran decidir por sí mismos; muy pocos habían preparado una voluntad anticipada por escrito. La mayoría de los participantes estuvo de acuerdo en que los pacientes deben conocer su diagnóstico inicial, principalmente para poder prepararse. La principal razón aducida por quienes preferirían ocultar el diagnóstico fue el deseo de evitar sufrimiento. **Discusión y conclusión.** Nuestros resultados destacan la necesidad de que el personal de salud promueva la discusión con las personas sobre la posibilidad de padecer demencia, así como la importancia de tomar decisiones por anticipado e informar de ellas a sus familiares.

Palabras clave: Enfermedad de Alzheimer, adultos mexicanos, demencia, comunicación, voluntad anticipada.

INTRODUCTION

The improvements in health services and scientific and technological advances have made it possible to considerably increase life expectancy in many populations. Developing economies, being in a process of demographic and epidemiological transition, have also increased their life expectancy. In Mexico, it went from 59.9 years in 1970 to 75.2 in 2020 (Instituto Nacional de Estadística, Geografia e Informática [INEGI], 2020). However, not all people who live longer do so in reasonably good health. In Mexico, as in other Latin American countries, many old people suffer from chronic diseases, neurodegenerative disorders, and limitations at a physical, cognitive, and social level, which considerably affect their quality of life and require many years of care (Pan American Health Organization [PAHO], 2017). Many people are forced to live in conditions of total or almost total dependence on others, a situation that some people accept resignedly but others consider unworthy.

Alzheimer's disease (AD) is the most common form of dementia and the best known. Dementia is a syndrome that causes a progressive decline in cognitive functions, accompanied by a deterioration in emotional control and social behavior. AD is a neurodegenerative disorder of multifactorial origin, which causes anatomical and functional alterations and affects memory, language, and other cognitive aspects. Slowly and inexorably, it destroys personality, relationships, and the ability to make decisions about how to live and how to die (Brewer, 2019).

As with other dementias (OD; vascular, Lewy body, and frontotemporal lobe), AD is one of the conditions that people fear most (Volicer, 2016). Whether by reading, hearing, seeing in the movies or meeting a person with the disease, many people have some knowledge of the effects that dementia produces, among them the loss of one's identity, for which some people consider this condition more fearsome than cancer (Donnelley, 2014; van Wijmen, Pasman, Widdershoven, & Onwuteaka-Philipsen, 2015). Although there is variability in people's preferences and decisions, the desire of some people to be able to ask for help in order to die peacefully has been documented (Williams, Dunford, Knowles, & Warner, 2007; Clarke et al., 2017).

AD is more common in elderly people. Given the rapid aging of the population, there will be more and more people at risk of suffering AD (Hickman, Faustin, & Wisniewski, 2016). After age 65, the probability of developing Alzheimer's doubles about every five years (Velázquez López, 2018). In 2020, the World Health Organization (WHO) reported that 50 million people worldwide were suffering from dementia; every year 10 million new cases are registered and close to 60% are living in low- and middle-income countries. The total number of people with dementia is projected to reach 82 million in 2030 and 152 million in 2050 (WHO, 2021).

Three stages have been established for AD: mild, moderate, and severe (Tarawneh & Holtzman, 2012). In the mild, the person can carry out their activities and make decisions. In the moderate, memory and language failures worsen, as well as the ability to perform personal care activities, thus increasing dependence on the caregiver. Finally, in the severe stage, the patient's deterioration is so advanced that permanent assistance is needed. In this phase, the salient characteristics that psychologically and socially defined the patient are lost (Hernández & Torres, 2017). The life span of patients with AD can vary but is usually between 7 and 10 years. Dementias cannot be cured and there are only treatments to slow its progression (D'Hyver, 2018). However, it is important to mention that in the last two years the FDA approved two drugs based on monoclonal antibodies, which have been shown to reduce beta-amyloid plaques, considered as pathophysiological agents of the disease. The drugs were approved for AD in the mild stage, (not without controversy due to some ethical concerns), they are not easy to administer, are very expensive and are not without potential adverse effects. Although their results so far have been modest, these drugs represent a promising advance and it is hoped that their efficacy will be proven (The Lancet, 2022; Hodes, 2023; Reardon, 2023; Alzheimer's Association, 2023).

In the mild stage of AD, the patient may make important decisions regarding their future. If not done previously, that is the right time to prepare advance directive documents (ADD) as the patient can still decide and express their wishes regarding treatments they would or would not want to receive in the future (Volhard et al., 2018).

Our research focused mainly on AD. In addition to being the most common type of dementia, it is more readily diagnosed at an initial stage. With other dementias, people are often diagnosed when they have already lost their decision-making ability (Gutiérrez-Robledo & Arrieta-Cruz, 2015). Even so, we were interested in knowing the opinions of mature adults regarding the prospect of having any dementia.

The cases of AD genetically determined by specific mutations represent a minority (Hickman et al., 2016). Other factors seem to influence the condition: cerebrovascular disease, high blood pressure, type 2 diabetes, obesity, and high cholesterol (Reitz & Mayeux, 2014). With them, some protective practices can be identified such as diet, physical activity, and other habits. Additionally, stimulating activities at the cognitive level have been recommended as they form a "cognitive reserve." While some people seek to acquire optimum habits to avoid suffering from AD, others simply trust that it will not happen to them or that there will be treatments to prevent or cure the disease (AMGEN, 2018).

In different countries, the interest of many people in planning future actions considering the possibility of suffering from dementia has been reported. Some patients diagnosed with dementia discuss their medical care together with their families and health personnel through a process known as Advance Care Planning (ACP). This includes considering medical decisions at the end of life and palliative care to address potential pain, distress, and discomfort (Irish Hospice Foundation [IHF], 2016; Piers et al., 2018). It is important to document the patient's wishes in an ADD in which a person with decision-making capacity establishes, for example, that they do not want to be given treatments to prolong their life in an advanced stage of dementia (Steinbock & Menzel, 2018). In Mexico, a person can sign an ADD stating their wishes concerning treatments in case of being in an advanced stage of AD in accordance with what is legally allowed: suspension or non-initiation of treatments, including those of life support (e.g., mechanical ventilation, artificial nutrition, and hydration), even when the death of the patient follows such a decision (González-Huerta, Gutiérrez-Soriano, & Álvarez-del-Río, 2017).

A required condition for making advance care decisions is that the patient be informed of what is happening or may happen. Although there is increasing consensus on the benefits of early disclosure of a dementia diagnosis and it has been reported that most dementia patients would like to be well informed, physicians do not always communicate such diagnoses while patients are still able to understand the implications (Briggs, McHale, Fitzhenry, O'Neill, & Kennelly, 2018).

In this article, we report the results of a study that is part of a research line initiated by the authors to explore people's opinions and interest in making decisions when facing the possibility of living with dementia. Here, we focus on learning some expectations, wishes, and preferences in a sample of mature adults should they develop dementia.

METHOD

Participants

We recruited a non-probabilistic sample of Mexican adults who lived in Mexico City or in Xalapa (capital of state of Veracruz), whose educational level varied from elementary school to college.

The inclusion criteria for participants were: 1) They were at least 50 years old; 2) they knew that Alzheimer's and other dementias are characterized by gradual memory loss, and that dementia is a progressive disease with no cure. The last criterion was confirmed by asking possible participants what they knew about Alzheimer's or other dementias. The exclusion criteria were that a person already had the diagnosis of some form of dementia, or that they could not understand the questions.

Measurements

Data were collected using a large survey created by the authors and used in a previous study (Álvarez-del Río & Marván, 2021). For purpose of the current study, the following questions were analyzed in addition to some general data: 1) Has someone close to you suffered from Alzheimer's or another dementia? If so, have you been directly involved in the care of this person?; 2) Have you thought about the possibility that you could suffer from Alzheimer's or another dementia in the future?; 3) If, in the future, a close relative was diagnosed with Alzheimer's or another dementia, would you tell them the diagnosis when they were still able to understand?; 4) If, in the future, you were diagnosed with Alzheimer's or another dementia, would you like to be told the diagnosis when you could still understand it? 5) Do your relatives know what your wishes are about possible future treatments (such as surgeries, artificial hydration and feeding, cardiopulmonary resuscitation), should you suffer from any disease and be unable to make your own decisions because you are then suffering from Alzheimer's or another dementia? If so, how did your relatives learn your wishes (through talks, a document, or other media)? The possible answers to the questions 3) and 4) were "yes," "no," or "I'm not sure" and participants were asked to justify why they gave a certain answer.

Finally, participants answered two 5-point Likert items (from strongly disagree to strongly agree): 1) If I develop Alzheimer's or another dementia in the future, I trust that an effective treatment will have been discovered by then; 2) If I develop a disease and I cannot make decisions due to Alzheimer's or another dementia, I trust that my relatives will make the best medical decisions for me (regarding surgeries, artificial hydration and feeding, and cardiopulmonary resuscitation among others).

Five judges (physicians, psychologists, and experts in bioethics) were asked to evaluate each item based on the following criteria: relevance, possible bias, and consistency of the wording with customary Mexican cultural expression. Some changes were made and then the survey was piloted with 14 persons who met the inclusion criteria without participating in the study.

Procedure

Researchers went to several public places (parks, malls, and small shops) where they approached mature people and asked if they would be willing to participate in a research about dementia. Other participants were recruited in adult recreative centers. Once people agreed to participate, they were asked to answer a few questions to determine if they fulfilled the inclusion criteria for participation in the study. If the criteria were fulfilled, the participant and researcher agreed upon a place for the survey to be conducted.

Participants signed the informed consent and were told that the information was confidential. The fact that there were no right or wrong answers to the questions was emphasized. Participants were also told that they could withdraw if at any point they decided not to complete the questionnaire. The researcher read aloud each of the items to make sure that all were properly understood. It took from 15-35 minutes to complete each survey. The survey was responded from July 2019 to August 2020.

Statistical analysis

We used descriptive statistics to calculate the frequency of participants who gave each response and chi square tests to know the association between variables. Comparisons among groups were made using non-parametric statistical tests (U Mann-Whitney and Kruskal Wallis) due to the non-normality of the data.

Ethical considerations

The research protocol was approved by the Ethics and Research Boards of Medicine Faculty, Universidad Nacional Autónoma de México (registry number 035/2019).

RESULTS

There were 524 people who were invited to participate in the study and the acceptance rate was 85%. From the 446 people who agreed to participate, 14 with middle/higher education and 57 with basic education were not included because they did not know either that dementias are characterized by gradual memory loss, or that dementias have no cure. Then, 375 persons completed the survey, but an additional 7 with basic education were excluded because they did not understand the instructions for answering the survey. Thus, the final sample included 368 adults whose sociodemographic characteristics are depicted in Table 1.

Table 1
Sociodemographic characteristics of the participants

	M	*SD*
Age	61.0	8.7
	n	*%*
Gender		
Men	122	33.2
Women	246	66.8
Who lives with		
Couple	75	20.4
Couple and children	124	33.7
Children	82	22.3
Another family member	34	9.2
Carer	1	.3
Another person	1	.3
Alone	51	13.9
Educational level		
Basic school (9 years)	133	36.1
High school (12 years)	95	25.8
College	140	38.0
Religion		
Derived from christianity	325	88.3
None	14	3.8
Other	*29*	*7.9*
Occupation		
Professional position	95	25.8
Non-professional employment	66	17.9
Business casual	48	13.1
Housewife	101	27.4
Retired	43	11.7
Does not work	15	4.1

Notes: *M* = mean; *SD* = standard deviation.

Two hundred thirty-two participants (63%) had considered that they might suffer from Alzheimer's or another dementia in the future. There were significant differences when comparing this result according to the educational level of participants ($x^2 = 9.34$, $p = .009$): there were 72.9% ($n = 102$) participants with higher education who had considered the possibility of suffering a dementia, 56.8% ($n = 54$) with middle/higher education, and 57.1% ($n = 76$) with basic education. Moreover, there was a higher percentage of people who had considered this possibility among those who had known someone with dementia than among those who had not: 69.4% ($n = 111$) and 58.2% ($n = 121$) respectively ($x^2 = 4.40$, $p = .036$). However, there were no significant differences either by gender or when comparing the results of participants who had or had not been involved in the care of a person with dementia.

Considering only the results of those participants who had considered that they might suffer from Alzheimer's or another dementia in the future, less than half (43.5%, $n = 101$) stated that their relatives knew about their wishes concerning possible treatments in case they suffered from any disease and could not decide for themselves because they had dementia. There were 52.9% ($n = 54$) participants with higher education whose relatives knew their wishes, 35.2% ($n = 19$) with middle education, and 36.8% ($n = 28$) with basic education ($x^2 = 6.59$, $p < .037$). Furthermore, there were more participants who had been involved in the care of a person with

Table 2
Percentage (n) of participants who agreed or disagreed that if they have Alzheimer's or another dementia in the future, they trust that an effective treatment will have been discovered by then, as well as they trust that their relatives will make the best medical decisions for them

	Agree	*Neither agree nor disagree*	*Disagree*
There will be an effective treatment by then	63% (232)	14.9% (55)	22% (81)
My relatives will make the best medical decisions	88.3% (325)	5.4% (20)	6.3% (23)

dementia whose relatives knew about their wishes concerning possible treatments, than participants who had not been involved ($x^2 = 7.03, p < .008$): 59.6% ($n = 28$) and 32.3% ($n = 20$) respectively. There were no significant differences either by gender or when comparing the results of participants who had or had not known someone with dementia.

Most of the participants who answered that their family knew their wishes stated that it was from informal talks (86.9% $n = 93$). Only 4.7% ($n = 5$) had a notarized document and the rest had an unofficial document.

Concerning the Likert questions, most participants stated that if they developed dementia in the future, they trusted that an effective treatment would have been discovered by then, as well as they trusted that their relatives would make the best medical decisions for them (Table 2).

When comparing the results of both Likert questions by gender, educational level, whether or not participants had considered the possibility of having dementia before completing this survey, and whether or not they had known someone with dementia or had been involved in the care of

Table 3

A. Reasons given by participants for telling a relative the diagnosis or for wanting to know one's own diagnosis in case of developing dementia in the future

Category	*Description*	*Examples of responses*
To be prepared	To take actions to cope with the disease.	*To know what to do.* *It is important to be informed.*
To receive medical attention	Self-explanatory.	*To receive healthcare treatment.* *To ask for help and attention.*
To have support	To receive attention and care from friends or family.	*To receive help from the children.* *To try to give good advice to the patient.*
To plan care measures	To establish actions for the safety of the patient (either the family member or oneself).	*To take precautions about healthcare.* *To be prevented and be more careful.*
To have a good quality of life	Self-explanatory.	*To plan ahead and have a better life.* *To try to have a good quality of life.*
To enjoy close personal relationships	To solidify relationships with loved ones before the disease progresses.	*To say goodbye to my loved ones before I stop recognizing them.* *To enjoy family.*
To know the truth is a right	Self-explanatory.	*People have the right to know.* *It is a right.*
To be able to take decisions	To decide and indicate how one would like to face the disease regarding treatments and care.	*To decide the best care option in advance.* *It is important to be informed for decision making.*
To resolve pending issues	To resolve pending issues.	*To put things in order.* *To be able to solve all legal issues.*
It is important	It is beneficial to inform (even if no reason was given).	*It is important that the person knows the truth while he/she is conscious.* *The patient should know.*
Possible improvement of the disease	Expectation that the patient (family member or oneself) will improve.	*There may be a chance to reverse the disease through a better understanding.* *There may be a cure once the diagnosis is made.*
I would like to know	This self-explanatory category was only used in the case of "telling a relative the diagnosis".	*I would like my family to let me know.* *I think that I would also like to know.*

B. Frequency and percentage of the reasons given by participants

Telling a relative the diagnosis	*n*	*%*	*Wanting to know one's own diagnosis*	*n*	*%*
To be prepared	97	32.4	To be prepared	129	38.1
To receive medical attention	39	13.0	To receive medical attention	50	14.7
To know the true is a right	38	12.7	To resolve pending issues	41	12.1
To be able to take decisions	31	10.4	To be able to take decisions	35	10.3
To have support	25	8.4	To know the true is a right	23	6.8
It is important (without explaining why)	21	7.0	To plan care measures	21	6.2
To plan care measures	20	6.7	To have support	17	5.0
To resolve pending issues	10	3.3	To enjoy close people relationships	8	2.4
To have good quality of life	9	3.0	It is important (without explaining why)	6	1.8
I would like to know	6	2.0	Possible improvement of the disease	5	1.5
To enjoy close people relationships	2	.7	To have good quality of life	4	1.2
Possible improvement of the disease	1	.3			

Table 4

A. Reasons given by participants for not telling a relative the diagnosis or for not wanting to know one's own diagnosis in case of developing dementia in the future

Category	*Description*	*Examples of responses*
To prevent suffering	To know their diagnosis would distress the patient (either the family member or oneself).	*The patient would suffer a lot.* *To avoid worry.*
It is useless	Knowing the diagnosis would have no benefit.	*The patient doesn't need to know.* *It is useless.*
It would be painful for me	This self-explanatory category was used only in the case of "telling a relative the diagnosis".	*I think it is sad to me.* *It seems cruel to me.*
Denial of reality	Self-explanatory.	*I was born healthy and I would like to die healthy.* *Nobody can get sick of this disease.*

B. Frequency and percentage of the reasons given by participants

Not telling a relative the diagnosis	*n*	*%*	*Not wanting to know one's own diagnosis*	*n*	*%*
To prevent suffering	18	60.0	To prevent suffering	6	50.0
It is useless	8	26.7	It is useless	3	25.0
It would be painful for me	4	13.3	Denial of reality	3	25.0

a person with dementia, the only significant difference was that participants who had considered the possibility of having dementia were less likely to believe that if this happens, there would be an effective treatment by then: mean rank 176.10 and 198.82 respectively ($U = 13828$, $p = .039$).

When participants were asked if a close relative was diagnosed with dementia, if they would tell that person their diagnosis when they were still able to understand (to abbreviate, "telling a relative the diagnosis") 80.4% ($n = 296$) answered that they would tell, 8.7% ($n = 32$) that they would not tell, and 10.9% ($n = 40$) reported being unsure. When participants answered if they would like to be told that they have dementia while they could still understand (to abbreviate, "wanting to know one's own diagnosis") 92.9% ($n = 342$) claimed that they would like to be told, only 3.8% ($n = 14$) answered that they would not like and 3.3% ($n = 12$) answered that they were unsure. There were no significant differences in the answers to these two questions based on participants having known someone with dementia, having cared for someone with dementia, their educational level, or their gender.

Reasons given by participants were grouped into 14 categories that are defined in Table 3A. The most prevalent reason was *to be prepared* followed by *to receive medical attention*. The answer *to know the truth is a right* was in third place when participants were asked about "telling a relative the diagnosis" and in fifth place when answering "wanting to know one's own diagnosis". The answer *to be able to take decisions* was in fourth place in both cases, and the answer *to resolve pending issues* was in eighth place when participants were asked about "telling a relative the diagnosis" and in third place when they answered "wanting to know one's own diagnosis" (Table 3B).

The reasons given for not "telling a relative the diagnosis", and for not "wanting to know one's own diagnosis" were grouped into the categories defined in Table 4A. The most frequent answer to both questions was *to prevent suffering* (Table 4B).

The answers of the participants who were not sure whether they agreed or not with "telling a relative their diagnosis" or with "wanting to know one's own diagnosis" were grouped into four categories that are defined in Table 5A. In the case of the question "telling a relative the diagnosis" the most frequent answers were *to prevent suffering* and *depending on the circumstances*. In the case of "wanting to know one's own diagnosis" the reasons depending on the circumstances, and *I don't know how I would react* shared first place among participants' responses (Table 5B).

DISCUSSION AND CONCLUSION

This study continues a recent line of research conceived to explore the opinions of mature adults on some ethical dilemmas in the care of people with dementia and their interest in maintaining control if they get sick - topics that had not been explored in our country (Álvarez-del Río & Marván, 2021). In this article, we report the results of a study that explored the opinions of mature adults about their expectations, wishes, and preferences about how to be treated if they developed dementia, as well as if they would like to be informed of their diagnosis and if they would like their relatives to be informed if they were the ones who suffered from the disease.

Although most people invited to participate in this study accepted, not all those interested were able to participate because they did not meet the inclusion criteria of knowing the more general aspects of dementias, mostly people with basic education. This indicates that there is con-

Table 5

A. Reasons given by participants for not telling a relative the diagnosis or for not wanting to know one's own diagnosis in case of developing dementia in the future

Category	*Description*	*Examples of responses*
Depending on the circumstances	It is necessary to consider the context to decide whether to inform of the diagnosis.	*Depends on the situation.* *Depends on the patient's desire to know.*
Ambivalence	Identification of advantages and disadvantages to informing of the diagnosis.	*It would be like predisposing the patient, but it is better to be prevented.* *it would be painful for me to say it, but I know it is the best.*
I wouldn't know how to inform	This self-explanatory category was only used in the case of "telling a relative the diagnosis".	*I am not prepared to let my family know.* *It is hard news to give.*
I don't know how I would react	This self-explanatory category was only used in the case of "wanting to know one's own diagnosis".	*I don't know if I could handle it.* *I don't know what I would do if I knew the truth.*

B. Frequency and percentage of the reasons given by participants

Telling a relative the diagnosis	*n*	*%*	*Wanting to know one's own diagnosis*	*n*	*%*
To prevent suffering*	11	36.7	Depending on the circumstances	4	40.0
Depending on the circumstances	9	30.0	I don't know how I would react	4	40.0
I wouldn't know how to inform	8	26.7	To prevent suffering*	2	20.0
Ambivalence	2	6.7			

* We assume that these reasons are incomplete. If there is an indecision, this response only explains why participants would not want.

siderable ignorance of the disease in a significant number of people who, due to their age, are more likely to become ill with dementia in the coming years. This is worrisome and should be addressed by conducting information campaigns aimed at the general population, so that if they get sick, they and their families would be better prepared to participate in decisions about their condition.

The ignorance among people with a basic education seems to explain the difference between those who had given thought to the possibility that they might suffer from Alzheimer's or another dementia in the future and those who had not. There were significantly more participants with a higher educational level that have considered this possibility, which means the opportunity to make decisions about how they want to be treated in case of developing AD or OD.

Less than half of the participants who had thought about the possibility of suffering from dementia had communicated their wishes to their relatives in case it was necessary to decide about medical treatments when they could no longer communicate their wishes. Again, the influence of the educational level is seen here, since it was the people with the highest educational level who had transmitted their wishes the most. Although we do not know if this has been confirmed in other studies, at least two studies have documented that people with a higher educational level express more acceptance of voluntary euthanasia for people with advanced dementia, which seems to imply a greater openness for decision-making at the end of life and communication of wishes (Brinkman-Stoppelenburg et al., 2020; Cohen et al., 2006). One likely explanation is that a higher educational level increases the perception of value for autonomy and individuality (Brinkman-Stoppelenburg et al., 2020).

Another factor that had an important and understandable influence on participants having communicated wishes to their family members was having met someone with dementia, an experience that probably allowed them to be more familiar with the problems that arise when medical decisions have to be made when people cannot decide for themselves. Communicating one's wishes in advance avoids a terrible burden on family members who would otherwise have to decide about the life of their relative. It can also reassure people that they will not receive treatments they would not want.

A surprising negative finding was the fact that very few participants had officially recognized advance directive documents (ADD). This suggests that is necessary to reinforce awareness among citizens of the importance of completing such documents. As Porteri points out, ADDs offer patients the opportunity to maintain a biographical history and protect their personal wishes. However, it is highly recommended that ADDs be prepared in a precise manner to avoid ambiguity and confusion when applying them and that they be formally delivered in a timely manner to both medical personnel and family members to ensure that the wishes of those who sign them can be honored (Porteri, 2018). To put our results (4.7% with an official ADD) in perspective, we do not know what percentage of the Mexican population has an ADD, but we do know that the percentage in our participants is low in comparison to the approximately 36% of the adult population in the USA that has been reported as having an ADD, a figure that the authors of that study considered should be increased (Yadav et al., 2017).

Most of our participants were confident that if they did develop dementia in the future, effective treatments would then be available to cure the disease, a finding that coincides with what has been reported in 2018 (AMGEN, 2018). However, in our study, participants who had considered the possibility of developing dementia were the least likely to believe this. None-the-less, most of our participants also trusted that their family members would make the best medical decisions for them. This may explain the low number of ADDs: to the extent that participants trust their relatives to make the correct decisions for them, the less they need to worry about signing a document to establish what they want.

A highly important issue in the care of patients with dementia is the timely communication of the diagnosis, while patients can still understand the implications of suffering a disease that will gradually prevent them from being aware of it and from making decisions about their life and their medical treatments (Carpenter & Dave, 2004; Mastwyk, Dow, Ellis, & Ames, 2016). Similarly, studies have emphasized the importance of medical personnel being clear when informing the patient and avoiding euphemisms such as referring to "memory problems" (Briggs et al., 2018; Yates, Stanyon, Samra, & Clare, 2021). The impact of the diagnostic communication must be recognized, which is a way of respecting the autonomy of patients (Carpenter & Dave, 2004; Holroyd, Turnbull, & Wolf, 2002). Lastly, adequate disclosure may imply a complex process since the patient is already experiencing a certain cognitive deficit (Briggs et al., 2018).

A significant majority of our participants would tell a relative their diagnosis of dementia or would agree that the doctor told them, but this majority was even higher when participants were asked if they would want to know their own diagnosis in case of developing dementia. This discrepancy has been reported and some of the explanations for the difference were paternalism among caregivers, reluctance among family members to deal with relatives' potentially negative reactions, and the implications of a dementia diagnosis for their own lives (Carpenter & Dave, 2004).

When participants answered that they would inform a relative and also that they would want to know their own diagnosis, the two main reasons given were, in this order, to be prepared and to receive medical attention. Other reasons included their right to know the truth, to be able to take decisions and to resolve pending issues - which all are somewhat related to their desire to be prepared. These findings coincide with other studies that have reported the reasons patients have given for wanting to know their own diagnoses (Mahieux, Herr, & Ankri, 2018). People who understand that they have a limited time to act because they are going to lose their abilities, want to take advantage of that time and do what they are still capable of doing concerning their illness and other aspects of their life (Mastwyk et al., 2016; Yates et al., 2021). As Carpenter and Dave comment "Disclosure allows patients to be involved in planning their own care, and it enables family members to anticipate care needs and prepare for changes that are likely as dementia progresses" (Carpenter & Dave, 2004).

Much as what happens with patients suffering from other diseases, dementia patients want to receive optimum care, which can be given with more precision when a diagnosis is made and shared.

The main reason given by participants who would not tell a family member their diagnosis or who would not want to know it themselves was to avoid the angst inherent in knowing that they suffer from dementia. Even when this relatively good intention behind hiding the diagnosis from a relative is recognized, it is important to be aware that doing so limits the patient's autonomy when it might still be exercised (Carpenter & Dave, 2004). The same loss of autonomy applies to those who prefer to ignore their own illness, but at least they are deciding for themselves, and all decisions regarding their care must be clearly delegated to someone else. Even though it was not mentioned directly by our participants, the social stigma related to dementia causes shame that has been expressed in the form of concealment, invisibility and silencing and must be taken into consideration. It has been reported that persons who begin experiencing early manifestations of AD or their relatives will postpone medical consultation for fear of being diagnosed with the disease and being seen in another way by those who know them (Lopez, Rose, Kenney, Sanborn, & Davis, 2020).

Participants who expressed uncertainty about telling a relative their diagnosis or about wanting to know their own, considered their choice would depend on the specific circumstances involved and that it would have both advantages and disadvantages. Both positions are understandable, especially in reference to informing another person, since it may be assumed that one knows one's own desires if one has already thought about that possible situation. These responses reinforce the importance of reflecting on the fact that anyone can develop dementia, and hence we should each think about what we would want and communicate our desires to significant others regardless of whether we would like or not like to be informed of our diagnosis.

Another reason expressed by those who were unsure of giving the diagnosis was "not knowing how to inform". It is understood that it is the doctor's responsibility to communicate the diagnosis, but afterwards the family members will have to talk with the affected person about their situation and they may feel that they do not know how to do so. Family members would be justified in not knowing how to speak and would need advice from the patient's doctor.

What is not justified (even if it happens) is that doctors do not communicate the diagnosis to a patient because they do not know how or feel very uncomfortable doing so. As difficult as it is to communicate a harsh diagnosis, physicians must learn to do so; it is part of their professional duty, as it has been for many physicians to communicate unfavorable prognoses when patients are suffering from other life-threatening illnesses. One way in which doctors have avoided the difficulty is by informing only family members of the disease when patients would be able to understand their diagnosis (González-Huerta et al., 2017; Low, McGrath, Swaffer, & Brodaty, 2019).

It is not only the task of doctors; health professionals in general are the link between society and the health care system, contributing to forming people's opinions towards a variety of issues. Therefore, they should talk to their patients and to society in general about the possibility of developing dementia and the importance of expressing their will in advance about decisions concerning their health care. Of course, they should do that with empathy and understanding people's values and beliefs, all of which will make the communication about such a complicated diagnosis easier, at the same time that it will facilitate the decisions that will have to be made in the future.

The findings of this study must be interpreted in the context of its limitations, and some suggestions should be taken into consideration. First, the study has a selection bias for people who know how to read and write as illiterate people were not included. Second, we do not know if our results are generalizable to people who declined to participate, who did not fulfill the inclusion criteria or who were excluded. Lastly, participants were not asked about their general health, and we do not know if some of them had a severe illness that made them think they were nearing the end of their life, in which case they might have found it difficult to identify with the situation we presented to them.

Our research contributes to better understanding people's preferences and dilemmas related to communicating the diagnosis of AD or OD when such patients can still understand their situations and decide about their present and future care. Most people in this study wanted to know their dementia diagnosis if they have it, so they could be prepared, but some would hesitate about telling others the same diagnosis. On the other hand, even though people wanted to prepare themselves in case of suffering from dementia, few have done what was already in their hands, that is, communicate their wishes to others through an official document.

Given that the incidence of dementia will continue to grow, it is important for all persons to be better prepared to talk about the disease both before and in the event of facing it. It is especially unfortunate when a diagnosis is not communicated, not because physicians or relatives doubt that it is the right thing to do, but because they may not know how to do so.

The decisions that must be made about a patient with dementia are very complex and it would be very helpful to base such decisions on the same person's expressed desires –preferably through an ADD– even if what the person decided was that another family member should always speak for them.

A culture should be fostered that promotes more accompaniment by health professionals to discuss in a timely and empathetic way with people about the possibility of suffering from dementia and the importance of communicating a diagnosis when some relative already suffers from it. This will allow people to make decisions that their family knows.

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Conflict of interest

The authors declare they have no conflicts of interest.

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