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Crossing, Trudging and Settling: A phenomenological inquiry into lived experience of Asian family caregivers of older persons with dementia

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ABSTRACT

Throughout Asian societies, family members often adopt the role of caregiving for older persons, providing essential care for loved ones with dementia. To date, there has been limited insight into the lived experience and meaning ascribed to the journey of these caregivers. This descriptive phenomenological study aims to explore the lived experience of Asian family caregivers of persons with dementia. Semi-structured face-to-face interviews were conducted with 16 family members caring for aged persons with dementia. Interviews were audio-recorded and data analysed using Colaizzi's technique. Analysis revealed the essential structure of a caregiver's journey with three major transitions, namely: (1) Crossing the threshold from ordinary world into caregiving world, (2) Trudging on the road of trials and obstacles, and (3) Settling into a new normalcy. Understanding the lived experience of Asian caregivers can help clinicians in targeting relevant support and information, and prepare new caregivers for the demands of their role.

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Introduction

By 2050, approximately 17% of the global population will be at least 65 years old.¹ As the risk of dementia increases with age, the global incidence of dementia will concomitantly increase with global population aging. Worldwide, it is projected that there will be 81 million persons above the age of 60 with dementia in 2040.¹ This is of particular concern for Asia, as approximately 40% of the projected global load of persons with dementia will be within this region alone.²

This demographic trend portends an increased demand for caregivers, typically informal family caregivers, to meet the burgeoning need.³ Previous research has shown that caregiving for older persons with dementia can be physically, psychologically and emotionally demanding.^{4,5} Applying the Model of Coping and Cognitive Appraisal, caregivers face 'caregiver stress' when caregiving demands exceed their coping ability.⁶ Caregiver stress is heightened in the presence of challenging behaviours or demanding physical care needs, contributing to high burden and poor mental health among caregivers.^{7,8}

In the Asian context, filial piety is a strong driver for informal caregiving of the elderly, with adult children seen as indispensable providers of care to allow older adults to age at home.^{9,10} This is of utmost importance in Singapore, with its rapidly ageing population

and the recognition that family caregivers form the bulwark responsible for preventing or delaying the institutionalization of their care recipients.¹¹ The profile of family caregivers was identified in the Singapore Survey on Informal Caregiving, with adult children representing 77% of the caregivers caring for older adults 75 years and above.^{11,12} Unfortunately, filial piety can also be expressed as a social pressure, leading to some caregivers feeling that the role is forced onto them as a social obligation.⁹ This can lead to increased societal expectations, particularly in Asian communities, of adult children taking up the caregiving role, which contributes to a higher level of perceived caregiver burden.^{13,14} The majority of published studies focused on the 'task' aspect of caregiving but not the meaning of the lived experience of caregiving.¹⁵

There is a need to further explicate the unique stresses of Asian family caregivers as suggested by earlier quantitative studies.^{10,12} Little is known about the meaning of the caregiving role for family caregivers of persons with dementia in the Asian context. Using a descriptive phenomenological approach, this study aims to explore the lived experience of informal family caregivers of persons with dementia in Singapore. Understanding the caregiver 'voice' from the Asian perspective will complement published work on caregiver burden and deepen insights into the gestalt of the caregiver experience.^{8,14,16} In addition, given Singapore's position as one of the fastest-ageing populations in the world,¹¹ the insights gleaned from our study will afford healthcare professionals and policy-makers a deeper understanding of the complex phenomenon of caregiving for

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family members with dementia, which can inform future development and research of initiatives to support family caregivers in the Asian context and beyond.

Material and methods

The descriptive phenomenological approach was used to better capture the lived experience, or first-person subjective life, of Asian family members caring for loved ones with dementia, providing insight into the complexity and subtlety of the shared experiences of caregiving while allowing retention of its richness and depth.^{17–19}

A purposive recruitment strategy was used to sample family caregivers from a larger study conducted between July 2015 to May 2017 of caregivers of frail older persons who were admitted into the general medicine and geriatric medicine wards of a 1300-bedded tertiary hospital in Singapore. Inclusion criteria included adult family caregivers of older persons with dementia who were aged 65 and above; not residing in assisted or long-term care facilities; dependent in activities of daily living; and had a recent non-elective hospitalization at the study site. To facilitate an in-depth understanding of the phenomenon across different caregiving experiences, we sampled a diverse population across age (range: 38–69 years), gender, race and relationship to persons with dementia. A diverse group of caregivers across Chinese, Malay and Indian ethnic groups were recruited to ensure a representative sample of family caregivers from the main ethnic groups in Singapore.^{11,12} Ethics approval was obtained from the Domain-Specific Institutional Review Board of the National Healthcare Group, Singapore.

Data collection

The interviews were conducted in a room conducive to privacy and interviewing, either in a tutorial room in the hospital or in the participants' homes. An interview guide was used (Table 1). All interviews were recorded, transcribed verbatim and checked for accuracy by the researchers. While the interviewer (EYC) has a background understanding of caregiving due to her clinical experience as a registered nurse, she was careful to bracket her own experiences and thoughts about caregiving before each interview by suspending her prior conceptions,²⁰ thereby ensuring a fresh perspective with each episode.¹⁹

Data analysis

A descriptive phenomenological approach was used. All prejudices and presuppositions held by the researchers were set aside – or

Table 1

Abbreviated list of Semi-structured questions.

1. How did you take on the role of a caregiver to your care-recipient?
2. What do you do on a typical day to care for your care-recipient?
3. What would you consider as a "good day" for you as a caregiver?
4. What is a "bad day"?
5. How did you learn to provide care?
6. Do you get any assistance from others with caring for your care-recipient?
7. What kinds of challenges do you face in providing care to your care-recipient?
8. How did/ can you overcome these challenges you mentioned?
9. Do you feel you have expectations to meet from others (e.g. care-recipient, family members and friends, society)? How do you cope with these expectations?
10. What do you think are barriers (or challenges) towards being an effective caregiver?
11. How have you been since you became a caregiver to your care-recipient?
12. Do you feel you have control over your life in general?
13. How has your relationship with your care-recipient been since you started caring for him/her?
14. What are the positive and negative impacts of caregiving?

'bracketed' – before reading and discussing each individual transcript. This allowed the true meaning of the caregiving phenomena to emerge for the researchers to see the phenomena as they really were.^{18,19}

Colaizzi's 7-step approach for a rigorous analysis of qualitative data was adapted in the analysis of the transcripts, aiming to develop a condensed essential structure of the lived experience of caregiving for a person with dementia.²¹ Each transcript was first read as a whole, followed by extraction of significant statements. These were then used to form meanings as they emerged. The formulated meanings were then organized into clusters of sub-themes and eventually themes. These themes were then matched to the individual significant statements. Through this, the resulting themes highlighted the lived experience of caregiving. Throughout the analysis, the researchers engaged in reflexive dialogue, and differences in opinion were discussed until agreement was reached.

Trustworthiness of the study

Study rigour was based on the aspects of trustworthiness.^{22,23} To ensure credibility, the interviews were transcribed verbatim using audio recordings supplemented with field notes and member checking. Triangulation of the interview audio data against objective data was done to improve consistency of findings.²⁴ To address dependability, constant reflexivity was conducted by the interviewer to address personal assumptions. Three researchers independently engaged in analysing each transcript. Prior to data analysis, the researchers 'bracketed' their individual preconceptions such that they could work inductively with the data to generate the description of the caregivers' lived experience. A detailed audit trail was kept of the discussions among team members about how agreement was arrived in the coding and themes.

Findings

Sample

We interviewed 16 family caregivers of different ethnicities, comprising 13 females and three males. These were mainly adult children (75%) with an average age of 57 years and average caregiving duration of six years. Further demographic information is shown in Table 2. The interviews lasted 36 to 100 min.

Structure of themes

A total of 278 significant statements regarding the caregiving experience of a family member with dementia were extracted from the transcripts, and nine subthemes and three theme clusters were identified (Table 3). Results of the analysis revealed the essential structure of a caregiver's journey with three major transitions: (1) Crossing the threshold into the caregiving world, (2) Trudging on the road of trials and obstacles, and (3) Settling into a new normalcy. Akin to the description of the Hero's Journey, the journey arc of the central character ('caregiver') often involves leaving the comfort of everyday life to face a series of extraordinary events involving challenges and changes.²⁵ This transition ultimately forces the character towards practical, intellectual, psychological and philosophical adjustments that define, by the end of the odyssey, the character's 'new normal'. Interestingly, an adaptation of the 'hero's journey' has also been described in the Patient-Journey Model in narrative accounts of patients' experiences with illnesses.²⁶

Theme 1: Crossing the threshold into the caregiving world

Crossing the threshold and being transported into the caregiving world entail an interruption of the predictability and comfort of the

Table 2
Demographic information of participants (N = 16).

PID	Age	Sex	Relationship to care recipient	Race	Education level	Living together	Working	Domestic helper
P1	68	Female	Wife	Chinese	Secondary	Yes	No	No
P2	59	Female	Daughter	Chinese	Tertiary	Yes	No	No
P3	38	Male	Son	Chinese	Tertiary	Yes	Part-time	No
P4	46	Female	Daughter	Malay	Secondary	Yes	No	No
P5	66	Female	Wife	Indian	Secondary	Yes	No	No
P6	58	Female	Daughter	Indian	Secondary	Yes	Full-time	No
P7	69	Female	Daughter	Indian	Secondary	Yes	No	No
P8	43	Female	Niece	Chinese	Tertiary	Yes	No	Yes
P9	55	Male	Son	Chinese	Secondary	Yes	No	No
P10	69	Female	Daughter	Chinese	Tertiary	No	No	Yes
P11	66	Male	Son	Chinese	Tertiary	Yes	No	Yes
P12	55	Female	Daughter	Malay	Tertiary	Yes	No	No
P13	57	Female	Daughter	Chinese	Tertiary	Yes	Full-time	Yes
P14	54	Female	Daughter	Chinese	Tertiary	Yes	Full-time	No
P15	58	Female	Daughter	Chinese	Tertiary	Yes	Part-time	No
P16	58	Female	God-Daughter	Others	Secondary	Yes	No	No

Abbreviation: PID, Personal Identifier.

status quo. The journey often starts with the stark realisation of their loved ones' caregiving needs, which prompts a serious contemplation of whether to assume the mantle of caregiving. Family members often feel compelled by Asian societal norms to prioritize care-recipients' needs above their own, leading to the watershed crossing of the threshold.

Sub-theme 1.1: Realising the need for caregiving

For some caregivers, the realization that they had entered the caregiving world was insidious, with a gradual increase in care needs of their loved ones. One caregiver (P2, daughter) described the realisation process as '*...subconsciously...I became a caregiver already*'. For others, crossing over to this new world was abrupt, often due to a trigger event such as the care-recipient having a fall or a stroke that resulted in hospitalization. A caregiver (P4, daughter) shared how she experienced an epiphany and '*realise(d) that something (was) wrong*' for the '*first time*' when her loved one started talking to herself after waking up one night.

Sub-theme 1.2: Answering the call

Upon realizing that their care-recipient required a higher level of care needs, family members have to grapple with the needs of care-recipients' vis-a-vis their own. Some found it a natural progression. Others mentioned the overhanging weight of societal expectations. A caregiver (P2, daughter) lamented that she '*had to do it because I'm the eldest*'. Another common sentiment was that whether '*married or unmarried, daughters are the one(s) to be caregivers*.' (P14, daughter) In particular, individuals who are perceived to have the least family or work responsibilities often found themselves thrust with

Table 3
Themes and subthemes. Essential structure: The Caregiver's Journey.

Themes	Sub-themes
Crossing the Threshold from Ordinary World into the Caregiving World	Realising the need for caregiving
Trudging on the Road of Trials and Obstacles	Answering the call Facing the reality of caregiving Learning the ropes and hacks Recharge for self-sustenance Seeking solace through religious faith Reinterpreting caregiver-care-recipient relationship
Settling into a New Normalcy	Building mastery in caregiving role Coping with uncertain future

caregiving responsibilities. For instance, one caregiver (P12, daughter) decided that '*since (she) was not working (she) will look after her (care-recipient)*'.

Several took the plunge into the caregiving world in response to the call of duty, despite being unprepared. One caregiver (P8, niece) '*jumped into the picture to care for (her care-recipient's) business and care for (her care-recipient)*.' Another caregiver (P11, son) boldly '*jumped into (caregiving) when (he) had no knowledge, no skills*.' Having entered the caregiving world, a caregiver (P2, daughter) shared that caregivers often felt that they are stuck with the caregiving role and would '*just have to move on as... (they) cannot come out already*'.

Theme 2: Trudging on the road of trials and obstacles

Having crossed the threshold into the caregiving world, caregivers have to cope with many challenges. To trudge on this obstacle-laden journey, caregivers learn the ropes and coping hacks, and take deliberate steps to recharge themselves. At various stages of the journey, caregivers often re-examine the relationship with their loved ones.

Sub-theme 2.1: Facing the reality of caregiving

Having embarked on this journey, reality starts to set in. Caregivers often describe how they would wake up early to capitalise on the sleep hours of their care-recipients to do the basic household chores. Caregiving was likened to an all-consuming full-time 24/7 job without reprieve.

Then after that when she is resting, I have to run to the market come back and cook...school time I have to rush, send my son, then later fetch him.. It's like a daily job. (P4, daughter)

The stress is exacerbated for caregivers who have to juggle work responsibilities with caregiving duties. One caregiver who tried to work from home while caring for his father with dementia recounted how the repetitive obsessive behaviour of his father was '*driving us nuts*' and also '*affects my work, very much*.' (P3, son). The absence of financial security is also identified as a key source of stress, which is often aggravated by the need to sacrifice one's career to assume full-time caregiving. Many caregivers were fearful about how they were going to manage the cost of caregiving in the future.

Disconcertingly for some caregivers, the major source of stress emanated from fellow family members. A caregiver recounted how aggrieved and frustrated she felt when her siblings were not involved

with the daily tasks of caregiving yet were quick to blame her when her care-recipient was admitted (P4, daughter). It was also difficult to involve other family members in caregiving activities. One caregiver (P4, daughter) was exasperated that her siblings were not keen to learn a 'simple thing' such as changing diapers.

The incessant daily grind inflicted by the demands of caregiving often affected their physical and mental well-being. One caregiver equated the stress of caregiving with wartime experience:

There's a mental torture in me I think. . . It caused me to have a lot of stress. . . Imagine you cannot sleep properly every night. It's just like during wartime. The soldiers have to be alert. (P9, son)

Another caregiver confided how the stress could be so overwhelming that it drove her to contemplate suicide.

Very stressed... Do you know that with her problem, she was so difficult? I almost went up to 12th floor and jumped. (P16, god-daughter)

Sub-theme 2.2: Learning the ropes and hacks

Caregiving entails a serendipitous journey of learning through reading, observing, and the iterative 'trial and error' cycles. While some preferred learning through formal training offered by hospitals, others preferred to learn on their own. One caregiver (P1, wife) attended 'every talk that was relevant to dementia' and also 'read nursing books'. Beyond head knowledge, a caregiver shared that 'observing is very important to get to watch and learn from' healthcare professionals to integrate practical aspects of caregiving (P8, niece).

In the process, caregivers built wide range of hacks that enabled them to engage their care-recipients and manage behavioural problems. An example was given by a caregiver on how she managed to get her care-recipient to eat her food, which was previously rejected by the care-recipient as it was prepared by her domestic helper -

She (care-recipient) said, 'No, no, no. she (domestic helper) want to poison me cannot.' . . . So, I take the same plate, I bring it to the kitchen. I don't let her see. . . So I just turn one round, I come back and say, 'I cook the rice for you. . .' She said okay. Then she will finish her meal. (P10, daughter)

In the provision of care, caregivers emphasised that all care-recipients are 'very different'. Caregivers thus have to be mindful of the unique characteristics and preferences of their loved ones, and to customise the caregiving approach accordingly.

I observed, and I actually looked at individual characteristics of a person. How to care and how best he likes to be cared for. . . My auntie. . . my uncle. . . they're very different. You have to approach them in very different ways. (P8, niece)

To remain resilient in the face of ever-changing caregiving challenges, caregivers had to adopt an 'adaptable' mind-set in order to 'adjust to the needs of the time.' (P10, daughter). For instance, one caregiver adapted to her care-recipient's lack of appetite by making her food saltier to whet her appetite and will address any corresponding side-effects when they occur. 'I put extra soy sauce for her. Then she will eat. Let her enjoy the food. If she develops high blood pressure? We meditate. This is better than forcing her to eat bland food' (P14, daughter)

Others reframed caregiving as a challenge. For instance, a caregiver who stays alone with her spouse views her daily caregiving struggles as 'challenges': '. . . I have to think of new ways every day. Every day there are challenges.' (P1, spouse). One caregiver developed the

habit of writing a daily journal, and practised gratitude by 'giv(ing) thanks for what I have.' (P13, daughter). Some also engaged the help of live-in foreign domestic helpers with whom they shared the caregiving tasks and created respite time.

We kind of double-up. She's (domestic helper) doing all the housework. . . cooking, the washing. I keep an eye. And when she's done, she then keeps watch on him, so I can go and have my bath, my meal. (P11, son)

Sub-theme 2.3: Recharge for self-sustenance

Caregivers needed to recharge their energy regularly, akin to replenishing a car's fuel throughout its journey. Recognising that they cannot do everything by themselves, some caregivers deliberately planned to take time out for breaks. This helped them become more introspective.

You need to have some time for yourself. You must humble yourself and admit that you cannot do-it-all. . . Don't bear the burden alone like a snail or a turtle. You cannot move forward. (P13, daughter)

Many caregivers recognised the importance of regularly recharging. For instance, one caregiver (P10, daughter) believed that 'We must help ourselves first before we help others.'

If I need a break, I will go out for a walk or go out with my friends. I need the break, away from him and I think that helps. That's how I find my way to get along. (P3, son)

Some caregivers made arrangements such as a day care facility to seek respite. However, some care-recipients refused to attend the day care facility and in fact, scolded the caregiver for making this arrangement. Commensurate with the practice in many Asian societies, caregivers often engaged their family members in the caregiving support network. Many caregivers found this support network essential in keeping them going.

My sisters. . . they will come back. . . I only look after for half-day. So, for the half-day I let my maid, the others, few hours to look after my father. (P13, daughter)

Sub-theme 2.4: Seeking solace through religious faith

Religion and spirituality was an important source of support for some caregivers, providing a precious resource which can be drawn upon to cope with the emotional stress and burden of the caregiving journey. Some caregivers sought solace in their faith to gain 'strength, patience, and understanding' (P8, niece). Religion and spirituality also provided perspectives about the caregiver role which enabled them to view their situations more positively.

I look at it in a positive way. . . I always believe as I'm a Christian, I believe that God will never put me in a position or give me responsibilities that I can never handle. (P8, niece)

Consistent with the multi-ethnic society of Singapore, the caregivers in our study come from different religious backgrounds. One caregiver (P9, son) turned to his Taoist religion because otherwise he would 'have nowhere to find an answer' when managing the stress of caring for his care-recipient. Similarly, caregivers of other religious faiths such as Catholicism (P16, god-daughter), Christianity (P13, daughter), Islam (P4, daughter) and Hinduism (P5, wife) also drew comfort and hope from religion, for instance, 'entrusting the future

into God, praying that things will get better' (P5, wife). They often attributed improvements in their care-recipients as the 'grace of God' and accepted deteriorations, as the 'will of God' (P5, wife; P8, niece). Caregivers who value religion and spirituality as their key source of support often carve out dedicated time from their hectic schedules for related activities such as praying and meditation.

Every day, when I have finished my tasks, I must have quiet time for myself. . . I will use the time to pray. (P13, daughter)

Sub-theme 2.5: Reinterpreting caregiver-care-recipient relationship

Not uncommonly, caregivers found themselves revisiting the caregiver-care-recipient relationship and having their pre-existing notions challenged. For instance, some caregivers viewed caregiving as a one-sided relationship in which their loved ones were passive recipients of largely physical care. These caregivers tended to dichotomize the provision of physical needs as separate from emotional needs. One caregiver (P1, wife) admitted that while she took care of the physical needs, the 'emotional needs she never really paid much attention.' Not surprisingly, relational aspects of caregiving in their interactions with their care-recipients were often neglected.

I never really communicate with my mum, the very most I just kiss her. . . because I have no mood to talk. (P2, daughter)

In contrast, other caregivers adopted proactive efforts to engage their care-recipients. This was often achieved by allowing their care-recipients a degree of autonomy and by organizing shared activities. One caregiver (P11, son) shared his goal for his care-recipient to be 'as independent as possible.' Another caregiver (P7, daughter) looked forward to meal times at home because such shared moments made them 'feel like they are in a family. . . cooking and eating together.'

As part of the meaning-making along the caregiving journey, caregivers also revisited their prior relationship with their care-recipients. A spousal caregiver (P5, wife) felt the need to reciprocate as her care-recipient had previously 'looked after (them), so now is (her) turn to look after him.' When deliberating care options for their loved ones with dementia, one caregiver (P2, daughter) credited the 'unconditional love' shared with their care-recipients as the motivating strength in continuing the caregiving journey. Another caregiver (P12, daughter) would 'rather look after (her) parents than let them go into a nursing home.'

Theme 3: Settling into a new normalcy

Caregiving is a demanding journey that involves a re-calibration of what constitutes normality. Caregivers are required to make sacrifices, balance competing demands, and in the process, develop and acquire mastery. Those who accept this new normalcy maintain a greater sense of control over their situation as they contemplate the uncertain future.

Sub-theme 3.1: Building mastery in caregiving role

All the participants shared that taking on the caregiver role involved personal sacrifices. One caregiver (P12, daughter) 'missed those days' of the past. For others like one caregiver (P5, wife), the caregiving role was so consuming that her life appeared to 'revolve around my care-recipient, suffering a lot all because of her. . .' Some seemed to have lost control of their lives. One caregiver (P16, god-daughter) described that since she started caregiving, 'I don't know honestly my mind is always on her. I don't care what happens to me.' Some caregivers gave up their jobs and even neglected their health.

Especially my father also declining, so I go for part-time job. . . I quit my job this year full time. . . Yes, totally sacrifice. . . (P4, daughter)

On the other hand, several caregivers assessed that they were able to thrive in their transition to a 'new normal' in their caregiving role, much like the 'hero' at the end of the hero's journey. Having learnt how to cope, one caregiver (P13, daughter) felt that 'caregiving was not as tough'. Another caregiver's (P4, daughter) approach to worry was to only be concerned 'about things that are within your control'. As a result, they felt that they have acquired an increased sense of mastery.

Sub-theme 3.2: Coping with uncertain future

When contemplating about the future, caregivers are often preoccupied about their care-recipients' health deterioration. Some felt that they were ill-prepared and fearful about where to find help. They were also worried about their own future care needs. One caregiver (P15, daughter) was very concerned, fearing ' . . . what would happen if something happens to (her)?' Another caregiver (P7, daughter) felt that though she was able to care for her care-recipient, she is uncertain for herself as she 'didn't know what to do. Will (she) be the same or will (she) be strong?'

A minority of caregivers felt bereft of hope when thinking about the future. One caregiver (P9, son) painted a bleak picture that they 'have no hope already. . . because (they) are faced with all these problems.' For another caregiver (P11, son), the caregiving journey had 'no end to it. . . until you die. . .'

In contrast, caregivers who transitioned to a new normalcy demonstrated a mind-set shift about the uncertainty of the future. An adult child caregiver coped with the management of future changes in their caregiving journey by 'taking one step at a time', facing each challenge as it presented itself (P11, son). These caregivers accepted the inevitability of further health decline in their care-recipients and instead chose to focus on demonstrating love for their loved ones in the present. In this way, they would be able to face the eventuality of the care-recipient's demise without regret.

If he deteriorates and has to go to nursing home, we will accept it as it we know this is inevitable. . . When my father is still around, I show love to him. Even if he passes on the next day, I will not regret. (P13, daughter)

Discussion

In line with the rapidly aging Asian population and surge in care demands for older persons with dementia, the role of the family caregiver as part of the healthcare team should be accorded greater importance.¹¹ The study found that the caregiving world is complex and multi-faceted with a broad spectrum of worldviews. The caregivers' lived experience is akin to that of a long arduous journey marked by three main phases of transition: crossing the threshold into caregiving world, trudging on the road of trials and obstacles, settling into a new normalcy. The adaptation of the 'hero's journey' to the context of caregiving in dementia^{25,26} allows the identification of transitions through these three phases as caregivers navigate their caregiving journey. The adaption of the 'hero's journey' has also allowed the caregivers' lived experiences to be strung together as a narrative journey to communicate the overall essence of the caregiving experience.^{19,26}

The first phase involved crossing the threshold from a liminal "between and betwixt" state to enter the caregiving world in response to the need for caregiving. The difficulty settling into the role was similarly experienced by caregivers settling into the role of caring for their loved ones with Alzheimer's Disease as well.²⁷ Whilst some willingly embraced the role despite having limited preparation,

many took on the caregiver role as part of their social obligation as children or spouses of the care-recipients. This could be a reflection of the study's Asian context, with a strong societal expectation of filial piety.¹⁴ Hence, adult children in particular are traditionally expected to care for their ageing parents, with placement in long-term care facilities often perceived as a failure to dispense their responsibilities.^{10,28} As singles are more likely to stay with their elderly parents, it is not surprising that many single adult children ended up assuming caregiving responsibilities. Moreover, many Asian countries possess a patriarchal social system, with greater expectation for females to take up the caregiving role.^{29,30} This may explain why female spouses or adult daughters are thrust into the caregiver role as their social responsibility.

In the second phase of the caregiving journey, caregivers are confronted with the harsh reality-check of the unrelenting, demanding and incessant nature of caregiving which can often lead to feelings of being overwhelmed with caregiving responsibilities.³¹ Similar to findings from earlier studies, behavioural disturbances of care-recipients heightened caregiver stress above and beyond care provision for activities of daily living.³² Not surprisingly, behavioural and psychological symptoms of dementia are well-reported stressors that predispose to depression and anxiety among caregivers.^{33,34} An unexpected source of stress among some caregivers arose from conflict with family members who might not fully understand the demands of the caregiving situation. The double-edged nature of family interactions is echoed in a recent study of caregivers of hospitalized older adults, which reported that caregivers found comfort from supportive family members but experienced mixed emotions when facing conflict with misunderstanding family members.³⁵

Encouragingly, during this arduous second phase, caregivers also undertake a parallel serendipitous learning journey to acquire the required skills to cope with caregiving tasks and stressors. This experience of 'learning by doing' was like the experience of caregivers learning how to manage incontinence in stroke survivors, who became more experienced and flexible in their caregiving approaches and tasks to adapt to new situations, thereby becoming more confident in care delivery and better at coping with the stress of caregiving.³⁶ Caregivers in our study highlighted coping hacks, including customising caregiving approaches to the unique characteristics and preferences of their care-recipients, practising positive reframing and being present in the moment.

The importance of self-care ought to be stressed as the health status of caregivers has been shown to be at risk of deterioration after taking on the caregiving role.³⁷ Psychosocial support for caregivers in Asian communities should take into account existing caregiving norms such as filial piety, assisting caregivers to address excessively high expectations of themselves.⁹ Changing the perception that caregiving is a pure self-sacrificial responsibility of one designated caregiver would encourage caregivers to receive help from others, including financial assistance.

Strategies to recharge for self-sustenance include seeking respite from community support services, which has been shown to reduce perceived caregiving burden.³⁸ Unfortunately, acceptability of community support services such as day care services may result in resistance from care-recipients in some instances.³⁹ Reflecting the Asian culture of shared filial responsibility amongst siblings,^{28,40} another viable strategy is to engage other family members in the support network to share caregiving duties and to derive emotional and financial support.

Our study also found that some caregivers drew upon their religious faith as a precious resource in the caregiving journey. Earlier studies allude to religiosity as a protective factor that mediates the stress of caregiving in dementia.⁴¹ Prayer and spirituality have been found to help caregivers of persons with Alzheimer's disease cope with the emotional stress and burden of caregiving.⁴² Although evidence indicates that ethnicity may mediate the positive effects of

religiosity on caregiver well-being, religiosity and spirituality have potential as a protective strategy in Asian societies where caregivers often turn to religion to derive emotional support.^{29,43,44}

The third phase culminated in the settling into a new normalcy in the caregiving journey. For those who were unable to accept their circumstances, they were apprehensive about the future, feeling trapped in endless despair. In contrast, akin to the 'hero' in the hero journey, caregivers who thrived gained a sense of control over their lives that resulted in better coping with the uncertain future. This sense of control, termed as mastery, has been demonstrated to act as a protective factor against the stress of caregiving.^{45,46} Mastery has been found to be a potential buffer against caregiver burden, anxiety and depression.⁴⁷ High levels of mastery are associated with less depression, particularly among caregivers with below-average levels of caregiving competence.⁴⁷ The establishment of such 'role acceptance' was a key motivator towards informal caregivers engaging in long-term care of individuals with Alzheimer's Disease, enabling them to accept their role responsibilities without any regret or negative relationships.²⁷

Implications

Insights derived from this phenomenological study about the lived experience of informal family caregivers have important clinical implications. Our study highlights the need to screen for at-risk caregivers.⁴⁸ By explicating the three phases along the hero's journey, it provides a framework for clinicians to better understand the attendant needs and stressors associated with each phase.²⁶ This can then inform the design of targeted stage-specific interventions to support the caregivers.

For instance, adult children who are thrust into the caregiving role to meet societal expectations of filial piety are often ill-prepared for the physical, mental and emotional demands of caregiving, and can worry about their caregiving performance.^{13,14} Recognizing this, clinicians engaging with new caregivers who are in the first phase, can play a major part to help them adjust to their new role and the challenges ahead. At this initial stage, it is essential that caregivers are mentally prepared for the caregiving challenges ahead. Clinicians can educate caregivers with the knowledge about dementia and how the condition may affect their loved ones, and how to locate available resources. Family support is essential to help these neophyte caregivers ease into their role. They should also be linked up with programs that provide caregiving training and financial support, to better equip them for their new role. An example of possible support is demonstrated in South Korea, with family caregivers of persons with dementia having access to training and financial support through a long-term care insurance programme.⁴⁹

For caregivers in the second phase who are struggling in the caregiving journey, they should be encouraged in the learning journey and be equipped with coping hacks such as being taught how to individualize caregiving approaches to care-recipients' characteristics and preferences, to practice mindfulness and positive reframing. Caregivers should be taught to use encouragements as coping strategies, rather than behavioural disengagement and criticisms, as encouragements predicted gain.⁴³ In addition, caregivers should be educated on effective self-care strategies such as managing self-expectation; intentionally planning for time-out breaks; harnessing family support and community respite resources; and where appropriate, tapping upon the resource of religiosity and spirituality. The value of respite was reinforced in the caregivers' interviews, demonstrating how the provision of time away from their caregiving responsibility to 'recharge' allowed them to better cope and manage their responsibilities. As filial piety could be a responsibility to be shared amongst the siblings, the caregiver can be taught to share the caregiving load with their siblings.^{29,40} A potential strategy is the

'rotation' approach, with siblings taking turns to care for their aged parents. Given that Asian caregivers tend to set high self-expectations and worry when they do not meet these expectations,^{14,50} it is also helpful to provide culturally appropriate strategies to assist them in the caregiving role, such as helping them realise that they do make a difference to their care-recipients, despite not meeting their own self-expectations. Caregivers who successfully negotiate phase two would go on to develop a higher sense of mastery over their lives, allowing them to thrive in their new role as caregivers.⁴⁷ They settle into a new normalcy, corresponding to phase three of the caregiving odyssey. Besides affirming these caregivers and acknowledging their 'hero's journey', they also represent a ready relatively untapped resource who can be harnessed to act as role models and to assist in providing peer support to other caregivers. In addition, their successful acceptance of their role would greatly motivate them to continue in the long-term care of their care-recipients.⁴⁷

Limitations of study

There are several limitations that warrant comment. One limitation is that some of the findings may be culturally specific, such as unmarried Asian adult children segueing into the caregiver role as they commonly live with their aged parents. Additionally, extremely stressed or burdened caregivers would not have participated in the interviews. In line with the research aim, we purposively sampled caregivers with some experience in caregiving in order to provide rich insights into the experience of the caregiving journey. Hence, our findings are not transferable to new caregivers whose lived experiences are likely to differ. Another limitation was that due to the nature of our study, we were unable to conduct the final validation stage of Colaizzi's method of data analysis to 'return to the participants' to elicit their views on the exhaustive description of the phenomenon. Nevertheless, our attempts to validate the findings with two caregivers caring for older persons with dementia found that their experiences were adequately represented by the findings.

Future studies

Future studies may wish to focus specifically on new caregivers and explore protective factors and psychosocial interventions such as building psychological resilience for dementia caregivers. In particular, there is a need for high-quality research to support the design and evaluation of caregiver-centric training programmes and interventions that builds personal mastery as it has been shown to protect against the negative effects of caregiving.^{47,51}

Conclusions

This phenomenological study provided precious insights into the lived experience of family caregivers of persons with dementia in an Asian society. We found that the caregiving world is similar to an arduous journey characterized by well-defined transitions that cohere with the essential structure of a hero's journey with three main phases: crossing the threshold into caregiving world, trudging on the road of trials and obstacles, and settling into a new normalcy. The first phase begins with family caregivers entering the caregiving world. The second phase describes how once they are in the caregiving role, they struggle and develop hacks to manage the many challenges faced. The third phase ends with caregivers finding themselves in a new normalcy, one where their original world has been forever changed. The findings can help clinicians better understand the caregiving phases with its corresponding stressors and needs, so that targeted support and information relevant to that particular phase can be rendered. Our findings also provide valuable educational insights including the need to better prepare new caregivers

to equip them with the knowledge, skills and confidence to engage with the caregiving "hacks".

Ethical Approval

This study was approved by the Domain-Specific Institutional Review Board of the National Health Group, Singapore (NHG DSRB Ref 2015/00444). Participants provided written informed consent.

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Conflict of Interest

None.

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Supplementary materials

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