Filial Piety in a Modern Age: An Exploration of Familial Caregiving for Alzheimer’s Patients & Caregiver Burden in Singapore

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ABSTRACT

With an increasing number of Alzheimer’s disease patients in Singapore, complications related to the degenerative disease have become highly relevant. Standing out among these complications are inflated caregiver burden resulting from the cultural expectations associated with filial piety. Filial piety, a value ingrained in Chinese culture, requires adult-children to display love, obedience, and respect towards their parents as well as provide physical care when required (Bedford, 2019). Expectations associated with filial piety, however, have been associated with severe caregiver burdens that persist even after patient institutionalization (Whitlatch, 2001). Expectations to provide care presents numerous challenges for adult-children of patients: economic instability, psychological exhaustion, and social isolation (Lai, 2009; Langda, 2011; Win, 2017). These implications associated with caregiving are heightened when the patient being cared for is diagnosed with Alzheimer’s, as the disease has a unique cognitive-degeneration component that inhibits an individual from conducting independent actions after a certain point (Pratt, 1985). This article aims to shed light on the relationship between the level of involvement and the severity of caregiver burden among familial caregivers of Alzheimer’s patients in an effort to identify how to better support familial caregivers of Alzheimer’s patients. Through the use of a quantitative correlational analysis, a relationship between the two data points of involvement level and burden level was established. This research serves to identify a potential problem, not propose methods of reconciliation. While the data collection process for this study was inhibited by the COVID-19 pandemic, theoretical data is provided in an effort to develop new understandings and draw hypothetical conclusions.

Introduction

Alzheimer’s Disease

Alzheimer’s disease, a neurodegenerative disorder that affects thinking, memory, and reasoning skills, prevails as a significant health concern for the global population. The irreversible, age-related disorder causes brain cells to degenerate and, eventually, die. In its most severe stages, Alzheimer’s can result in an individual’s incapacity to articulate comprehensive thoughts. Due to the degenerative nature of the disease, Alzheimer’s patients often rely on caregivers for simple tasks, such as eating and walking (Fan, 2007). Familial caregivers—family members (often a child or spouse) who assume a caregiving role—of individuals with Alzheimer’s exert great amounts of time and energy into their patients without the compensation provided to professionals. As a result, these individuals are often unable to support themselves, their families, or take advantage of professional opportunities (Pratt, 1985). This, when coupled with the emotional weight of taking care of a family member, has great economic, psychological, and relational costs, contributing to what has become known as “caregiver burden” (Pratt, 1985). These “caregiver burdens” affect familial caregivers even after care-receivers are admitted into institutionalised care (Whitlatch, 2001). Despite the varied living arrangements, ranging from hospitals to nursing homes, familial caregivers “continue to provide a great deal of hands-on care for and remain emotionally involved with their relatives after placement” (Whitlatch, 2001). Caregivers
continue to visit, help with “feeding and personal care”, communicate with nursing home staff, and take numerous other measures to remain involved in the care-receivers life (Whitlatch, 2001).

Filial Piety

Filial caregiving is encouraged by certain cultural norms, namely, in regard to Chinese culture, filial piety. Filial piety, also known as 孝順 (xiào shùn), is a “foundational virtue” in Confucian ethics and, in turn, Chinese culture (Miao, 2015). The virtue refers to a set of cultural norms that characterize the “material and emotional aspects of the Chinese parent-child relationship” (Bedford, 2019). More specifically, filial piety requires a child to display love, obedience, and respect towards their parents as well as provide physical care when required (Bedford, 2019). The concept of filial piety is reflected in the very structure of the Chinese character 孝 (xiào), of which the upper component represents age while the lower represents “child” (Bedford, 2019). Conjointly, the character indicates that “the child supports and succeeds the parent” (Bedford, 2019).

Filial piety has served as a guiding principle for how individuals should conduct themselves within traditional Chinese families (Bedford, 2019). However, cultural expectations associated with the value, such as familial caregiving, have also been associated with severe caregiver burden—particularly when coupled with caring for an individual with a disease as debilitating as Alzheimer’s.

Singapore

The costs of familial caregiving for Alzheimer’s patients are extensive and estimated to affect around 50 million people globally (Whitlatch, 2001). This number is expected to rise dramatically due to the rapidly aging populations in countries such as Singapore, where elderly citizens—aged 60 and over—are expected to make up over 30% of the population by 2030 (Tan, 2012).

Filial piety was introduced to Singapore with the first influx of Chinese immigrants to the country in the 1830s (Ee, 1961). The Chinese population in Singapore grew dramatically in the late 1800s, reaching an estimated 190,000 individuals; this mass increase in population resulted in a heightened influence of Chinese culture in Singaporean society (Ee, 1961). Thus, the virtue of filial piety has become deeply ingrained in Chinese-Singaporean culture (Ee, 1961). An increasing elderly population along with the expectation of filial piety in Chinese-Singaporean culture raises a concern regarding the wellbeing of Chinese-Singaporeans, as the two conjointly perpetuate caregiver burden (Jakobsen, 2011).

Literature Review

In this literature review, nine major works comment upon burdens frequently experienced by familial caregivers. More specifically, three works comment upon general caregiving burden, three works comment upon burden perpetuated by filial piety, and three works comment upon the direct impact of familial caregiving on caregivers for Alzheimer’s patients, both within and outside the context of institutionalisation. Through these works, three main caregiver burdens catalysed by familial caregiving and filial piety emerge: economic constraints, psychological influence, and relational implications.

Filial Piety & Burden

Existing literature overwhelmingly identifies filial piety as “a major motivational factor behind caregiving in the Chinese culture” (Lai, 2009). However, in a similar proportion to which it is described as a “motivation”, filial piety is described as an “obligation”.
The latter description holds a much more negative connotation—kin “obligations” are often forced and undesired as a result of burdens they entail (Lai, 2009). Among the various expectations associated with the filial piety, specific actions are directly associated with caregiving: “fulfilling responsibility”, “making payments”, and “making sacrifices” (Lai, 2009). Specifically addressing sacrifices, kin are often expected to give up economic opportunities for familial obligations (Bedford, 2019). This sacrifice, among others, can cause economic, psychological, and relational distress, with higher levels of investment and involvement potentially catalyzing higher levels of burden (Lai, 2009).

Economic Burden

Olwen Bedford and Kuang-Hui Yeh, professor at National Taiwan University and professor at the Institute of Ethnology in Taipei, respectively, identified that general mass modernization has resulted in an increase of “women in the workplace” as well as “greater geographic mobility”; however, caregiving expectations, in combination with economic advancements, can inhibit an individual's ability to pursue personal goals and, as a result, can create personal economic burden (Bedford, 2019).

Similarly, Teresa B.K. Tsien and Guat Tin Ng, professors at Hong Kong Polytechnic University, claim that as one enters the workforce, they “do not give up their family caregiving responsibilities” entirely, rather “struggle” to combine both work and familial responsibilities (Tsien, 2010). Kenneth M. Langda, a public health professor at the University of Michigan, further comments upon this work-related complication, highlighting that familial caregivers are often unable to simultaneously fulfill the role of a caregiver as well as a full time employee (Langda, 2011). Langda identified that over 6% of familial caregivers for individuals with Alzheimer’s give up profession-related promotions in order to continue fulfilling their role at home and/or at caregiving institutions.

Psychological Burden

Existing literature indicates that caregiver-related psychological distress often stems from the lack of preparation that familial caregivers generally receive for the role. Due to the improvised nature of the job, they often lack a comprehensive understanding of their role. The 2015 National Alliance for Caregiving and AARP Public Policy Institute survey, administered to examine caregiver experience in the United States, identified that over 51% of Alzheimer’s patient caregivers provide nursing tasks with a lack of preparation in the field (Schultz, 2016). Furthermore, 21% desire additional assistance and information surrounding their role (Schultz, 2016). This lack of clarity, coupled with the intense demands of the work, often leads to significant distress. In fact, health sciences professor Wilson Abreu identified that a significant portion—over 38%—of family caregivers experience psychological distress and “phobic anxiety”, a depressive symptom characterized by intense fear and distress (Abreu, 2017).

This psychological distress among familial caregivers is often increased when coupled with additional cultural expectations to care for family members, such as filial piety. Shanghai Academy of Social Sciences professor Wenrong Liu highlights that, from the perspective of a member of younger generations, the failure to fulfill “traditional” and “expected” roles of caregiving increases anxiety and guilt (Liu, 2017). However, forsaking filial piety for independence also leads to positive feelings, including hope and determination, by-products of independence (Liu, 2017). Conjointly, these juxtaposing emotions perpetuate the “psychological and mental cost of devotion” (Liu, 2017).

Relational Burden

Alongside the negative psychological and economic implications that caregiving incites, a lack of preparation to serve in this capacity often leads to relational strains between caregivers and their respective patients. Palliative care doctor at the Singaporean Tan Tock Seng Hospital, Khin Khin Win, identifies that caregivers who are “unprepared for their
transition into the caregiving role” can experience great relational strain with their patients (Win, 2017). Particularly in regard to Chinese-Asian individuals, rapidly transitioning from solely expressing filial obedience to fulfilling a caregiving role can incite “relational frustration” between both caregiver and care-recipient; this frustration often stems from “social expectations to care for elderly family members” that is often of great inconvenience (Win, 2017). Kathryn Betts Adams, former associate professor of social work at Case Western Reserve University, ties familial caregiving to relational burden in a more general, non-culture-specific, context.

Through a phenomenological study, Adams explores traditional implications of transitioning from solely a family member into a caregiver. Subjects of Adam’s research commented upon the loss of a parent to the degenerative disease and the implications such loss has on child-parent relationships:

“I have to be the mother and she has to take the role of the daughter and at times she does not do well with that...She is not my mother.” (Adams, 2016).

Numerous other subjects in the study echoed these views, claiming that the shift to a caregiving role drastically changes family relationships, often in a negative manner (Adams, 2016).

Significance & Purpose

While there is extensive literature commenting upon the complications that familial caregiving for an Alzheimer’s patient presents, to my knowledge there is no existing literature that evaluates a potential correlation, in a culture where filial piety is present, between involvement level of familial caregivers even after an Alzheimer’s patient is institutionalized and the caregiver burdens, they experience. The lack of this literature merits attention, as without a comprehensive understanding of burdens affecting familial caregivers, geriatric facilities are unable to identify how these caregivers need to be supported. As a result, they are unable to adapt their care to help mitigate such burdens. Furthermore, the lack of literature with a pointed focus on this cultural overlay of filial piety is of concern, as the nuance of “expected” care for others leaves little room for personal care. Individuals who are pushed into this work are likely to lack preparation and mediums of emotional support such as therapy.

Mary Ann C Bautista, Yao-Tsun Li, and Rahul Malhotra, researchers at Duke-NUS in Singapore, identified this gap in research while conducting an empirical study exploring the experience of informal caregivers of older adults in Singapore. Their paper highlights that future studies should explore “the process, structure, and cost among formal and informal caregivers” (Bautista, 2018). My study addresses the “cost” nuance recommended in their study through a quantitative, correlational study examining the effects of caregiving involvement on caregiver burden after institutionalization in a culture where filial piety is present.

Method

Hypothesis and Research Question

This section focuses on the methodology used to address my research question. My study addresses the question:

“Through a quantitative, correlational study, how do Chinese-Singaporean adult-children of Alzheimer’s patients perceive personal caregiving burden as a function of involvement level after institutionalization?”

In answer to this, I hypothesized that the more involved familial caregivers are, the greater the burden they experience. I came to this hypothesis due to trends in existing literature that highlight the inhibitory nature of familial caregiving and filial piety, the implications of which are best summarized by Olwen Bedford and Kuang-Hui Yeh in the literature review above.
To test my hypothesis, a quantitative, correlational study method via a two-part online questionnaire was employed. A correlational research method is used to determine whether or not there is a relationship between two variables and, if there is one, determine the strength of said relationship (Keselman, 2004). This methodology does not serve the purpose of determining cause and effect but rather to solely identify a relationship. In regard to my research, this method proved to be fitting, as the internal attribution of burden cannot be manipulated (Cohen et al., 2013).

Sample & Limitation

I was ultimately unable to access a cohort and administer my survey as a result of the outbreak of COVID-19, which disproportionately affects the elderly. Singapore, the location of this study, raised the nation’s DORSCON (Disease Outbreak Response System Condition) risk assessment level to Orange in February, indicating a severe outbreak that is easily transmissible and is to be carefully monitored (Singapore Ministry of Health, 2020). As a result of the increased precautionary measures, I was not granted admittance into any geriatric facility in Singapore. Of all known institutions that cater to individuals who are representative of my cohort, none were willing to participate in the study, even when adapted online for ease. Furthermore, when adapted online, the survey presented the additional challenge of navigating patient confidentiality laws in Singapore which prohibits the identification of those with Alzheimer's disease.

Had I been able to survey caregivers in person, subjects would not have been required to release personal information, such as an email address. In response to these complications, I reached out to facilities in other regions of the world where filial piety is evident in a subsection of the culture, including Hong Kong, Malaysia, and Taiwan. However, my outreach was met with similar responses. While I did not end up successfully establishing a cohort, I planned to conduct my study with the help of numerous geriatric facilities in Singapore (i.e. Apex Harmony Lodge, St. Andrew’s Nursing Home, Orange Valley Nursing Home). The institutions I contacted ranged from nursing homes to hospital wards—all of which provide institutionalized care. I planned to access and sample the cohort online. Through these facilities, I ideally would have reached a total of 300 individuals: 150 professional caregivers and 150 familial caregivers. The two distinct groups would be related by an Alzheimer’s patient—a single professional caregiver would care for the same patient as a familial caregiver. This subject number was chosen as it is the number of participants which my seminal source had; however, as a result of traditionally low response rates to surveys, I expected to receive around 80 responses, or two groups of 40. The final nuance to my cohort was that the Alzheimer’s patient who related the two caregivers was supposed to be ethnically Chinese-Singaporean.

Seminal Source

My method employed a two-part survey, adapted from a seminal source: “Dementia in Relation to Family Caregiver Involvement and Burden in Long-term Care” published by Lauren Cohen and colleagues from UNC Chapel Hill and Duke University. This study explores the relationships between severity of dementia, level of involvement displayed by familial caregivers, and their perceived caregiver burden. The method utilized in the study is relevant to my own research, as Cohen et al. also work to draw a correlation between levels of involvement and caregiver burden, though it does so in a different context (Cohen et al., 2013).

In efforts to test for burden, Cohen and colleagues administered four surveys to professional caregivers in their respective home as well as familial caregivers for the same patient: the Minimum Data Set Cognition Scale (MDS-COGS) to measure one’s ability to complete functional tasks (i.e. dressing, decision-making, etc.), the MDS Activities of Daily Living Scale to measure one’s independence, a modified version of the Murphy’s 2000 Involvement Scale to measure familial caregiver involvement after institutionalisation, and the Zarit Burden Interview to measure familial caregiver burden (Cohen et al., 2013).

For purposes of my study, the Murphy’s 2000 Involvement Scale and Zarit Burden Interview were utilised.
in efforts to test a modified question that mirrors my seminal source. Rather than relating a patient's functional level, their family member’s caregiver involvement levels, and the family member’s burden levels, I constructed my study to focus on identifying a relationship between involvement level and burden. Thus, the Minimum Data Set Cognition Scale (MDS-COGS) and MDS Activities of Daily Living Scale were not utilised in my research.

Survey Instruments: Murphy’s 2000 Involvement Scale

The Murphy’s 2000 Involvement Scale utilised in Cohen and colleagues’ research contained 12 categories, each of two questions, that serve to measure levels of familial caregiver involvement in various caregiving-related activities such as playing games and conversing, monitoring finances, paying visits, etc. The scale was administered to both family and professional caregivers. Professional caregivers answered based on the patterns of involvement they had observed among family members.

This scale served the purpose of ensuring that data points that had major discrepancies between self-reported data from the familial caregiver and observed data from the professional caregiver were factored out of the study (Cohen et al., 2013). Both family and staff reported continuous (numerical) and categorical (e.g. never, rarely, sometimes, quite frequently, or nearly always) frequencies of each activity in the past month thorough questions such as “In the past month, how many times has the patient’s family member visited them?” and “In the past month, would you say the patient’s family member visited her/him never, rarely, sometimes, quite frequently, or nearly always?” The questionnaire is scaled by grouping respondents into equally distributed categories that correspond to categorical data responses (Cohen et al., 2013). The categorical groups were assigned a numerical range that was identified by ‘natural breaks’ in the clustered data (Cohen et al., 2013). For example, the group of respondents that represented “often” visitation may be defined by a range of 14-17 visits in a month.

For relevance purposes, the number of categories used to measure involvement in my study (see Appendix A) was reduced to three: visitation, games/conversation, and correspondence with staff. The three categories chosen were identified as they most closely resemble expressions of filial piety. For example, the category of “visitation” directly resembles filial actions as it is a sacrifice of personal time to benefit the parent, an expression of filial piety as indicated by previous literature (Lai, 2009). On the other hand, categories like “helping out at the nursing home” were not included in the study because they are not direct expressions of filial piety: helping out at a home could be done for a multitude of reasons (e.g. paid compensation). Thus, the reduced number of categories enables one to identify how expected involvement, under filial piety, corresponds with burden.

Survey Instruments: Zarit Burden Interview

The second survey of my study, the Zarit Burden Interview, or ZBI (see Appendix B), would have been administered solely to familial caregivers. The questionnaire measures caregiving burden by presenting 22 negatively-connotated questions such as “Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?”. Respondents answer on a 5-point Likert Scale ranging from 0-5, and the questionnaire is scaled from 0-88 with higher scores representing severe caregiver distress. The peer-reviewed scale has been used for geriatrics purposes by a multitude of organizations (Cohen et al., 2013). Furthermore, the scale’s internal consistency alpha is 0.89, indicating that it is highly reliable (Cohen et al., 2013). The ZBI is relevant to my study, as it provides a numerical data point that indicates burden level. Also, unlike other scales that measure burden, the ZBI is tailored towards caregivers and meant for self-reported data, which is needed when reporting internal attributions such as burden.

Data Collection Process

The two surveys used to collect data were to be distributed by an online survey program known as Qualtrics. While I
was ultimately unable to collect data, my intention was to send both the survey link as well as a statement of informed consent and debrief form out to subjects. My seminal source conducted the study on slightly over 300 participants. In order to replicate the method, I planned to do the same; however, as stated in the methods section above, I expected around 80 respondents as a result of a traditionally low response rate to surveys.

Unfortunately, due to the COVID-19 pandemic, I was unable to access a cohort of geriatric patients and caregivers with which to conduct my study; this, however, was a relatively common phenomenon among research students this year. In response, I opted to utilize a theoretical set of data to develop new understandings. With this, I constructed two theoretical sets of data: one which supported my hypothesis and one that did not.

Findings

Method of Analysis

I first organised data in Microsoft Excel. Numerical involvement level frequencies from the Murphy’s 2000 involvement scale, (e.g. 5 times per month) were related to the corresponding ZBI score reported by the same subject. Had I been able to collect data rather than use a theoretical data set, at this point I would have factored out involvement frequencies reported by professional caregivers. This would have been done as such data solely served the purpose of identifying numerical discrepancies between the two cohorts. Thus, my analysis would consist of half the responses I collected for the Murphy’s 2000 Involvement scale and all responses I collected for the ZBI, which I estimated to be around 40. My theoretical data was analysed through the use of a two-sample linear regression T-Test, which is used to identify whether a relationship between two independent sets of data are significant or due to random chance (Keselman, 2004). In the T-Test, I used involvement level data as the x-axis variable and caregiver burden data as the y-axis variable. This resulted in a scatterplot with a line of best fit that serves as a visual representation of the correlation between the two variables (Keselman, 2004). Each category of involvement required its own test.

The scatterplot was then utilized to develop an r-value, or correlation coefficient, which indicates the strength of the relationship between the two variables (Schober, 2018). A positive r-value a proportional, positive linear relationship: as one variable increases, the other increases (Schober, 2018). In contrast, a negative r-value indicates negative linear relationship: as one variable increases, the other decreases (Schober, 2018). Value range between +1.0 and -1.0, and the closer an r-value gets to 0.0, the weaker the relationship between the two variables is (Schober, 2018). As it relates to my study, I hypothesized the two variables to have a strong, positive relationship indicated by an r-value close to +1.0. This means that as involvement levels increase, so do burden levels.

Along with this, the data was used to develop an r-squared value between 0 and 1. R-squared is used to measure how closely the “line of best fit” matches the data points. The higher this value, the closer the model matches the data (Schober, 2018). This value is calculated by simply squaring the r-value.

After analysing the correlation between each category of involvement and caregiver burden, I derived a p-value from the data set. P-values indicate whether a relationship between two variables is statistically significant or not: a p-value less than 0.05 indicates that the outcome of a study could not have occurred by random chance while a value greater than 0.05 indicates the opposite (Schober, 2018). If my p-values were less than 0.05, I would have been able to conclude that high levels of involvement with Alzheimer’s patients catalyse great feelings of burden among familial caregivers.

Theoretical Approach: Data Supported

If my hypothesis was supported, the data would have, after analysis, indicated a strong correlational relationship. A theoretical set of data that supports my hypothesis is detailed in Figure 1 and Table 1. This data is based on a cohort of 32 theoretical respondents, a number chosen as it mirrors the estimated number of 40 responses I would have received from familial caregivers had I been able to execute on my method. In this data set, visitation frequencies
were used as a proxy for involvement level. Referring to Figure 1, a line of best fit with a positive slope is observed. The correlation coefficient between involvement level and burden level is +0.824, indicating a strong positive correlation. This coefficient indicates that as a familial caregivers visitation level increases, so does their level of burden. The p-value developed from the theoretical figure is less than 0.001, indicating a statistically significant set of data. This value means that an increase in burden level can be attributed to an increase in involvement, expressed by visitation, displayed by caregivers.

![Figure 1: Involvement Level (Visitation) & Burden Level](image)

**Table 1: Statistical Data**

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<thead>
<tr>
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<th>Involvement Level (Visitation) v Burden Level</th>
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<tr>
<td><strong>R-value (Correlation Coefficient)</strong></td>
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<tr>
<td><strong>R-squared (Variability accounted for by model)</strong></td>
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<tr>
<td><strong>P-value</strong></td>
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<td><strong>Line of Best Fit Equation</strong></td>
<td>y = 16.4713x + 4</td>
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**Theoretical Approach: Data Not Supported**

If my hypothesis was not supported by my research, the data would have indicated a negative correlational relationship between involvement score and burden score. The derived r-value from the data set would have been a negative numerical value. A theoretical set of data that does not support my hypothesis is detailed in Figure 2 and Table 2. In this data set, visitation frequencies were used as a proxy for involvement level. Again, this data set is based on a cohort of 32 theoretical respondents. Referring to Figure 2, a line of best fit with a negative slope is observed. The correlation
coefficient between involvement level and burden level was found to be -0.390, indicating a moderate negative correlation. The p-value developed from the theoretical figure is 0.027, indicating a statistically significant set of data. This value means that an increase in burden level can be attributed to an increase of involvement, expressed by visitation, displayed by caregivers. This does not support my hypothesis.

**Figure 2:** Involvement Level (Visitation) & Burden Level

![Figure 2: Involvement Level (Visitation) & Burden Level](image)

**Table 2:** Statistical Data

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<th>Involvement Level (Visitation) v Burden Level</th>
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<tr>
<td>R-value (Correlation Coefficient)</td>
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<tr>
<td>R-squared (Variability accounted for by model)</td>
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<td>P-value</td>
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<td>Line of Best Fit Equation</td>
<td>y = -8.25x + 61.4375</td>
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</table>
Discussion

Conclusions Based on Theoretical Data Sets

While these data sets are theoretical, the outcomes allow one to develop conclusions and draw new understandings about the initial research question. If the first set of data was the outcome of the study and my hypothesis was supported, one could conclude that familial caregiver burden is highly relevant and of great concern. Furthermore, the data set would highlight that these caregivers require extra emotional and practical support beyond institutionalisation, such as training in caregiving and mental health support. This assistance could address the guilt, stress, and other burdens of filial piety and familial caregiving.

If the second theoretical data set was the result of my study and my hypothesis was not supported, the data still contributes to the existing literature regarding the subject. However, instead of highlighting room for reform, this data would suggest that familial caregiving for Alzheimer’s patients after institutionalisation is a sustainable practice that does not threaten the well-being of the caregiver. Instead, such a conclusion would indicate that increased involvement from familial caregivers does not increase their burden level.

New Understandings in Challenging Times

While theoretical, the results of this study become increasingly relevant in communities such as Singapore where the population is both rapidly aging and is struck heavily by the pandemic. In light of the recent restrictions placed on facilities, it is likely that the future of geriatric care will differ from that witnessed prior to 2020. Familial caregivers will likely be among the cohorts who are most impacted by this. While the future of such care is currently ambiguous, it is studies such as this that remind society to pause and consider those who work behind the scenes. Understanding the full cost of caregiving—including the relational, professional and personal toll—will ensure that these caregivers are not disregarded and instead supported in the midst of likely severe changes.

Limitations: Beyond COVID-19

It is crucial to consider the limitations of this study. The main limitation of this study was clearly my inability to obtain the data required for analysis. The location of study as well as state of the world in the midst of the pandemic resulted in my inability to execute on my method. As a result, I am unable to provide concrete data. This itself is a limitation, as findings and discussion are based on a theoretical approach.

Furthermore, a limitation lies in the methodology of this study, as it did not allow for extensive insight into areas of burden for caregivers. For time purposes, the Murphy’s 2000 Involvement Scale was adapted to have fewer, more relevant questions than the original 12. While this did support the research, the discard of numerous questions limited understanding of all caregiver-patient interactions that cause caregiving burden. Likewise, as a result of the general nature of the ZBI scale, any results do not indicate what specific burdens caregivers experience. For example, despite the overwhelming literature indicating that familial caregivers experience economic burden, the ZBI would not be able to conclude that this specific burden is experienced. As a result, I am unable to make specific recommendations on how the burden experienced by caregivers might be reduced.

Finally, it is important to recognise that because of a small (estimated) sample size, conclusions cannot be generalised to the broader population of Chinese-Singaporean adult-caregivers for Alzheimer’s patients. The intended data set was to be composed of caregivers for individuals from a single geriatric care facility; thus, while data may have been representative of individuals from that specific facility, it cannot be generalised to all familial caregivers. This said, the findings do give insight into potential areas of concern/burden areas for caregivers. Therefore, the results can be used as a guideline for where institutions might better support this population.
Future Research

Future research surrounding this topic should evaluate the correlation that this study attempted to evaluate. Beyond this, future research should look into whether established correlations are applicable to other East Asian countries, such as Taiwan and China. At this point, one would not be able to generalise findings to all individuals in Chinese cultures, as the study was solely based in Singapore. Finally, future research should increase involvement categories and population size in order to obtain more specific, beneficial, and accurate results.

Additional research on this topic is essential, as with an increased understanding of what catalyses the burdens which the population experiences, one can better understand how to support them. Whether it be through caregiver training or therapy for psychological release purposes, institutions and individuals will have a clearer indication of what needs to be done to mitigate the burden this population experiences. Familial caregivers are often considered the backbone of many families: ensuring vulnerable family members are cared for and safe at their own expense. In response, it is only fitting that gaps in research that prevent maximum understanding of the cohort is filled.

References


