

The Experiences of Family Caregivers in Response to a Dementia Diagnosis Disclosure

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Abstract

Background: Dementia is a serious disease that can lead to disability because it impacts the individual's memory, cognition, behavior, and capacity to perform activities of daily living. While most people prefer to receive a full diagnostic disclosure, the actual care requirements of family caregivers, based on their perspectives, are often unknown. The primary aim of this study was to explore the experiences of family caregivers in response to a dementia diagnosis disclosure and analyze the care needs of caregivers.

Methods: A qualitative study conducted in accordance with COREQ guidelines. The grounded theory approach was undertaken in 20 family caregivers of patients with dementia, who were selected using purposive sampling. Data were analysed using the constant comparative method.

Results: Diagnostic disclosure: Start the long road of care challenges was identified as the core category of this study, which was defined as describing the experiences of family caregivers of patients with dementia after first being informed of the patients' diagnosis, which activates their willpower to progress against the disease. Five major categories describing the experiences of family caregivers following a dementia diagnosis was developed: 'deciding to seek medical attention,' 'the moment of disclosure,' 'conveying information,' 'maintaining the patients' functioning,' and 'receiving support and living well with dementia.' Subcategories within each major category also emerged.

Conclusions: Clear diagnostic disclosure is important for ensuring that positive developments can occur in response to disclosure. Healthcare professionals must develop strategies to prevent disclosure from triggering overreactive emotions from patients with cognitive impairments, assist them in understanding their illness in a tactful manner, and ensure that they understand how to cooperate in any subsequent care plans.

Background

Dementia is a serious disease that can lead to disability because it impacts the individual's memory, cognition, behavior, and capacity to perform activities of daily living [1]. A World Health Organization (WHO, 2018) survey reported that approximately 50 million people live with dementia worldwide, which is projected to double over the next 20 years and triple by 2050, at which time an estimated 152 million people will be living with dementia. The global population of people living with dementia is growing at a rate of 9.9 million individuals each year, equivalent to a new case being diagnosed every three seconds [2]. As of 2020, 1 in every 77 people in Taiwan is estimated to be living with dementia [3]. Dementia has significant economic implications and is associated with a substantial care burden for the individual, their family, and the community. The increasing rate of dementia diagnoses is likely to be associated with a high societal cost, and the accelerated growth of this population represents a threat to global societies and healthcare systems [1].

Most individuals who might have dementia want to be informed of their diagnosis, including 92% of patients with dementia and 88% of their family members [4]. A study conducted in North Wales showed

that 94.8% of study participants would prefer to be informed about their diagnosis and a majority of them (84.1%) wanted to be informed about it jointly with their family members [5]. Zou et al. found that 95.7% of caregivers indicated a desire to know about their own diagnosis if they developed dementia, and 82.9% of caregivers would prefer it if the family member who has dementia knows that they have dementia [6].

Dementia patients perceived that being informed about their illness would be beneficial, allowing them to join support groups, devote more time to things that make them feel happy, better handle their finances, obtain assistance and support, develop a care plan with professionals, and learn coping strategies [4, 7]. Those caregivers who argued against diagnostic disclosure believed that knowing about dementia would only make the patient feel uneasy, with no beneficial effects [8]. Other reasons that family caregivers provided for choosing not to disclose a dementia diagnosis included preventing the patient from becoming upset or experiencing difficulty understanding the diagnosis, perceiving the diagnostic disclosure as unnecessary, or following the recommendation of a doctor [9]. Dementia affects both the patient and their family members because most patients are cared for by family members and depend on their assistance and support for individual care and family activities [10]. Most caregivers experience stress, loneliness, and social rejection during the caregiving process. Compared with family caregivers caring for patients without dementia, those who care for patients with dementia often report more negative impacts [11].

What are the experience of family members of patients with dementia in terms of diagnostic disclosure? Do differences between Eastern and Western cultures and styles of thought affect the countermeasures taken after diagnostic disclosure? Few studies to date have explored the intrinsic experiences and needs of family members of patients with dementia. The primary aim of this study was to explore the experiences of family caregivers of patients with dementia in response to a dementia diagnosis disclosure and analyze the care needs of family caregivers.

Methods

Study design

This study employed grounded theory method and was undertaken according to the consolidated criteria for reporting qualitative research (COREQ), to explore the feelings and thoughts experienced by family members of patients with dementia following disclosure of the patient's dementia diagnosis. The researcher consolidated information collected through a review of literature, clinical experiences, and discussions with experts to develop a set of semi-structured interview guidelines (see Table 1). A preliminary study was conducted to verify the appropriateness of the interview guidelines before recruiting patients.

Table 1
Interview guidelines for family caregivers

1. Under what circumstances did you learn that your family member was diagnosed with dementia?
2. Do you wish that the doctor would fully disclose your family member's diagnosis and condition to them? What are the reasons for your answer?
3. How did you feel when the doctor informed your family member about their condition?
4. How do you feel about your family member's condition?
5. How did your life change after your family member became ill? How did you view or handle these impacts?
6. How did the interactions between you and your family members change when they became ill?
7. What are you worried about in terms of your family member's situation?
8. Is there anything else that you would like to share with me?

Setting and participants

A theoretical sampling method was employed in this study to recruit family caregivers of patients with dementia from the outpatient department of a hospital in northern Taiwan. The inclusion criteria for family caregivers were as follows: (1) currently caring for a family member with dementia; (2) conscious clear and able to communicate in Mandarin or Taiwanese; (3) willing to participate the study and sign the informed consent form; and (4) not a hired caregiver.

A total of 20 family caregivers of patients with dementia showing willingness to participate in the study, aged 41–83 years (17 females and 3 males, mean age of 61.6 years), completed the interviews (see Table 2).

Table 2
Participants' basic information

| Participants' code | Gender | Age | Identity | Marital status | Occupational status |
|--------------------|--------|-----|---------------------|----------------|---------------------|
| C1 | Female | 69 | Wife | Married | Unemployed |
| C2 | Male | 62 | Son | Married | Full time |
| C3 | Male | 68 | Son | Married | Full time |
| C4 | Female | 70 | Daughter | Widowed | Unemployed |
| C5 | Male | 68 | Son | Married | Unemployed |
| C6 | Female | 53 | Daughter | Unmarried | Full time |
| C7 | Female | 54 | Daughter- in-law | Married | Full time |
| C8 | Female | 44 | Daughter | Unmarried | Full time |
| C9 | Female | 57 | Daughter- in-law | Married | Full time |
| C10 | Female | 56 | Daughter | Married | Unemployed |
| C11 | Female | 71 | Wife | Married | Unemployed |
| C12 | Female | 63 | Daughter | Married | Unemployed |
| C13 | Female | 69 | Wife | Married | Unemployed |
| C14 | Female | 54 | Daughter | Unmarried | Unemployed |
| C15 | Female | 41 | Grand- daughter | Divorce | Unemployed |
| C16 | Female | 65 | Daughter | Married | Unemployed |
| C17 | Female | 83 | Wife | Married | Unemployed |
| C18 | Female | 55 | Daughter | Unmarried | Unemployed |
| C19 | Female | 65 | Wife | Married | Unemployed |
| C20 | Female | 65 | Daughter | Unmarried | Unemployed |

Ethical considerations

This study was approved by the institutional review board of a regional hospital in northern Taiwan (No. 201701078RINC). Prior to conducting the interviews, the researcher clearly explained the participants or

their rights, including that they could choose to withdraw from the study at any time without affecting their care or other reprisals, and obtained their written consent.

Data collection and analysis

The participants' comfort and privacy were considered throughout this study. Data were collected by conducting one-on-one, face-to-face, in-depth interviews in the hospital's consulting rooms or at participants' homes. All interviews were held by the primary researcher (female Registered Nurse, PhD), and who explained the purpose of the study and the estimated length and methods for the interview, assured the participants of their confidentiality throughout the study, and obtained the participants' consent before conducting the interviews. Each interview was recorded by a digital voice recorder and lasted for 40 to 50 minutes. Each participant was interviewed just once. Data collection was continued until data saturation was reached. The interviews were immediately transcribed to ensure the completeness of the data.

The primary researcher had experience and previous training in conducting an interview. The collected data were inductively analyzed using the constant comparative method [12]. and taken to avoid potential interactive effects between the researcher and the data, to prevent the potential effects of bias and preserve the objectivity of the analysis.

Trustworthiness

This study adopted the four criteria of credibility, dependability, confirmability, and transferability that were proposed by Lincoln and Guba to evaluate the collected data and ensure the rigor of the analysis [13].

Credibility: There was no relationship between the participant and the researcher prior to the study. Under the guidance of an attending physician, the researcher interacted with the participants during their outpatient treatment to prolong engagement and build trust with the participants. The in-depth interviews began with open-ended questions. The setting for interview were considered to ensure that the participants felt free to express themselves and confirm their intended meanings.

Dependability: The data collection and data management was performed by the researcher alone. The data analysis process involved the continuous, repeated, and detailed reading of the transcribed interview contents. The opinions, settings, and overviews of the interactions that occurred during the interviews were recorded to allow others to validate and confirm the consistency of the data. The researcher continuously and repeatedly performed data analysis, induction, and verification to ensure reliability.

Confirmability: The researcher used a field note to engage in constant self-reflection and adjusted, and maintained an objective and neutral stance throughout the study through feedback from professional experts and peers.

Transferability: The participants in this study were family caregivers of patients with dementia who were willing to share their true experiences regarding the effects of the disclosure of a dementia diagnosis on

their lives. The researcher regularly corroborated the information with the participants to ensure the completeness of the situated data. The participants were diverse in terms of sex, age range, and occupation, which demonstrates the richness of the data.

Results

Based on the data, a framework of the experiences of family caregivers following a dementia diagnosis was developed (Figure 1). **Diagnostic disclosure: Start the long road of care challenges** was identified as the core category of this study, which was defined as describing the experiences of family caregivers of patients with dementia after first being informed of the patients' diagnosis, which activates their willpower to progress against the disease. This category also comprises the processes through which caregivers attempted to identify strategies for delaying disease-related deterioration, adjusted the interactions with patients, and shared the experience of accepting and living well with the disease.

Five major categories describing the experiences of family caregivers following a dementia diagnosis was developed: 'deciding to seek medical attention,' 'the moment of disclosure,' 'conveying information,' 'maintaining the patients' functioning,' and 'receiving support and living well with dementia.' Subcategories within each major category also emerged.

Deciding to seek medical attention

The caregivers described deciding to seek medical attention for the patients after becoming aware of the patients' abnormal behaviors.

Behavioral changes

The caregivers became aware that the patients were exhibiting unusual behaviors, such as forgetting where they had placed an item they were looking for, asking when mealtime would be after eating, or losing money and suspecting family members of theft. Such as C1 described, "[the patient] kept asking me whether he had eaten, so I felt something amiss about him".

During the conversation, he began to become unreasonable, and things would disappear. He is looking for things every day.....He used to carry a lot of money, necklaces and other things, but he often lost them and couldn't find them. (C3)

Wandering off and getting lost as a warning sign

Many caregivers described suspecting that something was amiss when their family member lost their way home. Such as C5 said, "At first he lost his way and denied it. He had already lost his way three times before the diagnosis". And C17 said, "[the patient] went missing after I went to fetch the medications".

Seeking information

The caregivers described turning to the Internet to seek information regarding their suspicions and hoping to find answers from healthcare professionals. For example:

I think she should not only be degenerate, because we have also had the opportunity to talk to other older people, but it's a bit different.....I looked up information online by myself and found that there are two major types of dementia—Alzheimer's disease and vascular dementia. But I had to ask the doctor which of the two my family member was diagnosed with. (C10)

The moment of disclosure

At the time of the diagnostic disclosure, caregivers had some thoughts and emotional responses.

Mentally prepared for the diagnosis

Prior to seeking medical attention, some caregivers already suspected that their family members had dementia and were, therefore, unsurprised by the diagnosis. Such as C2 described, "Older people have declining cognitive functions, which differs for everyone. To me, this is normal, so I feel indifferent about it. Everything declines as you age". And C5 said, "I was mentally prepared. I knew that there was a high chance that the patient would have dementia at that age".

Bewilderment and helplessness

Some caregivers became anxious about the expected progression of dementia and the confusing behaviors of their family members. They described feeling helpless when they think about the long caregiving journey ahead. C11 stated, "At this point, I don't know what I should do next. At the beginning, it was total confusion, like a drowning person who is unable to reach out to their rescuer".

Preparing for the long battle ahead

After the caregivers came to terms with the lengthy and irreversible nature of dementia, they prepared themselves for the long battle ahead. For example:

As a family member, when I was informed of the patient's diagnosis, I knew I had to prepare myself for the long, challenge-riddled journey ahead..... Compared with other diseases, the course of dementia is very long. For example, my mother had cancer before and passed away in half a year. In fact, the hard work is very short-lived, but family members with dementia have to take care of the patient for a long time., This is a great responsibility.. (C6)

Conveying information

After being informed of the diagnosis, family caregivers wondered how to convey the dementia diagnoses to the patients.

Not willing to talk about the illness

Some of the caregivers were worried that the patients would not be receptive to the diagnosis and would feel distressed upon learning of the diagnosis. To them, ignorance is bliss. C2 said, “The patient feels that she’s very strong, so it’s pointless to tell her. She won’t accept the truth because she feels good about herself!”. And C18 stated, “I’m not sure how she really feels. But to me, I think it’s best to not increase her psychological stress”.

Appeasing the patient

When responding to the patients’ inquiries about their illness, some caregivers took a tactful approach by not fully informing the patients about their condition. C9 said, “She’s always curious about her condition, but I don’t think she is able to accept the truth. I decided to give her a chance by giving hints along the way”.

Expecting cooperation after disclosure

For some caregivers, avoiding any delay in the opportunity to seek care or establishing care routines was critical. They expected the patient to cooperate after being informed of their diagnosis. For example:

I really want to tell him about the diagnosis so that he can cooperate with me after understanding his condition. When I tell him to take his medication, he will ask why he needs to take so much of it and wants to withdraw. Therefore, I want the doctor to tell him clearly about his illness and have him accept the truth. Otherwise, he keeps attempting to withdraw from taking his medication. (C1)

Maintaining the patients’ functioning

Although the caregivers were generally aware that no cure exists for dementia, they expressed a desire to delay the patients’ deterioration and maintain their normal functioning.

Regularly administering medications

The caregivers expected the patients to be able to adhere to their medication regimens to delay the deterioration of their condition. Such as C11 described, “I want to give the patient any medication that could delay their deterioration”. C20 said, “She should take any medication that could alleviate her changes”.

Scheduling activities

Some caregivers hoped that they could help the patients delay the onset of social and functional decline by encouraging participation in social activities. For example:

I have to find ways to stimulate him. Sometimes it’s a gathering with friends. I learned to play card games myself, and I accompany him to card games, teach him how to play, and ask some friends over to play. (C8)

Preventing patients from wandering and getting lost

The caregivers used tools, such as identity bracelets or keeping records of the patients' fingerprints to facilitate the rapid identification of patients in case they wandered and became lost. C14 said, "We kept thinking about how we can prevent her from getting lost, and we decided to give her a GPS tracker". C15 also said, "Of course I'm worried about him getting lost. I gave him a bracelet so he can easily be tracked down".

Receiving support and living well with dementia

The caregivers were better able to identify with the patients' resignation and struggles once they understood the disease, which helped them change their mindset and accept their family members' fate. Due to their age, the patients slowly came to terms with their declining functioning and learned how to live well with dementia.

Understanding and accepting

Once the caregivers understood the changes that can occur as dementia progresses, they gradually began to empathize with the patients' abnormal behaviors, which they cannot control. The caregivers began to think differently and learned to accept reality. C16 said, "I don't think he wants it to be like this. He doesn't know exactly why he ended up like this". Another for example:

I think I can accept her for what she has slowly become. One reason is that she didn't do this on purpose, and another is that this disease is irreversible, so I really have to coexist with her current state anyhow.
(C12)

Changing the interaction methods

When faced with the unusual behaviors exhibited by the patients, the caregivers chose to go with the flow and change the way they interacted with the patients. C16 said, "All I can do now is to appease him as best as I can, even when he's wrong. It's best to avoid conflict". C11 said, "Sometimes he throws a tantrum, so now I try to appease him".

Sharing caregiving duties

The caregivers reached a consensus with their family members in terms of caregiving duties. C10 said, "It's important to share caregiving duties because everyone needs to get the necessary support when in need". And C5 stated, "I laid out a lot of plans and asked my siblings to cooperate with me".

Discussion

Transformation in response to dementia diagnosis begins when an individual is initially informed of their illness, the caregivers were able to gradually understand and accept their family members' diagnoses. This finding was similar to the core category of "shared processes in the family," which was identified by Pesonen et al. [14]. A diagnosis represents a mutual turning point for the family. Although the meaning of

dementia differs between a patient and their family members, they must reach a consensus to cope with the disease together.

The caregivers were generally aware of the changes in their family members' behaviors, which prompted them to seek treatment for the affected family member and attempt to identify the causes of the disease. Prior to the diagnosis, the caregivers continuously checked and validated the condition of their family member with suspected dementia because the patients were often unaware of their dementia symptoms [15]. The affected family member getting lost was one event that prompted caregivers to recognize the disease severity and choose to seek professional assistance [14]. The study by Mastwyk et al. also revealed that patients with dementia and their family members often sought medical treatment due to memory problems [4]. Therefore, identifying symptoms and seeking professional assistance are regarded as shared processes among the family [14]. A majority of the caregivers were well aware of the diagnostic disclosure, and they expressed the desire for a doctor to conduct a memory test and a brain scan to assess the problems and validate the symptoms [4]. Even though they were well aware of the signs and symptoms of dementia, the caregivers often described feeling shocked and bewildered upon being informed of the diagnosis. This finding was similar to the findings reported by Derksen et al. [16]. Some caregivers also described being shocked by the diagnosis because they did not suspect anything was amiss, which is associated with a lack of understanding regarding the presentation of dementia [17]. Once the caregivers understood the long-term disease course and irreversible nature of dementia, they would prepare themselves to cope with the disease as long as possible. This mindset is associated with the finding that most patients with dementia are cared for by their family members and depend upon them to assist and support their activities of daily living [18]. The disease itself is regarded as both a personal experience for the patient and an issue that the whole family must cope with because a family's equilibrium is disrupted when a family member is diagnosed with dementia [14]. Despite some caregivers being aware of the high likelihood that their family member would be diagnosed with dementia even before seeking treatment, they continued to hope that they were wrong. The diagnosis of dementia confirmed the previous suspicions of the caregivers, demolishing their hope and forcing them to prepare themselves for the long-term challenges ahead.

The stigmatization of dementia was one reason that caregivers were concerned that the patients might not accept their diagnosis, and disclosure could cause distress. Therefore, caregivers often do not wish for their affected family members to be informed of their diagnosis. This finding is in accordance with those reported by van den Dungen et al. and Mitchell et al., who found that caregivers sometimes chose not to disclose their family members' diagnosis to them to prevent unease or anxiety and because they regarded the disclosure as being pointless [19, 20]. In the present study, some caregivers attempted a tactful approach to convey information regarding dementia to the patients without persuading them to understand the disease completely. The caregivers who chose this approach appeared to be influenced by the stigmatization of dementia, describing the situation as a "cognitive impairment" to avoid impulsive reactions from their family members [6].

The family caregivers attempted to help the patients comprehend their current condition and prognosis in the hope that understanding would enable the patients to cooperate in their follow-up care plans. This finding supports the findings reported by Mastwyk et al., in which caregivers expressed the desire that their family members understood their condition so that treatment plans could be devised and offered to them, and the patients could learn coping strategies [4]. The strategies adopted by the caregivers to delay deterioration in their family members' conditions include routine medication administration, scheduling activities, and preventing patients from wandering around and getting lost. These strategies support the findings of van der Roest et al., who reported that caregivers took their own initiative to find information about the disease and sought solutions [21]. Coping strategies included managing their everyday activities; keeping a list of important items; using cues and clues; writing reminders in a diary, notebook, or calendar; promoting their health; engaging in memory training sessions; and maintaining their activity levels [22, 23, 24, 25, 26].

The caregivers were better able to identify with the patients' feelings of resignation and their struggles with the disease when they had a better understanding of the disease. Caregivers often chose to accept the patients' fate and attempted to change their own mindsets to help their family members live well with dementia. Throughout the period of adjusting to their roles, the caregivers developed a better understanding of the functional capacities of their family members and the value of their relationship [16]. Mutual attempts were made to find ways to acquiesce or accustom themselves to the symptoms [14]. This approach reflects the values and beliefs of Asian people. The Chinese people, who believe that everything that happens to their corporeal form is a matter of fate and view acceptance as the best way to live with things that cannot be changed. Therefore, the family members were compelled to accept the dementia diagnosis and take on the caregiver role [27]. The caregivers changed how they interacted with the patients, complied with the patients' needs, and strengthened their relationships during the process. A diagnostic disclosure not only prompts caregivers and patients to rethink and adjust their interactions to identify effective coping measures but also allows them to recognize the value of their relationship [14]. However, caregivers also felt the burden of their responsibilities, which they wished they could share with others. During this process, they accepted both that their family member was diagnosed with dementia and that their family member's illness was part of their lives. After experiencing the patient's functioning impairment and cognitive decline, the caregiver and the patient recognized the patients' humiliation, loss of control, and the need to rearrange their roles and responsibilities [24].

This study employed a retrospective interview technique, which can be limited by the participants' inability to completely recall past experiences. Therefore, the authenticity of the retrospective data remains incomplete. To overcome this problem, a longitudinal study can be conducted in the future, in which data is collected at multiple time points after diagnosis. Such an approach would reveal additional details regarding the participants' actual life experiences and reveal the changes that occur in response to the use of various coping strategies. In addition, the primary diagnoses of patients cared for by the participants in this study were Alzheimer's disease and vascular dementia, and they were typically older individuals (mean age: 85.6 years, standard deviation; 5.40 years). Therefore, these results may not be generalizable to patients with other forms of dementia. Subsequent studies can target younger

populations or those with early-onset dementia and compare differences in their experiences with dementia diagnosis disclosure.

Conclusion

This study describes the experiences of family caregivers of patients with dementia in response to being informed of the patients' dementia diagnosis. The caregivers accompanied the patients to seek medical attention and addressed the impacts of the disease from the moment of disclosure. They sought methods to delay disease progression and altered their interactions with one another, accepting and coping with the disease together. Diagnostic disclosure: Start the long road of care challenges was identified as the core category of this study. Changes began once the patients and caregivers were informed of the diagnosis and accepted it. Despite feeling overwhelmed, the caregivers accepted the reality that their family members were diagnosed with dementia and accepted the role of long-term caregiving. Maintaining the patients' functioning was identified as the important goal. The caregivers aimed to identify strategies to alleviate the patients' deterioration and allow them to continue living their lives. Following the diagnostic disclosure, the caregivers had a clearer direction of how they should change themselves to live well with dementia. Clear diagnostic disclosure is important for ensuring that positive developments can occur in response to disclosure. Healthcare professionals must develop strategies to prevent disclosure from triggering overreactive emotions from patients with cognitive impairments, assist them in understanding their illness in a tactful manner, and ensure that they understand how to cooperate in any subsequent care plans.

Declarations

Ethics approval and consent to participate

This study was approved by the Research Ethics Committee at the National Taiwan University Hospital (NTUH-REC No. 201701078RINC). Prior to conducting the interviews, informed consent was taken from the participants. All methods in this study were carried out in accordance with all guidelines and regulations.

Consent for publication

Prior to conducting the interviews, the researcher clearly explained the participants or their rights, including that they could choose to withdraw from the study at any time without affecting their care or other reprisals, and obtained their written consent.

Availability of data and materials

The dataset analysed in the current study are available from the corresponding author on reasonable request. The data are not publicly available due to the information could compromise research participant privacy.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

Chen MC. designed and conducted the study, collected and analysed data, and drafted the manuscript. Lin HR. participated in the data analysis process and helped to draft the manuscript. All authors have approved the final version and agree to be accountable for all aspects of the work.

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Figures

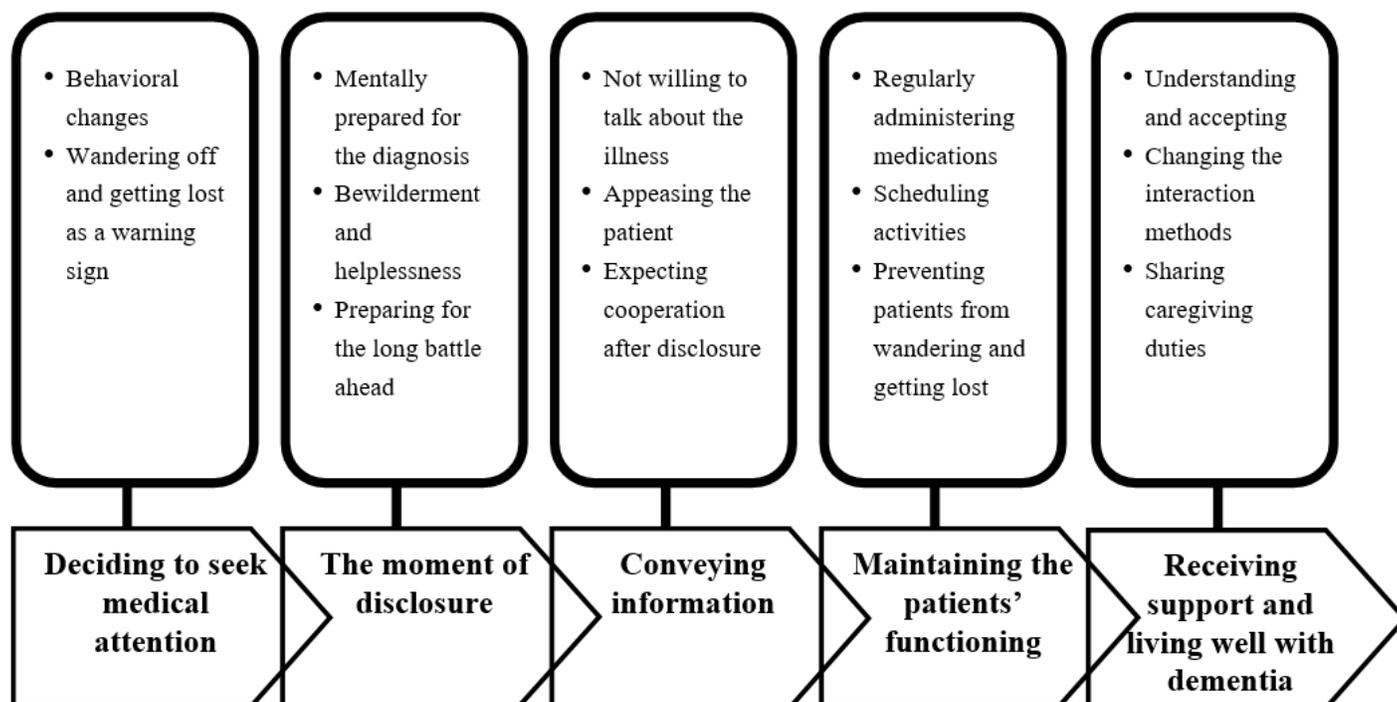


Figure 1

Diagnostic disclosure – Start the long road of care challenges