



The change of intimate relationship between people with Alzheimer's disease and their adult child caregivers: An interpretative phenomenological analysis

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~~An interpretative phenomenological analysis of the intimate relationship~~ The change of intimate relationship between people with Alzheimer's disease and their adult child caregivers: An interpretative phenomenological analysis

Abstract

This study aims to explore the change of intimate relationship between people with Alzheimer's disease and their adult child caregivers as the disease progresses. Twelve adult child caregivers were recruited through purposive sampling. Explanatory phenomenological analysis was conducted to analyse data collected by semi-structured in-depth interviews. This study found a ~~dynamically~~ dynamically changing relationship between adult child caregivers and their parents with Alzheimer's disease during care giving that evolved with the progress of the disease. The relationship was the most intimate in the middle stage of the disease for most caregivers and a new reciprocal relationship developed due to caregiving. Caregivers experienced different degrees of self-growth when providing care, though caregiver burdens were common. The positive experience and perception of caregivers were important for improving the quality of life for adult child caregivers of people with Alzheimer's disease.

~~The positive experience and perception of caregivers were important for improving the overall quality of life for both people with Alzheimer's disease and their adult child caregivers.~~

Keywords

Alzheimer's disease, intimate relationship, interpretive phenomenological analysis, caregiver, personal growth

Introduction

Alzheimer's disease is a neurodegenerative disease that develops in the mid-to-late adulthood. It is the most common type of dementia, accounting for 60%-70% of people with dementia (Li et al., 2022). Based on the epidemiological and demographic data, it was estimated that overall prevalence of dementia was 6.0% in people aged 60 years and older in China with a total number of 15.07 million, among which 9.83 million were with Alzheimer's disease (Jia et al., 2020). Alzheimer's disease is clinically characterized by non-reversible progressive memory impairment and other cognitive dysfunctions, which usually resulted in decreasing capacity to carry out the activities of daily living and some behavioural disorders. Currently there is no medication that can cure or reverse the process of Alzheimer's disease pathology (Passeri et al., 2022).

Most people with Alzheimer's disease are 65 and older living 5 to 10 years after diagnosis. There is evidence that some people may live up to 20 years after diagnosis (Goldberg, 2022). Family caregivers play a central role in the care and support of people with dementia. Home is often the preferred place of care, especially during the early and middle stages of dementia, due to family members' capacity to ensure quality, well-being, maintaining integrity of the family, and consideration of costs (Bressan et al., 2020). Caring for people with dementia usually involves multiple family members: over 60% of home caregivers are family members who live with patients, such as spouses (25.7%), adult children (20.9%), and children's spouses (15.2%) (Kimura et al., 2019).

Caring for people living with dementia can be challenging. A decline in the caregiver's physical health, social isolation and financial burden have been reported (Mwendwa et al., 2021). Caregiving experiences are not static but are changing throughout the disease trajectory and care continuum (Kokorelias et al., 2021). The relationship and interaction between people with Alzheimer's disease and their caregivers directly influence the quality of care. Knowledge on the change of their intimate relationship after the symptoms of Alzheimer's disease onset can provide insights for appropriate support to the caregivers.

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4 The burden on caregivers of people with dementia and other related diseases has been
5 widely concerned, whereas only a few studies have explored the changes in the intimate
6 relationship between people with Alzheimer's disease and their caregivers in the long
7 period of fighting dementia together (Quinn et al., 2015). Some previous studies
8 focused on care provided by spouses and changes in intimacy in the nursing process
9 (Albert et al., 2023; Conway et al., 2018; Ha et al., 2021; Hammar et al., 2021).
10 However, there has been little research on the change of intimate relationship between
11 persons with Alzheimer's disease and their adult child caregivers as the main care
12 providers. Therefore, this paper focuses on the experiences of adult child caregivers of
13 people with Alzheimer's disease to better understand the changes in the intimate
14 relationship between them and their parents at different stages of this disease.
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26 **Methods**

27 *Methodology*

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29 Interpretative Phenomenological Analysis (IPA) was adopted in this study. The
30 relationship between caregivers and the person with Alzheimer's disease can transform
31 gradually over time (Albert et al., 2023; Conway et al., 2018; Ha et al., 2021; Hammar
32 et al., 2021). Qualitative research allows for an in-depth examination of these changes.
33 Qualitative studies capture the essence of subjective experiences of caregivers as they
34 react to the changes in their relationship with the care-recipients (Quinn et al., 2015),
35 and participants can express and articulate without being limited to what are asked on
36 a questionnaire or measured by an instrument. IPA involves intensive analysis of
37 detailed personal accounts of participants; a small size is recommended to meet the
38 phenomenological, hermeneutic, and idiographic underpinnings of IPA and allows the
39 exploration of meaningful similarities and differences between participants with
40 focused data of relevant experiences (Smith, 2009). IPA typically adopts open-ended
41 questions that impose minimal constraints on participants' interpretation so that
42 participants can possibly offer the information on all aspects of the phenomenon being
43 explored (Smith & Eatough, 2007). Therefore, a small sample is usually needed to
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4 obtain sufficient data for IPA studies. [Reflexivity \(Finlay & Gough, 2003; Olmos-Vega](#)
5 [et al., 2022\) was considered in the design of the study, data collection and analysis.](#)
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8 ***Participants***

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11 This study was conducted from December 1st, 2019 to December 1st, 2022 in a
12 dementia unit of a geriatric hospital. The COVID-19 pandemic impacted the face-to-
13 face interviews, which resulted in a long study period. ~~Participants were adult child~~
14 ~~caregivers whose parents living with Alzheimer's disease.~~ ~~Participants were adult son~~
15 ~~or daughter caregivers who had father or mother living with Alzheimer's disease.~~ The
16 inclusion criteria were: 1) Having ~~father or mother~~parents (not including parent in law)
17 who were diagnosed with Alzheimer's disease and with a clinical dementia rating score
18 of 2 or 3; 2) Aged 18 years or older; 3) Having provided care for at least 6 months.
19 Exclusion criteria was severe visual or auditory impairments which influenced
20 communication. The doctors in charge of Alzheimer's disease patients helped with the
21 recruitment of participants. They gave a brief introduction to potential participants and
22 only those who expressed interests were introduced to the researchers. Both the doctors
23 and the researchers informed participants that refusing to participate or withdrawing
24 midway would not affect the patient's further treatment.
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40 Following the principle of data saturation in qualitative research, this study interviewed
41 12 participants who had intact expression ability and strong willingness to
42 communicate. Six participants were daughters and six were sons aged from 46 to 67.
43 Their parents were seven men and five women aging from 73 to 90 years old with an
44 Alzheimer's disease course from 3 to 15 years. Their parents had been admitted to the
45 centre who were in the middle or late stages of Alzheimer's disease and had been
46 diagnosed by qualified dementia specialists. Table 1 shows demographic information
47 and care status of the participants.
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56 ***Data collection***

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59 Participants received a semi-structured face to face interview lasting from 30 to 100
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4 minutes. All participants were encouraged to talk about their feelings and experiences
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6 and to discuss the changes in intimate relationships with their parents with Alzheimer's
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8 disease. An interview schedule was developed based on the literature review and
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10 finalized after consulting with clinical experts, including feelings, experiences, and
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12 coping strategies of participants during their caregiving period in different stages of
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14 Alzheimer's disease. The interview questions mainly included: 1) What do you think
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16 about your relationship with your mother/father since the confirmation of Alzheimer's
17
18 disease? 2) What kind of things did you do with your father/mother in daily life before
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20 he/she got Alzheimer's disease (eg. travel, shopping, and cooking, etc.)? Do you still
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22 do these things together? Do you have any new experience and memory to share after
23
24 your father/mother got Alzheimer's disease? 3) What motivates you to continuously
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26 take care of your father/mother with Alzheimer's disease? 4) Is there any other
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28 information or feeling you want to share? The order of questions can be flexibly
29
30 adjusted according to the reply from the participants to ensure the fluency of the
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32 conversation.

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34 At the time of data collection, one interviewer was a residential physician, and the other
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36 was a dementia specialist. Both of them were experienced in diagnosing and managing
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38 patients with Alzheimer's disease. The interviewers received training on IPA interview
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40 skills, and had ensured the consistency by comparing the results through joint and
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42 individual interviews before the start of the study. ~~Reflexivity (Finlay & Gough, 2003;~~
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44 ~~Olmos-Vega et al., 2022) was considered in the design of the study, data collection and~~
45
46 ~~analysis.~~ The interviewers received training on IPA interview skills. They carefully
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48 explained the purpose and process of the study to the participants. During interviews
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50 they constantly reminded themselves not to bring in implicit assumptions. After
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52 conducting each interview, they reflected with each other on the interview guide for the
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54 following interviews.

55 56 ***Data analysis***

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59 The analysis process follows Smith's IPA six steps (Smith, 2009). The first author
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4 transcribed the interview recordings verbatim. Another author, a psychologist who is
5 experienced in psychoanalysis took notes depicting initial reactions to participants'
6 responses and thought about the emerging themes from the conversation. During data
7 analysis, the authors repeatedly read each interview transcript and coded them
8 independently. They analysed each transcript one by one, and cross-analysed all
9 transcripts until a list of themes and sub-themes were agreed by all authors. They
10 continuously reflected on how their experiences might influence their interpretations of
11 the results to minimize the potential occupational impact. To fully explain the feelings
12 and experiences of the participants, statements were extracted from interview
13 transcripts for each theme. In addition, the authors shared comprehensive descriptions
14 of the themes and sub-themes with participants to ask for feedback to minimize the bias
15 from the researchers.
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28 **Findings**

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31 There have been four themes emerging from data analysis, including role reversal,
32 changing intimate relationship, motivations for care, and personal developments. In the
33 findings below, "most" is used if any themes or sub-themes appeared in half or more of
34 the interviewers' transcripts.
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40 **1. Role reversal**

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43 Almost all participants had experienced their roles being reversed since their parents
44 began suffering from Alzheimer's disease.
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47 1.1 Caring for basic activities of daily living of parents with Alzheimer's disease

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50 That is, parents provide care to children when they are young; children provide care for
51 parents when they are old. In the early stage, as parents with Alzheimer's disease were
52 still capable in basic activities of daily living, the adult caregivers only needed to ensure
53 the safety of their parents and to remind some daily affairs, such as reminding them to
54 take medication on time and giving help in handling financial issues when necessary.
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~~Adult caregivers only needed to remind their parents to take their medication on time and handle financial issues for them.~~

Mr. C (a 67 years old son caregiver whose mother was 90 years old and had been diagnosed with Alzheimer's disease 15 years ago): "In early-stage, I always wanted to know what she was doing, whether in a safe environment, whether the medication was on time, but I didn't have to take care of her diet and way of living. Later, with the disease getting worse most of her daily life issues depended on me to deal with."

~~With the progressing of the disease, all the participants felt that they had not only gradually lost support and protection from their father or mother, but also became "parents" of their parent with Alzheimer's disease. Most of the participants reported that their parents acted more and more like children needing care in daily routine activities, for example, haircutting, cleaning, standing up and walking. All the participants felt that they had gradually lost support and protection from their father or mother and became "parents" of their parent with Alzheimer's disease. With the progressing of the disease, participants felt that their parents acted like children needing care in daily activities; for example, haircutting, cleaning, standing up and walking.~~

Mr. A (a 46 years old son caregiver whose father was 75 years old and had been diagnosed with Alzheimer's disease 6 years ago): "It's the other way around. For example, he gave me a haircut and a bath when I was a child, and now I give him a haircut and a bath. What can I say? The roles were reversed..."

Mrs. B (a 50 years old daughter caregiver whose mother was 77 years old and had been diagnosed with Alzheimer's disease 5 years ago): "I never thought I would clean my mother's ear one day. Now you have to clean her body and cut her nails regularly, and this kind of things were what my mom did for me when I was a kid..."

Mrs. F (a 50 years old daughter caregiver whose father was 73 years old and had been diagnosed with Alzheimer's disease 3 years ago): "Now it becomes that I take care of him. I am like the strong one now and he is like a child. It's reversed..."

Without considering age, the adult children acted like parent and the parent being the child in reverse, not only at home, but also when they went out.

Mrs. H (a 55 years old daughter caregiver whose father was 83 years old and had been diagnosed with Alzheimer's disease 8 years ago): "When I took him out, I had to hold him, and when I was a kid he supported me. Sometimes he calls me mom..."

They still loved each other, enjoyed being together, and just slowly changed their roles. Sometimes the AD parents even recognized their children as their own parents. Intimate relationship is like a bond that transports care, but the caregiver and recipient at different times are opposite.

1.2 Promoting mental health and well-being of parents with Alzheimer's disease

Adult child caregivers not only provided care to meet the basic needs of their parents, such as showering, ear picking, and nail cutting, but also involved their parents in leisure activities promoting their mental health and well-being, such as reading picture books, going shopping and sightseeing.

Mr. J (a 57 years old son caregiver whose mother was 77 years old and had been diagnosed with Alzheimer's disease 5 years ago): "Just like nursing a child, in order to let her exercise her brain every day, I have to show her my children's books, the kind that children read and with only pictures because she said she did not want to read any words. Then I just let her look at the painting and the colour..."

In order to maintain their mental health and well-being, some children caregivers insisted on taking their parents out for shopping and walks so that they can still receive cognitive stimulation in the maximum scope possible, just like parents take their children out to explore the world when they are young.

Mr. E (a 47 years old son caregiver whose mother was 71 years old and had been diagnosed with Alzheimer's disease 4 years ago): "She has got Alzheimer's disease for quite some time. At that time she knew the world around not so bad, and my mother loved to go to the market

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4 and crowded place as she was a talkative person. I took her to the market nearby and showed
5 her around, got some food for her. She was quite happy like a child...”

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8 Mrs. B: “I got an annual park pass, so that I could take her for a walk in the park when I had a
9 rest and she always loves to take pictures. So I took some pictures of her, she was very happy.
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11 These memories were good...”

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15 Mr E and Mrs B’s experiences show that their care for parents with AD are not limited
16 to care for basic physical needs, but also emotional and mental support. When
17 interacting with parents, the adult child caregivers not only play the role of “parents” in
18 their behavior, but also show compassion towards their child like parents from the
19 bottom of their hearts. Therefore, the role reversal appears to be comprehensive,
20 occurring in both behavior and spiritual world.

2. Dynamically changing Changing intimate relationship

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31 2.1 The relationship between the child caregivers and their parents with Alzheimer’s
32 disease was the closest in the middle stage

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36 Most participants stated that there was not much change in the intimate relationship
37 with their parents in the early stage of this disease compared to before the onset of
38 Alzheimer’s disease symptoms. However, in the middle stage of Alzheimer’s disease,
39 the relationship became more intimate than before. As these adult child caregivers
40 provided care and support for the parents who were semi-disabled and were still able
41 to communicate though sometimes abnormally, they tended to spend more time in
42 accompanying and caring for parents on their own. The adult caregivers were
43 appreciating the opportunity to be able to express love by intimate behaviours, such as
44 hugging and kissing, which is not usually seen in the conservative culture. They also
45 treasure the time that they could spend together on dementia treatments that help the
46 parent with AD to recover memories.

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58 Mr. A: “In the middle stage, he really needed support and when it’s severe, it is more difficult
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4 to take care of him and communicate normally. We went outdoors, showed love to each other
5 by touching, and sharing feelings by expressions more than ever, in which time we were most
6 close...”
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10 Mr. C: “We are a military family, which is an orthodox, conservative family. That kind of
11 intimate gestures, such as kissing and hugging, were hard to find in our family. But after the
12 disease there was gradually more and more interaction. I hugged and kissed her face, she was
13 happy to accept, this had never experienced before...”
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19 Mrs. D (a 63 years old daughter caregiver whose mother was 79 years old and had been
20 diagnosed with Alzheimer’s disease 8 years ago): “I looked up a lot of dementia treatments on
21 the internet, like nostalgia therapy, light therapy. I also looked up old movies, and I watched
22 them with her when she was in good state, and it brought back some old memories. She told
23 me about her past days, and I felt like we were closer than before...”
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30 Meaningful interaction is the key to maintain the close relationship. Patients with mid-
31 stage Alzheimer’s disease require more companionship than before, but they still
32 reserve some language communication ability to interact and express emotions. Their
33 adult child caregivers usually receive positive feedback from their parents, such as a
34 reply of “thank you”, or even a simple smile. These interactions can generate more
35 profound experience and make their relationship more intimate.
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42 ~~In the later stage of Alzheimer’s disease, most of the participants experienced caring~~
43 ~~burden because the patients’ cognitive function further declined. However, most of the~~
44 ~~participants experienced caring burden when their patients’ cognitive function further~~
45 ~~declined in the later stage of Alzheimer’s disease,~~ which often accompanied by urinary
46 incontinence, sleep disorders, abnormal behaviours, and psychological symptoms, such
47 as anxiety, depression, delusions. Some of them had to send their parents to nursing
48 homes for professional long-term care or to the hospital when there were acute
49 complications that need medical treatment.
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4 Mr. G (a 60 years old son caregiver whose father was 85 years old and had been diagnosed
5 with Alzheimer's disease 12 years ago): "He really does not sleep in the most serious time.
6 He had been kept awake for three days and three nights, which made me so desperate. We
7 tried everything but it did not go better. I had to take her to hospital. Now I visit him
8 whenever I have time, and the nursing staff will take some photos or videos of my father's
9 meals or daily activities to me every day. Although he can only recognize me occasionally,
10 which makes me very happy."

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18 Mrs. B: "My mother didn't eat much after she got pneumonia, and she often talked gibberish,
19 saying that someone in her family was going to kill her, and asking me to call the police
20 immediately after losing money in our house. Therefore I had to send her to hospital again
21 for treatment. When I came to visit her, she always asked when I would take her home. I was
22 very sad and didn't know how many times I cried. My life is now much easier and I finally
23 have time to do my own things. I come to see her every weekend, bring her favourite snacks
24 and fruits. I choose to continue to protect her in this way."

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33 They indicated that the care relief made them feel relaxed after separation, while they
34 still missed their parents from time to time. Despite living apart from the parents, adult
35 children kept in touch with parents by telephoning or visiting weekly or monthly to
36 maintain their parent-child relationships.
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42 Mr. L (a 64 years old son caregiver whose father was 77 years old and had been diagnosed
43 with Alzheimer's disease 7 years ago): "Although my father is no longer able to communicate,
44 I still visit him in the hospital once a week. If I am not busy at work, I will ask the nursing staff
45 about my father's situation almost every day."

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50 Mr. C: "I enjoy going over there (hospital) to visit my mother, spending some time with her,
51 taking her to garden every Sunday afternoon. I enjoy that."

52 53 54 55 2.2 A new type of intimate relationship was formed

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58 Some caregivers said that the intimate relationship did not change significantly by the
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4 disease. Some participants said that some new type of relationship developed between
5 their parents and them, which they had never experienced before. They became more
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7 sympathetic and empathetic to the parent during the caring process, like Mrs. B and Mr.
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9 J.

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11 Mrs. B: “My mother and I have always had a good relationship, and since she got this
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13 disease, I think my mother's life is not easy. She did not enjoy much for her whole life and
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15 she should enjoy her life when retired. But she got such a disease. I feel sorry for her and I
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17 will do my best to let my mother enjoy more for the rest of her life...”

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20 Mr. J: “When I was a child I did not care about her past, but when I got older and she had this
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22 disease, I wanted to care more about her, to better understand her and her life, and to take good care
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24 of her...”

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27 It appears that the long period of care made the child caregivers gain a deeper
28 understanding of their parents and developed a deep sympathy in their hearts, feeling
29 pity for their parents who had worked hard for a lifetime but was losing everything.

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32 Mrs. D also felt the hardship of her widowed mother and thought she should take care
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34 of her.

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37 Mrs. D: “It's not distant, it's not close, we are still in the same relationship, but I feel that she
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39 is a great mother who raised four of us. My father passed away early so her life was hard. I
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41 should accompany her more and take care of her more.”

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44 Sometimes they felt there was a new friendship formed. Mrs. K and Mr. E felt that
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46 when they communicated with parents, it was more like talking with friends.

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49 Mrs. K: (a 53 years old daughter caregiver whose father was 73 years old and had been
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51 diagnosed with Alzheimer's disease 3 years ago) “...Since he got the disease we've talked
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53 about everything like friends and leaned on each other. I sang with him and walked with him...”

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56 Mr. E: “My mom loved watching movies, and we went to the cinema together like best friends,
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58 and of course we bought a bucket of popcorn. But I tended to choose the last row, near the
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4 door, why's that? Because I was afraid that she would suddenly freak out and we could leave
5 as soon as possible. But every time, she would quietly watch until the end, and it turned out
6 that my worries were unfounded...”
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10 [As it is known to all, Alzheimer's disease can lead to personality changes. Parents with](#)
11 [Alzheimer's disease not only lose their cognitive function, but also may act like a](#)
12 [strange person, which can produce a significant change in their relationship with their](#)
13 [children. Moreover, their previous power relationship as parent-child tend to become](#)
14 [more equal and relaxed friendship or fellowship in the process of accompanying day](#)
15 [and night.](#)
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23 2.3 Mixed feelings and experiences

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26 Most caregivers reported mixed feelings in the caring process. In the early and middle
27 stage of the disease, because caregivers were able to meet the growing needs of parents
28 at that time, they had increased senses of achievement and belonging. Most caregivers
29 felt satisfied by spending time and enjoyed meaningful moments with parents due to
30 caring. In later stage, they felt both happiness and helplessness and experienced quarrel
31 and frustration.
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39 Parents and children usually do not share equal relationship in Chinese traditional
40 families, especially fathers represent authority and esteem. Caring had given Mr A the
41 opportunity to get to know the father again and his affection for his father changed from
42 fear to love, or sometimes both feelings mixed:
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48 Mr. A: “If my father did not have this disease, to tell the truth, maybe we would not be so close
49 in our whole life. We were too shy to express our feelings before, so in fact, this disease also
50 has its advantages. As he needs more care, I resigned and stayed at home full-time to take care
51 of my father. Looking back now, that time was the happiest time I spent. This illness is an
52 opportunity to take care of him, but this opportunity is the opposite of taking care of a baby. A
53 baby is getting stronger, but my father is getting weaker and farer away from me. So it's kind
54 of pain, I get a chance to take care of him, you get closer, but I actually know that he's leaving
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me.... I don't dare to imagine I would lose him one day".

~~Most participants seemed to think positively about the disease and expressed even "gratitude" to their parents with Alzheimer's disease, as the care for the disease gave them opportunities to spend time together and pay attention to knowing each other's needs and care for their parents. However, the child caregivers still felt fear and astonished when their parents getting sicker, especially when they were not able to recognize their children. Most participants showed "gratitude" to their parents with Alzheimer's disease. They said if it were not for the disease, they would not have spent a lot of time and energy getting to know each other and care more about their parents. However, when their parents getting sicker, especially when they were not able to recognize their children, the child caregivers felt fear and astonished. Some caregivers expressed that they felt their parents both a loved one and a stranger, which made their moods fluctuate.~~

Mr. A: "A normal person's thinking should follow a normal pattern, but when it comes to him, it's strange. For example, when I call his name, he will be irritable and angry. My father used to have a different personality, which made me very sad."

Mr. C: "Once I went to see my mother, and she told me that the water I drank was toxic and told me not to drink it. It shocked me and I realized that she was really sick. How could my shrewd mother become a total stranger in front of me ?"

~~There was also another common positive thought about Alzheimer's disease, that is, it is better than other life-threatening diseases such as heart disease and cancer which lead to high risk of death. The participants were sad and glad at the same time, like Mr. E and Mrs. D. Mr. C said that although his mother was the most familiar stranger to him, he was grateful that his mother had Alzheimer's disease, it is better than life-threatening diseases such as heart disease and cancer. Therefore, the participants were sadness and glad at the same time. Mr. E and Mrs. D also have the same feelings.~~

Mr. E: "In fact, sometimes I think there are benefits of this disease, now she does not worry

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4 about the big and small things at home, so she is not so tired, and she is happy every day. I
5 hope to take care of her like this forever. But sometimes I see her burning into rage and I can't
6 help thinking: if only she didn't have this disease, now that I'm retired, we would be traveling
7 all over the world...How terrible the real condition is... ..”

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12 Mrs. D “I am actually quite content as my mother is in a relatively good condition. She has
13 only dementia, whereas other people have both heart disease and dementia and some people
14 have cancer and dementia. At least she's not that miserable. I feel happy because this disease
15 hasn't affected her life span, and we're still together...”

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21 Although most caregivers had done their best to extend the home care process, as the
22 disease progressed, they were not able to meet their parents' increasing needs at home
23 in the later stage of the disease. The findings illustrated a conflict between children's
24 desire to continue taking care of their parents at home and the lack of support for home
25 care.

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31 Mrs. H: “You can prepare a little bit ahead of time, and there's a lot of things that you can't
32 anticipate, which it's beyond our ability and there's no one who can really help us. It's really
33 helpless...”

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38 Mrs. I (a 61 years old daughter caregiver whose father was 83 years old and had been diagnosed
39 with Alzheimer's disease 12 years before) said: “He really would not sleep and we really can't
40 deal with him at home, but we have no place to go... The sleeping pills prescribed by the doctor
41 don't make a difference at all. Finally, I begged the doctor to prescribe more medicine to us.
42 I'm exhausted and unable to work properly. I am really helpless.”

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48 Mrs. I also stated that her work and life were completely chaotic and the needs of help
49 and the spiritual pressure on her life were high, which made her feel breathless and
50 stressful. There were often two voices in her mind which conflicted with each other
51 “give up” and “go on”.

52 53 54 55 56 57 **3. Motivation for care**

3.1 Filial piety

All the participants mentioned filial piety that expects children to take care of their older parents without doubt, which was influenced by the Confucius culture. Participants indicated that no matter what their relationship was before the diagnosis of Alzheimer's disease, they would take care of parents. Mrs. B and Mr. C thought caring for the parents was an obligation inherited from generations to generations and a responsibility that cannot be avoided in Chinese culture:

Mrs. B: "I grew up with my grandparents. I was taught to respect the elderly and love the young. I should commit my filial duty to my parents, this concept is in my blood..."

Mr. C: "She is my mom and nothing can change the fact. To care for her is not only a responsibility but also my important obligation... I have a duty to take care of my mother. She needs my care. I feel I have done a good job because I still have mom..."

Mr. C believed that providing high-quality care for parents enhances their sense of being loved by a mom, which in turn became the driving force behind care. Most participants felt proud of taking the responsibility, as they would be respected for being filial by their relatives and neighbours, or even been praised with an award of being a filial model by the community.

3.2 Reciprocity

Reciprocity between parents and children has been common. Mrs. D felt that she should be kind and caring for her mom, because that was how her parents took care of her:

Mrs. D: "My mother has always been so kind to me since childhood. Now my mother is old and she is disabled. Then I must be kind to her, you can say this is filial piety or affection, it is necessary that I need to be nice to her. This is a kind of reciprocal relationship, really. I feel that very deeply..."

Mr. J believes that companionship, love and material support is a way to repay his

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4 mother for giving him his life.
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6 Mr. J: She gave me life, and now that I'm retired, I have the time and energy to take care of her,
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8 so I want to give her company, love and material support as much as I can. I think this is my
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10 way of giving back to her.
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13 Mr. L expressed “just like when she took care of me without expecting anything in
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15 return” and wanted to provide high quality care for his father.
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18 Mr. L: Even if he is given money, he will not spend it. What I can do now is to let him eat well
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20 as much as possible, accompany him more, and try to improve the quality of life. I hope I can
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22 do more things for him, just like when she took care of me without expecting anything in return.
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25 [This gratitude feeling is an intrinsic driving force of reciprocity that transcends legal](#)
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27 [contractual relationships. Being kind to parents with Alzheimer’s disease can bring](#)
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29 [comfort to their children's mind and further strengthens their intimate relationship.](#)
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31 32 **4. Personal development** 33

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35 Most participants identified themselves as experiencing positive changes in personality
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37 and personal development.
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39 40 4.1 Personality and value changes 41

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43 Most participants believed the experience of looking after their parents with
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45 Alzheimer’s disease promoted self-growth and enriches their lives. For example, they
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47 tended to be more patient, tolerant, and compassionate to their parent than they would
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49 have been before:
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51 Mr. L: “Sometimes he has a bad temper and doesn't want to eat. Even a breakfast needs the
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53 whole morning to feed him. You must be patient with him.”
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56 The caring for the Alzheimer’s Diseases made most participants be aware of the ageing
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58 process and care about their mental and physical health. It reminded them to live with
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4 a healthy lifestyle to prevent the disease or to delay the onset of disease. .
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7 Mr. C: “Ever since my mom got sick, I think it's important to be healthy. We are also reaching
8 old age. If you do not have a healthy body, not only you suffer much, but also your children,
9 your family members bearing a great burden. But we can't stop it, as people get old, something
10 will go wrong now and then. So, try to be as healthy as possible. Let the disease occur less
11 often or later, preferably not at all...”
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17 The disease also prompts some participants to reflect on the meaning of life, one of the
18 common view is “nothingness” as stated by Mrs. D:
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22 Mrs. D: “I think life may be such a process, can be said to be a complete process, is that you
23 come out from the origin of nothing, to the end still know nothing, a process of returning to
24 the origin...”
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28 29 4.2 New knowledge and skills 30

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32 The caring experience has been seen as a way of learning new knowledge and
33 developing new skills. For example, some caregivers gained new knowledge of
34 dementia through online resources, seeking medical help and medical consultation.
35 They learned about the possible symptoms and a series of problems of the disease
36 through online and medical channels, in order to enhance their ability to control
37 unexpected situations, so that they could continuously adjust and adapt to their care
38 roles. They also developed new life skills through planning their parents' daily meals
39 and daily routines. This is illustrated by Mrs D.
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49 Mrs. D: “Since my mother was diagnosed with this disease, I began to browse online and pay
50 attention to the public accounts issued by doctors and experts, which gradually let me
51 understand this disease.”
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55 The caring experience has also been an opportunity for the caregivers to develop new
56 interests or even new career related to social care for older people in general. Mr A is
57 an example of new career development. The caring experience developed new interests
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~~and skills that he was not good at previously. He was considering change his career to help more families:~~

Mr. A: "I used to work in the field of decoration, and since my father got this disease, I have also been researching how to recreate similar environment, decoration, and so on. For the elderly living in this city, we restore the previous decoration style and help them retrieve some memories, such as how to use old-fashioned telephones. I don't know if it works, but for older people with such cognitive impairment at home, I will do my best to help them."

Therefore, it appears that although taking care of parents with Alzheimer's disease takes a lot of time and effort, these new skills such as how to manage the behavioural and psychological disorders, make the adult child caregivers more confident and even able to secure new jobs, especially in areas where nursing professionals and training on dementia care are insufficient.

Discussion

This study seeks to explore the experiences of adult caregivers of parents with Alzheimer's disease to understand how the relationship changes over the course of caring. A total number of 12 adult child caregivers caring for parents who are in the middle or advanced stages were interviewed. Four themes emerged from the interviews, which are: role reversal, changing intimate relationship, motivation for care, and personal development.

In this study, we find that almost all the participants experienced the role reversal since taking on the caring task. They provided care for meeting their basic needs and engaging them with activities that promote mental well-being, which they described as "parenting" to their parents. Previous studies also found that caregivers increasingly rearranged their lives to suit the needs of their loved one, and commonly found themselves having to master unfamiliar tasks as they take responsibility for those previously fulfilled by the care recipient (Hooper & Collins, 2019). Dementia caregivers are essentially living in a perpetual state of transition as they manage the

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4 continually changing needs of their loved ones (Hooper & Collins, 2019). In this study,
5 participants were self-motivated to continue the caregiving when they were able to meet
6 the demands of the people with dementia. The role transition period is crucial, as Yong
7 and Price (2014) found that successful adaptation is a significant factor in determining
8 wellbeing for dementia caregivers (Luján et al., 2014). Around the time of transition,
9 caregivers have rising needs for knowledge and information, emotional support, and
10 assistance with planning care (Lee et al., 2019). Therefore, it is important to help
11 caregivers understand the care needs to support them to transit to the caregiver role.
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20 Studies have shown that the success in the caring role depends on caregivers' positive
21 experiences and the high-quality relationship with the person cared for (Clemmensen
22 et al., 2021). Despite the negative effects, a closer relationship has been established
23 (Yuan et al., 2023), but not much research has noted the changes in intimate
24 relationships in various stages of the disease. We found that there were changes in the
25 relationship between adult child caregivers and people with Alzheimer's disease
26 changes as the disease progresses. In the early and middle stages of this disease, though
27 the support patients with Alzheimer's disease required from their caregiver gradually
28 increased as their cognition declines, the caregivers were able to meet their growing
29 needs and plan for interactive activities. A friendship type of relationship was
30 commonly described by the caregivers when talking about their relationship to the
31 parent in the middle stage. But in the late stage, such close relationship diminished due
32 to less communication resulted from the declining cognitive functioning and increasing
33 disability and medical complications, especially when the persons with Alzheimer's
34 disease were hospitalised or in nursing facilities. Caregivers often experienced mixed
35 feelings, including helplessness and setbacks, as well as relief and happiness. The
36 psychological burden as caregivers still reduced because of the belief that their parents
37 no longer worrying about their own children but instead being cared as children.
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56 Previous studies showed that there are cultural differences between western and Asian
57 caregivers (Yuan et al., 2023). The findings highlight the importance of understanding
58 the social context for understanding the caring experience of adult care givers for people
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4 with Alzheimer's disease. The Confucian value of filial piety stipulates that providing
5 care for older parents is the obligation of adult children, which leads to the belief that
6 it is one's responsibility to take care of family members. Belief in filial piety is prevalent
7 among Easter Asian caregivers (Hashimoto & Ikels, 2005), especially among Chinese
8 caregivers (Lim et al., 2011). Moreover, in China, looking after parents is not only a
9 cultural expectation; but also a legal obligation (Zhang et al., 2020). In 2012 'The
10 Protection of the Rights and Interests of Elderly People Act' emphasised children's
11 obligation to tend to the spiritual needs of the elderly. This law enforced the
12 responsibility of caring for older people on individuals and families. This study found
13 that the cultural norm, filial piety, was the essential drive for care provision in China.
14 When asked about their caring experiences, caregivers often used "must" and "it's my
15 responsibility". They indicated that the practice of the filial piety is the key drive for
16 providing care. In addition, cultural background is an important mediating factor
17 between caregiving and the mental and physical health outcomes of caregivers
18 (Sörensen & Conwell, 2011). Due to the cultural norm and law enforcement, taking the
19 responsibility of caregivers is not perceived as an unacceptable change among
20 caregivers. Previous study also showed that caregivers who are more conscious of filial
21 duty are more likely to take the pressure and burden of looking after parents than those
22 who are less conscious (Zhang et al., 2019) and would induce positive experiences and
23 beneficial outcomes of caring for the caregivers (Yu et al., 2016).
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43 Findings of this study suggest that the sense of achievement, improved relationship and
44 self-growth are incentives for them to continue care provision. Lloyd *et al.* (2016)
45 pointed out providing care makes their relationship closer and strengthens the sense of
46 achievement for caregivers as well as helps them gain self-growth (Lloyd et al., 2016).
47 The relationship between caregiver and care-recipient could have an important
48 influence on caregiver' motivations to provide care (Quinn et al., 2015). When the care
49 provided by caregivers meet parents' needs, they gained a sense of achievement and
50 satisfaction (Yuan et al., 2023). Similar to previous studies, we found that although
51 home care is very stressful and full of challenges (Liu et al., 2019; Victor et al., 2021;
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4 Yuan et al., 2021), caregivers recognised the benefits by looking after their parents of
5 Alzheimer's disease as suggested in the literature, including experiencing a sense of
6 personal accomplishment and gratification, personal growth, improved relationships,
7 and gaining a renewed perspective in life (Smaling et al., 2021). This study identified
8 another positive aspect of caregiving, that is, the improved awareness of the values of
9 life and skills of self-care. All the positive influences enhance caregiver's compassion
10 and sense of satisfaction, and improved their well-being despite the negative impact of
11 caregiving.
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20 **Conclusion**

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22 Fulfilling cultural expectation of caring for parents when they are old is the original
23 drive for caring for parents with Alzheimer's disease. The positive changes including
24 the intimate relationship, gaining new skills, and self-development make them even
25 more motivated to care for their parents. Caregivers had experienced dynamic changes
26 in their relationship with their parents with Alzheimer's disease since they undertook
27 the caring role. These findings contribute to understanding the underlying mechanism
28 of caregiving behaviour of adult child caregivers for people with Alzheimer's disease,
29 and identifying their needs of support when fulfilling the caring responsibility. This will
30 help the government policy makers, social organisations, health service institutions, and
31 family members to give people with Alzheimer's disease and their families a better life
32 by providing targeted assistance.
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45 **Limitations**

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47 This study only recruited child caregivers of patients with Alzheimer's disease in one
48 geriatric hospital that providing long-term medical treatment and social care in the
49 capital city of China. Participants were residing in one of the most developed cities in
50 China, so that they might be able to access better health and social care than residents in
51 other places in China. It may not represent the experiences of caregivers who lived in
52 less developed cities or who had not yet sought help from medical institutions.
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Ethical considerations

Ethical approval was gained from the Ethics Committee of the hospital where this study was conducted.

For Peer Review

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Table 1. Demographic information and care status of participants

	Mr. A	Mrs. B	Mr. C	Mrs. D	Mr. E	Mrs. F	Mr. G	Mrs. H	Mrs. I	Mr. J	Mrs. K	Mr. L
Years of age	46	50	67	63	47	50	60	55	61	57	53	64
Gender	M	F	M	F	M	F	M	F	F	M	F	M
Marital status	Single	Married	Married	Married	Married	Married	Married	Married	Married	Married	Married	Married
Caring for father or mother	Father	Mother	Mother	Mother	Mother	Father	Father	Father	Father	Mother	Father	Father
Years of care	6	5	15	8	4	3	12	8	12	5	3	7
Number of other caregivers and relationship with participant	1 elder sister	2 elder sister, younger brother	0	1 younger brother	0	0	3 two brothers and a sister	1 younger sister	2 younger brothers	0	1 elder sister	0
Live with parents before the hospital admission or not	Yes	No	Yes	Yes	No	Yes	No	Yes	No	No	No	No