

Project Title

'24/7' Caregiving: Family Members Providing Round-The-Clock Care for A Person with Dementia

Project Lead and Members

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Organisation(s) Involved

Tan Tock Seng Hospital (TTSH)

Healthcare Family Group(s) Involved in this Project

Nursing

Applicable Specialty or Discipline

Research, Nursing, Geriatrics, Caregiving

Project Period

Start date: January 2022

Completed date: December 2022

Aims

The aim of the research study was to examine the relationship between the intensive and prolonged caregiving of a person with dementia ('24/7' caregiving) and the family caregiver's physical and psychosocial well-being during COVID-19 in an Asian population (Singapore).

Background

The COVID-19 pandemic has exacerbated the difficulties faced by caregivers who have to provide continuous '24/7' care to persons with dementia with minimal formal and informal support. A hallmark of '24/7' caregiving is the time-consuming and

pressurising nature of care responsibilities that overwhelms and engulfs caregivers' lives. While caregivers have reported heightened levels of caregiving distress and burden during the pandemic, there remains limited understanding of their lived experiences of providing continuous care with little respite and the corresponding physical, psychosocial and emotional impacts of caregiving '24/7'.

Methods

We studied interviews of caregivers of PwD who were involved in a holistic caregiver support program delivered at Tan Tock Seng Hospital during the COVID-19 pandemic. The interviews were conducted between December 2020 and November 2021.

Results

We found three themes that defined the shared experiences of '24/7' caregiver. The first theme is '**A World Overturned**', in which the prolonged nature of COVID-19 and its restrictions created massive disruption and upheaval to the persons with dementia's daily routine, thus worsening the behavioural and psychological symptoms (i.e., insomnia and anxiety) in persons with dementia. This increased caregiving intensity and burden. The second theme '**Burning on Both Ends**' refers to the tedious challenge of balancing between caregiving and their personal lives that is essentially a zero-sum game, where many '24/7' caregivers often had to prioritise their care-recipient's needs and caregiving responsibilities over their personal time and space, therefore having to sacrifice their own needs. '**At Wits' End**', the final theme, refers to the overwhelming sense of desperation, hopelessness and helplessness that '24/7' caregiver feels about their caregiving situation. Exacerbated by the COVID-19 pandemic and its restrictions, many felt trapped in their circumstances and less in control over their caregiving situation, gradually resigned to fate.

Results are further elaborated in our published manuscript: Chew, E.Y.H.; Ong, Z.L.; Glass, G.F., Jr.; Chan, E.-Y. '24/7' Caregiving: A Qualitative Analysis of an Emerging Phenomenon of Interest in Caregiving. *Int. J. Environ. Res. Public Health* 2022, 19, 17046. <https://doi.org/10.3390/ijerph192417046>.

Lessons Learnt

It is essential to support family caregivers' psychosocial and emotional needs. On a personal level, this often begins with the provision of psychological and education support through various healthcare and social service touchpoints to help caregivers realize that they do not need to be alone during their caregiving journey, and that help is available. Skills such as expectation management and healthy boundary setting are key to help caregivers conserve their personal time and space. The importance of self-care and raising caregivers' awareness of the dangers of '24/7' caregiving must not be neglected as well to encourage sustainability in caregiving. On the community/neighbourhood level, through caregiver-led support networks, volunteer caregivers can proactively reach out to '24/7' caregivers to break down their barriers and help connect them to a network of informal social support, i.e., a virtual community of like-minded caregiver peers who are going through the same caregiving journey. Finally, at the societal level, it is important to heighten public awareness of formal support services, and the normalcy of acknowledging and acceptance of help-seeking behaviours in caregivers. Such acceptance could help uncouple the feelings of guilt and shame stemming from caregivers' perceived inability to provide the 'best' care for their loved ones. By doing so, caregivers might feel less burdened with the responsibility of care, enabling them to provide sustainable care for their loved ones through the support of the community around them.

Conclusion

While caregiving can be rewarding and meaningful, it is oftentimes simultaneously stressful, challenging and physically, mentally and socially isolating, especially for '24/7' caregivers who shoulder the caregiving duties and responsibilities alone with little to no avenue for support. Our study highlights the vulnerabilities associated with '24/7' caregiving; the implications of its physical and emotional effects are visible from the '24/7' caregiver's lived experiences and struggles as a result of having to provide continuous care during the COVID-19 pandemic with no respite or relief. This can be addressed through a whole-of-society initiative that recognises the importance of

sustainability in caregiving and greater community outreach efforts to be integrated into society on a multi-scalar level, especially at the neighbourhood and grassroots level, to strengthen caregiver support for the greater alleviation of high-intensity caregiving burden.

Additional Information

The manuscript for this has been published in the **International Journal of Environmental Research and Public Health (IJERPH)** - Chew, E.Y.H.; Ong, Z.L.; Glass, G.F., Jr.; Chan, E.-Y. '24/7' Caregiving: A Qualitative Analysis of an Emerging Phenomenon of Interest in Caregiving. *Int. J. Environ. Res. Public Health* **2022**, *19*, 17046. <https://doi.org/10.3390/ijerph192417046>.

Note: Singapore Health & Biomedical Congress (SHBC) 2022: Singapore Nursing Award (Oral category) – (Silver Award)

Project Category

Care Continuum

Qualitative Research

Informal Workforce Transformation

Volunteer, Caregiver, Community Engagement, Patient

Keywords

[Family Caregiver](#), [Caregiving](#), [Dementia](#), [Older Persons](#), [Caregiving Burden](#), [COVID-19](#), [Stress](#)

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24/7 Caregiving: Family members providing round-the-clock care for a person with dementia

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BACKGROUND

Families are often the **cornerstone of support** for persons with dementia (PwD). They devote significant time and energy to care for their loved ones and play an essential role in maintaining their health and well-being.

Yet, many feel isolated in their struggles with managing their care-recipients' behavioural symptoms and physical care needs and are **often subsumed by caregiving duties and responsibilities '24/7'**.¹ This is especially prevalent in Singapore, where most caregivers and care-recipients live together.

The COVID-19 pandemic has further exacerbated their stressors due to the suspension of community services such as day-care and senior activity centres.² Many caregivers had to provide continuous care with **minimal formal and informal support**.

AIMS

To gain insights into the **lived experience of '24/7' caregivers**, and explore the **impact of providing continuous care** during COVID-19.

This can **better inform the care and support practices** that can be implemented to meet the needs of this growing subgroup.

METHODS

Secondary analysis was conducted on data collected from caregivers of PwD who were involved in a holistic caregiver support programme during COVID-19, between December 2020 and November 2021.²

PROCEDURE

In-depth interviews (20-60 minutes) were conducted with caregivers online over Zoom to elucidate participants' caregiving experiences. Interviews were recorded, transcribed, and reviewed for accuracy.

DATA ANALYSIS

Thematic analysis was used to explore caregivers' experiences of caring for their loved ones during COVID-19, using **several stages of coding and reduction to enable broader themes at higher levels of abstraction to emerge**. Broad overarching themes were identified and defined, constantly reviewed by the team during regular meetings.

RESULTS

PARTICIPANTS

Key characteristics of a '24/7' caregiver include:

Lives together with care-recipient

No utilisation of formal support services

Has no help in managing caregiving duties (e.g. helper, family members)

Table 1. Participants' Demographics (N=7)
(Drawn from a larger qualitative study)²

PID	Age	Sex	Relationship	Living together	Working	Form of Help
CG2	80	F	Spouse	Yes	Retired	None
CG3	62	M	Son	Yes	Retired	None
CG4	60	F	Daughter	Yes	Full-time	None
CG9	63	M	Son in-law	Yes	Full-time	None
CG11	53	F	Daughter	Yes	Full-time	None
CG15	59	F	Spouse	Yes	Part-time	None
CG24	68	F	Spouse	Yes	Retired	None

THREE KEY THEMES

I. A WORLD OVERTURNED

The prolonged nature of COVID-19 and its restrictions created massive **upheaval and disruption** to PwDs' daily routine. This worsened the **behavioural and psychological symptoms (BPSD)** in PwD.

Impact of COVID on PwD	Subsequent Impact on Caregiver	Supporting Quote
Insomnia 	Disrupted sleep and poor sleep quality	<i>I wanted to rest a bit, but [my mother] was in pain. [She] needs me [at night], so (I have) no rest the whole day. Until the fifth day... my body shuts down. (CG3)</i>
Anxiety (Displayed through clingy behaviours)	Inability to stop watching over care-recipient	<i>I have to sleep with her. I took a raffia string to tie her hand with mine, so that when she gets up, I will also get up. (CG9)</i>

II. BURNING ON BOTH ENDS

As time and energy are finite resources, the balance between caregiving and their personal lives eventually became a **zero-sum game**. Many '24/7' caregivers **prioritised their loved one's needs and caregiving responsibilities over their personal time and space**.

↑ Increase in caregiving responsibilities



↓ Decrease in personal time and space, social and emotional support

“(It is) difficult to juggle between work, personal (commitments) and (caregiving) for the elderly. (It is) consuming in terms of energy and mental health. (CG4)

III. AT WITS' END

Many were **at wits' end** in handling their care-recipients' difficult behaviours (BPSD), with the **caregiving stress proven too much to bear**.

“I am very tired. I am (so) tired that **I can drop dead**. (CG11)

Exacerbated by COVID-19, '24/7' caregivers remained **trapped** in seemingly **immutable circumstances**. Caregivers feel less in control over their situation and **gradually resigned to fate**.

“I cannot do anything more... I have done all sorts of things, suffered all sorts of treatment. I feel so numb. Right now, I can only get through each day one at a time. (CG2)

DISCUSSION

The time-consuming nature of caregiving responsibilities have **restructured and engulfed the '24/7' caregiver's life**. This mirrors other studies which found that such caregivers often feel **trapped**, possess **limited mastery** and are ill-equipped to handle caregiving-associated incessant demands and emotional upheavals.³

Physical distancing and isolation measures during COVID-19 **restricted caregivers' access to formal/informal caregiver and respite support**.²

Round-the-clock caregiving without respite **amplified caregiving intensity and frustrations**.⁴

'24/7' caregivers experience **unprecedented levels of stress, depression, anxiety, fatigue & sleep disturbances** during the pandemic.⁵

IMPLICATIONS & RECOMMENDATIONS

Provide **psycho-education** to address caregivers' burnout and meet immediate needs

Alleviates potential **detrimental impact** on care-recipients' care.

Manage caregivers' **expectations** and encourage setting of healthy boundaries.

Encourages **conservation of personal time and space**.

Reinforce importance of **self-care** and discuss dangers of '24/7' caregiving.

Encourages **sustainable caregiving**.

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