

# Health literacy for caregivers of elders with alzheimer's disease

*Alfabetização em saúde de cuidadores informais do idoso com doença de alzheimer*  
*Alfabetización en salud para cuidadores informales de ancianos con enfermedad de Alzheimer*

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## ABSTRACT

**Objective:** To identify the level of health literacy in informal caregivers of elders with Alzheimer's disease. **Methods:** Descriptive study with a quantitative and qualitative approach, with health literacy as a theoretical framework. Research carried out with 42 informal caregivers of elders with Alzheimer's from a geriatrics outpatient clinic, using a questionnaire with sociodemographic data and the Health Literacy instrument. **Results:** The functional and conceptual levels were more prevalent, with regards to elders with Alzheimer's, than the empowering level. Caregivers searched, evaluated, and used health information and expressed abilities to use and judge the information received. **Final considerations:** The predominance of categories in the cognitive level of learning indicates the need to strengthen the empowering level of these caregivers. Health literacy made it possible to reveal the demands of informal caregivers of elders with Alzheimer's, evaluating their individual ability to offer this type of assistance. It is also a tool capable of reaching better health results.

**Descriptors:** Health Literacy; Caregivers; Aged; Alzheimer Disease; Nursing.

## RESUMO

**Objetivo:** Identificar o nível de alfabetização em saúde de cuidadores informais do idoso com doença de Alzheimer. **Métodos:** Estudo descritivo com abordagem quanti-qualitativa, utilizando como referencial teórico a alfabetização em saúde. Pesquisa realizada com 42 cuidadores informais de idosos com Alzheimer de um ambulatório de geriatria através de questionário contendo dados sociodemográficos e do instrumento *Health Literacy*. **Resultados:** Houve maior prevalência dos níveis funcional e conceitual sobre o cuidado ao idoso com Alzheimer do que o nível de empoderamento. Os cuidadores buscaram, avaliaram e utilizaram informações em saúde e expressaram habilidades de julgamento e uso das informações recebidas. **Considerações finais:** A predominância das categorias no nível cognitivo da aprendizagem indica a necessidade de fortalecer o empoderamento desses cuidadores. A alfabetização em saúde permitiu revelar as demandas do cuidador informal do idoso com Alzheimer e avaliar sua habilidade individual para essa assistência, sendo ferramenta capaz de alcançar melhores resultados em saúde.

**Descritores:** Alfabetização em Saúde; Cuidadores; Idoso; Doença de Alzheimer; Enfermagem.

## RESUMEN

**Objetivo:** Identificar el nivel de alfabetización en salud de cuidadores informales del anciano con enfermedad de Alzheimer. **Métodos:** Estudio descriptivo con abordaje cuanti-cualitativa, utilizando como referencial teórico la alfabetización en salud. Investigación realizada con 42 cuidadores informales de ancianos con Alzheimer de un ambulatorio de geriatría por medio de cuestionario conteniendo datos sociodemográficos y del instrumento *Health Literacy*. **Resultados:** Hubo mayor prevalencia de los niveles funcional y conceptual sobre el cuidado al anciano con Alzheimer que el nivel de empoderamiento. Los cuidadores buscaron, evaluaron y utilizaron informaciones en salud y expresaron habilidades de juicio y uso de las informaciones recibidas. **Conclusiones:** La predominancia de las categorías en el nivel cognitivo del aprendizaje indica la necesidad de fortalecer el empoderamiento de esos cuidadores. La alfabetización en salud permitió revelar las demandas del cuidador informal del anciano con Alzheimer y evaluar su habilidad individual para esa asistencia, siendo herramienta capaz de alcanzar mejores resultados en salud.

**Descriptorios:** Alfabetización en Salud; Cuidadores; Anciano; Enfermedad de Alzheimer; Enfermería.

## INTRODUCTION

The number of elders is growing more than that of any other age group, increasing the rates of chronic degenerative diseases<sup>(1)</sup>. With aging, there are physiological changes that increase the vulnerability of the elder. When associated to pathologies, these can lead to functional losses, demanding especial care and more knowledge from the caregiver about the specificities of the elder<sup>(2)</sup>.

Dementia is a chronic disease that has become a great public health problem due to the increase in the life expectancy of the world's population. In 2016, the number of individuals with dementia around the world was 43.8 million (confidence interval 95% - CI95% = 37.8-51)<sup>(1)</sup>. Alzheimer's disease (AD) is a type of dementia, a neurodegenerative syndrome that leads to impairments in the neuropsychiatric and cognitive functions, with manifestations of changes in behavior and personality, prejudicing the autonomy and the independence of elder people<sup>(3)</sup>.

The hindrances in autonomy and independence caused by Alzheimer's lead to the appearance of disabilities, frailties, and dependencies. Therefore, the elder with AD must receive a unique type of care, capable of attending to the demands related to their physical, cognitive, social, emotional, and psychological dependencies<sup>(4)</sup>.

In this context, the caregiver emerges as a human resource to attend the unique demands caused by the dependency of the elder with AD. The family has been the most common responsible for this type of care, but in most cases, they are unprepared to assume the role of care provider for the daily activities of the elder. Additionally, the difficulties to understand the changes and the progression of the dementia can make it more difficult to care for the elder<sup>(3)</sup>.

The development of this care requires understanding written texts and guidance received, including those regarding medications and skills. It also requires searching health services for information on the right decisions to make. These elements are the theoretical framework named "health literacy", which describes the abilities of seeking, understanding, evaluating, using, and sharing information, while also involving the decisions made by the caregiver about healthcare processes and procedures<sup>(5)</sup>.

Studies indicate that inadequate health literacy is associated to low quality healthcare<sup>(6)</sup>. However, in Brazil, specifically in the field of nursing, only one study was found in the health literacy of informal caregivers of elders with AD<sup>(7)</sup>.

The search for studies took place through a cross-section of the descriptors "Health Literacy", "Caregivers", and "Aged" in the databases *Literatura Latino-Americana e do Caribe em Ciências da Saúde* (LILACS), Scientific Electronic Library Online (SCIELO), Medical Literature Analysis and Retrieval System Online (MEDLINE), and SciVerse Scopus (Scopus), from 2005 to 2015.

Therefore, the gap found in this theme, associated to the growing number of individuals with AD who require care, justify the execution of studies on the health literacy of the informal caregiver of elders with AD. These researches are relevant for nursing, since the nurse will be able, through them, to get to know the needs of the elder and their caregivers, and thus to intervene immediately after, according to their demands and specificities.

## OBJECTIVE

To identify the level of health literacy in informal caregivers of elders with Alzheimer's disease.

## METHOD

### Ethical aspects

The research started after the Research Ethics Committee of the Universidade Federal do Ceará/UFC gave its approval. The anonymity of the participants was maintained, according to Resolution 466/2012 from the National Council of Health.

The objective of the research was explained individually to each caregiver. They were asked to sign the Free and Informed Consent Form (FICF). A copy of the form was given to the participant.

### Theoretical framework

The study used health literacy as its theoretical framework. The concept was understood as the search, understanding, use and sharing of information about the health of individuals and groups<sup>(8)</sup>. It was classified in three levels: functional, conceptual, and empowering<sup>(9)</sup>.

### Type of study

This was a descriptive study with a quantitative and qualitative approach, based on health literacy and its classifications<sup>(9)</sup>. The methodology of the study was guided by the instrument Consolidated Criteria for Reporting Qualitative Research (COREQ).

### Methodological procedures

#### Study setting

The study was carried out in the outpatient clinic of the Center of Attention to the Elderly, in the city of Fortaleza, from May to August 2016.

In the period of data collection, there were 1,738 elders registered in the service with a diagnostic of dementia. It stands out that the outpatient clinic had no information about the number of elders received with the diagnostic of AD nor on the number of caregivers.

### Data sources

The eligible population of the study was made up of 50 informal caregivers of elders with AD.

Participants were selected using the intentional sampling technique and by convenience. Inclusion criteria: being an informal caregiver of an elder diagnosed with AD and registered in the outpatient clinic; being the main responsible for the care to the elder. Exclusion criteria: reporting no doubts about how to care for the elder. Discontinuity criteria: impossibility of finishing the interview due to intense emotional outbursts; being called for the consultation of the elder during the interview and being unable to answer the questions at another time.

The field research was considered over when the saturation point of the theoretical sampling of the study was reached. When

data collection reached an amount of materials that was enough to attend to the needs of the study, and no new data was being added, the collection was considered concluded.

Five caregivers were lost during the process, and three were excluded. Therefore, the sample of the study was made up of 42 caregivers.

### **Data collection and organization**

In the first stage, the data collection instrument was made up of sociodemographic data (sex, age, race, marital status, number of children, educational level, profession and current occupation, family income and religion); in the second stage, the Health Literacy instrument was used. This instrument was created by Canadian researchers<sup>(10)</sup> and translated and validated for use in Brazil<sup>(11)</sup>.

In its Brazilian version, the Health Literacy instrument analyzes the health literacy of individuals, that is, how is it that they seek, understand, and share health information. It is made up of 27 questions that originate from a health preoccupation experienced by the participant; 16 were closed questions and 11 were open-ended ones. The closed questions discussed the satisfaction and understanding of the interviewed with regards to the information, using a Likert type scale. The open questions were about: the meaning of the theme discussed for the participant; the sources of information about health they use; their satisfaction and trust on the information they find; the usefulness, coherence, and their understanding of the information; the learning, sharing, and impact of the health information received<sup>(8)</sup>.

Before data was collected, the researcher went to the field to get to know the routine and the dynamics of the service. To carry out data collection, the caregiver that was accompanying the elder was invited, individually, to participate in the study. It stands out that all participants were accompanying the elder during the consultation.

Closed questions were recorded in writing, while open ones were recorded using a portable voice recorder. Notes were made into a field journal during and after the interview.

The quantitative data analyzed were the sociodemographic variables, organized in the SPSS (Statistical Package for the Social Sciences) statistical software, version 20.0.

The variables of the study were organized in (i) sociodemographic characteristics (sex, age group, marital status, number of children, educational level, profession, current occupation, family income and religion); and (ii) level of health literacy (functional, conceptual, or empowering).

Qualitative data that originated from the open questions about experience, behavior, emotions and feelings experienced, as well as the social interactions of the caregivers, were organized using the IRaMuTeQ (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*) software, version 0.6.

### **Data analysis**

For a descriptive analysis of data, the frequency of sociodemographic variables was determined, and qualitative data were analyzed by the researchers using the IRaMuTeQ software. A qualitative content analysis<sup>(12)</sup> was also carried out, and presented in categories.

In the IRaMuTeQ, the similitude analysis and a word cloud were used. In the similitude analysis, the study identified the coexistence of the words, seeking to connect them and identify the structure of a corpus of the text (within the specific theme); in the word cloud, in turn, the words were grouped and organized according to their frequency, to identify the keywords of the corpus<sup>(13)</sup>.

Then, the summary of the content analysis was carried out, meaning that the material was paraphrased: the parts that were less relevant or that had the same meaning were omitted and similar paraphrases were condensed and reduced, creating "coding units"<sup>(12,14)</sup>.

Qualitative data was processed according to the steps below:

1. Reports were transcribed entirely. There was no attempt to adapt them to the grammatical or verbal norms of the Portuguese Language, although some informal words/expressions, when repeated unnecessarily, were removed — such as "you know" and "right?".
2. The summary of the content of each question answered selected only the parts of the interviews considered relevant to answer the question of the research.
3. The selected materials were processed in the IRaMuTeQ software, where the similitude analysis and the word cloud were created.
4. Coding units were identified through the similitude analysis and the word cloud. Categories were created and examples taken from the statements of the participants. Similar statements were omitted, and only the most complete one remained.

It should be noted that each open question went through this organization and analysis process through IRaMuTeQ, and the material thus produced and presented in Charts 1, 2 and 3, below, illustrates the statements.

Other categories were created without using the IRaMuTeQ software, such as C4: quality of life; C8: other diseases; and C31: psychological support. These were manually elaborated by the researchers according to the content analysis summary<sup>(12)</sup>.

The categories and their respective reports were submitted to the blind appreciation of other researchers from the gerontology field, to find coherence and consistency between the categories and the results. Quantitative and qualitative data analyses were grouped and associated to health literacy levels<sup>(9)</sup>.

To identify the participants, the letter P was used, followed by a number that represented the order in which the person was interviewed (Participant 1: P1; Participant 2: P2, and so on). This identification was used after the statements from each participant that are shown in the results.

## **RESULTS**

Table 1 includes the sociodemographic characterization of the informal caregivers of elders with Alzheimer's disease.

The characteristics of the informal caregivers showed that they were mostly female (95.2%), from 40 to 59 years old (62%), married/in a stable union (54.7%) and had from one to two children (47.7%).

**Table 1** – Sociodemographic characterization of the informal caregivers of elders with Alzheimer's disease, n = 42, Fortaleza, Ceará, Brazil, 2016

Variables	n	%
Sex		
Female	40	95.2
Male	02	4.8
Age		
30-39	12	28.5
40-49	13	31.0
50-59	13	31.0
> 60	04	9.5
Marital Status		
Married/Stable Union	23	54.7
Single	13	31.0
Separated/divorced	05	11.9
Widower	01	2.4
Children		
None	12	28.5
1-2	20	47.7
≥ 3	10	23.8
Educational level (years of study)		
< 8	04	9.5
8-12	26	62.0
> 12	12	28.5
Profession		
None	22	52.4
From the health field	05	11.9
Others (hairstylist, self-employed, chartered accountant, civil engineer, journalist, graduated in Portuguese, and graduated in pedagogy)	15	35.7
Current occupation		
Housekeeper and elder caregiver	23	54.7
Self-employed	08	19.1
From the health field	03	7.1
Others (retired, craftsman, salesperson, public worker, production auxiliary)	08	19.1
Mean family income		
< 1 minimum wage	07	16.7
2-3 minimum wages	23	54.7
> 3 minimum wages	12	28.6
Religion		
Catholic	31	73.8
Others (evangelical, Jehovah's witness)	09	21.4
None	02	4.8

The caregivers were from 8 to 12 years of age (62%), with no regulated profession (52.4%), and 54.7% informed that being a caregiver and housekeeper were their current occupations. The mean family income per month went from two to three minimum wages (54.7%) and the most common religion was Catholicism (73.8%).

Chart 1 presents the grouping of the questions the caregivers were asked, and their answers with regards to their functional health literacy levels. It also presents the analysis categories of the study.

In the functional level, the caregivers seem to have a general understanding of the information they sought. However, their doubts are related to the evolution of the disease, the administration of medications, and nutritional aspects. This level has seven categories, presented through the statements of the caregivers.

Chart 2 shows the grouping of questions directed at the caregivers and their answers with regards to the conceptual level of health literacy, identifying their respective categories.

In a conceptual level, eight categories were formed showing the movements of the caregivers to clarify their doubts. They reported that they sought information from health services,

outpatient clinics, in literature or in the media. They showed satisfaction with some of these means, as categories C18, C20, C22 and C23 show.

**Chart 1** – Functional level (FL) of the health literacy of informal caregivers of elders with Alzheimer's disease, Fortaleza, Ceará, Brazil, 2016

FL questions	Categories	Statements
Ease to understand the information sought	C13: care with the medication — indications, effect, and administration	<i>What are the adverse effects of the medications she uses? (P1)</i> <i>What are the medications that are causing the effects? (P1)</i> <i>What is each medication for? (P5)</i>
Disagreement between pieces of information found	C15: dealing with the elder	<i>How would we deal with the progression? (P24)</i>
Understanding of the information sought	C16: diet administration	<i>What can I give her to eat? I want to vary but I don't know what I can replace. (P41)</i>
	C19: remaining doubts	<i>A doubt I still have now. (P5)</i>
	C24: knowledge about medication (indications, action, and effects)	<i>Knowing how the medication acts, each medication the elder takes, what are they for and what are their effects. (P2)</i>
	C25: attention and patience with the elder	<i>Knowing how to deal with the disease and the elder. And especially knowing how to treat the elder. (P4)</i>
	C26: knowledge about the disease	<i>Being aware of the development of the disease so you're prepared to monitor the stages. (P16)</i>

Note: FL - Functional level.

It stands out that categories C18, C22, C27 and C28 were made up using the reports of caregivers who sought information from the outpatient clinic. Therefore, in the search for information, the outpatient clinic was the source that they remembered the most as the one which generated satisfaction and learning.

In Chart 3, below, are the questions and categories formed with regards to the empowering level of the health literacy of the caregivers.

In the empowering level, there were only three categories, making it the least expressive in the statements of the caregivers. However, those who participate in group activities valued highly the experience exchange and the emotional support received. The family was pointed out as the main people with whom to share preoccupations and information learned on the care for the elder with AD.

Regarding the conception of health literacy, the empowering level unites all the abilities from the other levels, bringing together the capacity of critical judgment and decision making, whether with regards to the care or to the services that are offered.

From the statements presented in the charts, it became clear that the functional and conceptual levels of health literacy were the most frequent in the answers of the caregivers, showing the incipient level of the empowering one among the participants.

**Chart 2** – Conceptual level (CL) of the health literacy of informal caregivers of elders with Alzheimer's disease, Fortaleza, Ceará, Brazil, 2016

CL questions	Categories	Statements
First source of information  Satisfaction with the first source of information  Search for other information sources	C17: Difficult — lacks guidance and acceptance	<i>It was really difficult. There is no medication, no doctor, no nothing. Everything is difficult and takes time. (P6)</i> <i>Receiving this information is painful, knowing there will be no result, that it only ends with death. (P38)</i>
	C18: satisfaction	<i>We arrive without a direction, without knowing where to turn. They give us the information on how it will evolve. To start and receive guidance is an excellent field. (P26)</i>
	C21: negative experience with books	<i>The books should be more accessible to the lay public. I didn't like it because it is targeted only at doctors. I had to read it with a dictionary by my side. (P24)</i>
	C22: Information from the health services	<i>The team is excellent. I really like the information. (P1)</i> <i>People who are capable to do it, who studied and are prepared. (P38)</i> <i>They teach us a lot. (P8)</i>
	C23: information from the Internet	<i>There is more information and I can spend more time researching. (P34)</i> <i>Because it said a lot and it was all very much like things people had told be before. (P11)</i>
Difference after the information was received	C20: positive experiences with books	<i>I liked reading. Reading books really helped getting to know how to care better for my mom and especially how to understand her disease. (P1)</i>
	C27: learning	<i>I started to understand the disease, its causes and effects. (P10)</i>
	C28: taking better care	<i>So I could learn where to recognize, where to search and what to do, how to act. (P30)</i>

Note: CL - Conceptual level.

**Chart 3** – Empowering level (EL) of health literacy of informal caregivers of elders with Alzheimer's disease, Fortaleza, Ceará, Brazil, 2016

EL questions	Categories	Statements
Sharing the preoccupation with the family Sharing the information with the family Differences after sharing the information	C29: passing the information	<i>Where we live, there are many elders, and I pass the information and guide other people who also care for elders. (P22)</i>
Differences after participating in a group	C30: learning	<i>You exchange knowledge and experiences, and that's really important. (P41)</i>
	C31: psychological support	<i>You receive psychological support from the group. (P30)</i>

Note: EL - Empowering level.

## DISCUSSION

Among the caregivers, it became clear that their capacity for caring for elders with AD is in the functional and conceptual levels of health literacy, but with limitations. That means that their competences are in cognitive knowledge, in their understanding of information on the disease and procedures of care, while also being aware of where to search information in case of doubt. Caregivers still need to advance to interpret and evaluate situations of diminished health risk and promote quality of life.

The inadequate health literacy of the caregivers potentially affects the offering of care, and therefore, the health results of the person receiving the care. However, literature shows a variation from 0% to 52.2% in the prevalence of inadequate health literacy among caregivers<sup>(15)</sup>.

In the empowering level, it was found that the caregivers presented a limited critical capability in how they understood and took actions with regards to their rights to health services. That was also true for their abilities of risk evaluation and of interaction with other people from their social support network. This result shows that the relation between the caregivers, health professionals, and health services must be strengthened in the level of empowering. Understanding information, seeking and applying it, is not enough to offer adequate healthcare, which is related to knowledge and abilities specific to health prevention and promotion.

People with inadequate health literacy are less likely to be able to navigate through health services and find the services they need, or to adequately develop the actions of healthcare needed, presenting, in turn, worse health conditions<sup>(6)</sup>.

The low level of empowering may be related to the absence/ little participation in support groups, since these groups offer guidance on the disease, help dealing with difficulties and limitations, encourage positive attitudes and behaviors, and promote improvement to elder healthcare<sup>(16)</sup>. Caregivers who participate in support groups gained a lot from the intervention, presenting a diminution in their overload and in the difficulties in dealing with the elder with AD. They had a behavioral change and improved their ability to cope with difficult situations involving the elder<sup>(17)</sup>.

Caregivers with inadequate health literacy may have their adherence to the plans of care prescribed compromised, negatively affecting the health of the person under their care<sup>(18)</sup>. Little knowledge in the care of elders may compromise the assistance offered by the caregivers and lead to the decompensation that affects AD patients<sup>(18-19)</sup>. Therefore, it becomes necessary to increase the health literacy levels of these individuals, with regards to their understanding of the instructions offered by health professionals<sup>(20)</sup>.

Caring for a person with AD requires knowledge and the development of skills<sup>(21)</sup>, since the level of understanding of the caregivers about the adequate care to the elder will directly interfere in the quality of life of the elder, considering that a better informed caregiver will feel safer, more confident and more capable of developing the actions of healthcare required by the elder<sup>(2)</sup>.

In this context, it is important to encourage dialog between health professionals and the caregiver, since this will allow them to create an environment of trust to express their thoughts, seek information, raise questions, and reflect on the care being offered.

The access to the health service as the main source of information to clarify doubts was an important aspect for the caregivers. That shows how relevant it is to strengthen the relation between caregivers and health services, which are trustworthy sources of information that can give support to the caregiver during the assistance, thus positively interfering in the care to the elder<sup>(22)</sup>.

Increasing the health literacy levels of the caregivers is a necessary therapeutic resource to maintain house healthcare. Caring for the elder with AD demands adequate strategic, emotional, and institutional support. Therefore, it is worth remembering how important the nurse is in the support and attention to the caregiver. The nurse informs them about the AD and its evolution, indicates the adequate path to find help and a social support network, in order to contribute for the efficiency of the healthcare plans and strengthen the empowering of caregivers<sup>(19,23)</sup>.

The caregiver must be able to judge and make decisions when confronted with the particularities presented by the elder. This care also depends on their ability to evaluate and use this information, in addition to making choices that can diminish risks to health and promote quality of life.

The caregiver who seeks to be informed on Alzheimer's disease becomes more capable of directly assisting the elder, since they will be better prepared both physically and mentally, and will be aware of the situations that may arise during the healthcare to the elder<sup>(2)</sup>.

### Study limitations

The limitations of this study were related to the place where the interviews took place, which, despite being distant from others, had noise pollution, making the dialog between researcher and interviewee more difficult. The little time the caregivers had between the interview and the consultation of the elder led to the loss of participants in the study.

The presence of the elder during the interview was, for some caregivers, a reason to feel intimidated, and not respond to some of the questions of the research. This was minimized when the caregivers moved away from the elder to be interviewed, or when the elders had other people accompanying them, making it possible for the main caregivers to participate in the interview. However, in 12 interviews, this issue could not be minimized, since the elder required constant attention from the caregiver.

### Contributions to the Field of Nursing

Through this study, nurses can get to know factors that may interfere in the understanding of the caregivers of elders with Alzheimer's disease about the therapeutic process. That will offer support for interventions according to the specific characteristics of each caregiver.

### FINAL CONSIDERATIONS

In the characterization of their health literacy, the caregivers in this study presented a higher cognitive level in their ability to learn about how to care for the elder with Alzheimer's disease, when compared to their level of empowering.

The caregivers sought, evaluated, and used health information, and expressed abilities in the judging and using of information received, favoring the offer of a higher quality care to the elder. However, the predominance of the functional and conceptual level categories suggests the need to strengthen the empowerment of these caregivers.

The care for the elder with AD requires the nurse to continuously monitor the caregivers, to identify their demands of knowledge and of social and psychological support. Once these demands are included in the therapeutic process of the healthcare of the elder, it will be possible to offer a higher quality of life to both the elder and the caregiver.

Health literacy made it possible to reveal the demands of informal caregivers of elders with Alzheimer's, evaluating their individual ability to offer this type of assistance. It is also a tool capable of reaching better health results. One of the best ways to reach this dimension of care is encouraging the caregivers to participate in support groups, educational meetings and training courses offered by the service.

Intervention studies should be conducted that aim to promote knowledge, understanding, and develop skills in caregivers of elders with Alzheimer's, thus guaranteeing the qualification and the offering of social support to these caregivers.

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