Caring for Caregivers of Low Vision Individuals

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Abstract

The prevalence of adults with low vision has increased dramatically in rapidly aging countries. While research has shown that physical and psychosocial factors affect the quality of life of caregivers for low-vision individuals, there is still a lack of understanding of the caregiver's experiences in a fast-aging developing Asian country, like Singapore. Hence this study aimed to understand the quality of life of caregivers for low-vision individuals and its relationship with their physical and psychosocial factors that include caregiver burden, coping process, health outcome, and health utilisation. The study used a mixed-methodological approach: Phase one include a cross-sectional survey to measure the quality of life, caregiver burden, coping process, health outcome, and health utilization on a sample of 60 caregivers. Phase 2 included 12 semi-structured interviews with caregivers who were recruited from Phase 1 to explore the coping strategies and social aspects of the experience among those who care for low-vision individuals. Quantitative results from the survey showed that the caregiving journey has affected the mental health more than the physical health of the caregivers, and their burden was primarily due to personal strain rather than role strain. The caregivers tend to employ emotion-focusing coping than problem-focused coping and reported mainly psychological distress and physical problems. Correlation analysis showed that caregiver burden has a stronger relationship with emotional-focusing strategies than problem-focused strategies. Hierarchical regression analysis showed that the quality of life of the caregivers was predicted by the coping strategies, whereby caregivers are more likely to report a higher quality of life when they adopt more problem coping strategies and less emotional coping strategies. Thematic analysis revealed that caregiving journey have both positive and negative effects of caregiving on their quality of life from both mental and physical aspects. Three different coping patterns were revealed: Caregivers proactively seeking support to solve caregiving issues; Caregivers consciously reframing perception and accepting care responsibility, and Caregivers adapting and managing negative emotions. The interviews data also shed lights on the challenges in their caregiving journey: Lack of formal healthcare and social support, including helpline or peer support group, monetary support, and, social activity for caregiver groups. The clinical and research implications are considered. These findings are imperative for clinical implications and revisions of government policy.

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Chapter One Introduction to Thesis

This study aimed to explore how the experience of caring affects the caregivers supporting low vision individuals and the biopsychosocial factors influencing caregivers' quality of life. The key objective of the study was to provide a fundamental understanding of the unique needs and experiences of caregivers of those patients with low vision. Ultimately, future researchers would be able to use the results of the present study to develop a caregiver training package which is culturally appropriate to the caregivers' community in Singapore. In addition, the results from this study would provide initial information and serve as a basis for future research on developing and evaluating caregivers' training.

The impetus to embark on the present study is based on my work experience as a nurse researcher and my research focuses on the needs of patients with visual impairment in a National Eye centre in Singapore. A low vision service was established in the centre to support low vision people in their own homes with the aim of promoting independence in their lives. My prior-PhD involvement in a study on developing, implementing and evaluating a self-management training program for low vision patients in the Singapore National Eye Centre from 2013-2016 highlighted the significant unmet needs for information and skills among the caregivers to support the low vision patient in managing their vision-related activities and improve their functionality. Unfortunately, up to now, there are no training programmes available to support caregivers of patients with visual impairments in Singapore. This has become one of the drivers for developing my PhD study to explore the caregivers' experience and further understand the effect of this phenomenon on this group of informal caregivers.

Since commencing the research, the issue of unpaid, informal caregivers and the associated challenges with supporting the increasing numbers of people living with a disability have become a prominent contentious national topic of debate in relation to health and social care provision in Singapore. On 5 April 2021, the Ministry of Health, Singapore, called for a national grant to address the needs of caregivers and care recipients to develop new care models and intervention programmes that can be implemented nationally to strengthen the caregiving ecosystem, with outcomes that are effective and with lower costs at the systems level. Therefore, this research is timely, in providing insight into the caregiver population, in relation to their quality of life, caregiving burden and coping skills.

This thesis consists of eight chapters. Chapter One presents the introduction to the thesis. Chapter Two provides the background of the study including the prevalence of low vision, associated challenges for caregivers supporting individuals with low vision, and the social and health policies supporting caregivers in society from an international perspective. The chapter concludes with explication of the significance of the study.

Chapter Three presents a narrative literature review, critically examining the factors which impact the quality of life of caregivers of low vision individuals. The review included empirical studies relevant specifically to caregivers of patients with vision impairment and also drew upon studies of caregivers of chronic diseases in general. The review was guided by the theoretical model of the transactional model by Lazarus and Folkman (1984). The chapter also discusses the coping strategies among caregivers in general and how Asian cultural values deeply influence coping strategies and the quality of life in Asian families. The research questions of the study are also presented in this chapter.

Chapter Four outlines the methodological approach used to conduct this study. An overview of mixed methods is provided and the rationale for using mixed methods is discussed. A detailed presentation of the two phases in the study, including discussion related to sampling, recruitment, data collection procedure, data analysis and ethical considerations is provided in this chapter.

Chapter Five presents the study findings from Phase One, which is the quantitative phase of the study. Results from the bivariate analyses of the dependent and independent variables are presented. Finally, findings on the unique predictors of total quality of life are identified through the computation of sequential hierarchal regression models.

Chapter Six presents the qualitative findings based on the interview data gathered in Phase Two. It presents narratives on the caregiving experiences specifically depicting the positive and negative effect of caregiving, caregivers' coping patterns, and the challenges and the social support affecting the quality of life. The findings presented quotes from the participants to support the generated themes.

Chapter Seven discusses the integration of the results of both phases of the study and the contribution of the results to the theoretical understanding of the experience of caregivers of people with low vision. Considerations for innovative ways of working to meet the needs of this population are also discussed.

Chapter Eight outlines the key findings and the methodological challenges of conducting research with this population, including the strengths and limitations of the study. The study concludes with recommendations for clinical practice, future research and policy to improve the caring experience for this population within the Singapore context.

Chapter Two Background

This chapter presents the background for the study including the prevalence of low vision, the challenges experienced by caregivers supporting individuals with low vision and the comparison of the welfare arrangement systems in England, the United States and Singapore, to enhance understanding of the similarities and dissimilarities in the social welfare policies of caregivers. The chapter ends by advocating the significance of understanding the situations of caregivers of low vision individuals in the Singapore context.

2.1 Low Vision Prevalence

Low vision refers to conditions of reduced vision not correctable by glasses, medication or surgery, and is commonly divided into two categories: central loss of vision and peripheral loss of vision (Luu et al., 2020). A low vision person suffers either partial or total vision loss in either one or both eyes depending on the eye disease. This disease can occur in children and/or older adults. By 2020, worldwide , there were approximately 295 million people with low vision. The estimated world population of low vision will increase to 360 million by 2050 (Keel et al., 2021).

This incremental increase is primarily due to the increased life expectancy of the population with its resulting greater proportions of people in older age groups where the prevalence of vision impairment is higher, with 80% of those with vision impairment being in people 50 years of age and older (Keeffe, 2019). With a rapidly accelerating aged population in Singapore, the impact of low vision is expected to rise exponentially (Wong et al., 2019).

Low vision can occur in children, however older adults constitute the fastest growing low vision group within developed countries (Varma et al., 2013; Bourne et al., 2021), with chronic eye diseases accounting for more than 50% of low vision prevalence worldwide (Bourne et al., 2021). The leading causes of adult low vision are age-related macular degeneration, glaucoma and diabetic retinopathy which are associated with peripheral vision loss or central vision loss. Peripheral vision loss causes difficulties in detecting obstacles while walking, whereas with central vision loss the person will experience trouble reading and performing activities requiring near vision (Bohan, 2018). This is a significant public health concern as those with low vision report more difficulty performing activities of daily living, are at greater risk for injury, have a greater inability to provide for family, experience loss of independence and more importantly, this highlights the significant need of practical support from caregivers (Schmiedecke-Barbieri and Valdes, 2020).

2.2 Challenges for Caregivers Supporting Low Vision Individuals

Generally, individuals with low vision do not experience significant impairments in the basic activities of daily living such as self-care because, over time, they have acquired learned habits that do not require the use of intensive visual skills (Boey et al., 2021). At this stage, individuals with low vision compensate with their other senses such as touch, hearing, taste, and smell or by using sensorial devices such as Braille, tactile watches, talking clocks, liquid level indicators and audio books , etc (Young, 2015).

Low vision however has an impact on instrumental activities of daily living (IADL) including the tasks involved in managing a home, work, leisure and family care. A decrease in vision can significantly influence one’s ability to engage in desired occupations (French, 2017). Older adults with low vision tend to lose their ability to age in place due to difficulties with IADL (Crews et al., 2016). They may misread medication labels or leave their oven on and their ability to recognise faces may be compromised leading to safety issues such as taking the wrong medication, burns and robbery respectively (Hallemans et al., 2010). They report difficulty in such things as matching clothes, preparing food, completing housework, managing medication, handling finances, using transportation and shopping (Larizza et al., 2011).

Low vision results in increased falls, morbidity and institutionalisation (Enkelaar et al., 2019; Crews et al., 2016). With limited vision these individuals tend to face challenges in day-to-day life at home, in the workplace and the community of which they are involved. The low vision individual faces functional limitations such as mobility in unfamiliar environments, locating objects, mobility at night and under poor illumination and anxiety about or actually bumping into peripheral objects. In summary, low vision adversely impacts an individual’s quality of life, personal independence, and their ability to participate in society (Steverson, 2020). It also contributes to an increased economic burden on families and society (Keeffe, 2019).

A primary caregiver of someone with low vision can be a spouse, partner or family member who provides help with the activities of daily living. Family caregivers play a crucial role in facilitating individuals' successful adjustment to vision loss by understanding the limitations caused by a vision loss (Sturrock et al., 2018). The most common support activities provided by the caregivers of low vision individuals are transportation for medical cares, shopping for groceries, laundry and ironing and administrative tasks such as reading letter, managing finance , etc (Ni et al., 2020). Meal preparation, cooking and house cleaning are inherent in the tasks that the caregivers of visually impaired person perform (Steverson, 2020). In additional, family caregivers are often not prepared for the physical, psychosocial, or financial demands of caregiving and they typically do not receive compensation for their service (Chen, 2016; Reinhard and Feinberg, 2015).

Caregivers are often ill-equipped for the expanded roles and duties they now must take on (Wittenberg et al., 2020). A United States national caregiving report has indicated that 42% of informal caregivers reported completing complex medical and nursing tasks without any preparation or training (National Alliance for Caregiving, 2015). The caregivers may not understand the function limitations of those with low vision and how to appropriately adjust tasks to help the care recipients at home and at work. Caregivers can be overwhelmed by the demands to purchase different low vision devices (Weisser-Pike, 2013; Schmiedecke-Barbieri and Valdes, 2020). Moreover, there is no caregiver training in Singapore to prepare these caregivers of low vision individuals for their roles.

Having a visual disability may cause changes in social relationships because it may affect the way a person interacts with and relates to others   (Bohan, 2018). Wang and Boerner (2008) found the challenges determined from their qualitative study were due to the lack of visual cues and lack of understanding from others about the implications of having a vision impairment. From the caregivers'perspective, the caregivers may be unable to talk openly with their care recipients. Some caregiving studies have reported negative types of social exchanges, such as anger or hostility that created conflict between the caregiver and low vision individuals and lead to distress for both parties (Vukicevic et al., 2016; Jin et al., 2021).

In the transition from institutional to home care, the caregivers are vulnerable to high levels of stress (Basnyat and Chang, 2021). Caregivers do struggle with their role by performing too many tasks for the care recipients or by performing tasks inadequately, other potential dangers may arise, leading to dysfunction. Feelings of incompetence and frustration may threaten both the caregiver's and the care recipient's sense of agency (Kokorelias et al., 2020). Often caregivers of people of low vision are not involved in their rehabilitative programme (Larizza et al., 2011), as the programme is to provide adaptive living and occupation skills to the visually impaired, and not to their caregivers, to living independently at home , to obtaining employment and to participating in community life. The caregivers therefore are unlikely to understand how to use the optical and non-optical devices to help the low vision individuals to optimize their remaining vision (Weisser-Pike, 2018).

However, the role of family caregivers providing care to individuals with a disability, chronic illness or long-lasting health care needs, is recognised as an indispensable part of the provision of international health and social care systems (Wittenberg et al., 2020; Gaugler, 2021). Thus, family caregivers play a highly influential role as informal extensions of the healthcare system and this is reflected in national policies in Singapore, United Kingdom and United States.

2.3 Social Welfare Policies of United Kingdom, United States and Singapore

The present study considers how the social welfare systems in three jurisdictions: the United Kingdom, United States and Singapore. These three countries were chosen for a number of reasons. They are similar in experiencing rapid population aging, they are all industrialized, and are highly urbanized. These countries have strategically planned cost-effective ways of sustaining caregivers' contribution to social welfare policies to respond to the difficulties faced by those caring for elderly parents and their disabled children and partners (Kröger and Yeandle, 2013; Azman, 2021; Gaugler, 2021). Both the United Kingdom and the United States were selected for discussion as both countries have similar social services and policies for caregivers reflected in their welfare state regimes and policy logics, particularly at the intersections between employment, care and family policies (Qualls, 2021; Manthorpe et al., 2019). The social welfare policy in Singapore, has however adopted a different stance which is more prone to leave caregiver support to individual and families (Sciubba and Chen, 2017). These countries are also different in the values held by caregivers towards caring for disabled relatives. The three countries, therefore, provide points of comparison and contrast in social policy in meeting the challenge of population aging.

The following section focuses on examining and exploring the key feature of national policies from the United Kingdom, United States and Singapore that can support caregivers. Hence, the understanding of both national and international policies related to caregiving is paramount to develop the fundamental knowledge and understanding of how caregivers are supported in various contexts. Comparative analysis seeks to show what future policy directions may support the caregivers in their caregiving journeys within the Singapore context.

2.3.1 The United Kingdom Context: Recognition of Caregiving role and Carer’s Allowance

The United Kingdom (UK) is unique in its legislative focus on caregivers as they were recognised in a national policy on taxation and income support in the 1960s and 1970s and became the subject of official data collection in the 1980s (Kröger and Yeandle, 2013). By 1990 and 2000, caregivers acquired limited rights in national social care and employment systems. The central focus was the need to provide accessible, accurate and reliable information to help carers make important decisions about looking after the care recipient, and obtaining help from the statutory sectors. Three pieces of legislation were established to support the national carers’ strategy (Manthorpe et al., 2019). They are:

1. The Carers (Recognition and Services) Act (1995) which gave carers the right to request an assessment of their ability to provide care.
2. The Carers and Disabled Children Act (2004) which strengthened caregivers' rights to assessment and amended the earlier legislation to enable caregiver to have services in their own right.
3. The Carers (Equal Opportunities) Act (2004) made it a requirement that assessments cover carers’ wishes regarding education, training, employment and

leisure. This shift marked an attempt to recognize a caregiver holistically, as a 'total' person rather than just a caregiver.

In terms of development, the Care Act legislation in 2014 marked the beginning of a slew of systematic changes on how social care in England is provided, including carers' access information and advice (Jones, 2021). Significant changes in the Care Act include a threshold for out-of-pocket social care costs, increased recognition of carers' rights, and an enhanced responsibility for local government to address the needs of informal carers instead of this being done at a national level.

In addition, the UK government had implemented another approach to support caregivers through the provision of financial maintenance for caregivers. Specifically , one of the ways that the caregiver's income maintained , namely the Care's Allowance, refers to paying benefits directly to the carer and is seen as an effort to recognize and compensate for loss of other earnings. The Carer's Allowance is available as a social security benefit to replace lost earnings and is paid directly to carers who provide care regularly at least 35 hours weekly to a disabled or older person (Singleton et al., 2015). The most important feature of this initiative is that it acknowledges the rights of an informal caregiver to an independent income. The collectively funded income replacement provides benefits for employees who take temporary leave from work to care for a critically or terminally ill relative. In practice, the UK Carer's Allowance is payable to carers whose own personal income is low, regardless of the income or asset levels of a partner or spouse (Glasby, 2017). The Care allowance, however is not available even for those in the lower income bracket in Singapore.

The Carer's Allowance does not act as an incentive to encourage caregivers to stop work to care or to combine work and care. In principle, it avoids the financial dependency of the carer on the person being cared for and maintains limited protection for obtaining the eventual state retirement pension entitlement for the carer. On the basis of the above, it would appear that carers are well supported in UK (Pickard, 2018). In Singapore, financial or resource constraints were commonly cited by policymakers as barriers to developing support for caregivers (Sherraden, 2015).

2.3.2 The United States Context: Family-focused Support Programme

In the United States (US), the National Family Caregiver Support Programme (NFCSP) created in 2000, is the only federally sponsored programme that specifically addresses the needs of family caregivers of older Americans with disabilities and of older Americans caring for family members with disabilities regardless of age (Doty and Spillman, 2015). In 2011, 117,846 caregivers received individual counselling via the NFCSP. The individual counselling helps caregivers in managing their emotional reactions to the changes in care recipients, such as improving coping skills in time management, dealing with stress, reducing family conflicts among spouses, siblings, and children, and responding to the care recipient’s emotional and behavioural needs (Kepic et al., 2019). Counsellors can help facilitate effective communication within the family unit and be an advocate for resources and provide a form of psychosocial and emotional support which is crucial to maintaining the mental health of the caregivers (Jensen and Bauer, 2021). When the mental well-being of informal caregivers decreases to a point where they are no longer able to sustain care and perhaps need to seek care themselves (Lambert et al., 2021). This results in two people seeking mental care services, which might have been avoided if more had been done to meet the needs of the caregiver. So the individual counselling offered in via NFSCP, in the US reduced the likelihood of the caregiver needing the help of mental care service while, in Singapore, similar support for the caregivers of the low vision individuals is not available

Through the NFCSP, the US government provides indirect assistance to family caregivers of older Americans with disabilities in three main ways: (i) public programmess that finance long term care for older Americans with chronic disabilities or other services and supports used disproportionately by older Americans with disabilities; (ii) government-funded long term care information and referral services; and (iii) the 2010 health reform legislation, now being implemented, that makes it possible for all Americans— including family caregivers who might otherwise be uninsured—to obtain basic medical insurance coverage. Likewise, in the UK, caregivers have come into much greater focus since the US policy in 2000s, with the government introducing legislation to recognize caregivers.

The United States does not require employers to grant paid leave to workers to provide care to family members who are sick or disabled. The US Congress passed the Family and Medical

Leave Act (FMLA), which required public employers and large private employers to provide a minimum of 12 weeks' unpaid leave to employees to care for seriously ill family members. The unpaid leave comes with two protections: job security and maintenance of health benefits. An employee is entitled to return to the same or an equivalent position after the leave and to receive the same health benefits while on leave as received while working (Qualls, 2018). The caregivers indicated that taking the leave had a positive effect on their ability to care for a family member and on the emotional well-being and/or physical health of their family members or themselves (Davitt et al., 2016).

The NFCSP also provides funding for information and referral to community services, support groups, caregiver training, and respite services to give caregivers temporary relief. US tax policy allows family caregivers to take some direct caregiving expenses as tax deductions. The caregivers reported that these services enabled them to provide care longer than otherwise would have been possible, and they experienced less stress because of receiving these (Parker et al., 2015).

In recognition of the critical role of family caregivers in supporting older adult, two-thirds of US states have adopted the Caregiver Advise, Record, Enable (CARE) Act since 2014 (Qualls, 2021). The CARE Act is a legislative programme that requires hospitals to include the name of a family caregiver in each patient's medical record, notify the caregiver about discharge, and provide the caregiver with education and training on medical tasks. This programme treats all caregivers as unique individuals with heterogeneous needs and caregiver interventions can be initiated by careful assessments and care planning by health care providers (Parker et al., 2015).

2.3.3 The Singapore Context: Family-based Support, The Third Sector Role and FThe oreign Maid Scheme

It is estimated that there are over 210,000 caregivers for the ageing Singaporeans, with some 70 % of them above 40 years of age (Ng, 2019). However, there is no comprehensive national study on caregivers' health and there are no official statistics for the number of caregivers suffering from burnout because primarily , it is non-governmental organisations that provides support for those with disabilities and their families (Chia and Lim, 2020).

However, Singapore's ageing policy is known for its family-centric focus (Tan et al., 2021). The government introduced the Maintenance of Parents Act (MPA) in 1995, to enable indigent older people to seek legal recourse for financial support from their children, and the state's overt expectation is that the family will be the first line of care after the individual himself (Luxue, 2019). The caregivers of low vision individuals are themselves expected to pay for healthcare expenses for their care recipients. At the same time, caregivers are expected to look after themselves as Singapore espouses the philosophy of individual responsibility whereby the population is encouraged to cultivate a strong sense of personal responsibility toward their health (Fong and Borowski, 2022). The government provides tax relief of S$5,000 for caregivers who support disabled siblings, healthy or disabled parents and must be co-residential (Yu, 2019). For caregivers who are not co-residential with care recipients , the tax relief is S$3,500 (Yu, 2019).

In addition, the Singapore government promote the notion that sick older adults are to remain in their homes instead of being placed in nursing homes. Families caring for an older or disabled person at home have been shown to reduce their monthly cost of care from S$1,400 to S$700 per month (Haseltine, 2013). Low vision individuals therefore are rarely institutionalised but are cared for at home. At the national level, the annual cost of informal caregiving time contributed by both primary and secondary informal caregivers for Singaporeans aged 75 and above who receive human assistance with their daily activities , has been estimated at S$2.74 billion (Azman, 2021).

Thus, Singapore continues to pursue a policy of state-supported, family-based social inclusion (Ng, 2020). Furthermore, it is a traditional norm in Asian societies for families to support their older adults. The longevity of older adults coupled with lower birth rates among the young population in Singapore are making such caregiver support increasingly difficult (Thang and Mehta, 2020). As Singapore total fertility rate per woman has dropped from 3.07 in 1970 (Chan, 2011) to historic low of 1.1 in 2020 (Chew, 2021), the family nucleus have become smaller where having none, one child or two children has become a norm. With the rise in the number of families with fewer children willing and able to serve as caregivers, potential caregivers of low vision individuals are likely to face an additional responsibility to look after older adults.

A tenet of social service provision for caregivers in Singapore is the “many helping hands” approach of 1991. This philosophy hinges upon the collaboration of public, private, and volunteer sectors for the provision of social services. In practice, social services for persons with disabilities are provided by voluntary welfare organisations minimally regulated by government (Zhuang, 2016; Scheef et al., 2017). Therefore, caregivers of low vision people expect the voluntary organisations to run caregivers training programme for them but the voluntary services usually do not have the resources to do so (Ang and Malhotra, 2018).

In fact, there is no legislation mandating the provision of training for caregivers in Singapore. To better support informal caregivers in the community, the government worked with voluntary welfare organisations in the provision of a S$200 annual caregiver training subsidy, and a S$200 monthly home caregiving grant. The S$200 Foreign Domestic Worker Grant is only for families who require the assistance of a foreign domestic worker to care for elderly patients (Chong, 2020).

As a strategy to alleviate the unpaid caregiving burden and to facilitate women’s participation in the labour force, the Singapore government has, since 1978, introduced the Foreign Maid Scheme which allows the employment of foreign domestic workers (FDW) for work in households (Chiu, 2018). The FDW may be contracted to do household chores in addition to caring for infants, children or an older care recipient. For working adult caregivers, the FDWs are often a major source of support that enables them to cope with their caregiving responsibilities (Rozario and Hong, 2019).

2.4 Policy Comparison

Based on the above policy comparison the evidence suggests that policies in both the UK and US show some limited commitment to highlight rights for caregivers, albeit in different ways. As far as employment-related policies are concerned, the US has more formalized leave policies than the UK and Singapore. Although the UK and Singapore legislations focus on flexible working arrangements, it is not mandatory for employers in either country to consent to caregivers' requests for flexible working. Hence, working caregivers of those with low vision are likely to leave the workforce because of their caregiving duties (Vukicevic et al., 2016). Caregivers who retired early from paid employment to perform the caregiving role may benefit from greater flexibility to care for low vision individuals but the reduction in income as a result of the early retirement may create financial burden for the caregiver (Hazzan et al., 2021).

In relation to social care policy and practice, only the UK and US caregivers have a right to assessment, as such a policy does not exist in Singapore. As a result, caregivers of the low vision individual do not experience an unconditional entitlement to services, especially to services which would help them reconcile work and care. Hence, it can be seen that the caregivers of low vision are largely neglected in the Singaporean healthcare system. There is also a difference in how caregivers are being supported through social policies in Singapore and the United States. The Singapore policies provides indirect and non-monetary support to the caregivers. For instance, caregivers can only receive indirect compensation via various tax credit schemes. Non-monetary support includes Compassionate Leave of 3 days and family care leave of 2 to 3 days (Thang, 2017). Despite the introduction of family care leave to support working caregivers in the workplace, this initiative was not legislated (Yacob, 2015). In the US the Family and Medical Leave Act (FMLA) is the national law that enables employed caregiver to take up to 12 workweeks of job-protected leave to care for their family member without jeopardizing their job (Wacker and Roberto, 2018). But the FMLA does not provide paid leave, the federal FMLA leaves many workers especially low-income workers with no viable solution because they cannot afford the financial hardship of going without a pay-cheque when their family members become seriously ill (Feinberg et al., 2021). At the federal level, the American Association of Retired Persons supports the Credit for Caring Act. This legislation creates a new, non-refundable tax credit of up to US$3000 for eligible working family caregivers to help offset a portion of caregiving out-of-pocket costs such as home care, home modifications, adult day services, transportation, and assisted living (Qualls, 2021).

Healthcare and social policies in Singapore tend to be aimed at caregivers in a one-size-fits-all approach without identifying particular groups of caregivers for special provision. Such a broad approach aims to match the heterogeneity of circumstances in caring relationships and the range of medical conditions of those receiving care. However, caring for a disabled child is substantially different from caring for a spouse and both types of care differ in many respects from caring for older parents (Tyagi et al., 2021). In addition, caring for disabled children usually starts early in parenthood when parents are in their late 20s or 30s, or 40s, while caring for the elderly typically begins when offspring reach their late 40s or 50s. Thus, whether the Singapore social and health policies are effective in supporting the caregivers of the low vision individuals need to be examined.

2.5 Significance of The Study

This study is significant for several reasons. Despite research on the experiences of primary caregivers for individuals with other types of chronic conditions, such as cancer, Parkinson's disease and dementia, there has been little research on individuals who provide primary support to persons who have low vision. It is not clear whether these caregivers feel a sense of strain or feel burdened by their role. Although the health professionals in ophthalmology must address this potential stress by helping families cope with individuals of low vision, research has provided insufficient data and recommendations for such interventions thereby targeting the importance of social care provision for this unique group of informal family caregivers (Hazzan et al., 2021). It is estimated that by 2030, the percentage of over-65s Singaporean will have risen to 27% of the resident population (Kwan and Asher, 2022). The impact of low vision in older adult populations is large for much of the approximately 18.4% of the current population in the Singapore (Wong et al., 2019). The low vision individual needs regular support from caregivers and many of these caregivers are unpaid family members (Enoch et al., 2021b). But with fewer babies being born, there will be fewer adult caregivers to provide family care in the future and families may therefore be expected to provide more help to disabled elderly relatives than ever before (Straughan and Tan, 2022). This new demographic phenomenon may have numerous long-term effects and negative consequences for caregivers in the future which can be serious (Tan and Teo, 2018). It is timely to comprehend the needs of caregivers of low vision individuals and whether the social system that is set up to support those with low vision helps or fails to meet the needs of this specific population.

The majority of the literature to date has focused primarily on the unique role the family plays in providing both instrumental and emotional support to adult persons with low vision (Enoch et al., 2021; Jin et al., 2021; Varano et al., 2016). Both positive and negative aspects of providing support to the care recipients have been well-documented. In contrast, the impact of those providing care for low vision individuals has been largely understudied. Thus, the present study is significant as it is the first study in Singapore to assess the quality of life, coping processes and experiences from caregivers of low vision individuals.

Secondly, there is a rising demand for care giving and more importantly, provision of quality care for those needing long term care like low vision individuals who need to be recognized and supported for their wellbeing. However, there is no caregiver training programme for caregivers of those with low vision available in Singapore. Thus, the findings of this study will provide insights that will enable the development of a training programme that is culturally sensitive and beneficial for the caregivers of low vision individuals. Based on the findings from this project, the research seeks to initiate and develop caregiver programmes which will be initiated by nursing leads in SNEC to addressing the complex needs of caregiving to those with low vision, and how to connect the caregivers back to the health system.

Finally, using quantitative and qualitative data that complement each other, the findings of the study will provide in-depth understanding of the challenges, coping strategies and explore how social and health care policies have been supporting the caregivers within the Singapore context. The findings will be used in developing recommendations for new models of care to help caregivers of low vision individual in the community. In addition, the findings will have implications on social policy recommendations to sustain the caregiving challenges in Singapore.

2.6 Chapter Summary

This chapter discussed the many challenges confronting caregivers of low vision individuals. The policy contexts of the different countries presented provide an overview of caregiving policies which were then compared with national policies in Singapore. The following chapter provides a narrative review of the Singapore and international evidence-based studies on the caregiver literature, and the theoretical framework underpinning the study.

Chapter Three Review of the Literature

This chapter presents a narrative literature review summarising the evidence on the experience of caregivers for low vision individuals, and barriers related to the quality of life of caregivers. The narrative literature review was conducted by searching electronic databases and included studies from ophthalmic practices. The review also included studies on barriers related to the quality of life of caregivers of those with chronic illnesses such as stroke, dementia, and cancer.

The transactional model by Lazarus and Folkman (1984) was the theoretical model which guided the current study. The transactional model explored the experiences of caregivers coping caring for low vision individuals and exploring how it may impact their quality of life. This chapter also discusses the coping strategies of caregivers of the individuals with chronic conditions, and how Asian cultural values influence coping strategies within Asian families. The chapter concludes with identification of the research gaps in the literature and presentation of the research questions for the present study.

3.1. Quality of Life of Caregivers

Throughout the world, long-term care for sick and disabled persons has shifted from healthcare institutions to the home. The shift of care from health facilities to home also shifts the caregiving burden (Law et al., 2021; Lyons, 2017). Family members, as primary caregivers, must bear the burden of caregiving for sick and disabled persons at home (Bouchard et al., 2021; Asi and Williams, 2020). It is, however, often taken for granted by societies and individuals as a “natural’ expectation to take up the responsibilities of caring for the sick and disabled without proper training (O'Neill, 2018; Ogawa et al., 2018). As a consequence, this tends to have both direct and indirect implications on the quality of life of the caregiver.

Quality of life is a multifaceted concept including physical, mental and social well-being (Ware Jr et al., 1996), which captures the subjective evaluation of both positive as well as negative aspects of wellbeing and life (Bowling, 2019).   Quality of life dimensions includes meaningful social roles, family relationship, and social interactions (Rand et al., 2018; Wolinsky and Andresen, 2017). The wellbeing of caregivers can be measured by asking respondents to rate the perceived quality of their physical and mental health, for each day during the past 30 days identifying when it was either good or not good**.** (Sirgy, 2021).

The decision to care for family members with low vision is not easy (Khan et al., 2016; Kuriakose et al., 2017). The person with low vision is gradually no longer able to safely or adequately perform everyday activities with the progression of increased vision loss (Blaylock et al., 2015). Thus, their caregivers perform caregiving tasks such as the activities of daily living (e.g., feeding, bathing, dressing), instrumental activities of daily living (e.g., house-keeping, grocery shopping), and medical care. Caregivers also provide financial care to their care recipients by paying for their daily feeding, transportation, medication, and hospital bills (Silva-Smith et al., 2007; Hanemoto et al., 2017b). These kind of tasks may be physically as well as mentally demanding (Varano et al., 2016). Hence caring for a person with low vision creates chronic stress and psychological distress among caregivers which affect their quality of life (Jin et al., 2021; McDonald et al., 2020).

While many caregivers find the caregiving experiences of those with low vision rewarding (Varano et al., 2016) and manage to cope with stress, it is often at the expense of their own health and well-being (Ghosh et al., 2020; Kokorelias et al., 2020). Caregiving seems to be strongly associated with lower quality mental health and physical health (Berglund et al., 2015; Gately and Ladin, 2018). This suggests that caregiving has negative associations with several health outcomes such as depression, cardiovascular diseases and that the association seems to be most evident for mental health (Wittenberg et al., 2020; Varadaraj et al., 2021). This steady decline in caregivers' health is the result of not only the cumulative effect of burnout but also the fact that caregiving needs typically increase over time while the caregiver's own health declines simultaneously (Stefanacci and Riddle, 2019; Bruening et al., 2020). These are the sources of caregivers' morbidity, caregivers' burden and adverse quality of life (Chua et al., 2016; Ochoa et al., 2020).

Although numerous studies have been conducted on caregivers of low vision individuals globally, a comprehensive overview has not been conducted in Singapore. It is imperative to examine the caregivers' quality of life, socio-ecological factors and coping mechanisms influencing their quality of life and assess social needs in order to support the caregivers.

Therefore, in this study, scientific evidence and other relevant documents were reviewed to capture the challenges of caregivers of individuals with low vision globally. In order to gain insight into the current state of the literature, the researcher conducted a narrative review. The narrative review allows consideration of all forms of literature portraying caregivers of visually impaired individuals. A narrative review is a comprehensive synthesis of previously published information that provides a broad perspective on a topic (Byrne, 2016). At present, there is limited evidence on factors contributing to the quality of life of caregivers of low vision individuals. The aim of this review was to examine the existing evidence and identify barriers to good quality of life for the caregivers of low vision individuals.

3.2 Review Strategy

As this review aimed to collate studies that examine quality of life, and barriers which impede a good quality of life for caregivers of those with low vision, a narrative review approach was deemed appropriate. This technique is suitable when considering a range of quantitative and qualitative evidence (Ferrari, 2015) to synthesize and provide an overview of a broad area of research related to – caregivers' quality of life and the related barriers. In addition, the subject of caregivers' quality of life comprises a wide range of research methodologies, subjects, and topics, which makes statistical meta-analyses unsuitable.

This review used a systematic method of planning the search, critically selecting relevant papers, identifying themes through in-depth analysis and then applying these findings in the context of this study (Gregory and Denniss, 2018). The thematic analysis method was used to identify patterns and describe the different facets of the literature, while staying close to the results of the primary studies and synthesising them in a transparent way (Green et al., 2006; Siddaway et al., 2019).

3.3 Search Strategy

A literature search was conducted using six electronic databases: CINAHL, Science Direct, Scopus, PsycINFO, PubMed and Web of Science. An exploration of literature relating to the concepts of caregivers, caring and caregivers support for the visually impaired was undertaken focusing on literature with publication dates from 2001 to December 2021. The Boolean operators "OR" and "AND" were used to combine terms and were performed for all databases. To retrieve a comprehensive list of studies to meet the specified inclusion criteria, the Medical Subject Headings (MeSH) were identified for each of the search terms and were as follows:

Low vision terms	Low vision, glaucoma, diabetic retinopathy, retinitis pigmentosa, age -related macular degeneration, visually impaired, vision impairment
Caregiver terms	Caregiver, caregivers, carers, family caregiver

Combining the low vision terms and caregiver terms revealed a limited set of journal papers with a specific focus on quantitative and qualitative studies describing quality of life, and barriers-related to the quality of life of the caregivers. Whilst it is acknowledged that this was not an exhaustive, systematic review, findings were considered applicable to the research aim. The inclusion and exclusion criteria are listed in Table 3.1.

Table 3.1 Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Written in the English language	Editorials, letters, commentaries
Papers focusing on caregivers of those with low vision or visually impaired Paper focusing on caregivers of blind individuals	Children or young caregivers
Empirical studies	
Adult caregivers	
Unpaid caregivers	

3.4 Data Extraction, Appraisal and Synthesis

Article titles and abstracts were screened to ensure they met the inclusion criteria. The initial search conducted in March 2019 from the identified databases using the search terms resulted in a total of 67 studies. A review of the titles and abstracts resulted in 30 studies being rejected as they did not meet the specified inclusion criteria. Following extraction of duplicated articles, a total of 22 full text articles were retrieved and screened for eligibility, of which 15 studies met the inclusion criteria and were included in the review. All retrieved articles were read several times to enable the researcher to gain a deeper understanding of the studies. Data were extracted based on the date of publication and sample setting. The findings from this review are presented with consideration of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2015).

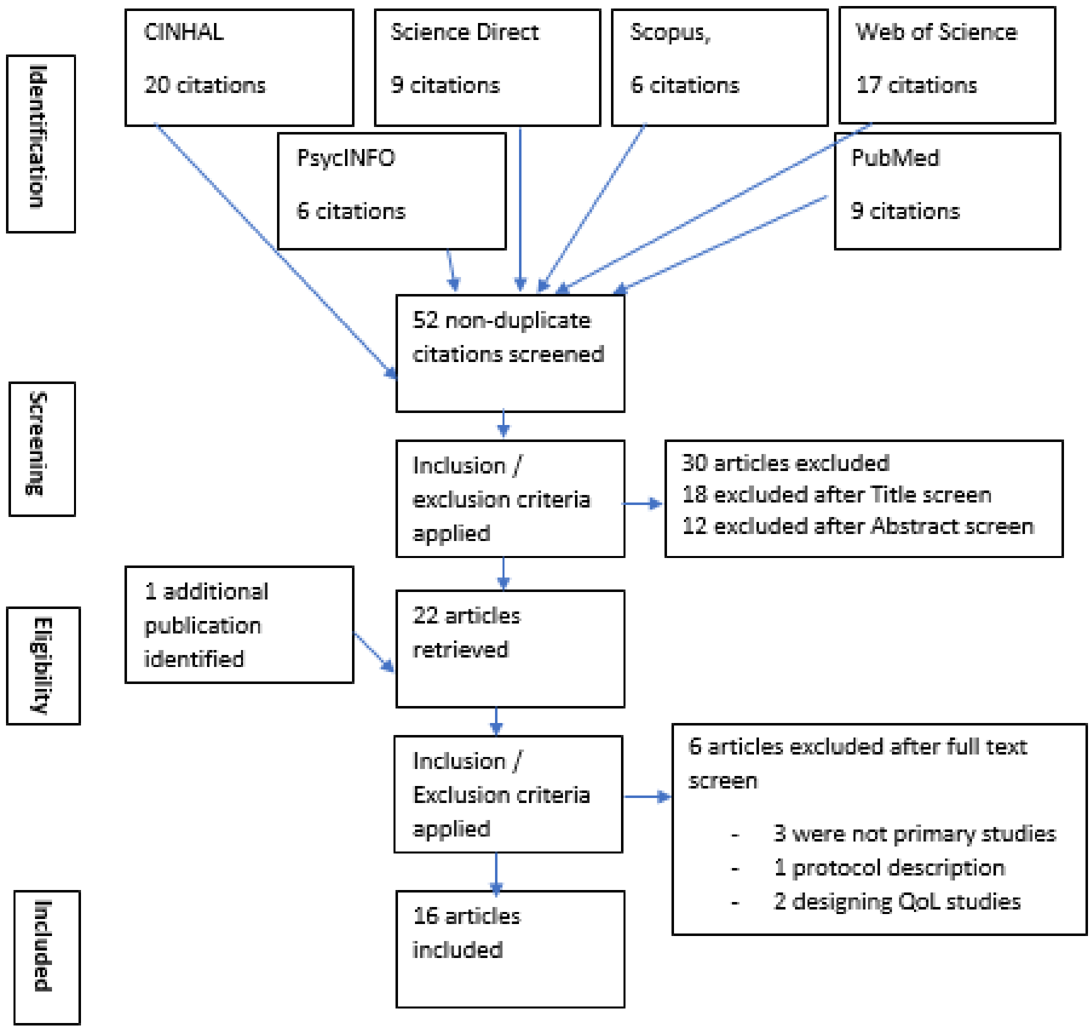

Figure 3. 1 PRISMA flow chart, showing the literature search, screening and sections of publications.

An updated search following the same search strategy conducted in December 2021 resulted in one study that met the specified inclusion criteria. The final studies included in the narrative review comprised projects which were categorized as qualitative and quantitative studies and synthesis utilising a thematic analysis was carried out (Hawker et al., 2002). Themes were defined and refined by the review researcher, rather than using themes identified by individual authors. The researcher initially undertook the review process and following this, the quality of the studies selected was further appraised, using the Hawker et al.,(2002) checklist.

The Hawker et al.(2002) checklist uses numeric scoring to evaluate studies across nine dimensions. The nine dimensions include the abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results of the study, transferability and implications. The checklist is scored using 4-point rating scales. To aid interpretation of scores, the researcher presented these as: 'high quality' (satisfactorily reporting on at least seven of the nine dimensions); 'moderate quality' (adequately reporting on at least five dimensions); and 'low quality' (satisfactorily reporting on four or fewer dimensions). Data were extracted on the study context, purpose, methodology/design, theoretical construct, participants, and main results by the first author. The studies included in the narrative literature review are summarised in Appendix A.

3.5 Studies Included In The Narrative Review

The 16 studies in the review came from different countries: Australia (2), UK (3), USA (6). Of the remaining five studies from Asia and Europe, one was from Japan, one from India, one from Germany, one from Canada and one reported cross-country studies (namely Australia, Brazil, Canada, France, Germany, Italy, Japan, Spain and the UK. The majority of papers were therefore from high-income countries with developed healthcare systems. Participants were recruited from low vision clinics.

Not surprisingly, there were limited clinical trials found for this review; all studies were descriptive and there were only three qualitative reports found. The results were, therefore, summarized in narrative format. The sampling method sizes of the studies included in this review were primarily convenience. Power analyses were reported for only one of the quantitative studies, thus it is difficult to determine the precision or generalisability of the findings. The quality of life and related barriers used in the quantitative studies to examine the outcomes of interest for the caregivers were also inconsistent.

Based on Hawker's et al (2002) checklist, six studies scored as high quality, 8 scored moderate quality, and 2 scored low quality. Consequently, none of the articles needed to be excluded due to being of very poor quality. In total, the review was based on 16 articles. The majority of the study designs were descriptive correlational cross sectional (n=11); one study was a randomised control trial and four studies utilized were qualitative designs. All studies were conducted with vision impaired populations inclusive of caregivers and based on a thematic analysis approach. Due to the varied designs of the included studies, findings from the selected studies were synthesised using a traditional narrative approach, involving thematic analysis, and the following themes were identified:

- Characteristics of caregivers
- Quality of life of caregivers
- Barriers-related to promoting better quality of life among caregivers

3.5.1 Characteristics Of Caregivers

Low vision is more common in older adults, hence caregivers are more likely to be aspouse and children who are still employed in the workforce. The review demonstrated the age of caregivers ranged from 45 to 65 years old (Larizza et al., 2011; Bambara et al., 2009; Gohil et al., 2015; Weyer-Wendl and Walter, 2016; Jin et al., 2021). This period of life is characterized by a myriad of roles; working and providing care for those with low vision ay the same time as caring for young families and carving out one's own career makes it more challenging. Some caregivers in this age-group often are perceived as approaching the height of their career trajectory.

Across the studies, the key characteristics of the primary caregivers included were being female, married, and employed at the time of the study (Larizza et al., 2011; Vukicevic et al., 2016; Bambara et al., 2009; McDonald et al., 2020; Gohil et al., 2015b; Ajay et al., 2017). It was found that females were more likely to provide caregiver services compared to males. This finding supported past international research where it was found that women were assumed to be the ones to provide the main source of support as caregivers, both in Western countries as well as in East Asian nations (Bouchard et al., 2021; Asi and Williams, 2020; S. Huang and Yeoh, 2018). Three of the studies showed that caregivers had graduated from high school and had received at least 10 years of education although fewer than half of these caregivers had a degree (Bambara et al., 2009; Cimarolli et al., 2004; Hanemoto et al., 2017). On average caregivers spend approximately 3- 6 hours per day providing care, and typical tasks included transportation, administrative work, shopping and preparing meals (Vukicevic et al., 2016; Shtein et al., 2016; Hanemoto et al., 2017a; Silva-Smith et al., 2007; Sussman-Skalka, 2003). The caregiving time and tasks reported in this review of low vision caregivers were comparable to the caregivers of general population. The majority of the studies that mentioned the nature of this relationship to care recipients found that the many were related as spouses, parents and offspring (Sussman-Skalka, 2003; Cimarolli et al., 2004; Bambara et al., 2009; Hanemoto et al., 2017; Silva-Smith et al., 2007; Weyer-Wendl and Walter, 2016; Gohil et al., 2015; Varano et al., 2016; Larizza et al., 2011; Ruiz-Lozano et al., 2022). It was uncommon for siblings and non-family member to be the as caregiver.

3.5.2 Quality of Life Of The Caregivers

There were only four papers which reported findings related to the impact of caregiving for low vision individuals on the caregivers' quality of life (Gohil et al., 2015; Weyer-Wendl and Walter, 2016; McDonald et al., 2020; Jin et al., 2021). These four studies utilised a generic quality of life tool as there is no specific tool for caregivers of low vision individuals. The tools used to measure QoL included the EQ5D (Gohil et al., 2015), Visual Analog Scale (McDonald et al., 2020) and General Quality of Life (Jin et al., 2021; Weyer-Wendl and Walter, 2016).

In the study by McDonald (2020a), the quality of life of the caregivers of low vision individuals was lower than the caregivers of those with Alzheimer's disease in UK (Fang et al., 2016). However, when compared to caregivers of those with dementia (Bleijlevens et al., 2015) the quality-of-life score as determined by the VAS score of caregivers of low vision individuals was higher with 74.5. Jin and colleagues (2021) showed the mean score of General Quality of life is 7.3 over 10.0 which is define as an excellent quality of life. In the same study impaired physical health was the predictor of depressive symptoms in the caregivers. Similarly, the mean score of quality of life for male and female caregivers by Weyner-Wendl and Walter (2016) were 6.93 and 6.61 respectively. The scores meant the quality-of-life score of caregivers were reported to be above average of 5.0. The VAS with a mean scored of 74.5 reported by the caregivers in the study by Gohil et al (2015) suggests the quality of life was not adversely impacted by their caregiving.

The current review identified emotional distress as another pervasive theme suggesting that emotional distress is a key feature related to quality of life for caregivers of low vision individuals (Hanemoto et al., 2017; Varano et al., 2016; Bambara et al., 2009; Weisser-Pike, 2013; Cimarolli et al., 2004; Khan et al., 2016; Vukicevic et al., 2016; Jin et al., 2021). These studies showed significant associations between depressive symptoms and gender (i.e. female), age (i.e. younger caregiver) and patient vision condition (i.e. those with worse vision). The review showed that caregivers who are female, younger and reported worse vision condition of their patients were more likely to report greater depressive symptoms. In addition, the depression symptoms among the caregivers of low vision individuals could be substantially higher that the global prevalence rates of caregivers at global level (Jin et al., 2021). Hence, the impact of caregiving on mental well-being becomes highly relevant.

Only the study by Khan et al., (2016) reported a significant improvement of the depression score for caregivers who complete training in low vision rehabilitation. This shows the importance of engaging caregivers in the same rehabilitation trainings given to their care recipients. However, two separate studies on two caregivers' interventions for caregivers by Cimarolli et al., (2004) and Larizza et al, (2011) highlighted no changes in depression scores among caregivers. Specifically , Cimarolli's study (2004) which conducted a support group session for caregivers to learn from other caregivers how to adapt to stress situations showed a significant decrease in role captivity and improved the quality of communication between caregivers and their visually impaired partners. While a three-armed Randomised Control Trial by Larizza et al.,(2011) showed the caregiver's intervention improved their knowledge in low vision aids and coping strategies, but no significant improvement in confidence and self-efficacy as caregivers.

Overall, the quality of life of caregivers of low vision individuals is not adverse. There is consistent evidence of a negative impact of caregiving on the mental health of the caregivers but limited evidence of a negative impact of caregiving on physical health of the caregivers.

3.5.3 Factors Contributing To The Quality Of Life

3.5.3.1 Caregiver burden

Based on the current review, one of the factors contributing to caregivers' quality of life was the caregiver burden (Vukicevic et al., 2016; Bambara et al., 2009; McDonald et al., 2020; Gohil et al., 2015). Caregiver burden can result from the degree of dependency of the low vision person, behavioural problems related to low vision and the time spent in caregiving and so on (Shtein et al., 2016; Varano et al., 2016; Khan et al., 2016; Hanemoto et al., 2017). The caregivers in these studies had to take the responsibility to take care of finances, prepare meals, assist operating in low vision devices, provide medicine at the correct time. So, these kinds of caregiving activities are time-consuming and inconvenient for caregivers. As a result, caregivers of those with low vision, who were employed full time needed to made work accommodations such as taking leave of absence, or taking time off for caregiving duties.

In terms of duties, the most frequent caregiving duty cited by caregivers was to act as a mobility guide and to make travel arrangements for medical appointments (Hanemoto et al., 2017; Varano et al., 2016; Jin et al., 2021; McDonald et al., 2020). Many of the care recipients were incapable of driving or going alone outside the house. The caregivers played a vital role in helping their relatives access medical care, with a high proportion of caregivers having to accompany their care recipients to their ophthalmology appointments and regular eye treatments. The average time waiting time in the clinics can be as long as half a day to 14.5 hours (Gohil et al., 2015; Silva-Smith et al., 2007; Weyer-Wendl and Walter, 2016; McDonald et al., 2020). Nearly half of the caregivers reported that treatment of the eye diseases led to their missing their work days and personal obligations of between 10-20 days per year (Gohil et al., 2015; Varano et al., 2016; McDonald et al., 2020). Traveling was onerous and part of the overall responsibility of the caregivers, which added to the burden of caregivers (Hanemoto et al., 2017; Shtein et al., 2016; Silva-Smith et al., 2007; Vukicevic et al., 2016; Varano et al., 2016). Due to the amount of time required to care for low vision individuals, there was a significant loss of wages and decreased employability for the caregivers.

According to studies reviewed, the caregivers did not get time for social activities or gathering (Varano et al., 2016; Vukicevic et al., 2016). Ultimately their lives only revolve around their low vision care recipients. Caregivers may be feel overloaded, feelings of entrapment, isolated from society and become emotionally exhausted (Cimarolli et al., 2004; Weisser-Pike, 2018). This is the perceived caregiver burden from the psychosocial result of caregiving.

The current review showed that age was associated with the degree of caregiver burden. Younger caregivers were found to report higher levels of burden due to the competing demands of caregiving, work, parenting, and other responsibilities of the caregivers (Jin et al., 2021; Varano et al., 2016; Weyer-Wendl and Walter, 2016). It was revealed that caregivers who were still in the workforce therefore needed help accessing and navigating services for balancing their life roles and responsibilities (Varano et al., 2016; Vukicevic et al., 2016). In comparison, older caregivers, in addition to the objective burden of care, faced personal challenges with respect to major life and health changes such as retirement and worsening physical health with multiple comorbidities, plus cognitive and functional impairment due to their age increment (Ajay et al., 2017; Jin et al., 2021; Weyer-Wendl and Walter, 2016).

There appears to be a large body of evidence on financial strain as a major factor contributing to the caregiver burden. The financial burden is often derived from the expenditure on the care recipients' daily needs, medication, transportation and monthly hospital appointments (Gohil et al., 2015; Weyer-Wendl and Walter, 2016; Vukicevic et al., 2016). More importanly, the financial strain was aggravated by insufficient public resource for the visually impaired community (Gohil et al., 2015; Weyer-Wendl and Walter, 2016). Thus, caring for a low vision patient can also affect the caregiver's retirement savings. In Singapore, adequate savings and personal arrangement are emphasized for income security in old age. For example, adequate savings must either be achieved through careful financial planning during employment or the extension of working lives to support the older person in the later stage of life (Dhirathiti, 2018). Therefore, adult children who assume the role of caregiver for aging low vision parents during their midlife not only will experience a large economic impact on their retirement savings, but also may substantially increase the risks of living in poverty in their later life stage.

From the aforementioned studies, caring for a low vision person is burdensome. Caregivers faced a variety of challenges as they simultaneously balanced caregiving with other demands such as their job and social relationship and so on. It is therefore evident that the caregiving burden is an influential factor that negatively affected the quality of life of the caregivers.

The association between the level of education and the caregiver burden was scarcely examined in the reviewed studies because of the paucity of primary studies of the caregiver burden among caregivers of low vision individual and the high degree of variability in terms of the factors investigated. But other caregiver studies showed a higher level of education can be a positive contributing factor in lowering the caregiver burden (Ge and Mordiffi, 2017; Isac et al., 2021). These two systematic reviews have reported that low level education may influence caregiver capacity to comprehend and apply health information in care decision making, contributing to a higher caregiver burden. Hence, a higher level of education has a positive and indirect effect on caregivers' health status. It is imperative to examine the caregivers of low vision individuals to see whether a lower education level increases their caregiver burden, thus affecting their quality of life.

3.5.3.2 Health Outcomes

There is strong evidence which suggests the caregiving role is related to increased mortality , a shorter lifespan, and often to states of poorer health compared to non-caregivers (Reinhard and Feinberg, 2020). A study by Jin and colleagues (2021) showed that one third of the caregivers of low vision individuals reported comorbidities including diabetes, arthritis, kidney disease, cardiovascular and neurovascular diseases. Their health was likely to decline as a consequence of the strain of providing caregiving to low vision individuals. Older caregivers of those with chronic disease are themselves biologically vulnerable to comorbidities and are at substantial risk of developing health problems themselves (Braine and Wray, 2018).

Poor diet is common among caregivers as it has been established that caregivers do not have time to prepare meals or exercise and this may lead to chronic medical conditions such as hypertension and heart disease in the long term (Reinhard and Feinberg, 2020) . There is also the likelihood that caregivers do not obtain their own prescriptions due to the high cost of medicines as compared to the non-caregiving population (Bevans and Sternberg, 2012). This may explain why the rate of caregivers who reported a chronic medical condition was nearly twice as high compared to non-caregivers (Teixeira et al., 2018). It is worth examining whether the health outcomes of caregivers of those with low vision are facing similar situations to those who are caregivers to those with a chronic medical condition.

In addition, the higher risk of deteriorating health may be related to the age cohort of the caregivers. The first National Singapore Survey on Informal Caregiving (Chan et al., 2013) reported more than half of caregivers belong to the 45-59 years' age group and those between 60-74 years formed the second largest group. Many middle-aged caregivers might be suffering from a chronic disease before they become caregivers (Parker et al., 2015), hence increasing the risk of negative health outcomes. The biological response to prolonged caregiver stress includes activation of the immune system which leads to increased glucocorticoid and catecholamine production (Teixeira et al., 2018). These hormones can result in hypertension , immune dysfunction, cardiovascular disease and diabetes (Byun et al., 2016; Kotronoulas et al., 2013). Thus, caregiving produces a multidimensional response to biological factors associated with the caregiving experience. The negative factors are likely to lead to the development of systemic disorders which potentially lower the caregivers' quality of life (Roth et al., 2019).

3.5.3.3 Health Utilisation

Some empirical studies have noted that caregiving responsibilities impose barriers to practicing self-care behaviours. However, the analysis of a large, nationally representative United States-based survey found no differences in the total number of medical appointments between informal caregivers and non-caregivers (Shaffer and Nightingale, 2020). The study suggests it is possible that the caregiving sample was previously relatively more engaged with the healthcare service compared to the general population, and the impacts of caregiving shifted these caregivers' average engagement to be comparable with that of non-caregivers (Shaffer and Nightingale, 2020).

But another study in the US revealed a different result. The utilisation of health care services was significantly higher for caregivers compared to non-caregivers (Rahman et al., 2019). The visits to general practitioners were three times more frequent among caregivers than non-caregivers. This trend was consistent throughout all health care services such as outpatient and inpatient visits. In addition, visits to pharmacists increased two folds, and psychologist visits increased three folds over a period of six months since 2018. These results implied that increased utlilisation of health services was related to the physical and psychological burden associated with caregiving. By examining health care services utilisation of caregivers, it is possible to address the health care needs of caregivers of low vision individuals more effectively, which subsequently improves their quality of life.

3.5.3.4 Coping Strategies and the Asian Culture

Most studies showed that caregivers experience had negative effects on the caregivers' health. But two studies by Varano et al.,(2016) and Jin et al.,(2021) illustrates the caregivers' experience in caring for those with low vision can have positive effects on caregivers. Caregivers accomplish the role of caregiver out of respect, commitment, love and/or a sense of duty for the low vision care recipient. Therefore, by providing care they may feel a sense of mastery and accomplishment that leads to a sense of reward, fulfilment, personal growth and source of satisfaction. Caregivers who experience positive impacts of providing care were likely to have employed effective problem solving and emotion coping skills (Braine and Wray, 2018).

Structural interventions focusing on problem coping skills training can prevent negative outcomes related to caregiver stress, enhanced emotional functioning, and improved quality of life for low vision caregivers and care recipients (Sussman-Skalka, 2003; Bambara et al., 2009; Weisser-Pike, 2013). Results from Weisser-Pike (2013) and Sussman-Skalka (2003) indicated that caregivers' interventions such as caregiver support groups, developed problem solving skills and increased role competence. The caregiver interventions which aimed to reduce the stress associated with caregiving activities were specifically designed to improve the quality of life of caregivers of low vision individuals. Coping literature suggested problem-focused strategies may be effective in reducing the burden of caring, while an emotion-focused strategy may help to reduce psychological stress (Tyagi et al., 2021; Hawken et al., 2018). Th study by Papastavrou et al.,(2012), proposed that caregivers with higher educational levels used problem-focused coping skills in dealing with difficulties instead of emotional coping skills.

The literature also highlighted the implication of cultural background within the context of caregiving. In Asian countries, cultural beliefs and traditional practices impose the expectation that adult children or spouse mostly females are expected to take the responsibility of caring for the young, old and disabled people (O'Neill, 2018). Prevailing research has proposed that Asian caregivers may see their caregiving efforts less as a burden and more as familial or societal fulfilment of a duty (He, 2021; Nie, 2021; Zhang et al., 2020).Family is often the first line of support and there is a cultural emphasis on filial obligations. Thus, it is not uncommon to affirm the presence of filial support in nearly all Asian families among caregivers (Yu, 2019; Zhang, 2022) whereby they are expected to respect, obey, honour and care for their parents.

The moral values of filial piety, however, have been associated with positive experiences for caregivers as they gain a sense of satisfactions from the appreciation of family members and by society (Washio et al., 2019; Liu, 2019). The possible reason perhaps as an important cultural trait, filial piety is a motiving force behind family caregiving, it predicts caregivers' meanings, gains, and values of providing care. These positive gains were reportedly related to reducing caregiver burden and stress (Vaingankar et al., 2020a; Devi et al., 2020), and motivation in long-term caregiving (Tan-Ho et al., 2020).

Asian caregivers not only provide physical and material support, but also emotional support, companionship and respect (Fauziana et al., 2018; Chang and Basnyat, 2017). The moral values of filial piety stress that caregivers should respect and provide care according to their parents' needs as parents have made sacrifices in their lives to raise and nurture them (He, 2021). Within Asian culture, family members who refuse to fulfil filial expectations are perceived as selfish by the other family members because filial values indicate a need for self-sacrifice to fulfil one's duty (Thang and Mehta, 2020; Zhang et al., 2020; Sim et al., 2017).

Culture can also help to explain differences in coping strategies among the caregivers, especially in relation to the willingness to accept help from sources outside the family. Research indicates that Asian people are least inclined to move beyond family, and caregivers in Asian believe in maintaining family secrecy (Cheng et al., 2013; Chang and Basnyat, 2017). It is known that Asia caregivers tend to be less willing to share and express their feelings, particularly negative ones, as it is considered disgraceful to reveal one's real feelings about being depressed or inadequate (Isac et al., 2021).

The current review revealed that coping strategies tend to be related to age factor. Coping studies showed that that problem-focused coping strategies were more frequently used by young caregivers and emotion focused coping strategies are prevalent among older caregivers (Lin and Wu, 2014; Chen et al., 2017; Monteiro et al., 2018). Problem-focused coping strategies generally aimed to confront the reality of a major difficulty by managing unacceptable consequences and by making efforts to construct a more endurable situation and are positively related to resilience (Roberts, 2018). Caregivers adopt different strategies to cope with adverse situations and try to make the caregiving task as well as the situation easier for themselves. The systematic review by Monteiro et al., (2018) reported that Asian caregivers preferred to employ emotion coping strategies in caregiving. Common emotion coping strategies include avoidance, and self-blame. The avoidance-focused coping strategy involves purposely avoiding activities related to a stressor which includes strategies such as denial. The Asian cultural belief allows caregivers to accept their caring roles even if they could not manage it and to adjust themselves to the daily caring duties to ensure harmony in family. While the self-blame coping strategy refers to criticizing oneself/ blaming oneself for things that happened. This means when an adverse situation occurs in the caregiving, the caregiver reflects and blames himself or herself when their performance as caregiver is suboptimal (He, 2021).

In summary, level of education, age and cultural values have strongly influenced the coping strategy in caregivers in Asian society. However cultural values may impede the caregivers in seeking additional social support even they are overwhelmed by their caregiving duties. The feeling of a sense of duty to their family members resulted in the caregivers being reluctant to utilise formal support services. Asian caregivers are influenced by collectivistic philosophies that emphasize interdependence and social harmony (Tan-Ho et al., 2020). These philosophies influence caregivers' beliefs such as honouring the family's name and discouraging the expression of emotion or weakness (Basnyat and Chang, 2021; He, 2021). Hence, it is imperative not only to understand the coping strategy of the caregivers of low vision individuals but also how the coping process is related to the quality of life of these caregivers.

3.6 Theoretical Framework

The Transactional Stress Theory has laid the groundwork for many stress and coping models for caregiving (Lazarus and Folkman, 1984), whereby the person and the environment are viewed as being in a dynamic, mutually reciprocal relationship. This theory is comprised of four concepts: stress, appraisal, response, and outcome. The underpinning premise of this theory is that when a person is confronted by a stressor, he/she undergoes a process of cognitive appraisal which in turn directs their coping response and ultimate outcome.

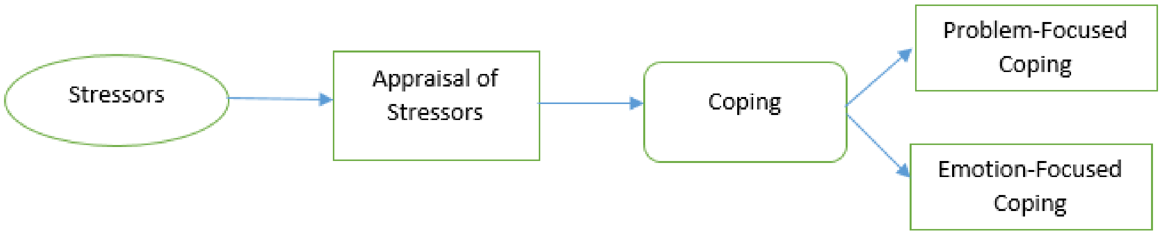

Figure 3.2 Transactional Stress Theory (Lazarus and Folkman, 1984).

According to this coping model, cognitive appraisals are considered to occur in two stages, primary and secondary. When confronted with a stressor such as the role of the caregiver or the caregiving burden for instance, the first stage involves the primary appraisal of the stressor. This process includes the initial appraisal which draws a conclusion of stress as harm or loss, threat or challenge, after which the subsequent stage of secondary appraisal takes place. Secondary appraisal refers to the individual ability to control the situation and manage negative emotional reactions towards the stressor. The second appraisal relates to the process of evaluation of available coping resources and options (Folkman et al., 1986). Cognitive reappraisal determined whether coping efforts were successful or unsuccessful. In successful situation positive emotions can be felt when coping provides relief from distress and management of stress, while failure to successfully resolve the situation produced distress.

The caregiver taking on this responsibility must adapt to a new challenge and, as affirmed by Lazarus & Folkman (1984), stress or burden can result from situations perceived by the individual as potentially overwhelming and a threat to their well-being and quality of life. According to this theory, a caregiver may suffer from physical, emotional, and psychological stress or burden because of limited coping skills, overwhelming caregiver tasks, and environmental stressors (Rodríguez-Pérez et al., 2017).

Lazarus and Folkman (1984) identified two types of coping strategies: problem-focused coping and emotion focused coping (see Figure 3.2). Problem-focused coping is directed at managing the stressful situation by selecting the most viable coping strategy, exploring alternatives and solving the problem by seeking information. Emotion-focused coping is directed towards altering one's emotional response to the problem and includes strategies such as avoidance, acceptance and wishing thinking. "Avoidance" involves not registering the proper problems they usually encountered and even diverting thoughts from the future consequences (Wray and Braine, 2016). "Acceptance" embraces the acceptance of the responsibility focusing on the personal sacrifice needed for caregiving and having no choice (Greenberg, 2006). "Wishful thinking" encompasses the idea that the problems or issues will go away or a miracle will happen (Brannen and Petite, 2008).

The systematic review by Hawken et al., (2018) highlighted that problem-focused coping, as a method for adjusting to the role and responsibilities of caregiving, was associated with a more positive adjustment and better quality of life, while emotion- focused coping was associated negatively with caregiver adjustment and linked to an impaired quality of life. Persistent reliance on an emotion-focused strategy over long periods of time is not considered to be beneficial for caregivers. Emotion-focused strategy behaviours also encourage individuals to disconnect from the problem, and this in turn prevents further attempts to cope and contributes minimally to directly addressing the stressor. The problem coping strategies such as "positive appraisal", and "seeking social support" were positively related to caregiver adjustment. “Positive reappraisal” encompasses strategies such as positive reframing, humour, reliance to current religious beliefs or turning to religion, positive reinterpretation and growth, positive action, positive thinking (Wray and Braine, 2016). “Seeking social support” strategies comprise support from friends and family and the search for information and communication, and emotional and instrumental support (Braine and Wray, 2018).

There was a dearth of studies that found that problem-focused coping was associated with better psychological health (J.-S. Jeong et al., 2018; Teixeira et al., 2018). However, Jeong and colleagues (2018) noted that not only was problem-focused coping associated with better physical health, but that emotion-focused coping was also associated with better physical health. Caregivers using a positive appraisal strategy tend to adopt both problem - and emotion- coping strategies to avoid caregiving conflicts and they plan caregiving. Research has found that the stress appraisal strategy influenced the quality of life of oncology caregivers (La and Yun, 2017). Thus caregiving appraisal plays an essential role in promoting the outcomes of caregiving. Hence, the literature on the relationship between emotion-focused coping and problem-focused coping and the caregiver’s quality of life are inconsistent. Hence more studies on coping in relation to quality of life of the caregiver of low vision individuals are needed.

3.7 Conceptual Framework Of The Study

Guided by the Lazarus’s coping model (1984), the present study has included demographic factors, caregiver burden, coping strategies, health-related outcomes and quality of life when developing the conceptual framework of the study. As shown in Figure 3.3, quality of life is adopted as the dependent or outcome variable. Caregiver burden, Coping Strategies, Health Outcomes and Health Utilization are independent variables. Additionally, age and education are selected as covariates for caregiver burden and coping strategies.

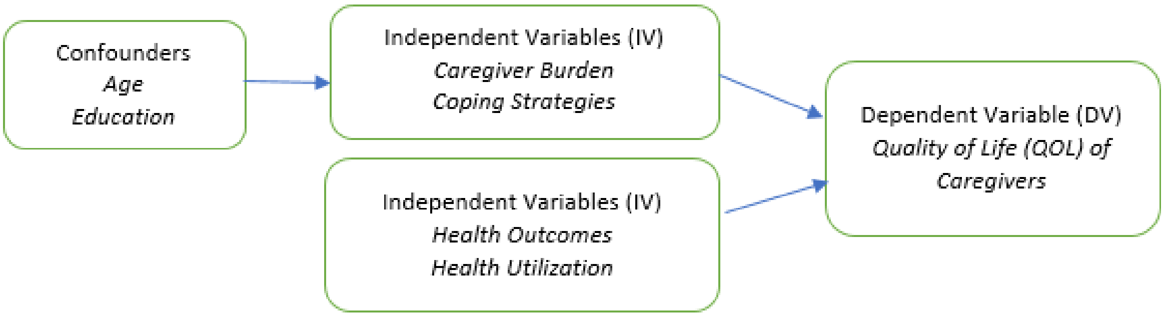

Figure 3.3 Conceptual framework of the study

Drawing from the current review, a conceptual framework that combined the independent variables, dependent variables and demographic factors was proposed. The integrated framework depicted each construct of main variables and the hypothetical relationships among variables. Hence the current study proposed that caregiver burden has negative effects on caregivers' quality of life in that the coping strategies employed by them are influencing an adverse quality of life for the caregivers. Caregivers demographics such as age and level of education are the confounding factors in caregiver burden and coping strategies. The caregivers with an adverse quality of life are not proactively seeking healthful behaviours, which negatively influence their health outcomes. Based on the conceptual frameworks and references from previous literature and theories, a total of seven research questions were proposed in this chapter.

3.8 Research Questions

Guided by the socio-ecological and coping theories, and findings from the narrative review, seven research questions are postulated as follows:

1. What are the characteristics, caregiver burden level and coping strategies of caregivers for low vision individuals?
2. What are the levels of quality of life, health outcomes and health utilisations of caregivers' caring for individuals with low vision?
3. What is the relationship between demographic profile such as age and education levels, with caregiver burden and coping strategies?
4. How is caregiver burden related to their coping strategies?
5. What are the relationships between quality of life, caregiver burden, health

outcomes, health utilisation and coping strategies?

6. What are the unique predictors for total quality of life of caregivers for individuals with low vision, after taking into account caregiver burden, health outcome, health utilisation and coping strategies?
7. What are the coping experiences and needs in relation to social aspects among the caregivers of low vision individuals?

3.9 Chapter Summary

In summary, the current review indicated that caring for a person with low vision can have a wide-ranging, even considerable impact on the caregiver's quality of life. However, to date, most research in this area has consisted of limited quantitative and qualitative investigations of the negative consequences of caregiving on caregivers' physical and mental health. In carrying out their caregiving responsibility the caregivers acquired adverse health conditions specifically mental health condition. Impaired mental health has a greater impact affecting the quality of life as compared to impaired physical health.

Caregiver supporting low vision individuals in everyday activities found theses were time-consuming affecting caregivers work attendance, social interactions and even forcing some of them to leave the workforce. Caregivers also faced a high level of burden of care from financial exhaustion from the medical treatment and a reduced source of income. Therefore, caregivers adopted problem and emotion coping strategies to cope with these adverse situations. The caregiver's coping strategies were influenced by their Asian culture and beliefs. These coping strategies have led to both positive and negative caregiving experiences which may influenced the quality of life in the caregivers. There is however, limited literature on health utilisation among the caregivers. If Singapore is to continue relying on the caregivers (Thang and Suen, 2018), to care for low vision individuals, then it is essential to encapsulate the health outcomes and health-seeking behaviours influencing the caregivers' quality of life.

There has been minimal research examining the caregiving experience of adults of low vision individuals. Thus, this study aims to examine the relationships between a series of variables identified and their contributions to caregivers' quality of life. In addition, the Lazarus coping theory (Lazarus and Folkman, 1984) is utilised to capture the complexities of having caregivers looking after low vision individuals. However, the findings of the studies reviewed were challenging to synthesise due to great diversity in how quality of life, caregiving burden, health outcomes, health utilisation and coping strategy were measured.

There was an abundance of information regarding caregiver burden, including the coping strategy of the caregivers. The current review highlighted caregivers' quality of life, caregiver burden, health outcomes, health utilisation and coping strategy influencing their quality of life. These caregiver issues continue to highlight the significance of this present study. The subsequent chapter will discuss the methodology of the study.

Chapter Four Methodology

This chapter describes the design of the study, target population, sampling procedures, instrumentation, data collection procedures, and data analysis methods. It outlines the rationale for selecting a mixed-methods approach and focuses on how the methods used meet the aims of the research. The philosophical foundations of mixed-methods are introduced and considered in relation to the theoretical issues of the study population. The two phases of the research design are detailed. Methodological concerns relating to the quantitative data collection are critically reviewed with justification for its use in the present study. The choice of the qualitative method of semi-structured interviews, is presented in detail with reference to the quality and rigour of the analysis.

4.1 Aims and Objective of the Study

This study will address the quality of life of unpaid caregivers who are caring for a low vision family member in Singapore. Narratives and information on the experiences, perceptions, challenges they faced, the coping strategy they employed to overcome those challenges, their health outcomes and health-seeking behaviours were collected through standardised survey instruments and face-to-face, semi-structured interviews to achieve the following research objectives:

1. Describe the sample characteristics, caregiver burden and coping strategy of caregivers for the low vision individuals.
2. Describe the quality of life, health outcomes and health utilization of caregivers for low vison individuals.
3. Determine the relationships of the demographic profile such as age and education with caregiver burden and coping strategy.
4. Determine how caregiver burden is related to their coping strategy.
5. Determine the relationship between quality of life, caregiver burden, health outcomes, health utilization and strategy.
6. Identify the predictors of overall quality of life with caregiver burden, health outcomes, health utilization and coping strategy.
7. Explore and identify the coping experiences and needs in relation to social aspects

among the caregivers of low vision individuals.

Phase One of the study which utilised a quantitative approach was conducted to achieve objectives 1 to 6, while Phase Two of the study which focused on a qualitative approach was conducted to achieve objective 7.

4.2 Research Design

The research design adopted is a mixed methods approach. The choice of the mixed method is based on the adopted paradigm and research question, which can enable a researcher to explore and understand complex human universal health processes (Meixner and Hathcoat, 2019). The advantage of using mixed methods research, is that it allows for the examination of complex problems within a single study by providing evidence to triangulate or corroborate findings with multiple sources of evidence (Creamer, 2018).

Mixed methods research is an emerging and evolving research methodology that requires both qualitative and quantitative approaches within the same study. The methodology is designed to integrate the qualitative and quantitative components together to answer the research questions. Mixed methods is important for informal caregiving research because questions that benefits most from a mixed methods design tend to be broad, complex and multifaceted (Bautista et al., 2018). The informal caregiving research fits within this paradigm because informal caregiving is a complex intervention that is part of a healthcare ecosystem (Zarit, 2018). Therefore, to determine whether caregiving research "works" or not involves assessing a wide range of factors.

The three types of common mixed methods included: convergent which refers to a collection of qualitative and quantitative data in a parallel manner; Sequential exploratory which is defined as a qualitative study followed by a small quantitative phase and finally, sequential explanatory which describes a quantitative study followed by a qualitative study research approach (Creswell and Creswell, 2017). With reference to the research question of the present study, the sequential explanatory design was deemed as the most appropriate (Figure 4.3). The sequential explanatory design is a sequential approach and is used when the researcher is interested in following up the quantitative results with qualitative data. Thus, the qualitative data is used in the subsequent interpretation and clarification of the results from the quantitative data analysis. Sequential explanatory studies can be particularly useful when trying to explain relationships in quantitative data and provide more detail on the mechanisms of those relationships, particularly for surprising or unexpected results (Clark and Ivankova, 2016).

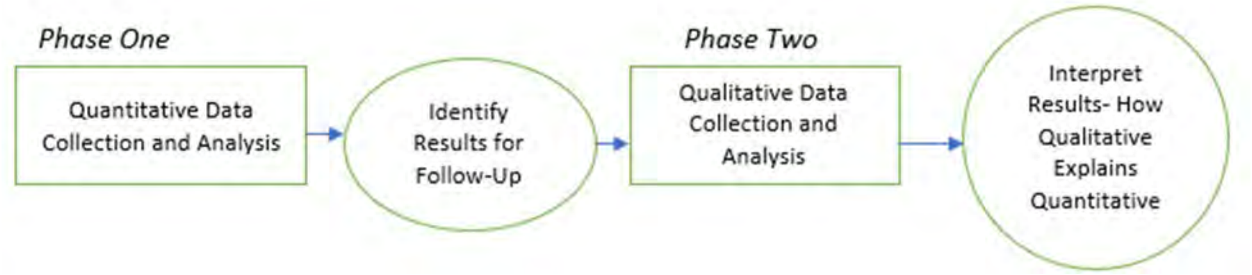

Figure 4.1 Mixed-Methods Sequential Explanatory Design. Adapted from Creswell and Creswell (2017)

Specifically, the current study used an explanatory sequential mixed methods study design for two reasons. First, this design enabled the researcher to examine caregivers self-perceived quality of life, caregiver burden, coping strategy, and what their health outcomes and health-seeking behaviours were. For example, the quantitative approach provided an understanding of these key aspects as they related to caregiving among caregivers of low vision individuals. The results of the quantitative phase were firstly analysed to identify the key variables such as caregiver burden and coping strategy influencing the caregivers' quality of life. Secondly, the qualitative approach, via interviews, explained how the caregivers' quality of life was related to coping strategies based on their personal and social perspectives and perspectives of caregiver burden. The collection of quantitative results could not provide a complete picture and therefore complementing the analysis with in-depth interview data added nuance to the regression results.

In the present study, integration of the research design occurred in two stages of the study, namely the data collection and discussion of the findings. The integration at the data collection stage is considered a crucial element of an explanatory sequential design as it serves as the bridge between the quantitative phase and the subsequent qualitative phase (Baran, 2020). In specific, it enables a researcher to link one type of data to the other type of data through the sampling framework (Watkins and Gioia, 2015). The quantitative data collected will used to inform the purposeful sampling criteria whereby this purposeful sampling criterion plays a crucial role in establishing a link between the two phases of the study. Such sampling in mixed methods is known as nested sampling, which involves using a subset of these in one phase of the study to participate in another phase of the same study (Gallo and Joo, 2018). In this approach of sampling, the researcher could choose a small number of participants to engage in interviews based upon their responses to a survey which is used to identify cases or individuals who are in a position to provide insights into the phenomenon of interest to understand it more deeply (McBride et al., 2019).

Sample selection to identify qualitative participants can be based on several criteria: on identifying qualitative participants using significant quantitative results, unexpected non-significant quantitative results, outliers, extreme cases, strong predictors in a correlational study, distinguishing demographic characteristics, or individuals from different comparison groups (Baran, 2020). The recruitment of the sample in the current study was not done in a uniform way because the researcher used mixed purposeful sampling, combining various purposeful sampling methods. Hence from the quantitative responses in the current study, the researcher identified 12 potential qualitative informants based on (1) quality of life scores, (ii) relationship with care recipients. The number of participants was based on Stake's (2013) recommendation of sampling 4 to 10 participants.

Purposeful sampling used in a qualitative strand may be applied to 1) are explore maximum variation in sample, 2) achieve a stratification sample, and 3) explore extreme case sample (Dickson and Page, 2021). The maximum variation sample provides maximum heterogeneity on specific attributes that may affect the topic, or to capture qualitative themes across a diverse, yet small sample. While a stratified sample is used to discover elements that are the same or different and finally, an extreme case sample is used to learn as much as possible about the outliers. However, the sample size does not increase the generalisability of qualitative findings from a sample to a population in some statistical sense (McBride et al., 2019). The purposive maximum variation sampling and stratified sample was chosen for the current study as there were caregivers of individuals with low vision. More specifically, the researcher wanted to understand the coping strategies influencing the impaired and good quality of life between sighted and non-sighted caregivers.

Integration of the results of the current study also occurred at the discussion of the findings. Findings from the individuals' survey instruments and interviews will be integrated narratively using a weaving approach and reported together, grouped by theme or concept (Fetters et al., 2013). This approach is to further understand how caregivers described the relationship among certain variables found in the qualitative component of the study. The qualitative interviews explored what the findings of the quantitative data mean from a qualitative perspective, adding depth and richness to the statistical findings. This is a continual methodological process of connecting, building and generating intentional integration which link to major quantitative and qualitative findings to identify points of convergence and divergence (Tashakkori et al., 2020).

These integrative findings with an overview on how the quality of life of low vision caregivers was influenced by demographic and socioecological factors in Singapore with expanded and in-depth contextual information on social and health systems in supporting the caregivers, was used to identify the imperative of new caregiver training and needed changes in social policy.

4.3 Research Philosophy Rationale

The present study adopted the pragmatism philosophy which has a considerable variety of different doctrinal positions regarding the best way to combine different approaches to answer research questions (Tashakkori et al., 2020). Pragmatism has been described as essential for bridging the theory–practice gap with a specific purpose: for engaging in inquiry-based practice, for conducting practice and theory grounded research, and for translating knowledge into clinical practice (Callingham and Hay, 2018). In this philosophy, quantitative and qualitative methods complement each other to provide a more complete understanding (Walshe, 2019). The philosophical approach for this study is to adopt a pragmatic approach guided by a mixed methods study design to enabled implies this requires that the researcher is open-minded to using appropriate and various methods that best address the research problem (Chiang-Hanisko et al., 2016; Reed, 2021).

Mixed method inquiry is a research paradigm that supports the use of a mixture of different research methods and modes of analysis. This may also include a continuous cycle of abductive reasoning while being guided primarily by the researcher's desire to produce socially useful knowledge (Reed, 2021). This paradigm supports the investigation of the social world utilising more than one methodological tradition, and more than one kind of technique for gathering, analysing, and representing human phenomena (Halcomb and Hickman, 2015).

There were a limited number of studies focusing on the quality of life of caregivers of low vision individuals within the Asian context using a mixed-methods approach. Thus, this study aims to make a contribution by utilising a mixed methods research design to examine the experience of caregivers of low vision individuals by exploring their quality of life and the factors influencing their quality of life. The next section will elaborate the explanatory sequential mixed methods design adopted for present study.

4.4 Methodology

Supporting the mixed methods approach, the methodology used to gather data for the present study is divided into two phases:

Phase 1: Cross-sectional survey
Phase 2: Semi-structured interviews

4.5 Phase One: Cross-Sectional Survey

A most prominent characteristic of cross-sectional designs is that all of the observed data are collected at a single point in time, providing a “snapshot” of the population of interest (Kesmodel, 2018). Data is often collected using survey questionnaires or structured interviews involving human respondents as the primary units of analysis (Setia, 2016). They are best used to identify patterns, correlations, and incidence rates of a subject of study within a population (Spector, 2019). In this study, the researcher used a cross-sectional survey to examine whether caregiver burden, coping strategy, health outcomes and health utilisation predict the quality of life of caregivers of low vision individuals.

4.5.1 Sampling

A mathematical formula was used to determine the needed sample size. Calculations were conducted to determine the number of subjects necessary to achieve statistical power for this study. The target population was caregivers of low vision individual but there are no available records of the number of caregivers of low vision individuals in Singapore. In addition, the low vision clinic in the Singapore National Eye Centre does not track the number of caregivers who accompanied the patients to the low vison clinic.

Hence, the study adopted the assumption that all low vision individuals have a caregiver. In 2017, the total number of low vision individuals visiting the low vision clinic was 674. The calculation was based on a population of 674 low vision patients which yielded a required sample size of 59. This produces a two-sided 95% confidence interval with a distance from the mean paired difference to the limit that is equal to 0.498, when the estimated standard deviation of the paired differences is 2.000 (Hahn and Meeker, 2011).

The initial intent was to recruit 60 caregivers; in total the researcher approached 92 caregivers with 32 declining participation. Twenty-two potential participants were not interested while ten potential participants claimed they were too busy to attend the scheduled interviews. A few requested telephone interviews but this was not feasible as the participants needed to sign the informed consent form, and needed guidance to complete the questionnaires. In total 60 caregivers participated in Phase One of the study.

In Phase Two, a nested sample of caregivers was selected for interview, using the maximum variation sampling criteria, taking into account the different scores in their quality of life and relationship to the care recipients. This is to have the broadest possible variety of experiences represented. Among the 60 caregivers, few caregivers had low vision themselves. Thus, four respondents who were caregivers with low vision were invited to join Phase Two of the study. The details of the interview participants will be presented in Section 5.8.1.

4.5.2 Inclusion Criteria

A caregiver was defined as an individual nominated by the patient who played a significant role in providing support to the low vision individual. According to the, National Alliance for Caregiving (2020) caregivers are defined as individuals who provide unpaid care to relatives in order to help them care for themselves. The caregiving role may include helping the care-recipient with personal needs (i.e., physical care, chores, finances), medical/nursing tasks, engaging with outside services, and visiting them, and does not necessitate that the caregiver live with the recipient. Based on this definition, individuals were included in the study if they provided any of the caregiving activities listed above for a care recipient diagnosed with low vision.

In addition, some additional inclusion criteria for the present study include: were unpaid primary caregivers of a low vision individual; they provided care for a period of a minimum 6 months; they provided a minimum of 3 hours of care per day; and were older than 21 years old. The estimation of time dedicated to caregiving for low vision person based evidence from the narrative review, was an average of 3 hours (see section 3.5.1). In terms of age, those older than 21 years old can participate in the research as the legal age of consent in Singapore to participate in research is 21 years of age (Thirumoorthy and Loke, 2013).

4.5.3 Data Collection Procedures

The present study obtained received ethical approval from the SingHealth Centralized Institutional Review Board (Appendix B). Following ethical approval, guided by the inclusion criteria, the researcher approached the optometrists and medical social workers running the low vision clinic to recruit potential participants. The researcher explained the research purpose and data collection process during the recruitment of potential participants. Potential participants who were keen to participate would to leave their contact numbers at the clinic and, the optometrists and medical social workers would pass the contact numbers to the researcher.

The researcher adopted several approaches and multiple networks in order to boost the participation rate due to the small population size of low vision individuals. In specific, the participants were recruited using snowball sampling through formal and informal networks. Through informal networks, the social work team called some potential participants, who were low vision patients based on their current social support records, and sought their approval to obtain the contact details of the caregivers.

The formal network was through the low vision clinic whereby potential participants were approached proactively by both medical social workers and the optometrist teams in charge of the low vision clinic. Using this formal network, flyers (Appendix C) detailing the study inclusion criterion, study purpose, participation incentives, and information regarding how participants could contact the researcher were displayed and distributed in the low vision clinic and medical social worker department. The flyers were also given to low vision patients by their medical social worker and optometrist, to boost recruitment, as understandably, low vision patients might not notice the advertisement.

Following the recruitment procedure, the researcher contacted potential participants to arrange for the survey administration. As a safeguarding measure for researcher who work alone for data collection, the researcher was required to provide details of the meeting to another colleague. In specific, if the caregiver requested the survey to be conducted at home, the researcher informed a colleague who was not involved in the study of the date and time of the meeting. After the meeting, a colleague was informed by the researcher of the completion of the survey administration. The colleague was to report to the police if the researcher did not contact her within three hours. These steps are in-line with the lone worker policy of the Singapore National Eye Centre.

During the survey interview, the researcher explained the research purpose, and distributed a patient information sheet (PIS) with detailed information on the research process potential participants. The PIS included a description of the study, approximate time required to complete the survey, information on the incentive offered to the participants, and instructions related to informed consent (See Appendix B and C). Potential participants were informed that they could withdraw from the study at any time with no prejudice. Written informed consent was obtained before conducting the survey.

All survey data was collected by the face-to-face interview method, and the researcher was physically present to ask the survey questions and assist the participants in answering them. During the face-to-face interview, the researcher took the initiative to asked if the participant was keen to join the Phase two interview. The survey data collection process for each respondent took approximately 60 to 90 minutes. On completion of the survey data collection, the researcher thanked the respondents for their participation and gave them $50 as a token of appreciation for their time. Respondents for Phase One were recruited over a period of 6 months from February 2018 to July 2018.

4.6 Data Collection Instruments

Five standardized questionnaires were used to measure quality of life, caregiver burden, coping strategy, health outcome and health utilisation of the caregivers of low vision person. Except for the Health Utilisation scale, the rest of the instruments are validated and have been used previously in the Singaporean context. Therefore, they are considered to be culturally valid. In specific, the selected instruments for use in this research project were the SF -12 Health Survey (Ware Jr et al., 1996), the Zarit Burden Inventory (Zarit and Zarit, 1987), the Way of Coping Questionnaire (Vitaliano et al., 1985), the Cumulative Illness Rating Scale (CIRS) (Miller et al., 1992) and, the self-developed Health Utilisation Checklist . Additional demographic questions was used to obtain relevant information from caregivers.

The content validity of the five questionnaires was confirmed by the medical social worker from the Singapore National Eye and a nurse researcher from the Singapore Eye Research Institute. The aim of content validity is to ensure the instrument chosen measures what it is intended to measure (Cronin et al., 2015). To ensure the instruments selected are reliable and consistent in their measurement, the researcher has reported identified the Cronbach's alpha on three key instruments, i.e. quality of life, caregiver burden, and health outcomes based on the current literature. The literature based on the Asian context reported the Cronbach's alpha as ranging from 0.70 to 0.82, except for the Health Utilisation questionnaire which was developed by the researcher hence there was no reliability test identified from the literature.

For the present study, Cronbach's alpha was also conducted to measure the internal consistency of the selected instruments for quality of life, coping process, caregiver burden, health outcomes and health utilisation. The score for Reliability tested using Cronbach's alpha value ranged from 0.43 to 0.87. Based on the methodological literature, it was asserted that an arbitrary value of 0.70 is a sufficient measure of reliability or internal consistency (Taber, 2018). Thus, except for the Health Utilization Checklist, the instruments selected for the current study were considered highly reliable.

4.6.1 SF-Health Survey (SF12)

The overall quality of life of the caregivers was captured with the SF-12 Health Survey. The SF-12 is a 12-item questionnaire that can be used to measure physical and mental health. Responses to questions are dichotomous (yes/no), ordinal (excellent to poor), or expressed by a frequency (always to never). The instrument produces two summary scores – the Physical Component Summary (PCS) and the Mental Health Component Summary (MCS).

Scores for each component are converted to a range of 0–100, with higher scores indicating better functioning and well-being (Ware et al., 2001). These scores are calculated by the standard algorithm described in the SF-12 manual (Ware Jr et al., 1996). The mean score for both PCS and MCS, is 50. When an individual respondent’s scale score is below 50, the health status is below the average range for the general population for each of the components (Ware Jr et al., 1996).

PCS measures the presence of physical disability, while MCS identifies psychological distress and measures emotional well-being. For example, the PSC measures physical functioning (i.e. ability to do physical activities, including bathing or dressing), physical effects on role (i.e. ability to work or carry out other daily activities as a result of physical health), bodily pain and general health. A high PSC score would mean a score of 50 and above where, the participant would experience no physical limitations, disabilities, or decrements in their well-being accompanied by high energy levels. A low PSC score of 50 and below would mean the participant would have limitations in self-care, physical, social, and role activities, they would experience severe bodily pain, and frequent tiredness.

Meanwhile, MSC measures vitality (energy), social function (i.e. ability or inability to carry out normal social activities due to physical and emotional problems), emotional effects on role (i.e. ability or inability to carry out work or other activities due to emotional problems) and mental health (i.e. any feelings of nervousness and depression (Ware et al., 1998). A high MSC score of 50 and above would mean an absence of psychological distress and limitations in their usual social/role activities due to emotional problems, and their health would be rated "excellent". A low MSC score of 50 and below would mean the participant would suffer from frequent psychological distress, social and role disability due to emotional problems. In this study, the SF 12 showed high internal consistency reliability scores for the PCS (Cronbach's alpha = 0.67) and MCS (Cronbach's alpha = 0.85) domains.

Reliability for the SF12 survey is also established by a local study examining positive mental health and its mediating effect on the relationships between mental health disorders and health outcomes (Vaingankar et al., 2020a). The reported reliability for PCS (Cronbach's alpha = 0.81) and MCS (Cronbach's alpha = 0.82) domain scores in this local study is comparable to the present study.

Permission to use the SF 12 survey was obtained from QualityMetric and the document is included in Appendix D.

4.6.2 Zarit Burden Interview (ZBI)

ZBI is a 22-item assessment tool specially designed to measure the caregiving burden experienced by caregivers of older people and disabled patients. The questions focus on several major areas such as the caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and the care recipient. Items are answered on a five-point scale ranging from 0 = never to 4 = always. Scores are added to give total score ranges from zero to 88, with higher scores implying greater caregiving burden (Whitlatch et al., 1991).

The ZBI generate scores for two dimensions: Personal Strain and Role Strain (Lai, 2007; Win et al., 2017). Personal Strain is defined as the level of stress as a result of the caregiving experience, and Role Strain is defined as the level of stress due to role conflict and overloading. Higher scores are indicative of a higher burden among caregivers for the low vision patient. Cronbach's alpha of the ZBI was 0.76 in this study. In a recent local study by Lau et al.,(2021) the internal consistency for ZBI is a Cronbach value of 0.93. This study revealed that caregiver burden was significantly associated with hospital admissions, length of hospital stays and number of outpatient visits.

Permission to use the Zarit Burden Scale was received from the Mapi Research Trust, and included in Appendix E.

4.6.3 Ways of Coping (WOC)

WOC is an instrument that informs whether the caregivers are coping well in caring with people of low vision. This 66-item instrument is used to analyse how a caregiver deals with the internal and external demands resulting from a specific stressful encounter through a range of thoughts and actions. The scale was used in the form of an interview and caregivers were asked to declare generally how they cope with stressful events related to caring for the low vision individual. The time frame for recalling the stressful event was during the past one week.

In specific, respondents were asked to answer the questionnaire with regard to a specific stressful situation and rate the frequency of each strategy on a 4-point Likert scale. The Likert scale ranges from 0 (not used) to 4 (used a great deal). The WOCQ consists of eight subscales or coping strategies: Confrontive Coping, Distancing, Self-Controlling, Seeking Social Support, Accepting Responsibility, Escape-Avoidance, Planful Problem Solving and Positive Reappraisal. Raw scores describe the coping effort for each of the coping strategies, with a higher raw score indicating a higher dependency on the behaviours when coping with a stressful event. Items on the questionnaire have been designed to be answered in relation to a specific stressful encounter that requires respondents to recall a stressful event from the previous week.

Conceptually, these eight subscales represent two underlying dimensions: problem-focused coping and emotion-focused coping (Folkman et al., 1986). Problem-focused coping refers to efforts to change stressful situations, whereas emotion-focused coping is a means of handling situations via cognitive and emotional efforts without altering the situation itself. Problem-focused coping includes strategies such as seeking social support, planful problem solving and confrontive coping. Strategies that include distancing, self-controlling, accepting responsibility and escape / avoidance, and positive reappraisal were categorised as emotion-focused coping. A higher score indicate that caregivers are more likely to frequently adopt a particular coping strategy when dealing with stress.

A study by Sawang et al.,(2010) has explored the WOC psychometric properties within the Asian context including Singapore, Indonesia, Sri Lanka and Thailand. The results of a multiple group analysis indicated that the measurement model was equivalent across samples and reported results. Good psychometric properties are considered to receive a Cronbach's alpha of 0.87. In this current study, both problem-focused coping and emotion-focused coping had good internal reliability of 0.83 and 0.93 respectively.

Permission to use this scale was received from Mind Garden and is included in Appendix F.

4.6.4 Cumulative Illness Rating Scale (CIRS)

The health outcome of the caregivers was measured by the CIRS and was included to gain an understanding of whether the caregiver themselves were experiencing a chronic illness whilst having to care for family with low vision. The items on the scale reflect the common health problems of the caregivers with an emphasis on morbidity and the overall severity of illness is based on the cumulative scores of all the items. The CIRS provides a comprehensive review of 14 conditions related to human organ systems including the heart, respiratory system, gastrointestinal tract, liver and renal organs. Each human organ system is rated using a severity score (from 0-4) to determine whether any system is impaired or disabling. In specific, each condition identified was rated on a scale from zero to four, where zero indicates that there is no problem affecting that system; one indicates a mild current problem or a past significant problem; two indicates a moderate problem requiring first-line therapy; three indicates a severe problem that may be associated with significant disability or is hard to control; and four indicates an extremely severe problem, organ failure, or severe functional impairment. Medical diseases are categorized according to major bodily systems, where the higher the score indicates a poorer prognosis (Fortin et al., 2011). The CIRS has been reported to be a valid indicator of health status in geriatric patients. Holcomb and colleagues (2012) asserted that the instrument does not required documented diagnoses as it assessed the clinical illness burden of 14 medical diseases in a multimodal way.

The final score of the CIRS is the sum of each of the 14 organ system scores, generating a summative score that ranges from 0 to 56. Currently, there are no CIRS-based cut-offs for illness severity and comorbidity indices. However, a very high score is impossible because it would represent several system failures (Hudon et al., 2007). A low score defined the caregiver as generally healthy. The current CIRS instrument has a Cronbach's alpha of 0.70 when used with this study's respondents as shown in Appendix G. In comparison to a past study, the CIRS has a Cronbach's alpha of 0.82 as reported in a study by Soon et al., (2013). The authors explored the psychological impact of contact isolation on patients in Singapore who were infected or colonised by multidrug-resistant organisms.

4.6.5 Health Care Utilisation (HUQ)

The HUQ was developed by the researcher to elicit the health care services utilisation used by caregivers. The questionnaire was developed after reviewing the current literature to identify important themes regarding health care utilisation (van den Brink et al., 2005).Utilisation of health care resources consists of sixteen questions: including physician visits, emergency room visits, outpatient visits, radiotherapist visits, visits to surgeons, use of Traditional Chinese Medicine, district nursing; and medications, special food, care products, and assistive devices. Each question elicits a response of either Yes / No, with a score of 1 = Yes =1 and 0 = No=0. The caregivers were asked which kind of health care services they had utilized in the preceding three months. The more health services being used by the caregiver may indicate they were proactive in health seeking behaviours. But a zero score does not imply that the caregiver is healthy, it could also imply that the caregiver is neglecting his/her health because of their caregiving responsibility. The Cronbach's alpha coefficient was 0.43 for the HUQ in this study as noted in appendix H. The low value of alpha in this study could be due to the low number of questions and the dichotomous response rate (Emerson, 2019; Tavakol and Dennick, 2011).

4.6.6 Demographic Questionnaire

The demographic section was developed to elicit the demographic information of the caregivers. It consists of fourteen questions asking the caregivers to identify their age, gender, ethnicity, marital status and educational attainment. The caregivers were asked to indicate their relationship to the low vision individuals, the number of years they had been a caregiver for the low vision individual and their socioeconomic status (see the demographic questionnaire at Appendix I).

4.7 Quantitative Data Analysis

The data from the survey questionnaire were input into the study databases on the laptop by the researcher. The completed questionnaires were assigned an identification number and respondents' demographic particulars were filed separately to protect respondent identity and ensure anonymity. For security purposes, the researcher entered the data into a password-protected work laptop which is locked and kept in the Nursing Administrative office. Only the researcher had the keys to the locker cupboard located in the Nursing Administrative office.

The data input were analysed using the Statistical Package IBM SPSS version 26.0. Specific data analysis procedures including descriptive analysis and inferential analyses were computed. In particular, descriptive statistics and inferential statistics that were produced by bivariate analysis (i.e. correlational test) and multivariate analysis (i.e. hierarchal regression) were computed according to the number of variables in the conceptual framework and the relationships that were being proposed.

The descriptive statistical analyses were conducted to generate means, standard deviations and percentage scores on key variables, including demographic information. Continuous data such as years of caregiving were presented as means ± standard deviations. Percentages were calculated for dichotomous variables such as gender and employment status. In general, these descriptive statistics were used to examine the trend and general pattern of caregiver's quality of life, caregiving burden, coping process, health outcomes and health seeking behaviours. Bivariate analyses were used to measure the strength and direction of relationships between two variables (Bowers, 2019). In this study, the bivariate analyses were computed among all variables, namely caregiver burden coping process, health outcomes, health utilisation, and quality of life, to demonstrate the significant relationships between them.

The researcher was interested in trying to explain how much different variables explain caregivers' quality of life, thus the hierarchical regression was employed as it considered the most appropriate statistics. The hierarchical regression allows the researcher to decide which order to use for a list of predictors to be put into blocks of variables. Hence, it provides a way of forcing the variables to be considered in the sequence chosen by the researcher (Mat Roni and Djajadikerta, 2021). The independent variables were entered in a particular sequence chosen on theoretical framework of the current study. The independent variable which needs to be statistically controlled was entered in the first block. Applying this method, one can assess the quality of the model or the impact of a group of variables after controlling the effect of the initial stage variables. The statistical model takes into the account the incremental variance explained by adding one or more predictors (Kulas et al., 2021). Entering the caregiver burden, health outcomes, health service utilisation, and coping strategies in a sequence enables the researcher to see how much each block of variables adds to the prediction of the caregivers' quality of life.

Pre-test data analyses of assumptions were conducted to ensure that any statistical threats to validity were properly addressed (Jeong and Jung, 2016). The explanatory variables were checked for multicollinearity using tolerance and the variance inflation factor (VIF). VIF values greater than 10 and tolerance values smaller than 0.10 may indicate multicollinearity among variants (Pallant, 2020). In the present study, the VIF ranged from 1.0 to 1.84, and Tolerance ranged from 1 to 0.54. All the VIF values were <2, indicating that there was no problem of multicollinearity. These assumptions must be met in order to use the hierarchical regression model (Bowers, 2019).

The outcome or dependent variable in the regression model was the score of quality of life. The predictor variables were the coping strategy, caregiver burden, health outcomes and health utilisation. The analysis proceeds in stages by sequentially entering blocks of independent variables in the regression model. Blocks of variables entered in later stages were thus tested for their extra contribution after the contributions of earlier-entered variables have been removed. The relative importance of the variables in the final multiple regression models contributed to the variance explained for the scores of the quality of life. Demographics variables were not entered in the model. Model 1 included caregiver burden, model 2 included health outcome and health utilisation and the final model included problem-focusing coping and emotion-focused coping. The R-square for the final model was also presented and interpreted.

4.8. Phase Two: Semi- structured Interviews

Semi-structured interviews were undertaken for data collection in the second phase as it is considered to be a means to facilitate the participants to tell their experiences, feelings and knowledge (Silverman, 2020). The interview questions were developed following quantitative analysis of the questionnaire data whereby finding from the quantitative analysis were used as the basis for formulating interview questions (King et al., 2018). In the present study the interview questions were informed by previous research and preliminary findings from Phase 1. The relatively high caregiver burden encouraged the researcher to explore how it has influenced the caregiver quality of life, caregiving experiences and coping strategies

Following the survey administration, semi-structured interviews with 12 participants were carried out to further investigate the caregiving experience in relation to the coping process and quality of life. These aim to provide a deeper insight into the caregiving phenomenon and to further explore the aspects of the coping process and quality of life that were not picked up by the questionnaires and to complement the findings from the quantitative analysis. Furthermore, the coping process in the caregiving experience can only be captured by qualitative approaches and it is perceived that theory-based psychometric scales can only assess part of it (Schwarzer and Knoll, 2003). For example, experimental measurement approaches, often remain at an individual and descriptive level, not allowing generalised conclusions for groups of individuals (Frydenberg, 2017). However, these questionnaires were not able to investigate why this was the case and what the caregiver's experiences were in relation to the coping processes. Yu et al., (2018) further reinforced the notion proposed by Schwarzer and Knoll (2003), which argued that the positive aspects of caregiving are difficult to conceptualize in a single paradigm and should be best understood from a multi-paradigm perspective. Thus, to comprehend the coping processes affecting the quality of life of the caregivers of low vision individuals, a mixed methods approach using both quantitative and qualitative methods would be most appropriate. The following section discusses the sampling, data collection and data analysis of Phase Two.

4.8.1 Sampling

From the group of 60 participants in Phase one, a subsample of twelve participants, eight women and four men, with differing scores on theirquality of life and different relationships to the care recipient participated in the qualitative phase. Of these participants, ten volunteered to be interviewed and eight were chosen. The researcher contacted four caregivers who had low vision themselves to participate in Phase Two. There were a total of twelve participants in Phase Two. In specific, maximum variation sampling was used whereby the twelve respondents were chosen based on different relationships to the caregiver (i.e. mothers as caregivers, adult children as caregivers), and different scores on quality of life (i.e high and low level scores). This variation in sample characteristics is known to be important to the study to capture a breadth of diverse perspectives and experiences (Dickson and Page, 2021). More importantly, the responses of these respondents would not influence the selection possibility, or the direction of the interview narratives. Hence, the aim of this qualitative approach was to allow participants to elaborate and add their diverse perceptions and views related to coping strategies and quality of life. The researcher also wanted to explore this dynamic to draw upon and expound on the experience between sighted caregivers and non-sighted caregivers.

4.8.2 Ethical Considerations

Since the research involved interviewing caregivers in vulnerable circumstances, several ethical concerns had to be given special consideration. In the present study, participants were asked to divulge details on numerous topics that were controversial and highly personal such as adverse life events, unconventional methods of coping with financial strain and negative perception of the services. For the discussion of more sensitive topics, the researcher was able to use her clinical nursing training to handle this sensitively and professionally.

Prior to starting the research, the researcher had gained experience working with individuals with visual impairment and their caregivers for more than 20 years. The researcher was a Registered Nurse in ambulatory care delivering surgical care to visually impaired patients and providing surgical education to their caregivers. Throughout this clinical experience, the researcher was comfortable in conducting in-depth interviews with caregivers using a neutral, non-judgmental and friendly approach.

Most of the interviews were conducted in the homes of the participants which allowed the researcher to record first-hand observational notes about their living conditions and household context. Participants seemed most relaxed in the interviews conducted at their homes. ; it was common for care recipients to be present briefly during the interviews. To prevent the care recipients from listening to the interviews, the researcher would suggest conducting the interview nearby, such as in open common areas in public residential neighbourhoods, or she requested the care recipients to stay in their bedroom for 1 to 2 hours while the interview could be conducted in the living room. This would enable the participants to have privacy. Some of working participants chose to be interviewed at their workplaces during their lunch breaks.

All participants were given details of the study, and their questions about the study were answered. Only in Phase 2 of the study, the researcher would then seek permission to make an audio recording of the interview. Written consent was taken from all participants. The researcher ensured that each participant was repeatedly informed that they were under no obligation to participate and could leave the interview at any point. They were given confirmation of confidentiality throughout the research process. In the written dissemination of the research their anonymity will be maintained. All participants were given pseudonyms to protect their identities while allowing for their data presentation. Transcripts are stored securely without identifying information about the participants.

While no interview ended prematurely for this reason, there were a few occasions where the interview had to be paused temporarily because respondents had become overwhelmed with emotion when conversations revolved around coping with their care recipients. These caregivers seemingly felt better afterwards, which was demonstrated by their being appreciative at the very end. However, the researcher found that most participants who participated in this research had a positive experience and found it helpful that their voices were heard. Care was taken to comfort these participants who still chose to continue their sessions, and the researcher could refer these participants to her institutional social worker for further assistance. This highlighted the importance of ensuring all researchers working with vulnerable persons have received the appropriate research support and training to manage these issues.

In order to protect the privacy of each subject, the content of each individual interview was withheld from the other participants. The researcher transcribed the interview data verbatim, and all interview transcriptions were prepared only by the researcher. All recordings were kept in a locked filing cabinet in the researcher's office. The researcher retained the data only for the length of time it takes to transcribe, code, and analyse them, after that the recordings were erased.

4.8.3 Data Collection

Upon identification of potential participants for Phase Two, the researcher subsequently contacted them to explain the purpose of data collection and inform them that the interviews were to be audio-recorded and offered to send the interview questions prior to the interviews. When respondents agreed to being interviewed, the researcher contacted them to arrange an interview at the venue of their choice. All interviews were conducted in the respondents' residence. Written informed consent was obtained before conducting the interviews. Each interview lasted between 25 to 60 minutes. Phase Two was conducted over a period of three months from December to March 2019 after the completion of Phase One. The literature recommend twelve interviews as a sufficient sample size to achieve maximum variation sampling in qualitative research (Braun and Clarke, 2021).

Throughout the interviews, the researcher was mindful not to make assumptions or selection of certain shared storylines or narrative accounts. The researcher was able to establish a trusting relationship with respondents because of her experience in working with low vision people. The researcher's professional background as a nurse equipped her with relevant knowledge and experiences of providing support for people with low vision in the clinical settings. Thus, respondents were more willing to share their experience, thereby allowing the researcher to gain insight into the experiences of being the caregivers of low vision individuals.

Even though the interviews were audio-recorded, the researcher used hand written interview notes. The researcher periodically verified the contents with respondents to ensure their views were accurately captured. Member checks are a means of controlling or correcting the subjective bias from the researcher and/or a useful means of checking the truth of any knowledge (Busetto et al., 2020). At the end of the interview, the researcher would read the written interview notes back to respondents. By asking the respondents to check for accuracy and resonance with their experience is one of the validation techniques in qualitative research known as member checking. If the respondent confirms the accuracy of the data and/or results, the findings can be deemed credible and the research is valid (Candela, 2019). Interview respondents did not review their transcripts.

Prompts were used by researcher when deemed appropriate to facilitate disclosure, and the questions developed were designed as open-ended to encourage rapport building between research and participant and to allow participants to express their own perspectives in their own words (King et al., 2018). To engage the participants further, the researcher also used techniques such as funnelling, storytelling and probing (Roulston and Choi, 2018).

In the present study, the final interview questions were derived from the previous interview questions used by Tan et al.,(2012) and additional questions from collecting the quality-of-life information from the current study. The questions in the interview guide by Tan and colleagues exploring the coping and well-being of caregivers of people with Parkinson Disease in Singapore, were well-formulated questions and culturally acceptable to the current study respondents. The final interview guide was structured around being the caregiver and specific issues relating to coping, quality of life and then the social aspect of caregiving. Further information about the interview guide by Tan et al., (2012) can be found in Appendix L.

Hence the current study used the interview guide (Appendix H) and based on the initial quantitative analysis, the following questions were additional to be asked during the interview schedule to deepen the exploration of the caregiving phenomenon:

- Please, tell me how does caregiving affect you?
- How does caregiving affect your social life?
- How to cope with challenges of caregiving?

- What are social needs to support caregiving?

4.8.4 Data Analysis

The researcher transcribed the interviews verbatim from the digital recordings to Microsoft Word documents. After completing the initial transcription of the 12 interviews, the researcher compared each transcript to the recording to ensure accuracy of the data transcription. Transcripts were analysed using reflective thematic analysis to generate a set of meaningful themes and subthemes associated with the research questions. Thematic analysis is an appropriate method of analysis for seeking to understand experiences, thoughts, or behaviours across a data set (Ozuem et al., 2022).

Deductive coding of the theme identification was adopted to explore caregivers' journey affecting their health, social life, the challenges which they reported in relation to their role, the coping strategies which they adopted and social needs they deemed beneficial. The deductive approach is useful for homing in on a particular aspect of the data or a specific finding that can be best understood in the context of a pre-existing theory or framework (Gareth Terry et al., 2017). The researcher followed Braun and Clarke's guidance on conducting thematic analysis, which comprised the following six steps: immersing oneself in the data, generating initial codes, searching for themes, reviewing themes, review themes and producing the report (Braun and Clarke, 2021).

1. Immersing oneself in the data. During this phase, the researcher became very familiar with the data by reading the interview transcripts and the data of caregiver characteristics (i.e spouse versus adult-child or parents, low vision versus non-low vision) and the field notes repeatedly. When the analysis initially began, two interviews were randomly selected and inductive coding took place. This was to understand the content of the interviews but also to identify nuanced differences in caregiver's perspectives.

2. Generating initial codes. Each interview was coded line-by-line and initial codes were developed from identifying salient words, phrases, and paragraphs. The researcher independently generated codes with the goal of organising the data by grouping the data by caregiver relationship and then by sighted and non-sighted caregivers. Deductive coding

Was used where codes which were similar were then grouped together with their corresponding data in line with the research questions. Jones (2020) referred to deductive coding done with specific research questions in mind as concept-driven coding. It became obvious in reading the interviews that coping patterns and unmet needs for tangible support affecting the quality of life were identified and coding was done with an eye to examining those factors. The researcher therefore went through the interview transcripts repeatedly to identify negative and positive factors affecting the caregiver's quality of life, coping strategies the caregivers adopted and social gaps in the system. The researcher identified the differences in sighted and non-sighted caregivers' coping strategies and unmet needs to support the caregivers of low vision.

3. Searching for themes. After generating an initial set of codes as a code book, the researcher compared her findings. For each code, she had identified quotes that represented positive and negatives experiences, challenges of caregiving and social needs of caregiving from the interviews to support her points. The researcher further reviewed the content within each coding structure for each theme/sub-theme to explore differences and similarities in the narratives given by different types of caregivers under each theme/subtheme. The themes were largely deduced from dimensions of caregiving influencing the caregivers' quality of life, various positive coping strategies, unmet needs for tangible support, financial support, peer support and social identity.

4. At each analysis stage, the researcher explored differences across different caregiver groups identities by constant comparison within and across different groups of caregivers (e.g., spouse versus adult-child or parents, low vision versus non-low vision). The most central of the emerging themes identified is the influence of Asian culture in the coping strategies affecting their physical and mental health. Themes that represented the studied phenomenon were constructed and there were only few overlapping themes. Using the coding systems, the researcher yielded the following themes: impaired quality of life, positive quality of life, proactively seeking solution, reframing perceptions and adapting and managing negative emotions, and lack of health care and social support.

5. Reviewing themes. At this point, Terry (2016) recommended reviewing and refining themes to see if some might be eliminated as not sufficiently supported by the data. The researcher had to decide whether there is coherence within themes and sufficient distinctions among them. Up to this point, the researcher had to read the entire data set with the seven themes in mind in order to examine whether the themes fit the data closely and to assess coherence and distinction. The researcher searched for quotes in the data that both supported and negated each of the themes. The researcher then examined these findings and finalised that the core themes represented the data and that three core themes were present across all the interviews.

6. Defining and naming themes. Next the researcher discussed the themes with the supervisors, identifying the essential features of each, and clarifying the main point of each theme and any important subthemes. Finally, three overarching themes with each theme given a name that captured its essential meaning, namely; Effects on mental and physical aspects of quality of life, Coping patterns, and Challenges in the caregiving journey.

7. Producing the report. The researcher presented the results with a list of quotes drawn from the interview transcripts that were identified for each theme and chose the quotes that best exemplified the themes. Core themes, themes, subthemes, and quotes are presented in table form (Appendix O) to promote better understanding of the phenomenon. The report showed there was difference in caregivers' quality of life because of the different coping strategy used by the sighted and non-sighted caregivers. The coping strategies employed by sighted and non-sighted caregiver were not only influenced by the Asian culture but also by the social and health care policies. Finally, a huge unmet health care and social support system puts immerse strain on the caregiver's quality of life.

4.9 Rigour of the Qualitative Study

To ensure the validity and trustworthiness of the qualitative interviews, the researcher adapted the framework from Lincoln and Guba (1985). Trustworthiness in qualitative research encompasses credibility, dependability, confirmability and transferability.

Credibility ensures the study measures what is intended and is a true reflection of the social reality of the participants. To ensure credibility, the selection of participants was based on the inclusion and exclusion criteria to ensure accurate data collection and information. Only participants who were aged 21 and above and providing a minimum of 3 hours of caregiving were included in the study. To strengthen credibility in this study, member-checking was undertaken. Member checking was conducted during the interviews, any ambiguity was clarified immediately, and the researcher summarised interview contents and confirmed these with the participant to confirm that the findings can be deemed credible and the research is valid. By listening deeply and raising questions with participants, researcher had a chance to clarify their thoughts, which will strengthen their findings.

Dependability confirms that the process is described in sufficient detail to facilitate another researcher repeating the research work. This requires a detailed audit trail on how the same key researcher conducted all the interviews. A consistent interviewing approach using the interview guide was utilised during the entire data collection process. All the audio-recorded interviews were also carefully transcribed verbatim by the researcher supporting the audit trail.

Confirmability, refers to the researcher establishing that the results accurately reflect the views of the participants and not the interpretations of the researcher. To ensure the confirmability of this research, the researcher verified the interviews, the extraction of the themes, and the construction of the sub-themes and main categories by cross checking with verbatim interviews, followed by verification with two supervisors. This establishes that data and interpretations are clearly derived from the data. Conducting the analysis with a team of investigators, helped to minimise the risk of interpretation bias.

Transferability relates to the ability of the findings to be transferred to other settings. As the qualitative research is specific to a low vision caregivers' context it is important that a "thick description" of the particular research context is provided allowing the reader to assess whether it is transferable to their situation or not. In this study, transferability was achieved by ensuring detailed information of the sampling and interviewing process is available. The description of the participant demographics and verbatim records, with direct quotes with well-developed interpretations, also facilitated transferability in replication of the study methods in other conditions or groups of individuals.

4.10 Integration of Quantitative and Qualitative analysis

The quantitative and qualitative data generated from the surveys and audio recording were presented as discrete data-sets. The findings from both datasets were woven together in the discussion section to explain the capacity of low vision caregivers to maintain their quality of life in response to the challenges of caregiving. The researcher also specifically compared the respondents' experiences of both sighted and non-sighted caregivers. The findings from the quantitative and qualitative methods, showed a convergence between surveys and themes. The interviews provided more content for understanding the underlying concepts of quality of life, coping process, and caregiver burden which were assessed by surveys. There was congruence within quality-of-life domains and caregiver burden reported and interview findings. The use of the engaged coping strategies that the participants reported through the surveys, aligned with the subthemes identified within their interviews. There was consistency reported between methods in terms of caregiver burden.

4.11 Chapter Summary

This chapter provided an overview of the methodology that was used in this study. The study used an explanatory sequential mixed methods study comprising of two Phases: a cross-sectional survey and a semi-structured interview. A total of 60 respondents were recruited for a cross-sectional survey and a subgroup of 12 were purposively selected for the semi-structured interviews. Maximum variation sampling was used to identify and expand the range of variation of quality of life and coping strategies from sighted and non-sighted caregivers. The quantitative phase guided development of the questions in the interviews (Creswell and Creswell, 2017). Ethical implications of conducting the research were outlined and the chapter concludes with consideration of the researcher reflexivity. Analysis of data obtained in phase one and phase two were presented with supporting literature to demonstrate rigor and transparency. The results of the quantitative and qualitative phases were integrated to find the explanations of what influences the caregiver quality of life. The next chapter presents the research results related to the quality of life of the caregiver, caregiver burden, coping strategy, health outcomes and health utilisation.

Chapter Five Results Phase One

This chapter presents the study's findings in three sections. The first section presents the information related to the' demographic profile of participants and the descriptive statistics of the main variables in this study. Section two discusses the correlational analyses that were used to assess the relationship between the main variables which include quality of life, caregiver burden, health outcomes, health utilisation, and the coping process. Section three presents the results of the hierarchal regression analysis that assessed the combined and unique contribution of the caregiver burden, health outcomes, health utilisation and coping process to the total quality of life. All statistical analysis was performed using IBM SPSS version 26.0. The results of each of the research objectives are presented:

1. Describe the sample characteristics, caregiver burden and coping strategy in caregivers of the low vision individuals.
2. Describe the quality of life, health outcomes and health utilisation in caregivers caring for individuals with low vision individuals.

3. Determine the relationship of the demographic profile with caregiver burden and coping strategy.
4. Determine how caregiver burden is related to their coping strategy.
5. Determine the relationship between total quality of life and the caregiver burden, health outcomes, health utilisation and coping strategy.
6. Assess the unique predictors of total quality of life among caregivers of the low vision individuals.

5.1 Sample Characteristics

This section will answer research objectives 1 and 2 as follows:

1. Describe the sample characteristics, caregiver burden and coping process in caregivers of the low vision individuals.
2. Describe the quality of life, health outcomes and health utilisation in caregivers caring for individuals with low vision individuals.

Table 5.1 Socio-demographic profile of respondents (N=60)

Characteristics	Categories	Frequency , *n*	Percentage, %	Mean (SD)
1.Age				56.5 (16.1) years old
2. Years of Caregiving				16.6 (12.5) years
3. Gender	Male	19	31.7	
	Female	41	68.3	
4.Ethnicity	Chinese	47	78.3	
	Malay	9	15	
	Indian	2	3.3	
	Others	2	3.4	
5.Education Level	No Education/ Primary Level	9	15	
	Secondary Education	39	65	
	Diploma and above	12	20	
6. Marital status	Single / Widowed/ Divorced	14	23.3	
	Married	46	76.7	
7.Housing Status	1 to 2 Room Public Housing	2	3.3	
	3 to 4 Rooms Public Housing	34	56.7	
	5 Rooms Public Housing and Private Housing	24	40	
8. Work Status	Working Full Time	21	35	
	Working Part time	12	20	
	Not Working	17	45	

Table 5.1 provide details of the socio-demographic profiles of the respondents. The study included 68% (n= 41) women and 31.7% (n=19) men. The age range of the respondents was 23 to 92 years, with a mean age of 56.53 (SD =16.1). The majority (78.4%, n= 47) of the participants were Chinese, followed by 15% (n= 9) Malay, 3.3% (n= 2) Indian and 3.3% (n= 2)

others. The ethnic distribution of the respondents was similar to that found by the Singapore Survey on Informal Caregiving (2013), where Chinese (62.6%, n=745), Malay (28.3%, n=337), and Indian (8.3%, n=99) were the major ethnic groups (Chan et al., 2013). Nearly all (97%, n=58) were Singapore citizens.

The average duration of caregiving in the present study was 16.6 years which ranged from 1 to 60 years. Low vision is not a life-threatening medical condition therefore the caregiving journey is a life -long process. In the study population more than a quarter of the caregivers (35%, n= 21) were parents who looked after low vision individuals since childhood, thus their years of caregiving often lasted until the care recipient became adults. However, the majority of people with low vision (about 65%) are those aged 50 years and over (Keeffe, 2019). For this group, the years of caregiving would likely to extend to more than 30 years if the care recipients reach the life expectancy of 80 (Chan, 2021).

In terms of their education level, more than half of the caregivers received some form of formal education. In the present study, the results showed that the majority (85%, n=51) of the caregivers had attained a minimum 10 years of formal education, 15% (n=9) either had only achieved primary school education or no formal education, and 20% of the caregivers were graduates from a polytechnic or university. Therefore, the caregivers in the present study were generally well-educated.

In the present study, a large proportion (76.7%, n=46) were married and a minority of the caregivers (23.3%) were single, widowed or divorced. The married status profile of the caregivers in this study was higher than that of the breast cancer caregivers (72% married) reported in a local study by Chow et al., (2020). In terms of housing, while almost all (96.7%, n=58) of the caregivers were living public housing of 4 to 5 rooms , a minority (3.3%, n=2) of the caregivers were renting 1-2 room(s) in public housing from the government. Hence, it can be seen that the majority of the caregivers in the present study can be considered as having a relatively high income as they were living in their own flats.

Almost half of respondents (45%, n=17) in the present study were not working at the time of study. In terms of employment, more than one third (35%, n=21) were working in full- time employment while the remaining 20% (n=12) were in part-time employment. This is in contrast to the profile from the review which found that majority of caregivers of low vision individuals were still employed in the workforce, despite the onerous caregiving duties.

5.1.1 Characteristics of Caregiving

Table 5.2 presents the characteristics of caregiving, the relationship with the care recipient, assistance from a foreign domestic worker, and addition support care from family and friend(s).

Table 5.2 Characteristics of Caregiving (N=60)

	Categories	**Frequency, *n***	**Percentage %**
1. Kindship with care recipients	Spouse	29	48.3
	Parent	21	35
	Children	6	10
	Others	4	6.7
2. Support from family and friend(s)	No	35	58.3
	Yes	25	41.7
3. Has live-in foreign domestic worker assist in caregiving	No	52	86.7
	Yes	8	13.3

In the present study, almost half of the caregivers were spouses of care recipients (48.3%, n=29), followed by 35% who were parents and, 10% who were adult children. A small proportion of caregivers were ‘others’ (6.7%) these were reported to be siblings, a niece or nephew of the care recipients. In terms of additional support from family and friends, almost half (41.7%, n=25) of the caregivers reported receiving support from social networks as shown in Table 6.2. Although not the focus of this study, it is important to note that there were eight foreign stay-in domestic workers in the present study who were engaged in caregiving to the low vision individuals. This shows that the presence of foreign domestic workers helps to reduce the caregiver burden for family members.

5.1.2 Descriptive Statistics of Dependent and Independent Variables

Table 5.3 contains information of the dependent variables which were the overall quality of life of the caregivers as measured by SF 12. SF-12 was calculated and analysed separately based on their scores on the physical and mental components.

Table 5.3 Mean and Standard Deviations of Dependent Variables of the Survey (n =60)

Dependent Variables (DV)	Mean (SD)	Range of Scores
Total Quality of Life -SF12	95.3(14.3)	62 to 117
SF 12 Physical Component (SF PCS)	48.6(9.4)	22.3 to 65.6
SF12 Mental Component (SF MCS)	46.7 (11.8)	19.5 to 64

5.1.3 Overall Quality of Life

In the present study, the overall quality of life score was 95.3 (SD=14.3), the Physical Component score (PCS) was 48.6 (SD =9.4), and Mental Component score (MCS) was 46.7 (SD=11.8) as shown in Table 5.3, Ware Jr et al., (1996) provided a norm-based scoring method that is based on the general United States population with a mean of 50 and standard deviation of 10. The overall quality of scores is a combination of mental and physical components, and the score is generally used for comparison purposes with the mean of the general American population.

Therefore, the mean PCS and MCS in this sample were lower to those of the general American population. The results showed that the impact of being a caregiver of a low vision individual decreased the physical and mental components of their health status. The mean mental component score was even lower than the mean physical component score. Thus, this suggests that the mental functioning of the care givers is more negatively affected compared to their physical functioning when caregiving for low vision individuals. Therefore, the caregivers experience more impairment of their mental health than their physical component based on the measurement of the SF12.

As compared to the findings on caregivers of those with breast cancer from a local study by Chow et al (2020), the physical functioning the caregivers of low vision individuals, was higher but the mental functioning was lower. The same local study of the 99 caregivers of those with breast cancer, reported a Physical Component Score of 53.2 (SD 6.9), and a Mental Component Score of 44.7 (SD 10.8). A 2011 national survey on ageing revealed the mean PCS was 48.3(7.6) and the mean MCS was 53.6 (8.2) for Singaporeans aged between 55 to 65 (Ng, 2011). As compared to the general Singapore population, the physical functioning of caregivers of low vision individuals was similar. However, the mental functioning of caregivers of low vision individuals was far lower to that of the average Singaporean. Thus, caregiving of low vision individuals may experience more mental impairment than physical impairment.

5.1.3 Caregiver Burden, Coping Strategy, Health Outcomes and Health Utilisation

This section reports the descriptive statistic of the independent variables which include and their means, standard deviation and range of scores as presented in Table 5.4.

Table 5.4 The Mean, Standard Deviation and Range of Scores of Independent Variables

Independent Variables (IV)	Mean (SD)	Range of the Scores
1. Caregiver Burden	35.5(17.7)	5 to 75
Role Strain	8.5 (6.2)	0 to 24
Personal Strain	19.75(8.9)	3 to 39
2. Coping Process		
Problem-focused coping	28.1 (7.9)	12 to 48
Emotion-focused coping	41.0 (11.3)	15 to 66
3. Health Outcomes	2.7 (3.3)	0 to 14
4. Health Utilisation	1.9 (1.6)	0 to 16

5.1.4 Caregiver Burden

Caregiver burden in the present study was measured by the Zarit Burden Interview (ZBI) with a focus on Personal Strain and Role Strain (Whitlatch et al., 1991). Personal strain is defined as the level of stress of the caregiving experience and role strain is the level of stress due to role conflict and overloading. A higher score means greater caregiver burden or distress. In the present study, the overall group mean result for the ZBI caregiver's burden was 35.5 (SD 17.7) as shown in Table 6, which is slightly higher than the suggested cut off of 33 and this can be interpreted as on or above the score indicating a severe caregiving burden (Hébert et al., 2000). In terms of subscales, the Role Strain ranged from 0 to 24 with a group mean of 8.5 (SD 6.2), whereas the Personal Strain ranged from 3 to 39 with a group mean of 19.75 (SD 8.9). These results suggest that caregiver burden was primarily due to personal strain instead of role strain.

5.1.5 Coping Strategy

In Table 5.4, the coping of caregivers was examined based on problem-focused and emotion-focus dimensions using the Ways of Coping Checklist where a higher score indicates that caregivers are likely to adopt a specific coping strategy (Hawken et al., 2018). In the present study, emotion-focused coping strategy ranged from 15 to 66 with an average score of 41 (SD 11.3) and problem-focused coping strategy ranged from 12 to 48 with an average score of 28.1 (SD 7.9). This finding suggests that caregivers of low vision individuals employed emotion-focusing coping strategy more frequently than a problem-focused coping strategy. As compared to the Asian caregiving studies (Lee and Song, 2022; Huang et al., 2015), a problem focused-coping strategy was less used than an emotional-focused coping strategy , which concurred with the current study of caregivers of low vision individuals. These results may suggest that the caregivers lack problem-coping skills to deal with caregiving stress.

5.1.6 Health Outcomes

Health outcomes are measured by the Cumulative Illness Rating Scale (CIRS), which is one of the existing tools used to measure multi-morbidity (Miller et al., (1992). In the present study, the CIRS score ranged from 0 to 13 with a mean score of 2.68. As expected, the health of caregivers of low vision individuals, who are mostly in their fifties, was likely to be associated with chronic diseases due to the risks caused by aging (Jin et al., 2021).

Table 5.5 details the frequency of each organ system's comorbidity and breaks down the reporting by severity. In the present study, the majority of the caregivers did not have any medical condition. The most common comorbidity reported by the caregivers was psychological distress such as depression and anxiety, with few caregivers reporting a severe psychiatric condition which needed medical treatment. The second common comorbidity was muscular-skeletal conditions such as back injuries and arthritis with some reporting a disability.

A vision impaired condition was the third most frequently reported medical condition by the caregivers as some of them also had low vision with disability. Hypertension, gastric and metabolic diseases were common chronic diseases reported by the caregivers with 10% requiring medications. Other types of systematic diseases such cerebrovascular, liver, stomach and lung disease were not common. None of the caregivers had kidney problems. The results suggest the likelihood of few negative health outcomes as the result of caring for low vision individuals. Within the reported health problems, the negative health outcomes were mainly psychological distress and physical problems.

Table 5.5 Frequency of Comorbidities as Assessed by the CIRS

	%				
Organ System	**No impairment**	**Mild Impairment**	**Moderate Severity**	**Severe /Constant Disability**	**Extremely Severe**
Psychiatric/ Behavioural	65.0	23.3	11.7	0.0	0.0
Musculo-skeletal	71.7	15.0	10.0	3.3	0.0
Eye, Ear, Nose, Throat, Larynx	81.7	11.7	3.3	1.7	1.7
Hypertension	83.3	10.0	5.0	1.7	0.0
Upper GI	85.0	10.0	3.3	1.7	0.0
Endocrine – Metabolic	85.0	8.3	5.0	1.7	0.0
Cardiac	88.3	6.7	3.3	1.7	0.0
Neurological	90.0	5.0	3.3	1.7	0.0
Vascular	91.7	3.3	5.0	0.0	0.0

Lower GI	91.7	5.0	3.3	0.0	0.0
Hepatic	95.0	3.3	1.7	0.0	0.0
Respiratory	96.7	3.3	0.0	0.0	0.0
Other GU	96.7	0.0	3.3	0.0	0.0
Renal	100	0.0	0.0	0.0	0.0

NOTE Abbreviations: GI, gastrointestinal; GU, genitourinary system.

5.1.7 Health Service Utilisation

The summary of health service utilisation from caregivers of low vision individuals is shown in Table 5.6. This scale examined the health care services used by caregivers and included questions related to medical and nonmedical health care services in the last 3 months.

Table 5.6 Summary of the Health Service Utilisation

	%(n)	
Health Utilisation Questions	**No**	**Yes**
1. During the past month, have you been hospitalised	88.3 (n=53)	11.7(n=7)
2. Visited doctor in the past month	41.7 (n=25)	58.3 (n=35)
3. Been visited at home by doctor	0.0 (n=0)	0.0 (n=0)
4. Telephoned doctor for advised	0.0 (n=0)	0.0 (n=0)
5. Visited Traditional Chinese Medicine (TCM) for the past month	76.7 (n=46)	23.3 (n=14)
6. In the past month, have you received physiotherapy treatment	95.0 (n=57)	5.0 (n=3)
7. In the past month, have you visited a dietitian	95.0 (n=57)	5.0(n=3)
8. In the past month, have you visited a radiographer	96.7 (n=57)	3.3(n=2)
9. In the past month, have you visited by a nurse	95.0 (n=57)	5.0 (n=3)
10. In the past month, have you visited a surgeon	96.7 (n=58)	3.3 (n=2)
11. In the past month have you visited a masseuse	90.0 (n=54)	10.0 (n=6)
12. In the past month, have you visited a counsellor	96.7 (n=58)	3.3 (n=2)
13. During the past month, in connection with your health did you receive medication	56.7(n=34)	43.3 (n=26)
14. During the past month, in connection with your health did you receive special food	86.7 (n=52)	13.3(n=8)
15. During the past month, in connection with your health did you receive assisted devices, e.g. wheelchair/ walking stick	90.0(n=54)	10.0 (n=6)
16. During the past month, in connection with your health did you receive assisted devices.e.g. care products / incontinence aids	98.3(n=59)	1.7(n=1)

As shown in Table 5.6, most caregivers in the present study experienced low levels of health care service utilisation in the past 3 months, with a range from 0 to 16 and a mean score of 1.97 (SD 1.6). The amount of health care service utilisation among the caregivers was similar to the population study where there was an average of 2.22 outpatient visits within a 6 months period among general Singaporeans aged 60 and above (Ge et al., 2020).

Less than a quarter of the caregivers (23.3%) sought treatment from a practitioner of Traditional Chinese Medicine. More than half of caregivers (58.3%) had visited a primary care doctor for chronic disease management and 43.3% of caregivers required medication for their health conditions. Less than one fifth (13.3%) were told to go on a special diet to optimise their health. The survey captured that the reasons for the health care visits was for curative services which suggests the caregiver's health condition was undergoing changes which required medication and changing of eating habits to optimize their health. Surprisingly, a low proportion of caregivers (11.7%) were hospitalized. The hospitalisation rate was similar to the aforementioned population study where 10.6% of the general Singaporean population was hospitalised in the preceding 12 months (George et al., 2012). This suggests that the health status of just a small group of caregivers was serious enough to warrant medical attention.

A small number of the caregivers (10%) sought the service pf a masseuse, and another 5% of the caregivers needed to visit a physiotherapist. These data are suggesting that a minority of caregivers were experiencing neuro-musculoskeletal discomfort or bodily pains and this may due to caregiving tasks. Some of the common tasks for caregiving include moving the home furniture to prevent low vision individuals from falling, adjusting low vision aids such as Closed Circuit Television (CCTV) for reading, helping to buy grocery. These physical tasks, if performed repeatedly for a long period might cause strain to the spine muscles and overall impaired physical health.

It is surprising that only 10% needed assistive devices such as a walking stick, less than 5% sought advice from a dietitian, counsellor, radiographer, nurse or surgeon, and 1.7% needed incontinence aids in past 3 months. Thus, this probably suggests that only a handful of caregivers were in poor physical health or had health conditions which needed walking devices or incontinence aids. The requirement for such assistance may be due to age-related conditions. For the small proportion of caregivers who required other health services such as a counsellor and dietitian, this may be an effort to seek additional advice or services to optimize self-care.

5.2. Relationship Between Demographic Profile, Health Outcomes, Health Utilisation, Caregiver Burden, Coping Strategy and Quality of Life

This section reports the findings to address research objectives 3, 4, and 5 as follows.

3. Determine the relationship of the demographic profile with caregiver burden and coping strategy.
4. Determine how caregiver burden is related to their coping strategy.
5. Determine the relationship between total quality of life and the caregiver burden, health outcomes, health utilisation and coping strategy.

Results from the correlation analyses are shown in Table 5.6. Pearson's product moment correlation was used to determine the magnitude of the relationship between quality of life, coping strategy, caregiver burden, health outcomes and health utilisation.

Table 5.7 Bivariate Analysis Between Predictors Variables, Domains of Quality of life and Total Quality of Life

Characteristics	1. Age	2.Education Level	3. Health Outcome	4. Caregiver burden	5. Health Utilisation	6. Problem-focusing coping	7. Emotion-focused coping	8. SF PCS	9. SF MCS	10. Total QOL
1. Age	-									
2. Education	-0.13	-								
Independent Variables										
3. Health Outcomes	**0.21+**	-0.1	-							
4. Caregiver burden	0.04	-0.16	0.17	-						
5. Health Utilisation	**0.22+**	-0.19	**0.58*****	0.24	-					
6. Problem-focused Coping	-0.15	0.12	0.06	**0.46****	-0.02	-				
7. Emotion-focused Coping	-0.03	0.09	0.06	**0.26***	-0.1	**0.60*****	-			
Dependent Variables										
8. SF PCS	-0.1	-0.06	0.04	0.06	-0.12	0.02	-0.08	-		
9. SF MCS	-0.16	0.16	0.08	-0.37	0.04	0.2	-0.12	-0.11	-	
10.Total QOL (PCS+MCS)	-0.17	0.09	0.09	0.01	-0.05	0.18	-0.15	**0.60*****	**0.80*****	-

+ $p < 0.10$, *$p < 0.05$, **$p < 0.01$, *** $p < 0.001$. Note Significant *p* value has been bolded.

SF PCS indicates SF 12 Physical Component Score, SF MCS indicates SF Mental Component Score.

5.2.1. Relationship Between Demographic Profile with Caregiver Burden and Coping Strategy

In the present study, two demographics variables were included in the analysis, namely age and education level. As shown in Table 5.7, age was positively correlated with caregiver burden. There is a positive but weak relationship between age and caregiver burden. While this relationship is in the expected direction, it was not statically significant (r=0.04). This suggests that younger caregivers might not experience a high level of caregiver burden.

Similarly, education was inversely correlated with caregiver burden but again the relationship was statistically insignificant (r= -0.16). This suggests that caregivers with a higher education level were not perceiving a lower level of caregiving burden. Unexpectedly, regardless of education level, the caregivers of low vision individuals were feeling the immense strain of caregiving.

In the present study, there are negative relationships between age and coping strategies but these relationships were not statistically significant as shown in Table 5.7 (problem-focused coping: r=-0.15, emotion-focused coping: r=-0.03). It may be that caregivers who are older tend to rely less on problem-focused and emotional-focused coping strategies as compared to the younger caregivers. Interestingly these relationships were not supported by statistical evidence in the present study.

As can be seen in Table 5.7, education level was positively correlated with problem-focused coping and emotion-focused coping strategies but these relationships not statistically significant (Problem-focused coping: r=0.12; Emotion-focused coping: r=0.09). These results suggest that the level of education was not associated with coping processes. The current findings were unexpected as it was thought that caregivers who are educated would be adopting both problem- and emotion-coping strategies in caregiving. The finding could be explained by the fact that the more highly educated caregivers are likely to have better jobs, and more support resources to help them deal with their caregiving problems (Rahman et al., 2019).

As expected, the age of caregivers was positively correlated with health outcome (r= 0.21, p < 0.10), and health service utilisation (r= 0.22, p < 0.10). Having said that, these two relationships were weak and had only marginally significant associations. Older caregivers had more chronic diseases and also so utilising more health services. The local population study reported more than 50% of Singaporeans had at least 1 chronic disease by the age of 50 years old, and multimorbidity was significantly associated with age (Low et al., 2019). Older caregivers with more chronic conditions would therefore require more health care service to manage their health status. This may be a plausible way to possibly explain this finding.

5.2.2. Relationship Between Caregiver Burden with Coping Process

As shown in Table 5.7, there was a moderately positive relationship between caregiver burden and problem-focused coping (r=0.46, p< 0.05) while caregiver burden has a positively weak relationship with emotion-focused coping (r=0.26, p <0.05). These two positive correlations were statistically significant. The results of the present study showed that the level of caregiver burden can be lowered if the caregiver adopted both problem- and emotion- focused coping strategies. In particular, the positive relationship between problem-focused coping and caregiver burden was stronger than that of emotional-focused coping. As expected based on evidence from other caregiving studies there were more benefits of using problem-focused coping strategies in the stress context (Hawken et al., 2018; Jeong et al., 2018; Teixeira et al., 2018). This result is supported by the theoretical framework of the present study indicating that when the caregiver burden increased, the caregiver adopted emotion and problem-focused strategies more regularly to cope with the caregiving demands and duties.

A moderate correlation was found between problem-focused coping and emotional-focused coping (r= 0.60, p <0.05), and this positive relationship is statistically significant. Unexpectedly caregivers who adopt more problem-focused coping strategies were more likely to use a more emotion-coping strategy. In other words, this finding suggest that caregivers were adopting both coping strategies to deal with daily stressful demands in caregiving duties. In response to the appraised demands of caregiving, adopting problem-focused coping strategies when facing negative events can help caregivers to solve difficulties, build confidence, and promote positive emotions. This interwoven relationship between problem- and emotion-focused coping makes it useful to think of the two as complementary (Caga et al., 2021). These coping strategies could be influenced by the Asian culture and related to the role of the family and social expectations within the culture (Lee and Song, 2022).

5.2.3 Relationship Between Quality of Life, Caregiver Burden, Health Outcomes and Health Utilisation for in Those Caring for Individuals With Low Vision

As can be seen in Table 5.7, there is no significant correlation between quality of life, physical and mental health, and caregiver burden. While no significant relationship was observed, there were weak positive correlations between caregiver burden with the physical component score (r=0.06) and total quality of life (r=0.01), as well as negative relationships between caregiver burden and the mental component score (r=-0.37).

As shown in Table 5.7, health outcome was weakly correlated to the physical health component score (r=0.04), mental component score (r=0.08) and total quality of life (r=0.09). These relationships were statistically insignificant which was a surprise to note. This evidence suggested the quality of life, and the physical and mental health of the caregivers was not related to health outcomes.

In terms of health service utilisation, there was a weak negative relationship between health service utilisation and physical component score (r = -0.12), but weak positive relationship with the mental component score (r = 0.04) There was also a weak negative relationship with the total quality of life (r = -0.05). However, these relationships were not statistically significant. Unexpectedly, there was no evidence from the results to suggest that health service utilisation was related to the physical health, mental health and quality of life of the caregivers.

Surprisingly, health outcome has a moderate correlation with health utilisation (r =0.58, p<0.05). This relationship was statistically significant. The results of the present study suggest that the caregivers of low vision individuals who had more chronic diseases were generally proactively seeking health care services specifically curative services. The possible explanation might be that caregivers were guided by the ethos of individual responsibility for their health, particularly to live a healthy lifestyle, and the concerted efforts of government to subside chronic disease programmes and prevention initiatives that serves to ensure the quality of later life (Malhotra et al., 2018; Tan et al., 2021).

5.3 Predicators of Total Quality of Life of Caregivers of Low Vision Individuals

The finding from this regression analysis was used to address research objective 6: To assess the significant predictors of quality of life. The selected predictors include caregiver burden, health outcomes, health utilisation and coping strategy. Specifically, hierarchical regression analyses were performed to identify the unique predictors of the total quality of life of caregivers of low vision individuals.

Both age and education variables were not included in the regression model as confounding or control variables as there were insignificant correlations between them and were found between all the independent variables, as shown in Table 5.7. In the hierarchical regression procedure, all predictor variables were separated into three blocks in specific hierarchical order. The order of entry of sets of predictors into the regression model was predetermined to address the intended questions. Caregiver Burden was entered in the first block; Health Outcome and Health Service Utilisation were included in the second block followed by Problem-focused Coping and Emotion-focused Coping in the third block. By applying this method, the researcher can assess the impact of a group of variables after controlling the effect of the initial stage variable. The researcher examined the R^2 for each model and examined whether each additional model was a significant change over the prior model. The hierarchical model explains the reasons for the differences in the caregivers' quality of life, and provides the advantage of revealing the change in the impact of previously introduced independent variables on caregivers' quality of life when a new independent or predictor variable is introduced.

A conservative $p \leq 0.05$ was considered for the present study to allow for independent variable to be included in the hierarchical linear regression models (Mat Roni and Djajadikerta, 2021). The independent variables were checked for multicollinearity using tolerance and the variance inflation factor (VIF). The VIF values greater than 10 and tolerance values smaller than 0.10 may indicate multicollinearity among variants (Pallant, 2020). These assumptions must be met in order to use hierarchical regression model (Bowers, 2019). In the present study, the VIF ranged from 1.00 to 1.84, and tolerance ranged from 1 to 0.54. Hence, it can be seen that all assumptions for hierarchical regression analysis have been met.

The result of the regression analyses is depicted in Table 5.8. For the present study, the selected caregiver burden was entered in Model 1 as step 1. In step 2, Model 2 included Health Outcome and Health Utilisation, in addition to Caregiver Burden, and in the final step, Model 3 included Problem-focused Coping and Emotion-focused Coping in addition to the previously mentioned variables.

As shown in the result, in Model 1, caregiver burden was a positive predictor for total quality of life but it only made a very limited contribution in predicting total quality of life. In fact, this regression model accounted for only 1.7% of the variance of total quality of life for the caregivers of low vision individuals. The result reflects that there was no predictive relationship between caregiver burden and caregiver total quality of life.

In Model 2, Health Outcome and Health Service Utilisation variables were entered, controlling for caregiver burden. As depicted in Table 5.8, the addition of the two independent variables resulted in an increase in R2 change of .03, (3, 56). Together, the two independent variables accounted for only 3% of the variance in total quality of life for caregivers of low vision individuals. The results in the model also showed that while health outcome was a positive predictor ($\beta = 0.27$, $p > 0.5$) and health service utilization was a negative predictor ($\beta = 0.18$, $p > 0.5$) for total quality of life but their unique contribution was statistically insignificant. Hence, the result suggests health outcomes and health utilisation were not predictive of caregiver total quality of life.

In Model 3, Problem-focused Coping and Emotion-focused Coping were entered, while controlling for caregiver burden, health outcomes and health utilisation. As depicted in Table 6.8, the additional two independent variables account for 16% of the variance in caregiver total quality of life. The additional two coping strategies resulted in a significant change in R^2 change of 0.16, (5, 54) =5.11, $p \leq 0.05$.

The results in Model 3 showed that both caregiver burden ($\beta = -0.07$) and health utilisation ($\beta = -0.20$) were negative predictors and, health outcome was a positive predictor ($\beta = 0.21$) for total caregiver quality of life. However, the three predictors remained statistically insignificant, when coping strategies were added into the model.

The results showed that both problem-focused and emotion-focused coping strategies were unique predictors for total quality of life, after the contribution of the other independent variables were accounted for. In specific, problem-focused coping was a significant predictor of totally quality of life, in a positive direction ($\beta = 0.46$, $p \leq 0.05$), indicating a higher quality of life is predicted by greater use of problem-focused strategies. Emotion-focused coping was found to have a negative significant relationship with total caregiver quality of life ($\beta = -0.44$ $p \leq 0.05$), indicating that a lower quality of life was predicted by greater adoption of emotion-focused coping strategies. The results suggest that both problem-focused coping and emotion-focused coping made a significant and unique contribution to the quality of life of caregivers in the present study.

Table 5. 8 Hierarchical Regression Analyses Predicting Quality of life from Caregiver Burden, Health Outcomes, Health Service Utilisation and Coping Process (N=60)

	Model 1		Model 2		Model 3	
Variable	***SE B***	**Beta**	***SE B***	**Beta**	***SE B***	**Beta**
Caregiver burden	0.1	0.10	0.11	0.02	0.11	-0.07
Health Outcomes			1.43	0.27	1.07	-0.019
Health Service Utilisation			0.71	0.18	0.67	0.21
Problem-Focused Coping					0.3	**0.46****
Emotion-Focused Coping					0.19	**-0.44****
Adjusted R^2	-0.017	0.94	-0.03	0.5	0.16	0.009
F-value	0.006	0.94	0.7	0.5	5.1	0.009

Note. $^{+}$p<0.10, *p<0.05, **p<0.01

5.4 Chapter Summary

This chapter presents the results and findings of Phase One based on the data from a cross-sectional survey. This includes findings on the socio-demographic profile, quality of life, caregiver burden, health outcomes and health utilisation. The caregiver profiles show more than half of the participants were female, married, and had obtained a secondary education qualification. In terms of kinship to care recipients, most of the caregivers were spouses and parents while a minority were children or other relatives such as siblings or a nephew/niece. A few caregivers received additional support from extended family and friends, while some had engaged foreign domestic workers to assist with caregiving. Nearly half of the caregivers were not working, and a quarter chose to work on a part-time basis because of their caregiving duties. More than half of caregivers were generally healthy although some had two or more comorbidities. Those who had more comorbidities were proactive in health seeking behaviours and the relationship was statistically significant.

In terms of the quality of life, the caregiving journey affected the mental health more than the physical health of the caregivers. Additionally, the caregiver burden was notably high among the caregivers due to personal strain. Caregiver burden, on the other hand, was positive related to both emotion-focused and problem-focused coping strategies. Problem-focused coping is highly related to emotional-focused coping. However, results from the correlation tests revealed age and education were not associated with coping strategy and caregiver burden, and this is in contrast to the extant literature.

The coping strategies, namely emotion- and problem-focused coping, were factors significantly contributing to the overall caregiver quality of life. Variables such as caregiver burden, health outcomes and health utilisation did not contribute to the overall caregiver quality of life. Therefore, the results suggest enhancing the effective emotion- and problem-focused coping strategies are likely to improve the caregiver quality of life. In Phase Two, caregivers were selected for the interview using a purposive sampling strategy, taking into account the different quality of life scores and relationship to care recipients. Based on the results in Phase one, the qualitative data collection via interview was aimed at better understanding the coping process in relation to the quality of life. Hence, the next chapter presents the qualitative findings from this research. The information presented is related to the themes that emerged from the thematic analysis of the interview data.

Chapter Six Results of Phase Two

In this chapter, findings from the interviews are presented in order to address the last research objective: To explore and identify the coping experiences and needs in relation to the social aspect among the caregivers of low vision individuals. The nested sample of 12 respondents was stratified into two groups to examine their experience in terms of the Asian culture, filial piety and familism. The interviews data also shed lights on the challenges in their caregiving journey. The thematic analysis identified overarching themes related to (1) effects on mental and physical aspects of quality of life, (2) coping patterns and (3) challenges in their caregiving journey. Quotations from the interviews are used to support and explain the subthemes made.

6.1 Sample Characteristics

Twelve caregivers of low vision individuals participated in the interview phase. As a group, the mean age was 54.7 (SD 14.6, range = 31 - 76), with almost one third of them being females (75%). The majority of the caregivers were either spouses (75%) or children (25%) who were living in the same household as the care recipients. These caregivers had been responsible for the care duties for an average of 14.5 years (SD 12.9, range = 3 - 49). Those who took part in the interview were generally in full-time employment with one working part-time and one retiree.

In terms of assistance, one of the caregivers received respite care from a homecare organisation for an average of 3 days per week, while two of them had engaged help from a foreign domestic helper. Based on the interviews, these caregivers sought additional help due to their personal circumstances. For example, as one of the caregivers was an older person, it was his daughter who employed the foreign domestic helper to assist in caregiving. While the other caregiver who sought external help was a young female caregiver who had two children and her husband travels out of Singapore for work regularly. Four of the caregivers were visually impaired couples; one of the male caregivers was a retiree, two male caregivers were in full employment, and one female caregiver had just lost her job (Table 6.1). The retiree used to work in a call centre in a tour agency. The two male caregivers in employment were working in the Singapore Association for the Visually Handicapped (SAVH);

one worked as a Braille transcriber and another one worked as a computer software technologist introducing up to date information. technology (IT) software to visually impaired customers. The female caregiver was being made redundant by the private company where she had worked as receptionist for 10 years. It is disturbing to note that visually impaired people often can only gain employment within the ‘blindness industry’, and many continue to experience difficulty in sustaining paid employment (French, 2017; Steverson, 2020). Prejudice towards visually impaired people within employment is still very common. These caregivers in the current study, not only received lower wage for more than 10 years but also no pay increment. Thus, non-sighted caregivers had less income, as the employment policy in Singapore although designed to help disabled people find employment (Chai et al., 2021), has not factored in pay increment against inflation.

Table 6.1 shows the quality of life scores of the twelve caregivers according to non-sighted and sighted care giver groups. For the non-sighted caregivers, the group mean for physical and mental components scores were 52.2 and 58.8 respectively. While the group mean score for sighted caregivers on the physical and mental components were 45.2 and 47.7 respectively. In comparison to sighted caregivers, the scores of the quality of life of the non-sighted caregivers, were generally higher. Among the respondents, more than half the caregivers had been taking care of low vision individuals for more than 10 years.

Table 6.1 Demographics data of interview participants in phase two of the study (N=12)

Participant	Gender	Age	Kinship to Care recipient	Years of Caregiving	PCS	MCS
Participant 1 *	Male	76	Husband	49	40.5	64.0
Participant 2 *	Male	61	Husband	20	55.5	57.8
Participant 3 *	Male	35	Husband	3	56.8	57.8
Participant 4	Female	31	Daughter	5	47.5	43.6
Participant 5	Female	64	Wife	16	45.6	39.4
Participant 6	Female	68	Wife	4	25.2	43.2
Participant 7	Female	38	Mother	7	45.5	33.4
Participant 8	Female	71	Wife	12	50.0	62.2
Participant 9	Female	56	Wife	10	47.5	43.6
Participant 10	Female	58	Wife	5	53.6	57.4
Participant 11	Female	46	Daughter	20	47.2	59.4
Participant 12 *	Female	53	Wife	23	56.0	55.6

*Husband and wives are couples with the same eye condition – low vision.

6.2 Thematic Findings

Thematic analysis was applied to analyse these interview data to gain a comprehensive understanding of the overall caregiver experience across the trajectory, particularly in relations to the effects of caregiving, coping strategies and the additional support required. In specific, analysis of the current codes from the qualitative data has revealed three levels of coding supported by three layers of overarching core themes, themes and subthemes relating to the caregivers' quality of life, different coping strategies and challenges in their caregiving journey. These core themes, themes and codes are depicted in Table 6.2. To promote a better understanding of the findings, the table below presents a description of the themes and subthemes, how they relate to the core theme and quotes from the interviews are included to supplement the qualitative findings.

Table 6.2 Identified Core Themes, Themes and Sub-themes

Core Themes	**Themes**	**Sub-themes**
Effects on mental and physical aspects of quality of life (Section 6.3)	Negative impact on quality of life (Section 6.3.1)	• Lack of vitality • No social life • Emotional distress • Deprivation of sleep • Constant worry of uncertainty
	Positive impact on quality of life (Section 6.3.2)	• Good social network • Maintain good social interactions
Coping patterns (Section 6.4)	Caregivers proactively seeking solutions (Section 6.4.1)	• Proactive in problem-solving • Seeking family social support
	Caregivers reframing perception and mentality (Section 6.4.2)	• Positive reappraisal • Accepting responsibility
	Caregivers adapting and managing negative emotions	• Self -Control

	(Section 6.4.3)	
Challenges in caregiving journey (Section 6.5)	Lack of healthcare support (Section 6.5.1)	• Unmet needs of tangible support Financial support
	Lack of social support (Section 6.5.2)	• Support from peer with similar identity • Social identity

6.3 Core Theme 1: Effects of Mental and Physical Aspects of Quality of Life

Most caregivers associated caregiving with negative effects, including loss of vitality, emotion distress, deprivation of sleep, and constant worry over uncertainty. Complaints such as feeling tired, difficulty sleeping, and stress were mentioned in the responses. There was also disappointment about not having time for themselves or to socialise with other people. Thus, caregiving had negative effects on the quality of life among the sighted caregivers.

6.3.1 Subtheme 1: Negative impact on quality of life

As a consequence of the demanding nature of caregiving work, lack of vitality was consistently reported by the sighted caregivers as a feature of the role. Caregivers performed multiple roles which creates a demanding role because of the different challenges which accompanied these varied functions. Two female caregivers, who are still in employment, felt the physical strain from the strenuous task of caring for their low vision individuals. When sighted caregivers struggle to cope with the constant demands of work and caring for a low vision individual, caregiving becomes a tiring task impacting their physical health.

> *My role as caregiver is tiring… very tired because I am working as part time cleaner and rush back from work to look after him [husband]… prepare three meals - breakfast, lunch and dinner. He cannot see so he cannot do any cooking. I also have to give the insulin injection for him - for his diabetic treatment (P5).*
>
> *I am too tired to go out for any events on weekends (P9).*

Long hours of caregiving resulted in greater restriction on social activity among the sighted caregivers. Most caregivers reflected the need to be constantly present with their care recipient. As a consequence, they had to reduce their social activities and some gave up social engagements and leisure. Many caregivers described how they had stopped engaging in certain activities, such as shopping, meeting up with friends or taking vacations as a result of their caregiving duties. Others had no time for other social activities such eating out, attending places of worship, and social interactions. Generally, the caregivers lack free time as they had to spend more time to provide their low vision individuals with care pertaining to mobility, self-care, transportation and household activities. This means that almost all of their free time is devoted to caregiving, negatively affecting their quality of life

> *I don't have social life… only attend family event with my family (P5).*

> *Social life was affected as I cannot go out alone. I must accompany him all the time. He cannot take the lift by himself (P10).*

Both sighted and non-sighted caregivers experienced emotional tension, stress and mood changes in their daily involvement with the care management of the care recipients. They described the need to keep his/her emotions in check to be able to cope with caregiving. The extant literature reported a substantial number of caregivers of low vision individuals experienced significant emotional distress. Caregivers need to deal with care recipients who had emotional changes associated with vision loss, yet caregivers do not possess sufficient training for this task. As a consequence, conflict may arises between the needs of low vision individuals and their caregivers.

> *Most of time he is depressed as caregiver I have temper and very taxing for me(P6).*

> *My wife needs emotional support…I try to calm her down when she cried (P3, Caregiver with low vision).*

> *He can be frustrated that he could not see.. I would read the to him..(P10).*

A young caregiver, a mother experienced loss of sleep and she had not referred to the medical social worker. The caregiver shed light on the lack of forma social support for caregivers. The caregivers' sleep disturbance was due to staying awake to keep an eye on her care recipient to prevent her from falling at night when navigating the home. The visual limitation of the care recipient put her at greater risk of falling. This mother caregiver additionally experienced anxiety and an element of fear regarding the on care recipient's ability to study in the Singapore.

> *I couldn't sleep because of my daughter and no one to turn to, the school teacher will talk to me see how I cope. ….She can go toilet herself but I am worried she may fall. I am concern the primary school she has to enrol in future. School in Singapore focus academic results (P7).*

Sighted caregivers often reported constant worry over the uncertainties concerning their evaluation of care recipient's abilities and uncertainty because of the changing symptoms of the eye disease. They worried for care recipient' safety and well-being. The caregivers' stress was largely tied to care recipient' physical condition.

> *It is difficult for me to image her vision loss as the eye condition is not constant. Sometimes she can see bright lights sometimes she could not see…she has frustration. Because I am working, I can be worried her safety I would call her to check on her (P11).*

6.3.2 Theme 2: Positive quality of life

The non-sighted caregivers did not express any physical or emotional stress during the interviews. Four of the non-sighted caregivers did not reveal they felt a the lack of vitality. The socio-emotional and physical quality of life of the couples who both suffered from the condition of low vision were not impaired. In fact, they often organized social activities among themselves or made the effort to attend religious activities. They were not isolated but fully engaged with friends who had similar eye conditions and enjoyed the resulting activities. Their poor vision did not affect their social lives but rather they lived proactively, catching up with friends, colleagues and extended families. Having the same vision situation and also long-term experience of caregiving meant the non-sighted caregivers had become used to the situation and perhaps overcome the associated difficulties.

One possible explanation for these findings could be that couples with low vision may have adapted to their life-long eye condition and are able to lead lifestyles that are minimally disruptive of their quality of life. The non-sighted caregivers were positively finding balance in their caregiving role through social support from family and friends. Over time, caregivers gradually found a balance between caregiving and other commitments so that other family members would not be neglected or overly affected by the caregiving.

> *Caregiving does not affect social life we try to make it family affair. Tomorrow is my mom's birthday I am going to bring my mom back from nursing home and bring her to my sister's place to celebrate. We go church together…(P2, Caregiver with low vision).*

> *Depending who is the friend I am meeting. I just went out yesterday actually I went out with colleagues yesterday for steamboat …there were 3 blind and 2 sighted colleagues (P12, Caregiver with low vision).*

6.4 Core Theme 2: Coping Patterns

Both sighted and non-sighted caregivers used similar and various methods to manage the caregiving. The coping strategies represented the efforts, both behavioural and cognitive, that caregivers employed in order to deal with stressful encounters. The caregiver believes he or she has control over a particular outcome, as well as conducting analysis to identify any available coping options for the stressor.

6.4.1 Subtheme 1: Caregivers proactively seeking solutions

The caregivers interviewed described how to execute proactive problem-solving, seeking family and social support which are problem-focused strategies (Braine and Wray, 2018). Caregivers in the study drew on these strategies to deal with the challenges they encountered. The caregivers felt that they can do something about their problems, thus they were more likely to use problem-focused coping. The problem-solving component involves processes of discovering the best solution.

Surprisingly, all caregivers interviewed including those who were non-sighted, were capable of proactively planning activities to keep the low vision relative occupied and planned holiday trips with care recipients. All the caregivers described their problem-solving abilities during the interviews. Problem-solving is to take action towards finding a solution to the specific situation challenged by caregiving that requires strategising, planning and instrumental action (Biggs et al., 2017).

> *On my day off I will bring my mother out as she stays at home most of the times. I will bring her for swimming at the public pool for 2 hours.. she enjoys the waterfalls. We just came back from a Cruise last year. We plan overseas trip once a year but must persuade her to go as she will say she cannot see what is the point of going. I send her to music classes 2 years ago to learn keyboard. Now she plays a few songs and she loves to sing (P11).*

> *I bring my husband to placed. We go marketing together for 3 to 4 hours .. we go to the library to borrow audio books.. I will take the opportunity to explore different library (P8)*

> *We went on cruise with family last year. We two will go for dining .. we will visit my mom in the nursing home (P2, Caregiver with low vision).*

The young caregiver whose daughter suffered with low vision was proactively seeking information from Singapore and overseas. She even literally put herself in the dark trying to understand how a blind person dines. She joined various international visually impaired associations to gather up-to-date information. Gathering relevant information to dealing with current problem, helped to increase the caregiver’s sense of control.

> *I visited the dinning in the dark.. I went to darkness to understand…*

> *I interviewed people with visually impaired…communication with them let me learn how to cope.. I visited visually impaired associations in Thailand, Japan and New Zealand I want to understand more on visually handicapped people to understand my daughter. I spread out my questions on Facebook and I joined the visual impaired Facebook in Japan (P7).*

One of the non-sighted caregivers had good understanding of his wife's diabetes condition and even knew how to provide suggestions to titrate the insulin injection. Two of the non-sighted caregivers had accompanied their spouses for medical visits. By planning and working on the problem, the caregivers have control over their stress by understanding the medical conditions of their care recipients despite their limited vision.

> *She needs two insulin injection…I advised her or suggest to her how much to injected. I accompanied her to see doctor because she thinks I communicate better than her… I attend the diabetes support group to understand the blood sugar and I roughly understand diabetes has impact on the eye and kidney (P3, Caregiver with low vision).*

> *I accompanied her medical review because she cannot find her way.. we make the same day appointment for medical check-up (P2 Caregiver with low vision).*

Similarly, the caregiver who had low vision himself took extra time and effort to find out the about places before they visited these areas; generally visually impaired people find mobility difficulty in unfamiliar environment. Confusing architectural designs, such as an unguided, open plaza or the complicated layout of shopping malls also proved to be treacherous for the visually-impaired.

> *I accompanied my wife for her medical review because she cannot find her way… We give ourselves early time to reach the venue and ask for help.. Maybe 1 hour to 45 minutes earlier to the place and people will help you … (P2, Caregiver with low vision).*

Another non-sighted caregiver used her listening sense to ensure the care recipient was adherent to their hypertensive medication. She listened to the sounds of the medication box and drinking of the water. Both sighted and non-sighted caregivers were proactive in planning and evaluated solutions to the problems. The caregivers demonstrated active control over the stressor. Active control means the participants indicated a strategy that was well implemented and was effective.

> *My husband seeing GP [General Practitioner] for hypertension.. I ever accompanied him to see the doctor .. I will check on him taking medication as I can heard him open the medication box and swallow the medication with water (P12 Caregiver with low vision).*

As expected, the caregivers relied on additional resources from family support and colleagues. The caregiver therefore created opportunities for the care recipients to engage in meaningful activities, in return these caregivers also obtained physical care and emotional support from family members. Caregivers engaged family and friends during their coping adaptation and often there was a positive impact of family support on the caregivers' experiences. These caregivers who had good relationships with family members would receive help from other family members even those not living in the same household.

> *I would plan own trips to Hong Kong Taiwan, Korea and China. We used to join tour but the passengers told me off found him troublesome using a white cane… He most willing to try unfamiliar places… (P10).*

> *When I go business trip, I will have to arrange my sister to come over to my place. My mother is uncomfortable to stay over unfamiliar places as she couldn't see. (P11).*

> *We sometimes have to change our social programs last minute to suit my father's schedule … my asked my brother to help if I cannot make it. (P4).*

> *We go for short trips and because we cannot see we must go with family (P2 Caregiver with low vision).*

The caregivers interviewed accepted the help of extended family members or adult children to play a role in providing psychological support to care recipients which in return provided respite for primary caregivers. Caregivers with a supportive social network were able to manage caregiving smoothly and keep their care recipients engaged with activities. The caregivers showed that there were cases where caregivers preferred turning to familial support instead of friends, neighbours or formal services. Caregivers received assistance such as non-monetary forms of support, such as visits with food or groceries, or emotional support in the form of regular telephone calls. The responses reflected that receiving social support from family provided to emotional support for caregivers as well as a respite from caregiving.

> *My two sisters would take care of my daughter when I visited them (P7).*

> *The daughters will buy dinner for us on the way home. They came to visit their father on and off (P9).*

> *My daughter and son-in-law will fetch us out every week… (P8).*

> *My husband siblings come to meet him every week (P10).*

> *The children come back to see us once a week .. my daughter will come by on weekends with food (P1, Caregiver with low vision).*

6.4.2 Caregivers reframing perception and mentality

The caregivers interviewed employed positive reappraisal, acceptance of responsibility and self-control which are emotion-focused strategies. Positive reappraisal coping strategies leads to a reassessment of a situation and the emphasis on discovering the advantages and the positive aspects in stressful situation. The caregivers adopted positive reappraisal to reframe the situation and took proactive actions. Reframing aspects of their experience enabled effective coping and involved looking on the bright side, and reframing perceptions positively. These strategies involved a conscious effort to alter perceptions, appraisals or cognitions surrounding caregiving to promote a greater sense of well-being (Hawken et al., 2018).

The caregiver expressed pride in overcoming initial fears by taking charge of and learning to perform unfamiliar tasks. This extract reflects how the caregiver has strived to adapt to her life changing by learning new skills and knowledge so as to provide better care for her husband and to cope with her caring role. As a consequence, the caregiver developed a high level of positive caregiving appraisal despite the hardships of her caregiving tasks.

> *First 6 months, he learned from me not from SAVH [Singapore Visually Handicapped Association]. What I think we must make him adapt like normal people. I bring him out every night after dinner. We went to nearby shopping mall.. for him to understand he can go out. I believe we can go through this crisis together… I make him familiar with the surrounds… go and open letter boxes.. I gave him household chores to do everyday. …He most willing to try unfamiliar places…He was so proud he even posted the place we visited on Facebook. I am proud of him (P10).*

> *What I like in caregiving in achieving in giving to the other party… I feel bad if I cannot achieve it.. There is good times and bad times and enjoyable moments… help each other is success. (P2, Caregiver with low vision)*

Some caregivers found motivation in helping their care recipients to adapt to changes by dedicating time and energy to lift their spirits and provide physical support. Commensurate with the practice in familism, caregivers often engaged their family members in the caregiving support network. The caregivers acknowledged that the support given by other family members helped them cope. This idea may be related to traditional family care provision and the sense of family responsibility in Asia traditional culture. Many caregivers found this support network essential in keeping them going.

> *Caregiving is a positive experience for me… I know his eye problem… we spend time doing things together… I will take leave to bring to Malaysia and sometimes his siblings would come and pick him out for activities (P9).*

The Asia cultural values of familism not only instilled a positive caregiving experience for the primary caregiver but was also important in encouraging other family members to assist caregivers and be part of their support system.

> *The caregiving journey is good…. because of his handicapped… the children come by every week to go out for a meal. and we are much closer, they are helpful… they took the trouble to make thing possible for him. If my husband is not handicapped, they may not come as they would assume, we are independent (P8).*

The caregivers experienced a prevailing attachment to their care recipients that motivated them in spending cherished time together and doing all they could to ensure that their care recipients was well taken care of. Despite the apparent difficulties caregivers generally revealed acceptance of the role as they acknowledge that the complexity and demanding nature of the role is inevitable and to be expected. The adult caregiver shared that this as an opportunity to get closer to her father and strengthen their relationship. She even described having personally 'grown intrinsically' as a result of her caregiving role. Particular areas of growth included increased patience.

> *Caregiving made me more patient and calm. It brings me and my father together. My father is appreciative of little actions such as taking him to the nearest bus stop (P4).*

The caregivers in the study accepted the responsibility to care for the low vision individuals. The caregivers felt obligated to care for the care recipients, which is an Asian value of filial piety. Filial piety emerged as one of the ways that helped caregivers accept their caregiving role more readily. All caregivers interviewed saw their role as an obligation and duty especially for parents, spouses and children to care recipients. However, the non-sighted caregivers do not perceive themselves as providing care because instrumental activities of daily living including transportation, housework, grocery shopping, meal preparation managing finances were activities they deemed normal for couples do be doing for each other. They were capable of navigating the challenges well accommodating the unusual needs of the low vision individuals.

> *It's your duty since we married in 1971… I don't feel as a caregiver. As a husband, there is no barriers…. (P1, Caregiver with low vision).*

> *I feel the same as looking after my son.. are the same level of burden (P7).*

Two prominent roles that emerged were those of the low vision individual's children and the female caregiver. Caregivers who provide care for their parents felt that it was their duty to their parents and perceived it was repaying their parents for raising them. An adult caregiver felt the need to reciprocate as her care recipient had previously 'looked after her', so now it is (her) turn to look after him. Female caregivers, for instance those who were spouses, mentioned that it was the woman's role to provide care in the family. Hence these caregivers expressed acceptance of their "fate" and the role in their family as caregiver.

> *He is my father, my family so it is our responsibility to stand by each other as family.. as family we also support each other when anyone is down (P4).*

> *To be disable is not a choice for my husband.. we need to face it.. it is my responsibility to take care of my family.. I have to do it (P10).*

It should be noted that despite the stress experienced in caregiving, the caregivers interviewed underscored the strong sense of filial duty that motivated them to continue to care. However, the duty of filial piety can be stressful for caregivers who do not have family support, especially those without children.

> *I have no help because I don't have children. Only one niece who stays nearby come by once a while to visit us. Many friends encourage me to put my husband in nursing home (P6).*

The caregivers, however, may not always feel that they identify with the term 'caregiver'; instead, they often perceive their role to be an expected or a natural responsibility of adult life. For spouses, taking care of their other half was considered part of the marital relationship, whether husband or wife. The moral obligation emerged as one of the ways that helped caregivers accept their caregiving role more readily. Finding a reason for doing it helps caregivers get through the day and sustain their motivation in the long-term. A sense of purpose helped caregivers identify with the role and commit to it.

6.4.3 Subtheme 3: Caregiver adapting and managing negative emotions

Self-control was the most common emotion-focused strategy adopted by caregivers in this study. Self-control is the individual effort to manage one's own emotions and actions. Caregivers interviewed adopted self-control coping to endure the stress. Confucian values advocates emotional suppression of negative emotions to preserve interpersonal harmony (Tuomola et al., 2016). By endurance, they mean to tolerate the stress and to persevere in maintaining harmony during periods of intense challenge and difficulty. Caregivers believe challenges or difficulties are a natural part of life and that if they endure them patiently, they will survive.

> *We quarrel sometimes … but it is natural as we are husband and wife.. but I keep quiet to stop the argument … Take care of handicapped people …one has to be very patience and very calm.. need to tolerate and see what she needs (P1, Caregiver with low vision).*

One sibling caregiver expressed the moral justifications for bearing the brunt of the caregiving burden. Expressing sentiment that embodied elements of both altruism and familism, the caregiver stated that she had no choice but to accept the role of primary caregiver because their other siblings either had their own families.

> *There is like or don't like to be a caregiver for my mother. It is the lifestyle…. I cannot say I don't like it… My two sisters are married…my mother has to stay with me (P11).*

6.5 Core Theme 3: Challenges in Caregiving Journey

This theme describes the challenges of both sighted and non-sighted caregivers faced with the lack of healthcare and social support. They were not receiving timely and sustained access to the health and social systems to support their caregiving journeys. The caregivers interviewed were struggling financially, and thought that the current levels of financial support for caregivers are not sufficient. They highly recommended improving coordination and accessibility of information, as well as provision of emotional support and tangible assistance such as support groups and financial support. Their social identity as strongly linked to the cultural values of filial piety and the duty of obligatory care provided the motivations for their caregiving.

6.5.1 Subtheme 1: Lack of healthcare support

In Singapore the healthcare service is not completely publicly funded, financial constraints with high medical costs were uniformly recognised as a major concern among caregivers. The non-sighted caregivers reported having to lower the value of their medical saving plans, and also they did not earn much during their employment as they are visually impaired. Although they have been working for more than 10 years, their savings from their previous employment were not sufficient for retirement. One of the non-sighted caregivers had to resort to look for a donor to pay for his son's tertiary education.

> *My wife and I don't earn much… even my son education I need to look for a sponsor… I don't have much in my saving for medical fees…My son needs funds to study degree I asked from donors (P2, Caregiver with low vision).*

Only non-sighted caregivers who have adult children received monetary support.

> *I have no Central Provident Fund and my also use up her medical savings...without my daughter giving is money… how to survive (P1, Caregiver with low vision).*

Financial difficulties were particularly experienced by sighted caregivers. One of the elderly caregivers continued to work in part-time employment to cover her subsistence needs. Both sighted and non-sighted caregivers were burdened financially because of insecurity about the future and whether they would have sufficient savings to support themselves. It is relatively common to know older Singaporean workers who postpone their retirement plans and work, without institutional pensions, at jobs with low earnings such as cleaners or taxi drivers or security officers (Chan et al., 2022; Lee and Qian, 2017).

> *I am 64 and working part time for 16 years now. I have been doing this job (cleaner) to finance the family…This work has no Central Provident fund and annual leave (P5).*

The Central Provident Fund (CPF) refers to Singapore's mandatory social protection system based on a save-as-you-earn scheme that is the main formal source of old-age security. This system encourages individual responsibility and leads to a high savings rate. The CPF covers compulsory retirement savings along with medical care and housing. In 2016, the CPF contribution rate was set at 37 per cent of total wages (20% for employees and 17% for employers) (Fong, 2020). The amount a person has, and correspondingly their ability to pay for public housing, healthcare and retirement, is dependent on how long they have been able to sustain continual employment over their lifetime and their level of earnings (Kwan and Asher, 2022). The sighted caregiver in the present study were facing financial hardship as they had used up their retirement funds and the non-sighted caregivers were unlikely to save adequate funds for retirement security.

> *…I could not sleep well thinking of financial support. I worried the money is lesser how can I survived. Not everyone has S$10k in savings. The transport to bring him for day care and medical appointment is by taxi and the trip is not cheap cost S$60 for return trip (P6).*

Caregivers suggested that practical help should include financial assistance from government. Specific computer software is required to assist the visually impaired to accomplish the job at hand and IT software is typically not available from the employers. The non-sighted caregivers had to purchase IT software to accommodate their visual needs at work so they needed the governmental support for purchasing expensive IT software in order to enhance independence and self-sufficiency for both caregivers and care recipients.

> *The magnification software for reading and printing text to speech costs S$2000. My wife installs herself to the work desk computer in the company, the company may not trust the software (P3, Caregiver with low vision).*

One of sighted caregiver advocated that direct financial support in terms of an allowance for caregiving would be beneficial. An allowance is an income benefit providing extra money to relieve financial hardships for these caregivers. But this initiative is not available in Singaporean social policy.

> *.. money or allowance from government will be helpful for caregivers…(P5)*

6.5.2 Subtheme 1: Lack of social support

Only the male non-sighted caregiver had access to community social work service as he was working in a visually handicapped association. He sought emotional support from a formal support group to enable him to unburden feelings which is considered as emotion-focused strategy. However, one of the sighted caregivers talked to a colleague to let go of emotions probably because she did not know how to access a counselling service. The act of venting their concerns and emotions can have a calming effect that is essential for caregivers' mental and emotional well-being.

> *I shared with my social worker how I cope when I am not happy with my wife… (P3, Caregiver with low vision).*

> *I often talked to my colleagues not to vent my anger but to talk what happen to me (P10).*

Not only is access to social service for emotional support not easily available for sighted caregivers of the low vision individuals, but also to have support in finding / receiving information on eye conditions related to low vision posed a challenge to theses caregivers. One of caregivers interviewed, relied on the information on a website to understand her husband's eye condition. Currently, there is no support group for low vision care recipients or caregivers in the Singapore context.

> *I will try to understand his condition and surf the web for the condition to understand more (P10).*

For emotional support, almost all the caregivers expressed the need to set up a national helpline offering caregivers emotional support. A helpline providing relevant information or advice may serve to reduce ambiguity or uncertainty for an individual and hence pre-empt the development of emotional strain, especially in facing an unfamiliar task or situation (Enoch et al., 2021b). The caregivers reported that having more information allowed them to manage their care recipients and have a general understanding of their condition, as well as empower them to make decisions and help themselves.

> *Helpline will be good for caregivers because not easy for disable to throw tantrum on caregivers (P10).*
>
> *Hotline [Helpline] for caregivers will be good (P12, Caregiver with low vision).*
>
> *Helpline for caregiver will be useful when we are free we can chat (P5).*
>
> *A helpline will be useful for me to talk to someone(P6).*
>
> *I will suggest mental support is needed for caregiver (P7).*

The caregivers desired a peer support group to learn emotional coping skills from others to support them emotionally. A peer support group would provide a platform to share the caregiving frustrations, their anxiety and stress. The caregivers needed to manage the intensity of the negative and distressing emotions that a stressful situation, caused by problem behaviours of low vision individuals has produced. In these cases, caregivers shed light on the unique needs that were not met by support groups available to them.

> *The caregivers need a listening ear. I often talked to my colleagues what happened to me … not to vent my anger … Support groups for caregivers will be good (P10).*
>
> *We need a support group for caregivers to come together to share our journey (P11).*

Many caregivers felt that they did not identify with the term “caregiver” because they perceived this role to be simply another part of their relationship with the care recipient. As the role of caregiver is not recognised and valued in contemporary society, the necessary support systems are not in place, and many caregivers make financial and personal sacrifices. Caregivers themselves can also sometimes unintentionally undermine their caregiver identity by concealing the extent of informal care provision in an effort to “protect” their care recipient, thereby reducing the likelihood of receiving social recognition or the support resources they need. However being identified as a caregiver, one becomes part of a wider group of caregivers in their community, and a sense of comfort is gained in simply knowing that they are not alone in the challenges that they face (Carroll et al., 2019).

> *We don’t see ourselves as caregivers. We are companions as we have the same eye condition. There is no barrier in caregiving (P12, caregiver with low vision).*
>
> *I am not seeing myself as a caregiver.. Caregiving is nothing difficult … (P8).*
>
> *I am not sure I am considered as caregiver …(P9)*

6.6 Chapter Summary

In summary, the thematic analysis identified the emergence of three core themes. Findings from this study also extend the traditional transactional model of stress and coping in other ways. The sighted caregivers were overwhelmed with taking care of their relative with low vision, while the non-sighted learned to cope effectively. It provides evidence of the influences of the social and cultural context on family responsibilities, coping strategies and quality of life. The findings also highlighted participants’ stress and burden in carrying out their family caring responsibility or living with low vision under the current social situation. However, the quality of life of the non-sighted caregivers was not affected either physically or mentally.

In the framework of Lazarus and Folkman’s Stress Coping Theory, the caregiver will assess whether or not a stressor is threatening, challenging or potentially harmful and whether or not he/she has the means to deal with that stressor. The caregivers employed different resources and adopted different cognitive behaviours; some coping strategies were the result of the negative effects of stress and had a main effect on their quality of life (Lazarus and Folkman, 1984). For instance, the caregivers felt their life circumstances directly affected their ability to undertake social engagements and felt their working life was hindered by what they appraised as their stressful situation which in return impacted their mental well-being. Fortunately, both sighted and non-sighted caregivers were able to cope with these demands by using a coping strategy in which enable them to provide a positive environment to the low vision individual. Having said that, sighted caregivers often lost social interactions with friends and family as they had to devoted more of their time to caring. However, the current social infrastructure and community to support caregivers of low vision are limited in providing support for long- term caregiving. The next chapter presents the integration of both Phase One and Phase Two studies with an in-depth critique of key findings and critical discussion of contributions to existing theoretical knowledge.

Chapter Seven Discussion and Integration of Quantitative and Qualitative Findings

The purpose of this study was to examine the relationships between caregiver burden, coping strategies, health outcomes, and health utilisation with the quality of life of caregivers of low vision individuals. The aim of this chapter is to critically discuss how both the quantitative and qualitative findings address the various research questions of this study. In general, themes derived from the qualitative interviews were utilised to complement and provide further insights on the results of the quantitative analysis. This chapter also includes discussion on how findings of the quantitative and qualitative phases are integrated and how these supported the proposed theoretical framework.

7.1 Demographics of Caregivers

Analysis of the demographic information revealed that more than half of the caregivers were primarily middle-aged, females, educated, married, and who had full-time jobs at the time of the study. Their profile was similar to those in the current literature reviewed in Section 3.5.1, who were also middle-aged, female, married, and had received a high school education. However, employment was not captured in this study. Likewise, when compared to the recent large UK dementia caregiver study (Gilsenan et al., 2022), the profiles were similar, although education level and employment were not recorded in this study.

7.1.1 Employment and Care-related Leave

It is interesting to note that 45% of the caregivers in the study were not in employment as some of them were retirees and some had left their jobs to become full- time caregivers. A similar situation was reported in the UK where over 2 million caregivers gave up work at some point to accommodate their caregiving roles, with 3 million having to work on a part-time basis (Glasby, 2017). Based on the Singapore Ministry of Manpower's 2017 Comprehensive Labor Force Survey, it was found that 12,500 caregivers had left their job within the last three years and cited caregiving to families or relatives as the main reason. In addition, the majority of these caregivers were aged 40 and over and were not due for retirement. The official retirement age in Singapore with effect from 1st July 2022 is 63 (Tan, 2021). One of the plausible explanations for this high level of unemployment among caregivers in the study may be due to the high work demand in Singapore. Singapore was ranked second for the longest workweek in the world, and a caregiver who is in employment will need to work as long as 48.2 per week (Yacob, 2015). Such long working hours make caregiving very challenging and may force the caregivers to give up working (P. T. Straughan and Tadai, 2018). Thus, caring for a low vision individual may lead to changes in work participation which subsequently reduces earnings (Varano et al., 2016; Gohil et al., 2015; McDonald et al., 2020).

The literature review in Chapter 3 suggested that caregivers of low vision required a minimum of 10-20 days of paid caregiver leave to accompany low vision individuals for eye medical reviews and treatment. However, in Singapore the government has encouraged all industries to implement Family Care Leave or Eldercare Leave of 2 to 3 days to facilitate the combination of caregiving and employment, which is definitely insufficient. Given that there is no legislation to mandate companies to offer employee caregiver leave, only about 20% of private companies have been willing to initiate it in Singapore (Mehta and Leng, 2017). In order to potentially decrease the number of caregivers leaving the workforce, current literature argues that legislated caregiving leave be provided to allow employees to remain remunerated while taking several days off to care for a disabled relative, is necessary (Chong, 2020).

7.1.2 Caregiver Kinships

Low vision is more common in middle-aged adults, therefore caregivers are more likely to be a spouse rather than children. In the present study, nearly half the caregivers were spouses of care recipients, 35% were parents and only 10% were adult children. This is also reflected in the marital status of caregivers at the time of the study. These findings are consistent with the results in the literature review which found that spouses were the primary caregivers of low vision individuals (Hanemoto et al., 2017; Bambara et al., 2009; Silva-Smith et al., 2007; Weyer-Wendl and Walter, 2016; Larizza et al., 2011; Gohil et al., 2015; Varano et al., 2016; Ruiz-Lozano et al., 2022). In caregiving research, it has been found that spouses are the first choice for the role of primary caregiver and an adult child is the second choice of a care recipient (Leonardi et al., 2018). The Singapore Survey on Informal Caregiving (2013) also showed a larger proportion of caregivers (77%) were adult children, only 16% were spouses and the rest were other family members such as siblings. The present study also found approximately one quarter (35%) of the caregivers were parents of low vision individuals. One possible explanation could be that care recipients who lose their vision from childhood, were less likely to have children or spouses who may be called upon to care for them and parents were therefore the primary caregiver.

In the sample of caregivers of low vision individuals, 68.3% were female. Similarly to the profile of informal caregivers in general, approximately 80% of the caregivers are female while men, who are regarded as traditional family breadwinner, are less responsible for informal caregiving (He, 2021; Bisom-Rapp and Sargeant, 2016; Bouchard et al., 2021). In the Singapore context, care has been predominantly embedded within the family system and associated with women who are either wives, daughters-in-law, and daughters (Ogawa et al., 2018). Thus, the eldest son's wife is expected to be the first to take on caregiving of her mother-in-law and the daughter who is unmarried is also expected to provide the caregiving (O'Neill, 2018). There is a social construct in the Asian context whereby women are expected to fill the role of caregivers based on the beliefs about women as natural care providers and the family having protective functions for its members (Qiu et al., 2018). The caregiving skills are commonly regarded as an innate skill naturally possessed by women (Huang and Yeoh, 2018).

However, the assumption that all women are naturally suited to caregiving and able to cope with the needs of low vision individuals raised some questions based on the evidence presented here. The qualitative findings presented a picture of woman caregivers coping with difficult situations and limited formal social support. The female caregivers, particularly the older caregiver, narrated restrictions on employment opportunities, concerns about their own physical health, and a sense of abandonment by the social security system. They illustrated the significance of this growing health and social care problem that can be perceived as quiet desperation among this group of women caregivers who provide a valuable service to family and society (Isac et al., 2021).

7.2 Experience of Caregiving: Integration of findings

7.2.1 Quality of Life: Physical Health

The current study utilises a mixed-methods design to provide some preliminary insight into the experiences of caregivers of low vision individuals in Singapore. The findings of both the in-depth interviews and surveys suggest that being a caregiver of low vision individuals decreased their physical and mental health. The quantitative data revealed the caregivers' physical and mental quality of life were lower as compared to the caregivers of oncology patients in a local study (Lim et al., 2017). The qualitative findings confirmed that their impaired physical health was due to exhaustion from caregiving, and work commitments. Interview narratives also demonstrated that the caregivers who were employed struggled with multiple caregiving tasks for a long duration, leading to a lack of energy. Current literature has showed longer caregiving hours and provision of personal care result in negative physical wellbeing of caregivers of low vision individuals (Varadaraj et al., 2021; Kokorelias et al., 2020; Varano et al., 2016). Moreover, impaired physical health was reported in the interview narratives of the sighted caregivers who were female, older and working. Impaired physical health was not reported in the interview narratives among non-sighted caregivers. A possible explanation may be that non-sighted caregivers were capable of managing their work and caregiving duties simultaneously, since they were working at the time of the study.

7.2.2 Quality of Life: Mental Health

The quantitative findings showed the impairment of mental health was greater than the physical health of care givers. Empirical evidence has shown that the impaired mental health of caregivers of low vision individuals were often due to caregiving-related challenges (Ruiz-Lozano et al., 2022; Varadaraj et al., 2021). This is confirmed by the qualitative findings where caregivers expressed emotional distress as they felt unable to leave their care recipients alone and, consequently, had less time for their own social activities. Caregivers interviewed also revealed sleep disturbances, experienced constant worries and fear about the ocular condition of their care recipients and were anxious about the risk of falls of care recipients.

This is in congruent with the current literature which found caregivers of low vision individuals are more likely to experience negative emotions such as loss of sleep, worry, stress, fear, frustration, and uncertainty associated with providing care (Kuriakose et al., 2017; Varano et al., 2016; Varadaraj et al., 2021). Impaired mental status can potentially reduce caregivers' capacity to continue caring for low vision individuals and may result in deteriorating care and even neglect. However, similar psychological distress was not reported from non-sighted caregivers in their interview narratives. A possible explanation could be that non-sighted caregivers lose their vision in childhood; thus, they are better prepared to face the challenges and know how to address the psychological distress of their care recipients.

In addition, previous literature in other chronic illness populations have indicated that impaired mental health is related to reduced social participation in society (Swartz and Collins, 2019; Ghosh et al., 2020). Time and energy spent on caregiving cannot be spent with family members or friends. The result is a feeling of time pressure and a reduction of time spent on activities that generally give pleasure and joy. A national survey in Japan reported that participation in social activities substantially improved caregivers' mental health (Oshio and Kan, 2016). This study observed that caregivers' psychological distress was reduced by more than 50%, after engaging in social programmes. Thus, caregivers of the low vision individual who engage in social interactions may be more likely to alleviate the adverse impact of caregiving on their mental health. Finally, the findings from the present study revealed that there were notable differences in the degree of impaired quality of life experienced between the sighted and non-sighted caregivers.

In the present study, the caregiver's quality of life was not associated with caregiver burden. This finding contradicts previous literature where caregiver burden was the main determinant of caregivers' quality of life (Hsiao et al., 2020; Young et al., 2017). Hsiao and colleagues (2020) discerned that the overwhelming caregiving demands, without formal social support for the caregiver, was the reason why the caregivers reported high caregiver burden and poor quality of life. Whereas the study by Young et al, (2017) observed that the Asian values of collectivism and filial piety positively influenced the caregivers' quality of life despite high level of caregiver burden. One possible explanation of this relationship in the present study is that the improvement in caregiver quality of life over time may be related to the caregivers' adaption to the caregiving role and their overcoming caregiving- related situations. The study by Rand et al., (2018) observed that impaired caregivers' quality of life was positively related to a longer duration of caregiving; more than 10 years and with a higher intensity caregiving of more than 10 hours per week.

7.2.4. High Caregiver Burden

High levels of caregiver burden were reported in the survey for the present study. The National Alliance of Caregiving in the United States (2015) reported that a high level of caregiver burden is often related to the duration of caregiving. The current literature reported that prolonged caregiving was positively related to caregiver burden, suggesting that the longer the caregiving period, the higher the caregiver burden (Gohil et al., 2015; Shtein et al., 2016; Vukicevic et al., 2016). This could possibly by explained by the inference that the high level of caregiver burden was due to the prolonged caregiving period for low vision individuals, with an average of 16.6 years as reported in this study. Thus, the finding suggests that there is a significant prevalence of caregiver burden in the caregivers of low vision individuals in Singapore.

The current literature showed that the experience of caregiver burden was frequently related to the demographic characteristics of the caregiver. For example, caregivers with a low educational level (Ge and Mordiffi, 2017; Isac et al., 2021) and who were younger (Jin et al., 2021; Varano et al., 2016; Weyer-Wendl and Walter, 2016; Ruiz-Lozano et al., 2022) were more likely to experience a greater burden from their caregiving. Caregivers with a low level of education may have limited capacity in decision-making about care, contributing to higher caregiver burden (Chiao et al., 2015). While it was reported that younger caregivers were often found to report higher levels of burden due to the competing demands of their role, and responsibilities for work and their own family (Gohil et al., 2015). However, the present study reported contrary findings whereby age and education level were not significantly associated with a higher caregiver burden. The explanation for the contrary findings might be that the majority of caregivers in the present study were considered as to be highly educated as those in the middle-aged group. They also could have adjusted to the caregiving situations and learnt adaptive caregiving skills through trial and error. This is elaborated through the qualitative findings that showed caregivers proactively sought support to solve caregiving issues. For example, the sighted caregivers who had no experience in caring for low vision and did not have information regarding low vision rehabilitation reported that they sourced relevant information through websites and joined overseas support groups. A few of the caregivers mentioned that they designed their own approach or ways of coping by arranging simple household chores for care recipients. These include taking a lift to go to pick up letters, allowing care recipients to prepare simple meals and run errands. One of the caregivers tried to "dine in the dark" to understand the experience of having low vision. Understanding the specific needs requires the unpaid caregivers to possess a level of understanding of the functional limitations of the impairment and how to appropriately adjust tasks to help the care recipients adapt (Weisser-Pike, 2018). Findings from the qualitative interviews provided further insights on the caregiving-related struggles of caregiver who had not attended any caregiver training.

7.2.4.1. Caregiver Burden Related Personal Strain

Further analysis of the quantitative findings demonstrated that, personal strain contributed to higher levels of caregiver burden scores than role strain. This finding indicated that personal feelings such as anger, discomfort, and stress experienced by the caregiver is more burdensome among low vision caregivers as compared to other aspects such as dependency of care recipient, reduced social life and lack of control over their personal life since taking up the caregiver's role. The qualitative findings showed similar phenomena, where personal strain impacted their quality of life more than role strain. In terms of personal strain, the caregivers interviewed revealed frustration and strain in providing caregiving to low vision individuals and communicated that they were unfamiliar with care work. They also reported strain in communication with low vision individuals. This is consistent with a scoping review conducted by Pur and colleagues (2022) which asserted that the identified personal strain among caregivers of low vision individuals is due to care recipients not being able to see caregiver's gestures and body language (Pur et al., 2022).

Evidence related to personal strain was also revealed in the qualitative findings where caregivers expressed that competing responsibilities and time demands were contributors to caregiver burden. These findings were consistent with the literature in a recent systematic review on the positive relationships between caregiving time and caregiver burden among caregivers of low vision individuals(Pur et al., 2022; Hazzan et al., 2021). Other challenges related to the impact of caregiver burden include disruptions to their work schedule, personal obligations and engagement in social activities among caregivers with eye diseases (Varadaraj et al., 2021).

7.2.4.2. Caregiver Burden as Related to Asian Culture

A local systematic review comparing caregiver burden from a cultural perspective found that Singaporean caregivers generally experienced a greater burden as compared to caregivers in Western societies (Loo et al., 2021). This may be explained by the co-resident phenomenon in Asian societies. The contribution of co-residence with care-recipients on predicting care burden is well-documented in Asian studies (Chen, 2016; Koo et al., 2021). Within Asian culture, it is common to have multigenerational family homes in countries like Singapore and East Asian societies (Shea et al., 2020; Thang and Mehta, 2020). Co-residing with low vision care recipients is also likely to come with relatively heavy and intensive caregiving. The situation could be: the closer the bond, the greater the amount of strain. Past studies suggested that the more caregivers feel that family members have a responsibility towards other family members the more likely they are to feel strain. This may place a more direct burden on the caregiver (Thang, 2019; Isac et al., 2021). Within Asian culture, caregivers commonly do not differentiate their caregiving role from their other daily activities as they viewed caregiving as just another part of family life (Huang and Yeoh, 2018; Quah, 2015). The caregivers interviewed suggested caregiving was based on social relationships such as familial and marital relationships. Hence, they tended not to perceive themselves as a caregiver. The caregiving duties among Asians tend to be culturally ingrained and the struggles of caregivers tend to go unnoticed or unaddressed by the society (Bastawrous, 2013). Filial piety obligations narrated by the caregivers are key to understanding the experience of caring for low vision individuals. In this context, the provision of care to a low vision individual is an obligation of family members. As such, filial piety strongly influences the way in which these caregivers carry out their roles and is a protective factor in keeping caregivers engaged in the process. There is a strong emphasis on familism instead of reciprocal affective ties in caregiving. Thus the caregivers tends not to express their true feelings about caregiving, and suppress the expression of emotion making them more vulnerable to depression (Hu et al., 2018). Hence, it is logical that greater caregivers' burden could be influenced by cultural norms.

7.2.4.3. Caregiver Burden Related Coping

While the present study did not present any evidence of a significant relationship between demographic characteristics and caregiver burden, findings from the quantitative analysis revealed a positive correlation between caregiver burden and coping strategies. There were positive relationships between caregiver burden and problem-focused coping ($r=0.46$, $p< 0.001$) and emotion-focused coping ($r=0.26$, $p <0.05$). These positive relationships , however, did not alleviate the high level of caregiver burden for caregivers of the low vision individual. Within the care literature, there was a paucity of studies examining caregiver burden and coping strategies. Two cross-sectional studies on caregiver burden and coping reported positive relationships. A study by Lu and colleagues (2017) shows that caregivers have used coping strategies with encouraging results in terms of decreasing the caregiver burden. While another study by Kazemi and colleagues (2021) reported that more regular use of emotion-focused coping, and problem-focused coping was related to lower caregiver burden among caregivers with a higher caregiver burden (Kazemi et al., 2021). These studies concluded the fundamental importance of caregiver training to increase caregiver's use of effective problem-focused strategies.

7.2.5 Coping Strategies Related to Asian Values

Again, the caregiver demographic characteristics such as age, and education were not significantly related to coping strategies in the present study, despite these factors having been shown to be important in other caregiving studies (Lin and Wu, 2014; Papastavrou et al., 2012; Huang et al., 2015). In the quantitative findings, caregivers adopted more emotion-coping strategies and the themes derived from the interviews corroborate these findings. In the narrative interviews, the most common emotion-focused coping strategy described was the high priority placed on one's capacity to endure situations that one cannot change (Y. Lee and Song, 2022). The caregivers interviewed adopted this coping mechanism to manage and gradually adapt to their negative emotions. The existing literature also showed Asian caregivers prefer to deal with stress by employing emotional coping strategies (Zhang et al., 2020; Leow and Chan, 2017). This is consistently found in the caregiving literature which shows that in the Asian culture, it is acceptable to expect the caregiver to endure caregiving related stress and not to discuss it with anyone outside the family (Mehtha 2020). This enduring process promotes the value of family harmony whereby the needs of the family as a whole are more important than those of individuals, and this value of familism is held strongly among Singapore Chinese families (Sim et al., 2017). This suggests that as a coping strategy, the caregivers consciously and constantly reframe their perception and regulate their emotions related to caregiving. Given the significance of family harmony within Asian culture, it can be perceived as a strength that motivates family members to stick with one another through difficult times like a health and care crisis. Interestingly, this finding did not emerge in other qualitative caregiving studies in Asia, and this therefore represents a novel finding.

Although some literature asserted that caregiving can be seen as a duty that caregivers are obligated to fulfil, qualitative findings in the present study revealed caregivers accepted the role and assumed it as part of their lives. The feelings of acceptance and sense of duty was another emotion-focused coping strategy that, could have made caregivers feel that things were beyond their control. This finding is understandable given that a significant value within Chinese culture is the acceptance of heaven’s will; this takes the form of accepting what happens in one’s life (Sim et al., 2017; Tan-Ho et al., 2020). The traditional expectation for those within a Chinese cultural context is to place the needs of family members above their own. However, emotion-focused behaviours tend to focus more on their ability to control their own emotions, however, acceptance of responsibility strategies rarely meant that caregivers reported a reduction in caregiving stress (Pan et al., 2022). In this study, most caregivers expressed coming to a stage of acceptance and shifting their focus to positive thoughts or emotions, which is consistent with Lazarus and Folkman’s definition of coping. The caregivers perceived coping as a purposive cognitive or behavioural change to deal with the appraised external or internal demands (Lazarus and Folkman, 1984). This is demonstrated in the interview narratives which show a greater reliance on emotion-focused coping strategy than problem-focused coping among the caregivers of low vision individuals. However, it is important to note that findings from the present study revealed that the acceptance of fate and familial duty does not improve their mental health, or quality of life.

A plausible explanation for that is the caregivers are bearing a heavy caregiver burden and enduring caregiver difficulties, which led to poor quality of life. The qualitative findings revealed formal social support services such as caregiver training to alleviate caregiver burden, are underdeveloped and community caregiving to the low vision population is limited in Singapore compared to the UK and US. In the UK, there is the National Federation of the Blind and in the US there is the American Foundation for the Blind. Both national foundations conduct caregiver training for the partially sighted and blind.

On the other hand, caregiving literature reported the norms of filial obligation and familism and associated them with positive caregiving experiences (Devi et al., 2020; Nie, 2021; Muyskens, 2020). In the qualitative findings, caregivers interviewed appraised caregiving as based on the obligation arising from being part of familial and marital relations. Caregivers found meaning through caregiving within the context of a relationship with another family member. This is consistent with previous literature showing that it was the meaning that people find through looking after other people, that motivates them to undertake an activity that demands sacrifices (Zhang et al., 2020; S. Wang et al., 2020). Filial piety and familism are not confined only to the Chinese ethnic group, but also pervade in the Indian and Malay cultures in Singapore (Mehta, 2017). The international literature on caregiving has also supported this notion as the motivation for caregiving. In Western culture, providing caregiving is considered a prosocial behaviour, that is, an action characterized by love, empathy, trust, and altruism (Revenson et al., 2016). It involves intrinsic motivations such as a desire to care, resistance to formal care and seeing caregiving as a part of one’s identity (O'Neill, 2018). Children who have stronger affection for parents are more likely to provide greater social support and be more committed as caregivers. The responsibility of being the caregiver does not exist solely because of the kinship relationship, but rather is created between family members as active participants (Chappell and Funk, 2012). Thus, the motivation of caregiving for both cultures is relatively similar.

The present findings revealed a plausible mechanism of how filial values function as a motivator of caregiving and a predictor of caregiving appraisals to help protect caregiver wellbeing. However, the present findings should not be interpreted as proof that caregivers with filial values are more likely to be exempt from the negative effects of caregiving challenges. Attention should be given to caregivers who are motivated by filial values to take on more responsibility, which may put them at risk for greater role strain.

Nevertheless, Asian values have been undergoing subtle changes in this rapidly developing society. A study conducted in Singapore reported that caregivers who internalised and prioritised societal expectations over their personal wellbeing most often faced internal conflict and were more highly likely to experience difficulties in maintaining their mental health, familial ties and caregiving duties (Ng et al., 2016). This is corroborated by the evolving attitudes towards such Confucian rules whereby younger Asian generations no longer perceive absolute submission or complete obedience to the family as instrumental values in a modern and globalised society (Tan-Ho et al., 2020). The caregivers want to be released from their caring burdens but feel obligated to care. The suppression of feelings and the obligation to take on the care recipient's suffering may cause caregivers to burn out (Tan-Ho et al., 2020).

This is not, of course, to assume that the same perceived sense of duty does not exist among Western families; the difference is the value of caregiving in western societies is focused more on individualistic-oriented values based on commitment, respect and affection (Muyskens, 2020). Thus, adult children are not morally responsible to be the caregivers for their disabled parents, and parents do not expect children to look after them (O'Neill, 2018).

Interestingly, most caregivers interviewed found caregiving made them a better person. Thus, the qualitative findings suggested the experience of caregiving has unique positive influences on the individual's sense of self. The feeling of accomplishment can lead to inner strength from things caregivers learn about themselves through their caregiving journey (Washio et al., 2019; Liu and Lou, 2019). Previous literature has reported that Asian caregivers who were capable of using a problem-solving approach had learnt how to regulate their emotions and constructed positive meanings from their experiences (Vaingankar et al., 2020b; Devi et al., 2020). The meaning that they find through caregiving motivated the caregiver to sustain their caregiving practices but also lead to positive appraisal. Thus, the caregiving experience was rewarding and contributed to positive effects on caregivers' quality of life (Huang et al., 2015).

This is in line with the assumptions of stress-coping theory (1984) whereby caregivers who can find a sense of purpose or meaning associated with their experience are less likely to be overburdened, lessening the negative implications of caregiving.

Based on stress-coping theory, caregiving challenges personal strain (Lazarus and Folkman, 1984). In this instance, the sighted caregivers realised that their social life, such as participating in social activities and maintaining social relationships, may have been affected by their role as a caregiver. The caregivers decided to sacrifice their time for socialising or networking according to filial values. These sighted caregivers do not use their coping skills to make a change in their social lives.

Filial values promoted coping skills such as positive re-appraisals, and seeking social support (Xiuxiang et al., 2020; Zhang et al., 2020). In this instance, caregivers may utilise their own internal resources such as support from family members or friends to cope with their caregiving. The problem-focused coping strategy employed by caregivers in the present study was to take advantage of family resources. The family resources may include the extended family or immediate family members who provide social support to primary caregivers by directly offering care or indirectly dealing with other affairs. The interview narratives revealed that both sighted and non-sighted caregivers relied closely on the tangible support from their immediate and extended family. Much support was offered by the family members aiding them to participate in daily activities, buy meals and accompany care recipients on short trips. The problem-focused coping strategies presented were a form of informal social support. Informal social support can be considered a mediator of secondary appraisal. Caregivers with high levels of social support tend to have greater capacity to mentally and physically respond to caregiver stressful events (George et al., 2020; Jones et al., 2019).

In addition, this finding is consistent with qualitative systematic reviews of Chinese caregivers which showed such caregivers tend to seek help from immediate and extended family (Cai et al., 2021; Tyagi et al., 2021). The two reviews reported that additional informal family support was considered to be encouraging, along with mental and financial support which could prevent isolation and depression from prolonged caregiving. According to Haya et al., (2019), reduced emotional and physical burden were reported by primary caregivers when more family members could be involved in caregiving, resulting in better social and personal life. This association is possible because informal social support may provide a sense of social security for the caregivers. From the social policy aspect, the Singapore public has been constantly reminded that family should be the first line of support (Thang, 2017). This is a distinctive coping strategy that is emphasised though family resources and connectedness strategies that have been strongly fostered by the Singapore government. Hence, family support is significant for the social welfare provision in many aspects in the country (Mathew and Ng, 2016; Thang and Mehta, 2020).

Concluding that constructs such as familism and filial piety have harmful effects on caregiving experiences is an oversimplification. As this study indicates, the effects of these values on caregiving simultaneously include positive and negative aspects. The caregiver's cultural backgrounds seem to help caregivers to appraise caregiving in a more positive light and accept the caregiving role. Furthermore, the findings of this study support the use of coping strategies as having a positive and significant effect on caregivers' quality of life. Both problem-focused and emotion-focused coping strategies have been recognized as ways to respond to stressful events, but the two are different in nature. This study found that problem-focused coping strategies have a reverse buffering effect, effectively improving caregiver quality of life. But the coping strategies of the caregivers of low vision individuals have yet to be extensively studied. Hence, both quantitative and qualitative data obtained herein may be useful for the development of intervention programmes for culturally appropriate coping strategies.

7.2.7 Caregiving Experience and Predictors of Quality of Life Among Caregivers

The results from the regression analysis revealed that the strongest predictor of impaired quality of life, was coping processes while caregiver burden, health outcome and health utilisation were not significant predictors. The quantitative findings showed both problem-focused and emotion-focused coping were unique predictors for caregivers' quality of life. problem-focused coping was a significant predictor of totally quality of life ($\beta = 0.46$, $p < 0.05$), suggesting a higher quality of life is predicted by greater use of problem focused strategies. However, emotion-focused coping was found to have a negative significant relationship with caregiver quality of life ($\beta = -0.44$ $p < 0.05$), suggesting a lower quality of life was predicted for those employing emotion-focused coping strategies. The regression model explains that both problem-focused coping and emotion-focused coping made a unique contribution, explaining 16% of the variation in the quality of life of caregivers.

These results were consistent with the aforementioned studies that have shown caregivers employing problem-focusing coping strategies experienced better quality of life. Coping research has reported that caregivers who used more emotionally-oriented coping a had poorer quality of life while problem-focused coping was generally associated with improved psychological well-being, and quality of life (Biggs et al., 2017; Ghane et al., 2016). Generally, emotion-focused coping is regarded as maladaptive and ineffective, with emotion-focused coping associated with negative outcomes (Liu, 2019). However, from the qualitative findings, few sighted caregivers reported a lack of problem-focused coping skills affected how they coped with caregiving. It is possible that a lack of formal caregiver training on problem and emotional coping skills could result in impaired mental health among the caregivers (Pur et al., 2022). In challenging and frustrating circumstances, the caregiver's ability to somehow relax and unwind is very important. Maintaining hobbies, outside interests and taking the mind off caring, together with securing a little personal time, are seen to be particularly essential in the caregiving journey (Sabo and Chin, 2021).

While, coping strategies, namely problem-focused and emotion-focused coping, were unique and significant factors for predicting, caregivers' quality of life, the model was only able to explain 16% of the total variance of the dependent variable. These findings suggested that other variables not measured in this study could be salient factors for explaining the quality of life among Singaporean caregivers of low vision individuals. As alluded to in the qualitative data, this may be related to the huge need for coping resources to support the caregivers. Specifically, the unmet coping needs identified were related to the lack of formal healthcare and social care support, peer support and monetary support in caregiving. These findings were consistent with previous studies demonstrating caregivers of low vision individuals often encountered obstacles in dealing with the complexity of the health-care systems due to the lack of economic and social resources (Gohil et al., 2015; Weyer-Wendl and Walter, 2016).

7.2.7.1 Lack of Coping Resources

The caregiving literature has advocated the importance of social and health care support as coping resources to sustain the quality of life of caregivers (Enoch et al., 2021b; Feinberg et al., 2021). In a recent survey conducted on UK health professionals, it was reported that there were existing gaps in emotional support and tangible resources for caregivers of low vision individuals (Enoch et al., 2021a). This survey reported that financial support from the UK government for low vision caregivers was not sufficient and there was urgent need of respite care. In specific, the caregivers of low vision individuals in the UK do not have timely access to support services because of difficulties in navigating an under-resourced and complex social and health system. The caregiving recommendation from the US government stated that direct monetary support or old age allowance for caregivers, income supplements, flexi-work arrangements, and tax relief or exemption were needed to support caregivers (Qualls, 2021). In specific, tax relief would cover a broad range of expenses incurred by caregivers including caregiver travel costs and, home modification (Wang and Wu, 2018). Past research argued that generous resources and extensive social services for caregivers must be made available by the government to improve the caregivers' quality of life (Feinberg et al., 2021; Hazzan et al., 2021).

In comparison to the health and social care approaches in the UK and US, the Singapore social and health policies underscores "the state as the last resort" (Yew, 2020). Self-reliance, family and community support are the three pillars of the social welfare framework, thus financial, social and health care support are not readily accessible to caregivers of low vision individuals (Thang and Mehta, 2020). This policy may have shaped the experience of caregivers in Singapore. In the community, many assistance schemes and benefits are targeted only to lower income Singaporeans (Theseira, 2022). It was asserted that, many of the caregivers of low vision individuals may not be eligible for these schemes (Wong, 2015).

In Singapore, there are three non-government service providers for vision rehabilitation; Singapore Association of the Visually Handicapped (SAVH), Guide Dogs Association of the Blind and iC2: PrepHouse which provides specific rehabilitation for children with low vision. These are non-profit organisations representing the visually impaired and offering core support programmes to people both newly diagnosed with visual impairments and those needing to acquire ongoing skills to live with visual impairment. Despite receiving assistance from the government, the interviews in this study revealed it is insufficient to address the caregiver stress that has occurred (Wong, 2015; Poon and Wong, 2017).

The lack of support within social and healthcare policy is a barrier to alleviating the burden and the responsibility of caregivers in Singapore (Basnyat and Chang, 2021; Mehta, 2020). This might explain why the caregivers in this study experienced difficulties in saving adequate retirement funds, and were facing financial hardships. Two of sighted elderly caregivers were working in part-time employment to sustain household expenditure. Their financial coping capacity was limited with low household income and inadequate savings. Few non-sighted and sighted caregivers received regular monetary support from their children. One of the non-sighted caregivers was unable to support the tertiary education of his son due to his low earning and financial constraints. The complex nature of caring for low vision individuals in Singapore is challenging, especially for ageing caregivers and non-sighted caregivers.

7.2.7.2 Lack of Financial Support

The caregivers expressed immense financial challenges, asserting that they were not well-supported by social and health care support systems in Singapore. For example, the caregivers interviewed were required to purchase specific IT software or devices to optimise residual vision for care recipients. The IT software is imperative to keep the low vision individual independent and able to gain and /or retain employment. But the costs of IT supports is generally expensive and, the subsidies to purchase such expensive software are not available. Moreover, negative attitudes and prejudice towards visually impaired people within employment is still very common (French, 2017). This is clearly reflected in the qualitative findings which showed that employers' reluctance to provide additional IT facilities to support employees with low vision, was one of the reasons the competent non-sighted caregiver had difficulty in gaining employment. In the present study, those non-sighted caregivers who lost their sight after childhood reported challenges to gaining employment when he/she loses their job.

Whilst recognising that the sample presented in this study is not representative of visually impaired workers, the narratives provided important insights into the problems experienced by visually impaired people including attitudinal, environmental and structural barriers at work (Manokara, 2021). Generally, visually impaired people take longer to accomplish tasks and consequently work longer hours. They do find mobility difficult in many workplaces, as well as in the physical environment (French, 2017). Despite the Singapore government's initiatives, since 2013, to enhance employability for persons with a disability, it is disturbing that the findings demonstrated that the problem of employment among people with disabilities has persisted and have proved so resistant to change (Chai et al., 2021).

The qualitative findings revealed non-sighted caregivers experienced greater financial constraints and underemployment than sighted caregivers. In specific, the non-sighted caregiver reported stagnant low wages for more than 10 years. A population-based Singapore study by Chai and colleagues (2021) showed that people with low vision had 50% greater odds of underemployment. Therefore, non-sighted caregivers were more at risk of underemployed or unemployment. In addition, a Singaporean in a low-paying job is more likely to experience stagnant wages and employment insecurity (Ng et al., 2018). In other words, the double barriers experienced by the interviewees, as caregivers and a person with a disability, further constrained their financial capacity and livelihood. These results also suggested there is a lack of social welfare policy for informal care provision customise to the low vision community, and less publicly funded support services. These are all related to the increased burden among caregivers.

The Singapore government has opted for a non-welfare state approach and is reluctant to make cash payments directly to support caregivers (Lim, 2017). Central Provident Funds (CPF), a contribution-based system, provides the financial security for older Singaporeans. The adequacy of the retirement funds depends on one's own savings and employer contributions. Individuals with a higher income or more consistent employment histories will have a larger retirement benefit (Fong and Borowski, 2022). However, the CPF does not provide insurance for unemployment or disability risks (Rozario and Pizzo, 2022). This raised the issue that Singaporeans who become unemployed may not be able to withdraw funds from the CPF until age 55 (Lim and Kuhanesh, 2022). Hence, caregivers with a low earning capacity or poor history of employment would not have adequate savings for retirement as the caregivers' CPF savings are often low due to their short contribution span to the scheme, and a history of part-time and low-waged jobs. Thus, the qualitative findings have revealed that the lack of financial support was a huge concern for these non-sighted and sighted caregivers.

7.3 Theoretical Contribution of the Transactional Model of Stress and Coping

The results of the present study support Lazarus and Folkman's (1984) predictions that coping strategies influence the low vision individuals' caregivers' quality of life. Within the transaction stress model, Lazarus and Folkman (1984) focus on the distinction between problem-focused and emotion-focused coping. The present study suggests inadequate coping skills can result in the caregiving experience being more stressful than it need be, and an appraisal that the caregiving situation is perceived as an immersing strain by the caregivers of low vision individuals. The caregiver's inability to cope with the demands of caregiving will, to a great extent, influence his or her physical, and psychological well-being. Indeed, in the present study caregivers were adopting more emotion-focusing strategies than problem-focused strategies. This is consistent with Lazarus and Folkman's theory which asserts that to successfully cope with stressful events during caregiving, the caregiver needs to practice less emotion-focused strategies which have more negative outcomes (Lazarus 1991).

According to the Transactional Model of Stress and Coping the caregivers determine how to best cope with the stressor at hand. In this instance, most caregivers in the present study were proactive in utilising problem-focused coping by confronting the problem directly through sourcing information pertaining to low vision caregiving duties. From this perspective, problem-focused coping involves active efforts to eliminate the problem in order to eliminate the stress, which is likely to result in more positive caregiving experiences among the participants.

The Transactional Model of Stress and Coping also suggested that another problem-focused coping mechanism, commonly adopted, was engaging their family support network. This is clearly reflected in the findings where the participants called upon their family support network when encountering stressful situations which gave them a sense of security. The adoption of problem-focused coping among caregivers helped them adroitly adapt to their caregiving roles and experience more positive caregiving gains. Frequent experiences of the positive aspects of caregiving may enhance their quality of life which is consistent with the current study and with a recent US study of caregivers of dementia patients (Hazzan et al 2022).

Based on the Transactional Model of Stress and Coping, in situations where the perception exists that the situation cannot be changed or the individual does not have the resources to initiate a change, the caregiver tends to adopt emotion-focused coping. The repeated emotion-focused coping adopted by the caregivers of the present study was that they were enduring the negative emotions expressed by care recipients, and accepting their responsibility as caregivers. The caregiver would silently endure undue hardship because they felt a sense of responsibility to care for the person with low vision. This is consistent with the Transactional Model of Stress, which describes this form of emotion-focused coping as an ineffective strategy for eliminating the stressor. As a result, the caregivers suffered from insomnia, and sacrificed their social lives for the sake of family harmony and demands. However, emotion-focused coping is strongly influenced by familism, a highly valued Asian cultural norm. These Asian values led the caregivers to appraise and accept the stressful aspects of caregiving which seem to be a negative coping style, and thus they are likely to experience poor mental health and physical outcome. The cultural expectations of endurance may be unhelpful to promoting the well-being of both caregivers and care recipients.

The caregivers in this study expressed the need for emotional support from community-based social services to cope with their emotional needs. Adequate emotion-focused strategies are lacking among the caregivers of this present study. Since the caregivers of the low vision person are expected, as a cultural norm, to take on the caring role, active emotional support is essential to assist caregivers to perceive the stressful situations and care demands in a positive manner.

Consistent with the assumption of the Transactional Model of Stress and Coping, the present findings suggest the possibility of enhancing the quality of life by improving the problem and emotion-coping skills among the caregivers. Hence, the results of this study provide convincing evidence that the Transactional Stress and Coping theory is an important theoretical framework for developing a problem-solving training programme to provide emotional support during stressful situations, and strengthen caregivers' coping skills in ways aligned with their cultural values.

7.4. Caregiver’s Quality of life , Health Outcome and Health Utilisation

A significant association was observed with health utilisation and health outcome (r =0.58, p<0.001) in the present study. Consistent with other studies, caregivers in this study with more chronic illnesses sought more healthcare services (Martindale-Adams et al., 2016; Hebdon et al., 2021). The dementia caregivers who were older and had functional disability, or depression symptoms or headaches tended to use more health care services (Martindale-Adams et al., 2016). Similar findings were reported by the cancer caregivers who were found to seek more healthcare services when they experienced health concerns (Hebdon et al., 2021). However, it is noteworthy to indicate that results from the regression analysis showed that health outcomes and health utilisation were not predictive of caregivers’ quality of life despite the fact that their inclusion was expected by prior research on caregiving. Previous research consistently found that comorbidity was associated with impaired quality of life in the general adult population (Agborsangaya et al., 2013). In specific, caregivers are often associated with poor health outcomes in relation to diminished involvement in self-care promotion (Qualls, 2018). One possible explanation could be the caregivers sampled already have optimal healthcare practices to which they adhere regardless of additional demands from caregiving. In addition, this study only assessed utilisation for acute services but not for routine or preventative care. Further research to capture the healthcare utilisation before and after the caregivers’ assumption of the caregiving role, would be best situated to answer how caregiving alters one’s healthcare utilisation.

7.5 Caregiver’s Quality of life and Caregiver Burden

It is interesting that the regression model also showed the caregiver burden was not associated with caregivers’ quality of life. The qualitative data offered plausible explanations because the caregivers were able to rely on informal social support to moderate the caregiver stress. There were secondary caregivers such as children and siblings or friends to provide instrumental and emotional support to ease the burden of caregivers. Several studies have reported that positive quality of life was associated with good social networks or external resources (Wallace et al., 2021; L. Wang et al., 2018; Ang and Malhotra, 2018; Takashi Oshio and Mari Kan, 2016; Shin et al., 2018).

7.6 Chapter Summary

This study contributes to the existing understanding of the journey of caregiving among caregivers of low vision individuals, by providing new empirical evidence and discerning the consequences of caregiving on the quality of life of the caregivers within the context of Singapore. The quantitative analysis uncovered a relationship between two ways of coping in enhancing their quality of life, it was the qualitative data that helped elucidate the dynamics of these ways of coping. The results have substantiated the level of caregiver burden and coping processes influencing the quality of life of the caregivers of low vision individuals in Singapore. The qualitative findings have corroborated and enriched the findings from the statistical analysis. This has added an interpretive understanding of the survey results and provided complementary insights to our understanding of caregivers' perspectives. Caregivers of low vision individuals were prone to experience restrictions to their personal engagements, social activities, and even retirement plans. The culturally ingrained caregiving underscored by the government social and healthcare initiatives may have resulted in a high level of caregiver burden and financial hardships. Caregivers with filial values view the caregiving role as a normative, moral responsibility, and they see meaning in caregiving. Filial values also promoted role rewards and coping skills, such as positive re-appraisals, and social support. Yet the caregiver's quality of life was impaired due to ineffective coping strategies, coupled with a lack of social and healthcare support within the community.

Chapter Eight Conclusion

First, this chapter presents the key findings based on a pioneering mixed methods study on caregivers of low vision individuals in Singapore. The present study presented comprehensive empirical evidence that caregivers of low vision individuals have poorer mental health status, insufficient coping skills and a high caregiver burden. Furthermore, the study was able to examine the potential impact of caregiving and identified some important areas of risk for caregivers of low vision individuals. Secondly, this chapter discusses the key implications of the findings for clinical practice and policy focusing on the supportive strategies that are required to improve the health and well-being of caregivers and the quality of care they provide. This is followed by an overall summary of the entire thesis. Finally, the chapter ends with the strengths and limitations of the study, as well the directions for future research of caregivers specifically for the visually impaired population.

8.1 Key Findings

To the researcher's knowledge, this is a pioneering study to understand the caregivers' experience of caring for low vision individuals, how caregiving relates to their quality of life, and to identify the problems of caregiving in the Singapore context. The caregiving journey for those caring for individuals with low vision is more than a 100-metre sprint. As there is still no cure for low vison, the dependence of low vision individuals tends to increase with their long-term survival. Ho (2021) argued that the Singapore government adopts the Eastern Model of the socio-economic system emphasising of self-reliance, family and community which are inadequate in supporting the caregivers and which in the long run, negatively affect the caregivers' quality of life. Hence, many national social policies have been put in place toward enhancing and maintaining strong family bonds throughout caregiving.

The key findings based on the present study are as follow:

Women comprised a large majority of caregivers in the present study. Most of them were married, had at least secondary education, and had an average age of 56.6 years old. The spouses of the low vision individuals constituted nearly half of the caregiver participants; the remaining consisted of parents and children. They were engaged with either part-time or full-time employment, although some were not working. The caregiving journey was an average of 16.6 years with relatively high level of caregiver burden.

The quality of life of caregivers of low vision individuals is truly affected both positively and negatively by their roles and responsibilities. Surprisingly the caregivers who had two to three chronic diseases were proactive in self-care which shows that Singapore government initiatives in health promotion and prevention are effective. A sighted caregiver who spends a lot of time providing care to a disabled person may not have time for leisure. A minority of the non-sighted caregivers, however were better off as they were relatively well engaged with social activities and easily had accessed to community social service.

It is important to note that caregiving requires much time and energy, often resulting in psychological stress and a reduced quality of life for the caregiver. Also, the responsibilities of unpaid caregivers increase over time, further exacerbating the negative impact upon the caregivers. The coping strategies which were utilised by the caregivers of the low vision individuals were deemed insufficient in reducing caregiver burden which resulted in their impaired quality of life. Education and age were not found to be a significant related to the level of this burden. To cope with the caregiving stress, the caregivers adopted emotion-focused coping more than problem-focused strategies, thus the caregivers might have a negative orientation to problem-solving. The caregiver's coping strategy was the only unique factor influencing the caregivers' quality of life.

The caregiver's coping strategy was influenced by the Confucian values of filial piety and familism policies promoted by the Singapore government, including caregiver appraisal of stressors and adoption of coping strategies. Filial obligation motivated caregiver involvement, and notions of filial piety led to increased acceptance of the caregiving role. Emphasis of family harmony and collectivistic values are prevailing values that influenced caregiver stress appraisal and coping behaviours. This leads to the suggestion that the caregivers may be more likely to experience higher levels of burden due to cultural caregiving values. Cultural values also provides the meaning for the caregiving effort leading to a positive experience of caregiving. The emotion-focused and problem-focused coping adopted by the caregivers were similar to those recorded in Western caregiving literature.

Relieving the caregiver burden and impacting coping strategies are the two foci which need immediate attention, which relates to the necessity to develop a caregiver training programme that will assist them in delivering the best care they can. Sustaining a caregiver's physical and mental well-being and promoting positive caregiving experiences requires robust intervention to address the changing circumstances caused by the transitions within the caregiver role. Formal social support for the caregiver is crucial in any successful care planning for a low vision person.

In general, the empirical evidence presented in this study suggests that the caring experience and coping patterns exposed a threat to the quality of life of the caregivers of low vision individuals. Indeed, caring for a low vision individual puts all caregivers at risk of stress and burnout. There is also little doubt that over time the complications and costs of caring for low vision individuals are exacerbated. Due to the below-replacement fertility in Singapore, it is likely that the number of family caregivers available to provide help at home will decrease. Hence, the healthcare system and policymakers in Singapore must consider implementing strategies to support caregivers in alleviating their caregiver burden, improving their coping skills, and restoring their quality of life by including financial subsidies, counselling services, caregiver training services, and respite care services. The next section addresses the implications of the study.

8.2 Implications for Clinical Practice

The present study generates a number of clinical practice implications.

1.The present study showed the stress-coping theory (1984) when the caregiver has control over the circumstance or situation, he/she has a sense of social support and problem-solving skills to confront the situation, he or she will appraise of the caregiving situation in positive terms. Therefore, effective caregiver training will needs to emphasise the domains of knowledge, skills development, emotional management (problem-focused and emotion-focused) skills for developing resilience and buffering distress. For the knowledge domain, the caregiver training programme should cover the medical information of the care recipient's condition and treatment options, to understand why patients require repeated visits and treatments and to lessen caregivers' stress and anxiety. For the skills development domain, caregivers should be taught specific low vision individual aid-related skills and adaptive techniques to increase care recipients' visual functional abilities. For problem-solving coping strategies, caregivers should be taught problem-solving self-efficacy, creativity in generating possible solutions, and effective choice in their role. The development of coping and self-management skills would increase caregivers' motivation and confidence to apply these skills in to caregiving role. Caregivers tend to experience a wide variety of negative emotions hence emotional management training should be directed towards the positive aspects of caregiving. This can be done by encouraging caregivers to the positives in life and changing their own attitudes to face the situation by focusing on the positive characteristics of the care recipients and recollecting their mutual and joyful memories. The caregiver training should also include two counselling sessions of 1 hour, to address problems, concerns, and/or feelings related to caregiving with the case manager. It is necessary to offer psychological care to the caregiver as part of caregiver training. For example, a case manager should engage caregivers in music therapy, physical exercise and mindfulness meditation. Research evidence found that psychosocial interventions such as relaxation techniques, such as listening to soothing music (Ferré-Grau et al., 2019), physical exercise (Egan et al., 2021) and mindfulness meditation (Goodridge et al., 2021) are all promising techniques that can improve caregivers' mental health. The caregiver training should be conducted as one-to-one instruction, once a month, for 2 hours for a 3-month period.

2. The caregiver training could also be offered as a web-based education course with the same aforementioned contents. The web-based self-directed format makes use of a more flexible learning system accessible for hard-to-reach caregivers (Klimova et al., 2019). Klimova et al., (2019) noted that web-based educational programmes help caregivers feel more confident about their care recipients' condition, reduce their stress and enhance their understanding and alleviate their concerns. They also found that an online application for learning enabled caregivers greater access to personalised learning and autonomy as they, could learn according to their own pace. This online learning is useful for caregivers who have limited time and also unable to leave home to attend in-person sessions. This would fulfill the personal, demands/ need and offered training for practical information in short bursts. Online programmes through a mobile application may be a compelling option for supporting

working caregivers, particularly beneficial to the growing number of working caregivers anticipated in the future.

3.The Singapore National Eye Centre should offer caregiver training in a culturally-sensitive manner by a nurse manager. With formal caregiver training and directions, caregivers would be able to develop self-efficacy (Qualls, 2018; Nkimbeng and Parker, 2021). The case manager needs to understand the family system of the care recipients, who is the primary caregiver, and who are the extended family members. The identity of the primary caregiver will be recorded by the nurse manager in the care recipient's medical record. Extended family members or friend who are involved in the caregiving will also be identified. The nurse manager will also liaise with the identified caregivers to inform them of specific details and benefits of the caregiver training. Besides the primary caregiver, caregiver training should be expanded to other caregivers in order to increase the pool of potential caregivers. These would include siblings, neighbours or friends of individuals with low vision.

4. An evaluation should be conducted to assess the impact of the caregiver training programme from its beginning for a 12 months' period. Specifically, the assessment of the caregiver's quality of life, caregiver burden and depression should be carried out before participants embark on the caregivers' training. A reassessment should be conducted after 6 months and then 12 months after completing the programme. The quality of life can be assessed using the SF 12 Health survey (Ware Jr et al., 1996). The level of caregiver burden can be assessed using the ZBI (Zarit, 2018). The presence and severity of states of depression in caregivers can be screened using the Patient Health Questionnaire-9 (PHQ-9).

The purpose of the caregiver training programme is to identify the caregivers who are at risk of depression or high levels of caregiver burden. When the caregiver is identified with having depression symptoms, the nurse manager should consider early referral to a psychologist or psychiatrist. An earlier referral provides more time for caregivers to manage their emotions, which can lead to a better mental health. When the caregiver is identified with having a high level of caregiver burden, the medical social worker must be informed to see what social support might be beneficial. The medical social worker will proactively help the caregiver and low vision person to access the health and social services. Accurate statistics need to be collected and recorded in a database and shared among ophthalmic health care providers who oversee the care of individuals with low vision.

5. Findings also revealed the importance of support groups for caregivers. Hence, nurse managers could set up a support group for caregivers, especially for those at-risk of depression or with emotional difficulties in carrying their caregiving duties. Support groups provide ongoing forums for caregivers to share their experiences and provide mutual support to one other. Support groups can offer a place to discuss the challenges and obstacles that caregivers contend with every day and to find the motivation and encouragement to care for self in the process. Caregivers with positive caregiving experiences can be invited to share their journey with new caregivers. However, caregivers may be more likely to attend a specific type of caregiver support because they feel reassured that they will meet people in a similar position to themselves (Finley, 2018; Fernandes et al., 2021). Two recent reviews reported formal social support was one of the main factors in improving the low vision individuals' caregivers' quality of life (Hazzan et al., 2021; Enoch et al., 2021b).

The caregiver support forum suggests support to comprises three sessions focusing on five topics: (1) Information about the care receiver's situation; (2) the Emotional impact of caregiving; (3) Self-care; the (4) Group and its members as a mutual support system and, (5) Positive caregiving experiences. These groups should last 60–90 minutes and there should be no fee to attend. To encourage participation and a flexible structure, caregivers are not expected to register in advance or to commit to attending for a set number of sessions. Instead of the traditional caregiver support groups which are in-person, the caregiver support group will be held through virtual platform (Benson et al., 2020; Friedman et al., 2018; Armstrong and Alliance, 2019). Offering support groups online may represent efficient ways to increase access for caregiver with lack of transportation and home care obligations which make face-to-face attendance difficult.

6. Drawing on these innovations and findings from the present study, the researcher will be developing Caregiver Apps for the low vision caregivers. A local Caregiver App was developed recently by Lwin et al., (2021) providing forums to discuss caregiving issues, make new friends, and answer caregiving queries, all of which make caregivers feel less alone in their situation.

The digital platform was also well received as a place for caregivers to buy and sell or give away items related to caregiving that may be difficult or expensive to find elsewhere. The Caregiver Apps' content will be similar to the online support group with information about different eye diseases; the Emotional impact of caregiving; Self-care; and Positive caregiving experiences. In addition, there will be self-care tips, relaxing music, a mindfulness session and even positive psychology to motivate the caregivers to use the app.

These interventions would increase caregivers social network as lack of time for social participation was identified as an issue by the caregivers in the present study. The caregivers also expressed the need to have a peer support group to share assistance in practical problem solving and emotional support. The self-care tips would increase the leisure time for caregivers who are working, to take a break from caregiving.

The pre- and post-app use surveys will consist of the same questions on the quality of life, caregiver burden and depression. The post-app use survey will also gather information about existing app feature and other potential features that could be added to the app in the future. The surveys will be conducted at 3 months and 6 months after using the online support group app. The online peer support services will also be made available to caregivers of other visually impaired institutions including the Singapore Association for the Visually Handicapped (SAVH), the Guide Dogs Singapore (GDS), and iC2:prehouse.

Although the Singapore government has taken steps to support caregivers in general, the present study yields several policy implications specifically in providing better support for the caregivers of low vision individuals. Indeed, the social support needs for caregiver of a low vision individual are relatively unique. The current research validated the limited access to social services and finance resources among population of the caregivers of low vision individuals. The key findings from the present study could be utilised to fulfil national ambitions to support caregivers of low vision individuals. There are also some revisions of the employment initiative for caregivers of low vision individuals needed. Perhaps, there is an imperative to set aside a budget for social welfare expenditure for the low vision community to ensure that caregivers are able to get sufficient financial support. A policy revision could help to reduce out-of-pocket expenses of low vision people as expenses could erode the financial security of caregivers.

To reduce out-of-pocket expenditure, Singapore policymakers should consider a special care allowance to compensate for lost income, shorter work histories and less lifetime earnings for caregivers (Mehtha 2020). The special care allowance can help with the purchase of home support services such as personal care, meal preparation, and essential housekeeping. The government should reach out to non-sighted couples with financial assistance. More often than not, they face discrimination at work and are unable to function when their vision deteriorates (Steverson, 2020). Additional financial support should be provided, specially to couples who lost their jobs either due to their vision disabilities or because they have reached the statutory retirement age of 63.

The Singapore government has a key role in employment legislation addressing the realities of combining work and caregiving and in publicising the value of supporting caregivers in the workplace. This research calls for a personalised approach to managing working caregivers of low vision individuals. Whilst in general, most family caregivers of disabled individuals may be perceived to be in similar situations, support required by caregivers of people with low vision may differ. The majority of caregivers of low vision individuals need caregiver-friendly work policies such as flexible work arrangements and a family leave policy to enable caregivers to remain in or join the workforce. With the increased longevity of people with low vision, a large proportion of the sighted and non-sighted caregivers will need to continue in work or get another job after retirement because their economic situation does not allow them to retire without any income. Caregivers should have the rights to request flexible working arrangements and be protected from a rigid work schedule. Such requests could involve changing their hours, times or place of work through provisions such as job sharing, home working, annualised hours and shift swapping. All employers should implement a care-related leave policy to accommodate the needs of individual families of the low vision people, and extending Family Care leave from three days to 20 days for working caregivers. These 20-days care leaves are essential to enable caregivers to carry out their intense care duties which include accompanying low vision individuals for multiple medical visits and regular eye treatments; attending caregiving training; the low vision rehabilitative programmes; enrolling in caregiver training programmes or support groups.

Social policy that focuses on affordable and accessible caregivers' services could be developed and expanded. There is certainly room for a comprehensive range of caregivers' services, especially affordable and accessible respite care that would give working and non-working caregivers, a break. These caregivers need a few hours of respite in a week to complete errands and also to recharge emotionally. Respite care for caregivers in an adult day care or overnight in nursing homes could provide caregivers with temporary relief from their caregiving responsibilities. The respite service should be made available at a reasonable low cost or no cost to increase caregivers' personal time for leisure activities or provide a break from care demands. Self-care is crucial in caregiving. Caregivers need to be continually reminded to take care of themselves. In fact, caregivers also need reassurance that using respite does not mean they are failing to meet their caregiving responsibilities but rather that through the use of such services, they are maintaining and enhancing their coping abilities.

Extra financial support for caregivers to participate in leisure and social programmes is essential to develop a sustainable supply of healthy caregivers (Yew, 2020). Leisure is an avenue for creating positive emotions. The community and government could offer vouchers for free coffee breaks with friends or neighbours thus, allowing caregivers to have a free mind for self without feeling guilty. Social networks or contacts with friends or neighbours not only provide companionship to address caregivers' emotional needs but they also are a source of instrumental support for caregivers of people with low vision.

8.3 Study Limitations

The present study has six limitations that should be acknowledged. First, the data in this study were obtained from only one tertiary eye institution through a convenient sampling method and therefore it may be biased to some extent; thus, carrying out a multi-centre research in future should be considered. Second, the disproportionate number of female caregivers in the sample, may limit its generalisability. Previous studies have shown that gender-specific factors are related to caregiver burden (Ge and Mordiffi, 2017; Rand et al., 2018; Malhotra et al., 2012), quality of life (Weyer-Wendl and Walter, 2016) and mental distress (Bambara et al., 2009; Ruiz-Lozano et al., 2022). However due to the small number of male caregivers who participated in the present study, the ability to conduct relevant subgroup analyses with sufficient power was limited. Third, the findings were based on the caregivers who consented to participate in the study but there 50% of caregivers who approached refused to take part. Therefore, the findings generated might not be representative of those who declined participation. Fourth, the present study did not obtain a psychological history from caregivers, which might have been a predictor of impaired mental health. Fifth, its cross-sectional nature limits the researcher's ability to identify direct causal relationships between the identified correlates and caregivers' quality of life. Finally, the majority of the sample population were financially well-off and had high level of education. Replication of this study with more low-income caregivers is indicated.

8.4 Recommendations and Directions for Future Research

Future research should consider simple random sampling to obtain a representative sample size of both male and female caregivers. This could be done by recruiting a stratified sampling from the eye clinics of three tertiary hospitals and the community. In the Singapore health system there are three integrated clusters: the National University Health System, National Healthcare Group, and Singapore Health Services. Each of the three clusters includes general hospitals, primary care services and community hospitals. The Singapore National Eye Centre is situated in the SingHealth Health System. The number of caregivers allocated from each low vision clinic would be proportional to the annual workload of low vision patients. Study subjects would be chosen using a simple random sampling procedure. It is also important to gain a richer understanding of the challenges and experiences from the hard-to-reach caregivers. on what challenges or caregiver burden they are facing. The hard-to-reach caregivers may include those who are working and could not find time to participate in the study. More than half of the caregivers recruited in the present study were not working. These can be those caregivers who may have been most burdened, stressed, or had negative experiences (Navaie, 2011).

Future study needs to explore the effectiveness of the interventions from caregiver training, Caregiver Apps and caregiver support groups. Research evaluating the impacts of these three interventions could substantially increase the caregivers' quality of life and obtain government funds to invest into these interventions. The well-being of caregivers is critical in the evaluation process. More research is needed to compare online social support and mobile Caregiver Apps, comparing different technologies, and cost–benefit analyses of such services. The utilisation of these caregiver interventions will be collected as it is a critical area for continued investigation in order to sustain relevant and effective programmes.

Future studies should be conducted among other cohorts of caregivers including parents of children with low vision, caregivers of spouses with low vision and caregivers of parents with low vision, to determine whether there is difference in their quality of life and caregiver burden. A longitudinal study comparing the needs of caregivers may be beneficial and would help capture how support needs may change throughout eye disease progression. Research looking at additional covariates such as the state of eye disease progression or severity of vison loss may also provide valuable insights into the needs of those in caregiving roles.

A previous study reported that care recipients with moderate and severe vision loss were depressed and higher level of caregiver time (Shtein et al., 2016), had a higher financial burden (Weyer-Wendl and Walter, 2016) and higher caregiver strain (McDonald et al., 2020). Due to the paucity of research related to the unmet support needs of caregivers of low vision individuals, more studies are needed to develop a more effective support system for caregivers. In future studies, it would be important to evaluate unmet needs in different stages of the care provision since non-sighted caregivers' needs can change over the course of their illness and their ageing trajectory. Understanding the kind of needs that emerge throughout time, and how they vary according to the intensity of care and dependency level, could inform the design and adequacy of interventions in the caregiving continuum as caregivers age.

In the present study more than a quarter of the caregivers' kinship to those being care for, was being a parent. More work needs to be done to explore the caregiving experience of parenting a child with low vision over the life course as the parent ages, to determine if it differs from the experience of other relative caregivers, and whether the impact of the parents' own aging process, changes or exacerbates caregiver stressors and subjective feelings of burden.

As there is very little discussion of the issues faced by non-sighted caregivers of low vision individuals. A qualitative approach to explore their unique experience would benefit caregiving research in the future. For example, a phenomenological study on couples with low vision to capture the experiences of this vulnerable population would provide in-depth understanding of the challenges to health and how the social care system could meet these couples' care demands. Enhanced knowledge in these areas may provide health care leaders and policymakers with the knowledge and ability to improve resource availability and to help caregivers to navigate access to resources which are beyond the family network.

8.5 Chapter Conclusion

The role of caregivers of those with low vision will only become increasingly more important with time, as life expectancies continue to rise and more countries' locales enter super-aging territory. In some ways, caregiver's time has become a pivotal public health and social issue facing Singaporean society. Effective policies toward caregiving should combine different forms of support and intervention, which address the needs of the caregivers. The initiation of caregiver assessment, support groups, online resources, and web-based tools to promote the best quality of life are essential for caregivers.

Reforming the social and health care systems to appropriately compensate and support caregivers with relevant education, training, and supportive services are imperative. The government ought to consider adopting some of recommendations for supporting caregivers including direct monetary support or a caregiver allowance, and assistive technology supplements. Financial support is only one of the solutions needed for supporting caregiving in Singapore especially for those non-sight caregivers and older caregivers who do not have children to support them. In addition to social care policies, work and employment policies need to be revised to alleviate caregiving burden among the working population,; organisational and institutional influences would include mandating workplace policies related to paid leave for caregiving and the offer of flexible work scheduling. The recommended future studies represent the crucial steps toward addressing the impending shortage of caregivers and easing the burden on those providing care for low vision individuals. Although the future for caregivers of low vision individuals remains uncertain, the findings, implications and recommendations of this study for more effective caregivers' training and revision of social policies seeks to improve the caregiver's quality of life in the twenty-first century.

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Appendix A: Narrative Review Table

Caregiver characteristics and aims/objectives in included studies.

Study and location	**Aims**	**Participants**	**Methods / Intervention/ Instruments**	**Relevant Findings**	**Hawker Score**
1.Jin et al., (2021) Australia	To analyse the degree of caregiver burden and depressive symptoms and factors related to these variables in caregivers of age related macular degeneration (AMD).	96 caregivers of people with Age Macular Degeneration.	Cross sectional Caregiver Burden Scale (CBS) Centre for Epidemiological Studies Depression (CESD-10) Fatigue Severity Scale General Self Efficacy Scale General Quality of life using a linear scale from 0 (poor QOL) to 10 (excellent QOL)	Main caregiving duties including cooking, cleaning, help with leaving the house, and accompanied their care recipients to eye appointment and eye treatment. The mean quality of life score was 7.3 (SD 2.0)/10.0, the mean GES score was 32.5 (SD 4.9). Caregiver burden was associated with younger caregiver, older care recipient, and poor vision from care recipients. Caregiver burden was not associated with gender and quality of life. Caregivers' quality of life was inversely related to depressive symptoms, but positively related general self-efficacy. Caregiver's depression was not related age, gender. Caregivers of AMD patients experienced caregiver burden as	36

				compared to caregivers to chronic diseases. One third of the caregivers reported with comorbidity such as diabetes, arthritis, kidney disease, cardiovascular disease and neurovascular disease. This group of older caregivers were at risk of physical strain and emotional distress. However, few of caregivers experienced positive impacts of providing care. This is likely due to pre-exiting strong familial ties or high-quality family relationship. One in five of the caregivers experienced depressive symptoms that is higher than global prevalence. Caregivers with depressive symptoms reported with high level of fatigue.	

2.Vukicevic et al., (2016) Australia	To explore the perceptions of caregivers of Age macular degeneration individuals.	643 caregivers of people with Age Macular Degeneration.	Grounded theory	Three themes extrapolated: 1.The impact of Caring-Impact on their relation increased caregiver responsibility, increase distressed because of sacrifices made. The impact of caregiving generated compassion, empathy, and ongoing worry for care recipients. 2. Eye Injections and information- Pain, anxiety and cost of treatment were expressed by caregivers. The problem of traveling was onerous and burden to caregivers. There was lack of information on the eye condition and how to help care recipients. 3. Activities of Daily Living- Caregivers need to act as mobility guide, caregiver need provide transport, caregivers need to understand the loss of ability to discern fine details by care recipient.	32

3.Larizza et al., (2011) Australia	To evaluate caregivers’ experiences after attending the Low vision self - management	A total of 60 caregivers of mean 67.2 (SD 14.8) years old of adults with low vision	Pre and post program evaluation survey. Self-designed questions on levels of understanding low vision, awareness of devices, aids, practical strategies, and confidence to deal with low vision. Questionnaires to assess emotional wellbeing and self-efficacy. General Self-Efficacy Scale (GSES) was used to assess self -efficacy. Depression, Anxiety, Stress Scale was used to measure Emotion well-being.	The Low vision self -management program increased awareness of low vision aid and practical strategies. But no significant improvement was reported on confidence, self-efficacy and emotional well-being reported no improvement. Qualitative feedback rated the low vision program as relevant and helpful.	29
4.Cimarolli et al., (2004) United States	Evaluate support groups for partners of adults with visually impaired.	A total of 28 caregivers of visually impaired individuals	Pre-test/ Post-test Depressive symptoms; Life satisfaction; Relationship satisfaction;	Participants reported group intervention was useful and learn from other caregivers how to adapt to stress situation and cope skills. Participants showed a reduction in role captivity and their self-reported number	26

	The goals of these groups included a discussion guide including the topics on alleviating stress and burdens, improving the sighted partners' understanding of the issues faced by the partners with visually impaired, and enhancing communication.		Understanding of what visually impaired could see; Role Captivity Scale score; Satisfaction with programme. Four different support group models: one with both the visually impaired and sighted partner, one in person with sighted partner only, one by telephone with sighted partner only, one self-directed with sighted partner only.	of major issues. But there were no changes in depression.	
5. Sussman-Skalka (2003) United States	To provide support and practice information to caregivers of individuals with vision impairment.	Total 12 caregivers participated in the pilot program	Pre and post program evaluation. Different support group models. Four support groups: one group meet by telephone conference call; three groups meet face to face. These four groups must meet for eight sessions.	Program evaluation based pre and post program interviews reported the participants improved in their understanding of what their care recipient could see and do. Their confidence improved on when and how to help the vision impaired partner and their ability to freely discuss stressful situations. The telephone support group benefitted the caregivers who has chronic health condition as they were unable not travel.	16

			Each group consists of three caregivers. One group had their care recipients. One group only caregivers what was on telephone conference.	For caregivers who stays geographic far also benefited from the telephone call. The training topics helped to raises issues that might have emerged otherwise. The topics prepared the caregivers in advance and enhancing the coping skills.	
6.Silva-Smith et al., (2007) United States	To explore the sociodemographic characteristics of caregivers of visually impaired, what support activities had been provided, and what was the caregiver burden.	A sample of 28 adults who reported being the primary support persons for individuals who were visually impaired was recruited for the study through a low vision services clinic	Cross sectional Caregiver Reaction Assessment scale. Self-esteem was measured in relation to eye care activities.	Caregivers provide instrumental support such as transportation, meal preparation, shopping and help with administrative task. As a results caregivers reported mild burden in their role but fairly high level of self-esteem.	25
7. Bambara et al., (2009) United States	To determine the prevalence of depression among caregivers of patients with low vision. To examine the association	96 caregivers of low vision Mean age 58.6 9 (SD 13.81) Average education level was 13 years	Cross sectional The Social Problem-Solving inventory revised short form. The Centre for Epidemiologic Studies Depression Scale.	The study suggests age, gender, vision loss of care recipient, caregiver burden, problem solving ability were related to caregiver well-being. Age was significant factor for depressed and non- depressed caregivers. Education	36

	between social problem solving abilities, and depression and life satisfaction among caregivers.		The Satisfaction with Life Scale. Caregiver Burden Scale	was not significant factor between depressed and non-depressed caregivers Risk factors of depression were young caregivers, young care recipient, female, care recipients with worse vision loss. Depressed caregivers were less satisfied with life and higher caregiver burden. Depressed caregiver had lower problem solving style and greater avoidant problem solving style, and greater careless problem solving.	
8.Weisser-Pike (2013) United States	Outlines a pilot training program for caregivers with provide hands-on experiences and education.	7 caregivers of low vision individuals	Descriptive study of program evaluation. The program provided one to one coaching to the caregivers which lasted 6 weeks. Each caregiver was seen 3 to 5 times throughout the program.	Caregiver of low vision required particular skills and abilities. The needs of the caregivers therefore included skills development to increase their knowledge and role competence. Caregivers feedback was that the sessions with the simulators had given them the most insight into the worlds of their care receivers.	18
9.Shtein et al., (2016) United States	To identify the range of factors that may contribute to the loss of vision from glaucoma.	31 participants: 21 were family members/friends of glaucoma patients with poor vision; 10	Structured Interviews Qualitative study using 6 focus groups.	The lack of families and social support systems. Family caregiver knew little about the eye condition and did not accompany patients for medical visits.	33

		were family members/friends of patients with good vision		Family caregivers were frustrated with patient's dependent status and denial of vision loss. Poor communication among caregivers and care recipients were emerged from the focus groups. Family caregiver expressed an interest in gaining more information of the eye condition and becoming more involved in the patient care.	
10. Weisser-Pike (2018) United States	To determine the caregiver outcomes of an intervention therapy for caregivers of low vision individuals. The intervention was individualised training of 3 to 5 visits of 45 to 60 minutes. The training comprised of education materials, experiential	Participants recruited from low vision clinic with 7 female caregivers and 1 male caregivers. Mean age 52.4 years.	A pre and post-tests. A self-designed questionnaire of 13 items to measure caregiver's perceived knowledge or understanding of the care receiver's eye condition, its effect on occupational performance, difficulties in daily activities related to vision loss, and skills required to help	The participants reported increased their understanding of the effect vision loss, improvements in their relationships, decreased challenges associated with caregiving, and increased rewards of caregiving. The experiential component was a hands-on session that provided participants to experiencing the effects of vision loss, and placing the caregiver in the care receiver's shoes. The caregivers reported a reduction in challenges and an improvement in satisfaction. The caregivers' experience was the caregiving role was both burdensome and rewarding.	19

	component and practical tools and tips. A total of 52 sessions were conducted over 31 visits		the care receiver to be more independent and to get around safely. Questions asked about the relationship between the caregiver and the care receiver, challenges associated with caregiving, and benefits of caregiving		
11. McDonald et al., (2020) United Kingdom	This study was examining the caregiver burden and quality of life of caregivers of chronic glaucoma patients.	A total of 38 informal caregivers of chronic glaucoma patients.	Cross sectional EQ5D questionnaire for quality of life Modified Caregiver Strain Index (MCSI)	Only 9 caregiver reported above average quality of life score with average of EQ5D mean score of 0.66 (0.21). Caregiver burden was 5.6(SD 4.9) with 47% of caregiver reporting zero score. Only three caregiver reported high caregiver strain. The caregiver strain was due to work adjustment, less than for other family members, and changes in personal plans before of caregiving. Caregiver quality of life was not negatively correlated to caregiver burden.	26
12.Gohil et al., (2015) United Kingdom	Assess the caregiver burden and factors determining the	250 matched dyads of patients with	Cross sectional	The quality of life measured by EQ5D VAS score was 74.5 % (SD28.2).	29

	burden in patients receiving ranibizumab therapy for Age Macular Degeneration.	Age Macular Degeneration and their caregivers. Mean Age: 64.4 (SD13.5)	Caregiver Reaction Assessment scale (CRA) EQ5D questionnaire	The caregiver burden score was 3.2(SD 0.5). The children caregiver reported higher caregiver burden than spouse caregiver. This study revealed a high unmet need for information and support for caregivers. The caregivers reported receiving no or little support from health system. Most caregivers were not satisfied with the practical advice given, only less than 40% caregivers received help to under the eye condition of care recipients.	
13.Hanemoto et al., (2017) Japan	To evaluate how different kind of eye drugs regimes and treatment affect caregiver burden.	71 pairs of patients with wet Age Macular Degeneration and their caregivers	Randomized Control Trial Caregiver burden measured by Burden Index of Caregivers. Depressive symptoms as assessed by the Centre for Epidemiologic Studies Depression scale. The 'treat-and-extend' regimen, which tailors the treatment to the patient's schedule, was	The findings reported only the 'treat and extend' treatment regime was more cost effective for caregivers of low vision individuals. It helped to reduced hospital visit and economic productivity losses. But despite the time and money savings, reduction of the caregiver burden was limited.	30

			compared with a treatment as needed (PRN) group.		
14. Ajay et al., (2017) India	1.The presence of each type of impairment (in physical function, cognition, near vision and hearing) of older persons is independently associated with family caregiver burden, 2. Increase in the number of impairments of older persons is associated with an increase in family caregiver burden.	140 caregivers Mean age 45.4 SD 15.7	Cross sectional Zarit Burden Interview (ZBI), a self-report inventory that examines caregiver burden.	The average caregiver burden by ZBI score was 21.2 (SD 12.9). The caregiver burden score increased with an increase in number of older person impairments; the score was significantly higher only for caregivers of older persons with all four, versus one, impairment. The four impairment were; physical, vision, hearing and cognition. Caregiver coping strategies and social support were not assessed due to cultural aspect of caregiving.	29
15. Weyner-Wendl & Walter (2016) Germany	To analyse the caregiver burden, incurred financial resources, invested time and quality of life of caregivers of age	150 caregivers were recruited from the Ophthalmology clinic. Mean age 60.66 (SD 15.24)	Cross sectional Quality of life used the Visual Analog Scale 0-10 (VAS), 0 “total unhappy” to 10 “perfectly happy”.	The quality of life for male caregivers and female caregivers were 6.93 (SD1.95) and 6.61 (SD1.87) respectively. The findings reported the caring time captured was 6.4 (SD8.5) hour. Most of	32

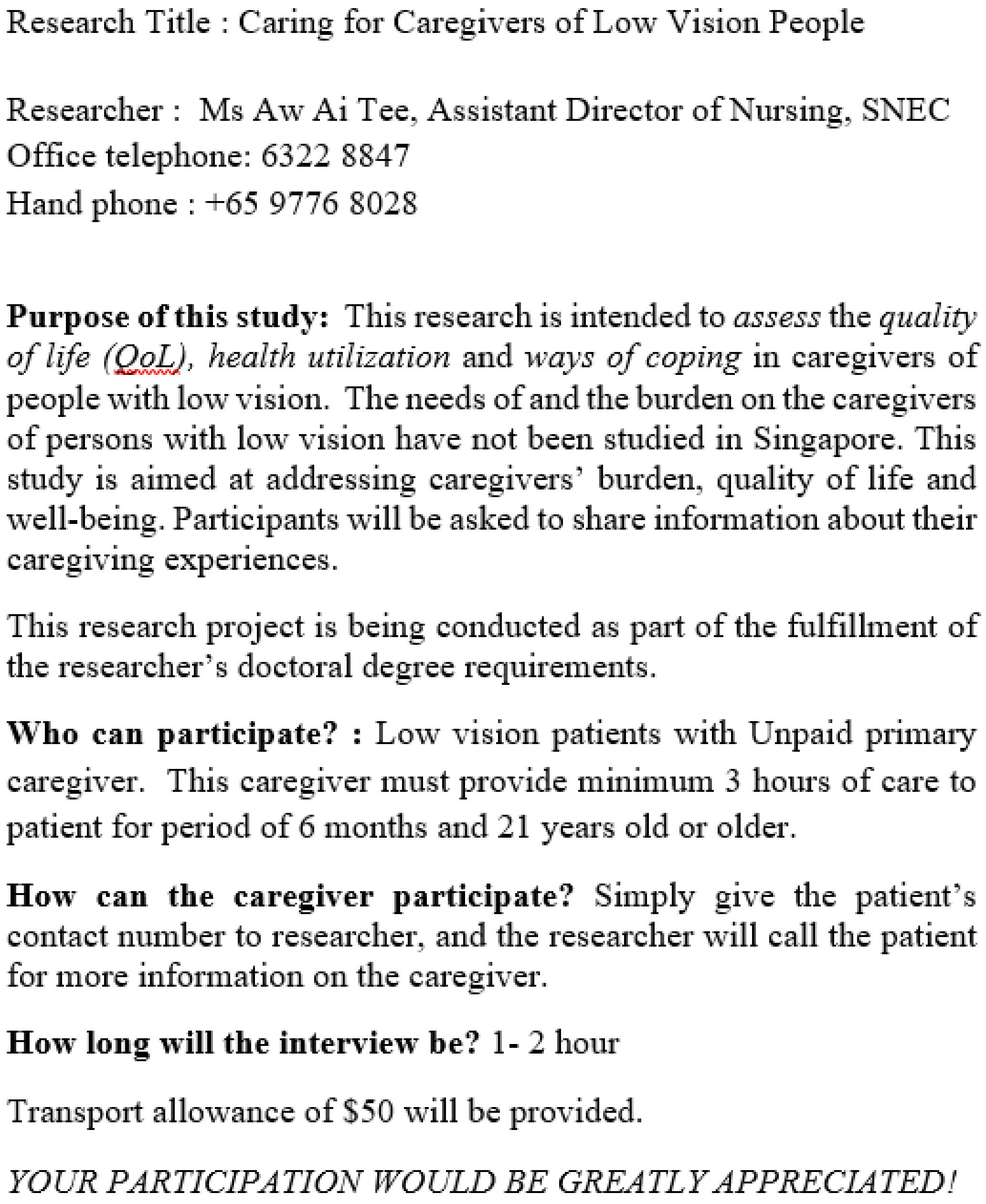
	macular degeneration.		Number of doctor's visit, the distance covered and time spent. Cost captured – costs of medication, parking fee, travel cost, visual aids, health services and co-payment. Time spent by caregivers were recorded.	the time was spent on household assistance and leisure activities. Annually the time spent accompanying care recipients for eye treatment took an average of 14.5 hour. Hence 35% of the caregivers could only take 3 days per year to accompany care recipients. The caregivers reported the most financial strain was brought by direct non-medical costs; travel costs, costs of housekeepers, and modifications. Spouse spent more direct costs per year as compared children caregivers. On average costs amount to 689 euro dollars and 461 euro dollars for children.	
16. Varano et al., 2016 Global Study of nine countries	To evaluate the physical and emotional impacts age macular degeneration on patients and caregivers. To identify any barriers to treatment.	A total of 890 caregivers were recruited from Australia, Brazil, Canada , France, Germany , Italy, Japan , Spain and UK.	Cross sectional The questionnaires were designed and devised by ophthalmologists, experts and research organization. The questionnaire was designed to measure the emotional and physical impact of age macular degeneration. However	The emotional impact experienced by the caregivers included negative and positive emotions. Negative emotions identified were sadness, fear, frustration, desperation, hopelessness, loss of motivation towards life and isolation and depression. Positive emotions reported were feeling useful, feeling good, sense of satisfaction, and contented.	32

			it was not validated and some questions may be perceived differently by respondents.	Physical impact identified were associated with instrumental support on arranging travel. The level of instrumental support increased with duration of eye diseases. Help with shopping and reading also increased with duration of eye diseases. Nearly half of the caregivers reported treatment of the eye diseases led to the caregivers to missed days in their employment and personal obligations of 10-20 days.	
17. Khan et al., (2016) Canada	The burden faced by caregivers of patients who either are legally blind or low vision. Explore factors related burden faced caregivers. The proportion of caregivers at risk of depression. Explore the factors related to being at risk for depression	Participants recruited from medical retina clinic from 1 institution. Total 236 caregivers complete the survey. The mean age was 64.8 years old, 59% was female.	Cross sectional Burden Index of Caregivers (BIC) composed of 5 burden domains; time dependent, emotional, existential, physical and service related burden. Centre for Epidemiologic Studies Depression Scale (CES-D).	The duration of caregiving was 6.1 (SD 5.6) years. The BIC score for Low vision (2.03) was higher than BCI of the blind (8.01). The two common burden cited by the caregivers of low vision were time-dependent burden and emotional burden. Caregivers providing close supervision for ≥2.5 hours per day were at 7.45 increased odds of depression compared to those who provided <2.5 hours. Caregivers who did not complete the vision rehabilitation were 4.23 odds of depression. Female caregivers compared to male caregivers	35

	faced by the caregivers.	Adult caregiver was 30% and spouses was 52%.		had fivefold higher odds of being at risk for depression. Caregivers who did not complete at least one vision rehabilitation were 4.23 increased odds of being at risk for depression.	
18. Ruiz-Lozano et al., (2022) Mexico	To determine the caregiver burden and depression of legally blind individuals.	Caregivers were recruited from tertiary eye care facility. A total of 115 caregivers were recruited for the study. Mean age of the caregivers was 51.2(SD 13.8), with 64.3% was female. Spouse caregivers was 35.7% and 33.9% was adult children caregivers. Sibling as caregivers was	Cross sectional Zarit Burden Interview-22 (ZBI) was employed to measure caregiver burden. Patient health questionnaire (PHQ-9) to measure caregiver depression.	Male caregivers scored higher ZBI (28.7) than female caregiver (19.2). Only 47.8% of the caregivers reported mild caregiver burden Parents as caregiver reported higher caregiver burden than spouse, children, siblings as caregivers. Older the caregiver was associated with higher depression score. Age and education were not related to caregiver burden. Female caregiver was less depression as compared to male caregiver. Parents reported higher depression score than spouse, children, sibling as caregivers. A total of 35 caregivers were referral to mental health clinic for further management. The degree of vision impaired was related to caregiver burden and depression.	32

		14.9% , there was 8.7% was parents as caregiver.		The longer hours of caregiving to blind individuals was related to caregiver burden and depression.	

Appendix B Advertisement for Recruiting Low Vision Caregivers



Research Title : Caring for Caregivers of Low Vision People

Researcher : Ms Aw Ai Tee, Assistant Director of Nursing, SNEC
Office telephone: 6322 8847
Hand phone : +65 9776 8028

Purpose of this study: This research is intended to *assess* the *quality of life (QoL), health utilization* and *ways of coping* in caregivers of people with low vision. The needs of and the burden on the caregivers of persons with low vision have not been studied in Singapore. This study is aimed at addressing caregivers' burden, quality of life and well-being. Participants will be asked to share information about their caregiving experiences.

This research project is being conducted as part of the fulfillment of the researcher's doctoral degree requirements.

Who can participate? : Low vision patients with Unpaid primary caregiver. This caregiver must provide minimum 3 hours of care to patient for period of 6 months and 21 years old or older.

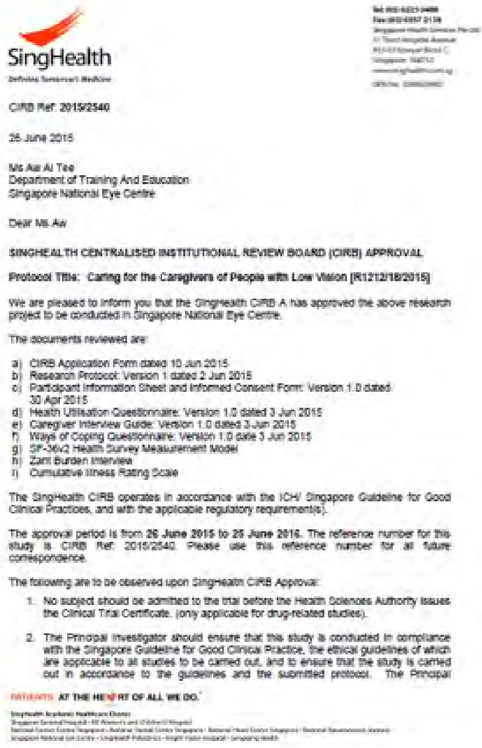
How can the caregiver participate? Simply give the patient's contact number to researcher, and the researcher will call the patient for more information on the caregiver.

How long will the interview be? 1- 2 hour

Transport allowance of $50 will be provided.

YOUR PARTICIPATION WOULD BE GREATLY APPRECIATED!

Appendix C : Singhealth Ethics Approval



SingHealth

CIRB Ref: 2015/2540

26 June 2015

Ms Aw Ai Tee
Department of Training And Education
Singapore National Eye Centre

Dear Ms Aw

SINGHEALTH CENTRALISED INSTITUTIONAL REVIEW BOARD (CIRB) APPROVAL

Protocol Title: Caring for the Caregivers of People with Low Vision [R1212/18/2015]

We are pleased to inform you that the Singhealth CIRB A has approved the above research project to be conducted in Singapore National Eye Centre.

The documents reviewed are:

a) CIRB Application Form dated 10 Jun 2015
b) Research Protocol: Version 1 dated 2 Jun 2015
c) Participant Information Sheet and Informed Consent Form: Version 1.0 dated 30 Apr 2015
d) Health Utilisation Questionnaire: Version 1.0 dated 3 Jun 2015
e) Caregiver Interview Guide: Version 1.0 dated 3 Jun 2015
f) Ways of Coping Questionnaire: Version 1.0 date 3 Jun 2015
g) SF-36v2 Health Survey Measurement Model
h) Zarit Burden Interview
i) Cumulative Illness Rating Scale

The SingHealth CIRB operates in accordance with the ICH/ Singapore Guideline for Good Clinical Practices, and with the applicable regulatory requirement(s).

The approval period is from **26 June 2015 to 25 June 2016**. The reference number for this study is CIRB Ref: 2015/2540. Please use this reference number for all future correspondence.

The following are to be observed upon SingHealth CIRB Approval:

1. No subject should be admitted to the trial before the Health Sciences Authority issues the Clinical Trial Certificate. (only applicable for drug-related studies).

2. The Principal Investigator should ensure that this study is conducted in compliance with the Singapore Guideline for Good Clinical Practice, the ethical guidelines of which are applicable to all studies to be carried out, and to ensure that the study is carried out in accordance to the guidelines and the submitted protocol. The Principal

PATIENTS. AT THE HEART OF ALL WE DO.

CIRB Ref: 2015/2540

investigator should meet with his collaborator(s) regularly to assess the progress of the study, and be familiar and comply with all applicable research policies in the institution.

3. No deviation from, or changes of, the protocol should be initiated without prior written Singhealth CIRB approval of an appropriate amendment, except when necessary to eliminate immediate hazards to the subjects or when the change(s) involve(s) only logistical or administrative aspects of the trial (e.g. change of monitor(s), telephone number(s)).

4. Only the approved Participant Information Sheet and Consent Form should be used. It must be signed by each subject prior to enrolling in the study and initiation of any protocol procedures. Two copies of the Informed Consent Form should be signed and dated. Each subject or the subject's legally accepted representative should be given a copy of the signed consent form. The remaining copy should be kept by the PI / medical record.

5. The Principal Investigator should report promptly to the Singhealth CIRB of:
   i. Deviations from, or changes to the protocol including those made to eliminate immediate hazards to the trial subjects.
   ii. Changes increasing the risk to subjects and/or affecting significantly the conduct of the trial.
   iii. All serious adverse events (SAEs) and adverse drug reaction (ADRs) that are both serious and unexpected.
   iv. New information that may affect adversely the safety of the subjects or the conduct of the trial.
   v. Completion of the study.

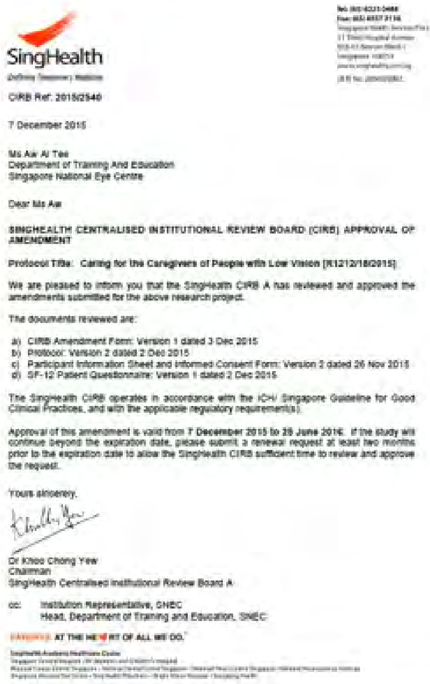
6. Study Status Report should be submitted to the Singhealth CIRB for the following:
   i. Annual review: Status of the study should be reported to the Singhealth CIRB at least annually using the Study Status Report.
   ii. Study renewal: the Study Status Report is to be submitted at least two months prior to the expiry of the approval period. A valid Singhealth CIRB renewal is essential, as any research performed outside of an approved time frame is not legal, and thus not covered by the hospital's research insurance in case of unexpected adverse reactions.
   iii. Study completion or termination: the Final Report is to be submitted within three months of study completion or termination.

Yours sincerely,

Dr Khoo Chong Yew
Chairman
Singhealth Centralised Institutional Review Board A

cc: Institution Representative, SNEC
Head, Department of Training And Education, SNEC

Page 2 of 2



SingHealth

CIRB Ref: 2015/2540

7 December 2015

Ms Aw Ai Tee
Department of Training And Education
Singapore National Eye Centre

Dear Ms Aw

SINGHEALTH CENTRALISED INSTITUTIONAL REVIEW BOARD (CIRB) APPROVAL OF AMENDMENT

Protocol Title: Caring for the Caregivers of People with Low Vision [R1212/18/2015]

We are pleased to inform you that the SingHealth CIRB A has reviewed and approved the amendments submitted for the above research project.

The documents reviewed are:

a) CIRB Amendment Form: Version 1 dated 3 Dec 2015
b) Protocol: Version 2 dated 2 Dec 2015
c) Participant Information Sheet and Informed Consent Form: Version 2 dated 26 Nov 2015
d) SF-12 Patient Questionnaire: Version 1 dated 2 Dec 2015

The SingHealth CIRB operates in accordance with the ICH/ Singapore Guideline for Good Clinical Practices, and with the applicable regulatory requirement(s).

Approval of this amendment is valid from **7 December 2015 to 25 June 2016**. If the study will continue beyond the expiration date, please submit a renewal request at least two months prior to the expiration date to allow the SingHealth CIRB sufficient time to review and approve the request.

Yours sincerely,

Dr Khoo Chong Yew
Chairman
SingHealth Centralised Institutional Review Board A

cc: Institution Representative, SNEC
Head, Department of Training and Education, SNEC

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SingHealth

CIRB Ref: 2015/2540

31 October 2018

Ms Aw Ai Tee
Department of Training and Education
Singapore National Eye Centre

Dear Ms Aw

RENEWAL OF SINGHEALTH CENTRALISED INSTITUTIONAL REVIEW BOARD (CIRB) APPROVAL

Protocol Title: Caring for the Caregivers of People with Low Vision [R1212/18/2015]

We are pleased to inform you that the SingHealth CIRB A has reviewed and approved the renewal of IRB approval for the study to be conducted in Singapore National Eye Centre.

Please note that annual IRB renewal is required and the review is based on the Study Status Report submitted. It is the Principal Investigator's responsibility to submit a Study Status Report for the study at least two months before the expiry date of the study for renewal of IRB approval. This approval is valid till **30 October 2019**.

The document reviewed is:

- Study Renewal Report Form dated 30 Oct 2018

The SingHealth CIRB operates in accordance with the ICH Guideline for Good Clinical Practices, and with the applicable regulatory requirement(s).

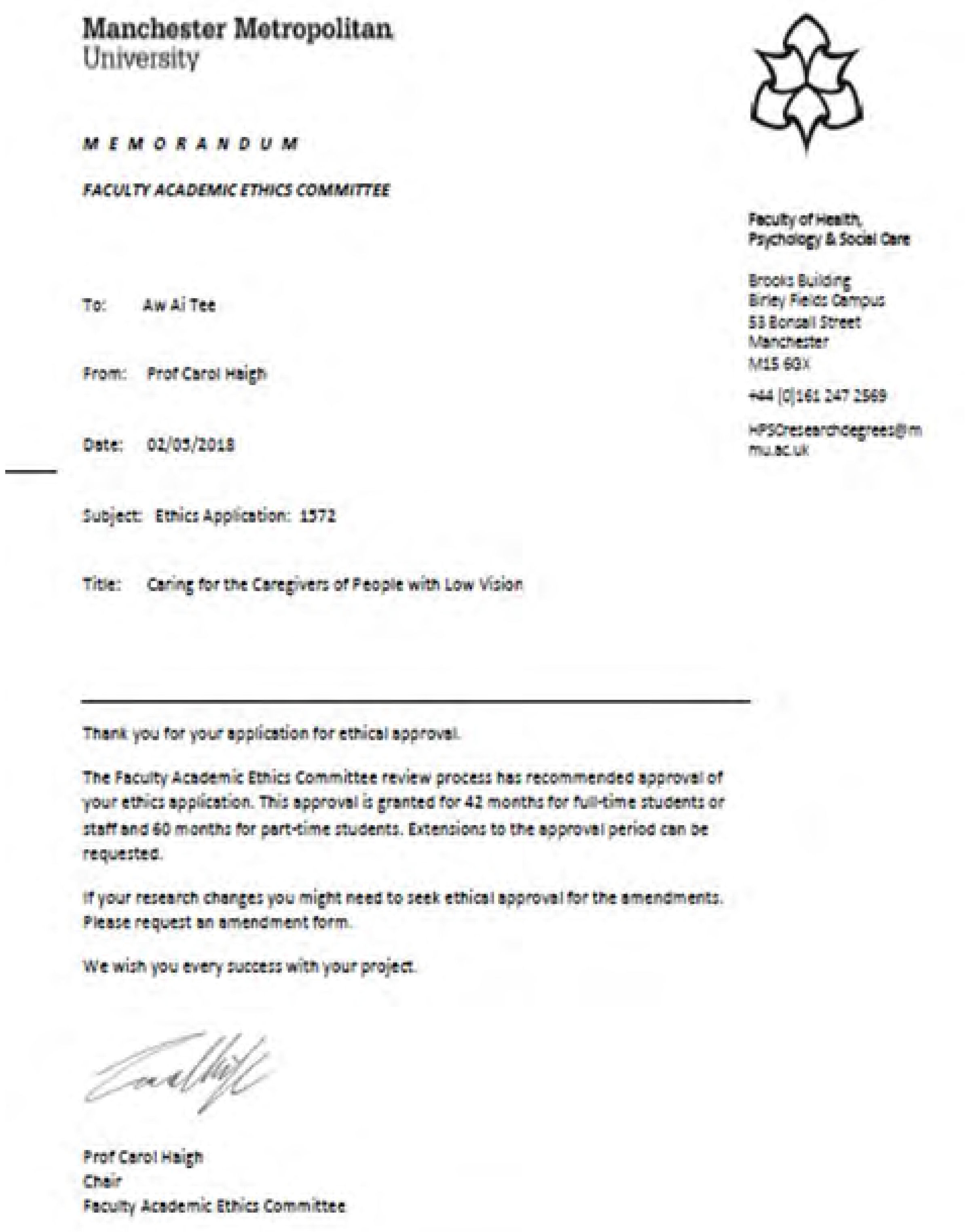
Yours sincerely,

Prof Ho Lai Yun
Chairman
SingHealth Centralised Institutional Review Board A

cc: Institution Representative, SNEC
Head, Department of Training and Education, SNEC

This submission is reviewed online. No signature is required.

Appendix D : MMU Ethics Approval



Manchester Metropolitan
University

MEMORANDUM

FACULTY ACADEMIC ETHICS COMMITTEE

Faculty of Health,
Psychology & Social Care

Brooks Building
Birley Fields Campus
53 Bonsall Street
Manchester
M15 6GX

+44 (0)161 247 2569

HPSCresearchdegrees@m
mu.ac.uk

To: Aw Ai Tee

From: Prof Carol Haigh

Date: 02/05/2018

Subject: Ethics Application: 1572

Title: Caring for the Caregivers of People with Low Vision

Thank you for your application for ethical approval.

The Faculty Academic Ethics Committee review process has recommended approval of your ethics application. This approval is granted for 42 months for full-time students or staff and 60 months for part-time students. Extensions to the approval period can be requested.

If your research changes you might need to seek ethical approval for the amendments. Please request an amendment form.

We wish you every success with your project.

Prof Carol Haigh
Chair
Faculty Academic Ethics Committee

Appendix E : Participant Information Sheet and Consent form

SingHealth

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

STUDY INFORMATION

Protocol Title:

Caring for the Caregivers of People with Low Vision

Principal Investigator:

Aw Ai Tee, Singapore National Eye Centre
Department of Nursing Administration
11, Third Hospital Avenue
Tel : 6322 8847

PURPOSE OF THE RESEARCH STUDY

You are being invited to participate in a research study. Before you take part in this research study, the study must be explained to you and you must be given the chance to ask questions. Please read carefully the information provided here. If you agree to participate, please sign the consent form. You will be given a copy of this document to take home with you.

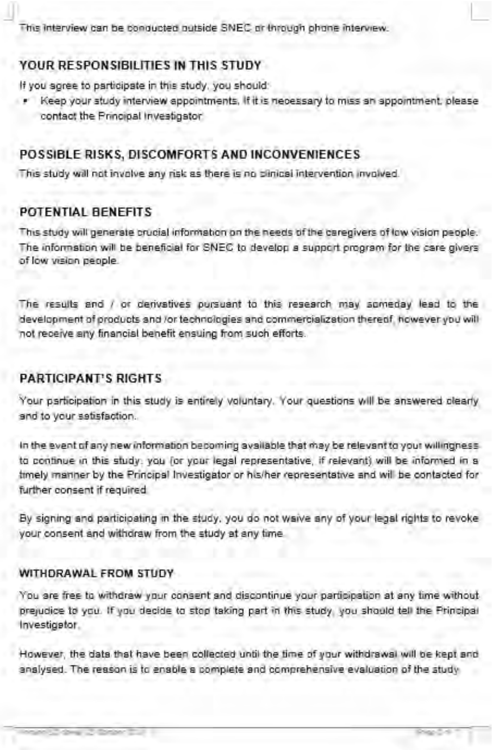
We hope to learn the experiences of caregiving for low vision patients in order to develop a support program for the caregivers. You were selected as a possible subject in this study because you are the primary care giver of the low vision patient.

This study will recruit 60 subjects from Singapore National Eye Centre over a period of *4 years* from Dec 2015– Dec 2019. About 30 care giver subjects will be involved in this study. PI will conduct interview on 60 participants by using 5 sets of questionnaires and another 12 participants will be individual in-depth interviews by PI.

STUDY PROCEDURES AND VISIT SCHEDULE

If you agree to take part in this study, you will be asked to fill in 5 sets of questionnaires:

1. SF12®Patient Questionnaire
2. Zarit Burden Interview
3. Vitaliarno Revised way of coping checklist
4. CIRS (Cumulative illness rating scale)
5. Health care utilization



This interview can be conducted outside SNEC or through phone interview.

YOUR RESPONSIBILITIES IN THIS STUDY

If you agree to participate in this study, you should:

- Keep your study interview appointments. If it is necessary to miss an appointment, please contact the Principal Investigator

POSSIBLE RISKS, DISCOMFORTS AND INCONVENIENCES

This study will not involve any risk as there is no clinical intervention involved.

POTENTIAL BENEFITS

This study will generate crucial information on the needs of the caregivers of low vision people. The information will be beneficial for SNEC to develop a support program for the care givers of low vision people.

The results and / or derivatives pursuant to this research may someday lead to the development of products and /or technologies and commercialization thereof, however you will not receive any financial benefit ensuing from such efforts.

PARTICIPANT'S RIGHTS

Your participation in this study is entirely voluntary. Your questions will be answered clearly and to your satisfaction.

In the event of any new information becoming available that may be relevant to your willingness to continue in this study, you (or your legal representative, if relevant) will be informed in a timely manner by the Principal Investigator or his/her representative and will be contacted for further consent if required.

By signing and participating in the study, you do not waive any of your legal rights to revoke your consent and withdraw from the study at any time.

WITHDRAWAL FROM STUDY

You are free to withdraw your consent and discontinue your participation at any time without prejudice to you. If you decide to stop taking part in this study, you should tell the Principal Investigator.

However, the data that have been collected until the time of your withdrawal will be kept and analysed. The reason is to enable a complete and comprehensive evaluation of the study.

The data collected for the study will be deemed to be given to SNEC and will not be returned to you. However, you retain your right to ask the Principal Investigator to discard or destroy any remaining data if they have not been anonymised.

Your doctor, the Principal Investigator of this study may stop your participation in the study at any time for one or more of the following reasons:

- Failure to follow the instructions of the Principal Investigator.
- The study is cancelled.

RESEARCH RELATED INJURY AND COMPENSATION

By signing the Consent Form, you will not waive any of your legal rights or release the parties involved in this study from liability for negligence.

CONFIDENTIALITY OF STUDY AND MEDICAL RECORDS

Your participation in this study will involve the collection of Personal Data. Personal Data collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available. Only your Investigator(s) will have access to the confidential information being collected.

However, the SNEC / SERI, Regulatory Agencies, Institutional Review Board and Ministry of Health will be granted direct access to your original medical records to check study procedures and data, without making any of your information public.

By signing the Consent Form, you consent to (i) the collection, access to, use and storage of your Personal Data by SNEC / SERI, and (ii) the disclosure of such Personal Data to our authorised service providers and relevant third parties for the purpose of future research studies ("Future Research").

"Personal Data" means data about you which makes you identifiable (i) from such data or (ii) from that data and other information which an organisation has or likely to have access. Examples of personal data include medical conditions, medications, investigations and treatment history.

Research arising in the future, based on this "Personal Data", will be subject to review by the relevant institutional review board.

Data collected and entered into the computer systems which are the property of SNEC / SERI. In the event of any publication regarding this study, your identity will remain confidential.

By participating in this research study, you are confirming that you have read, understood and consent to the SingHealth Data Protection Policy- the full version is available at www.singhealth.com.sg/pdpa.

Version 5.0 dated 13 October 2018 Page 3 of 7

WHO TO CONTACT IF YOU HAVE QUESTIONS REGARDING THE STUDY

If you have questions about this research study or in the case of any injuries during the course of this study, you may contact the Principal Investigator Ms Aw Ai Tee, office telephone: 6322 8847.

WHO HAS REVIEWED THE STUDY

This study has been reviewed by the SingHealth Centralised Institutional Review Board for ethics approval.

If you have questions about your rights as a participant, you can call the SingHealth Centralised Institutional Review Board at 6323 7515 during office hours (8:30 am to 5:30pm).

If you have any feedback about this research study, you may contact the Principal Investigator or the SingHealth Centralised Institutional Review Board.

Version 5.0 dated 13 October 2018 Page 4 of 7

CONSENT FORM

Details of Research Study

Protocol Title:
Caring for the Caregivers of People with Low Vision – A Pilot Study

Principal Investigator:
Ms Aw Ai Tee
Department of Nursing Administration
Singapore National Eye Centre
Office Telephone: 6322 8847

Participant's Particulars

Name:
NRIC No.:
Address:
Sex: Female/Male
Date of birth ____________ dd/mm/yyyy
Race: Chinese/ Malay/ Indian /Others (please specify) ____________

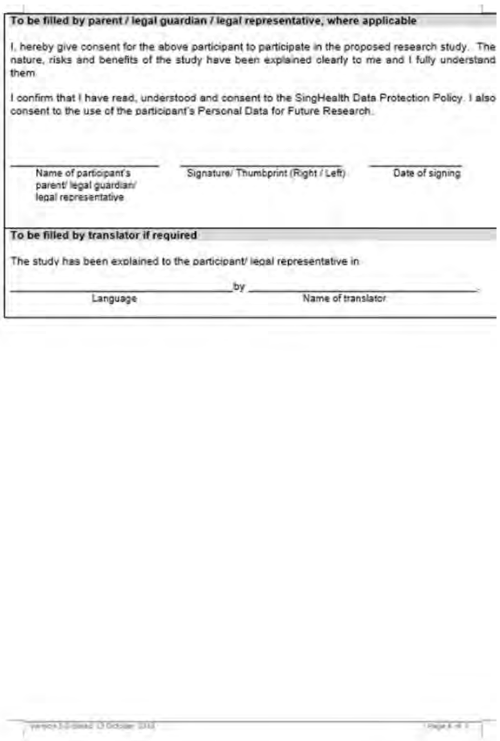
I agree to participate in the research study as described and on the terms set out in the Patient Information Sheet.

I have fully discussed and understood the purpose and procedures of this study. I have been given the Participant Information Sheet and the opportunity to ask questions about this study and have received satisfactory answers and information.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons and without my medical care being affected.

By participating in this research study, I confirm that I have read, understood and consent to the SingHealth Data Protection Policy. I also consent to the use of my Personal Data for the purposes of engaging in related research arising in the future.

Name of participant	Signature / Thumbprint (Right / Left)	Date of signing



To be filled by parent / legal guardian / legal representative, where applicable

I, hereby give consent for the above participant to participate in the proposed research study. The nature, risks and benefits of the study have been explained clearly to me and I fully understand them.

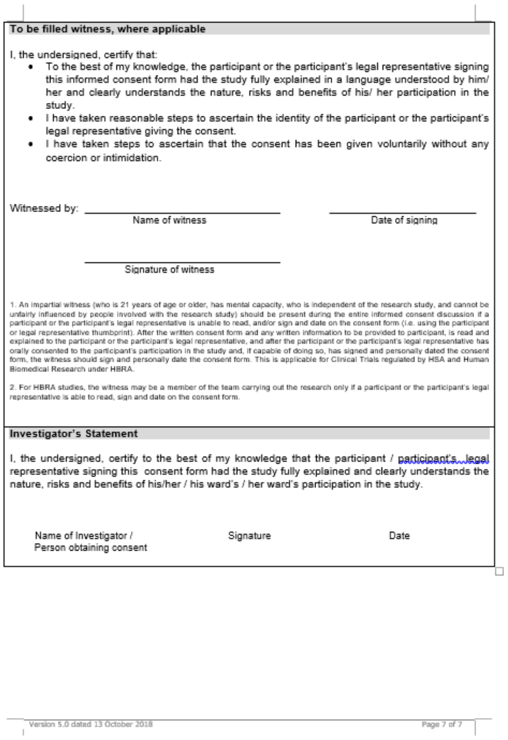
I confirm that I have read, understood and consent to the SingHealth Data Protection Policy. I also consent to the use of the participant's Personal Data for Future Research.

Name of participant's parent/ legal guardian/ legal representative	Signature/ Thumbprint (Right / Left)	Date of signing

To be filled by translator if required

The study has been explained to the participant/ legal representative in

____________________ by ____________________
Language Name of translator



To be filled witness, where applicable

I, the undersigned, certify that:

- To the best of my knowledge, the participant or the participant's legal representative signing this informed consent form had the study fully explained in a language understood by him/ her and clearly understands the nature, risks and benefits of his/ her participation in the study.
- I have taken reasonable steps to ascertain the identity of the participant or the participant's legal representative giving the consent.
- I have taken steps to ascertain that the consent has been given voluntarily without any coercion or intimidation.

Witnessed by: ____________________ ____________________
Name of witness Date of signing

____
Signature of witness

1. An impartial witness (who is 21 years of age or older, has mental capacity, who is independent of the research study, and cannot be unfairly influenced by people involved with the research study) should be present during the entire informed consent discussion if a participant or the participant's legal representative is unable to read, and/or sign and date on the consent form (i.e. using the participant or legal representative thumbprint). After the written consent form and any written information to be provided to participant, is read and explained to the participant or the participant's legal representative, and after the participant or the participant's legal representative has orally consented to the participant's participation in the study and, if capable of doing so, has signed and personally dated the consent form, the witness should sign and personally date the consent form. This is applicable for Clinical Trials regulated by HSA and Human Biomedical Research under HBRA.

2. For HBRA studies, the witness may be a member of the team carrying out the research only if a participant or the participant's legal representative is able to read, sign and date on the consent form.

Investigator's Statement

I, the undersigned, certify to the best of my knowledge that the participant / participant's legal representative signing this consent form had the study fully explained and clearly understands the nature, risks and benefits of his/her / his ward's / her ward's participation in the study.

Name of Investigator / Person obtaining consent	Signature	Date

Version 5.0 dated 13 October 2018 Page 7 of 7

Appendix E: Participant Information Sheet informed Consent for In-depth Interview

Appendix D: Patient Information Sheet and Consent (For In-depth Interview)

SingHealth

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

STUDY INFORMATION

Protocol Title:

Caring for the Caregivers of People with Low Vision

Principal Investigator:

Aw Ai Tee, Singapore National Eye Centre
Department of Nursing Administration
11, Third Hospital Avenue
Tel: 6322 8847

PURPOSE OF THE RESEARCH STUDY

You are being invited to participate in a research study. Before you take part in this research study, the study must be explained to you and you must be given the chance to ask questions. Please read carefully the information provided here. If you agree to participate, please sign the consent form. You will be given a copy of this document to take home with you.

We hope to learn the experiences of caregiving for low vision patients in order to develop a support program for the caregivers. You were selected as a possible subject in this study because you are the primary care giver of the low vision patient.

This study will recruit 60 subjects from Singapore National Eye Centre over a period of 4 years from Dec 2018 - Dec 2019. About 60 care giver subjects will be involved in this study. PI will conduct interview on 60 participants by using 5 sets of questionnaires and another 12 participants will be individual in depth interviews by PI.

STUDY PROCEDURES AND VISIT SCHEDULE

If you agree to take part in this study, you will be asked to participate in an in-depth face-to-face interview. The interview will be conducted on a one-on-one basis. The interview will last for an hour. The interview will be digitally recorded. No preparation is required of you to participate in this study. Be prepared to share your experiences and thoughts in the face-to-face interview.

PARTICIPANT'S RIGHTS

Your participation in this study is entirely voluntary. Your questions will be answered clearly and to your satisfaction.

In the event of any new information becoming available that may be relevant to your willingness to continue in this study, you (or your legal representative, if relevant) will be informed in a timely manner by the Principal Investigator or his/her representative and will be contacted for further consent if required.

By signing and participating in the study, you do not waive any of your legal rights to revoke your consent and withdraw from the study at any time.

WITHDRAWAL FROM STUDY

You are free to withdraw your consent and discontinue your participation at any time without prejudice to you. If you decide to stop taking part in this study, you should tell the Principal Investigator. If you withdraw from the study, any audio recordings related to you will be deleted.

However, the data that have been collected until the time of your withdrawal will be kept and analysed. The reason is to enable a complete and comprehensive evaluation of the study.

The data collected for the study will be deemed to be given to SNEC and will not be returned to you. However, you retain your right to ask the Principal Investigator to discard or destroy any remaining data if they have not been anonymised.

Your doctor, the Principal Investigator of this study may stop your participation in the study at any time for one or more of the following reasons:

- Failure to follow the instructions of the Principal Investigator
- The study is cancelled.

RESEARCH RELATED INJURY AND COMPENSATION

By signing the Consent Form, you will not waive any of your legal rights or release the parties involved in this study from liability for negligence.

CONFIDENTIALITY OF STUDY AND MEDICAL RECORDS

Your participation in this study will involve the collection of Personal Data. Personal Data collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available. Only your Investigator(s) will have access to the confidential information being collected.

However, the SNEC / SERI, Regulatory Agencies, Institutional Review Board and Ministry of Health will be granted direct access to your original medical records to check study procedures and data, without making any of your information public.

By signing the Consent Form, you consent to (i) the collection, access to, use and storage of your Personal Data by SNEC / SERI, and (ii) the disclosure of such Personal Data to our authorised service providers and relevant third parties for the purpose of future research studies ("Future Research").

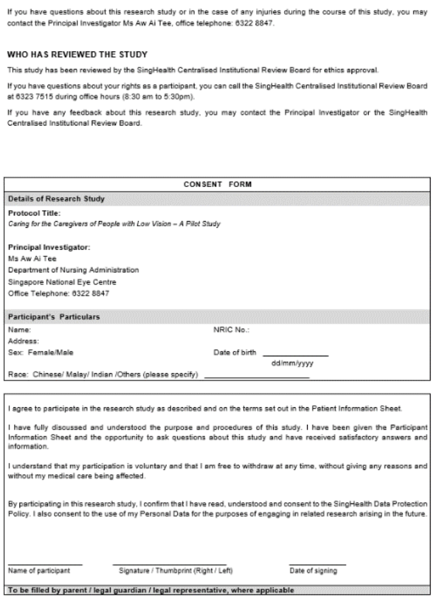
"Personal Data" means data about you which makes you identifiable (i) from such data or (ii) from that data and other information which an organisation has or likely to have access. Examples of personal data include medical conditions, medications, investigations and treatment history.

Research arising in the future, based on this "Personal Data", will be subject to review by the relevant institutional review board.

Data collected and entered into the computer systems which are the property of SNEC / SERI. In the event of any publication regarding this study, your identity will remain confidential.

By participating in this research study, you are confirming that you have read, understood and consent to the SingHealth Data Protection Policy- the full version is available at www.singhealth.com.sg/pdpa

WHO TO CONTACT IF YOU HAVE QUESTIONS REGARDING THE STUDY



If you have questions about this research study or in the case of any injuries during the course of this study, you may contact the Principal Investigator Ms Aw Ai Tee, office telephone: 6322 8847.

WHO HAS REVIEWED THE STUDY

This study has been reviewed by the SingHealth Centralised Institutional Review Board for ethics approval.

If you have questions about your rights as a participant, you can call the SingHealth Centralised Institutional Review Board at 6323 7515 during office hours (8:30 am to 5:30pm).

If you have any feedback about this research study, you may contact the Principal Investigator or the SingHealth Centralised Institutional Review Board.

CONSENT FORM

Details of Research Study

Protocol Title:
Caring for the Caregivers of People with Low Vision – A Pilot Study

Principal Investigator:
Ms Aw Ai Tee
Department of Nursing Administration
Singapore National Eye Centre
Office Telephone: 6322 8847

Participant's Particulars

Name: NRIC No.:
Address:
Sex: Female/Male Date of birth ______________ dd/mm/yyyy
Race: Chinese/ Malay/ Indian /Others (please specify) ______________________

I agree to participate in the research study as described and on the terms set out in the Patient Information Sheet.

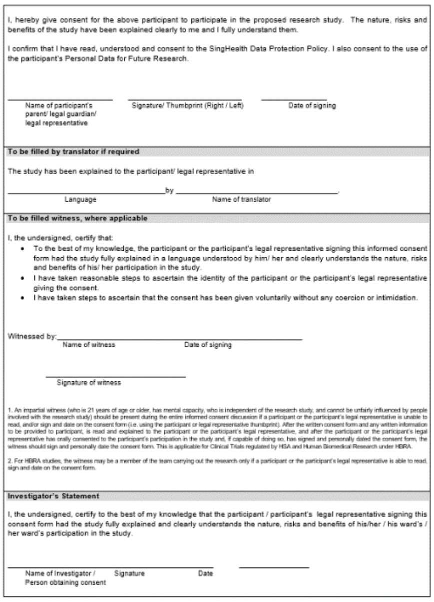
I have fully discussed and understood the purpose and procedures of this study. I have been given the Participant Information Sheet and the opportunity to ask questions about this study and have received satisfactory answers and information.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons and without my medical care being affected.

By participating in this research study, I confirm that I have read, understood and consent to the SingHealth Data Protection Policy. I also consent to the use of my Personal Data for the purposes of engaging in related research arising in the future.

Name of participant	Signature / Thumbprint (Right / Left)	Date of signing

To be filled by parent / legal guardian / legal representative, where applicable



I, hereby give consent for the above participant to participate in the proposed research study. The nature, risks and benefits of the study have been explained clearly to me and I fully understand them.

I confirm that I have read, understood and consent to the SingHealth Data Protection Policy. I also consent to the use of the participant's Personal Data for Future Research.

Name of participant's parent/ legal guardian/ legal representative	Signature/ Thumbprint (Right / Left)	Date of signing

To be filled by translator if required

The study has been explained to the participant/ legal representative in

______________________by ______________________.
Language Name of translator

To be filled witness, where applicable

I, the undersigned, certify that:

- To the best of my knowledge, the participant or the participant's legal representative signing this informed consent form had the study fully explained in a language understood by him/ her and clearly understands the nature, risks and benefits of his/ her participation in the study.
- I have taken reasonable steps to ascertain the identity of the participant or the participant's legal representative giving the consent.
- I have taken steps to ascertain that the consent has been given voluntarily without any coercion or intimidation.

Witnessed by:______________________________________
Name of witness Date of signing

____
Signature of witness

1. An impartial witness (who is 21 years of age or older, has mental capacity, who is independent of the research study, and cannot be unfairly influenced by people involved with the research study) should be present during the entire informed consent discussion if a participant or the participant's legal representative is unable to read, and/or sign and date on the consent form (i.e. using the participant or legal representative thumbprint). After the written consent form and any written information to be provided to participant, is read and explained to the participant or the participant's legal representative, and after the participant or the participant's legal representative has orally consented to the participant's participation in the study and, if capable of doing so, has signed and personally dated the consent form, the witness should sign and personally date the consent form. This is applicable for Clinical Trials regulated by HSA and Human Biomedical Research under HBRA.

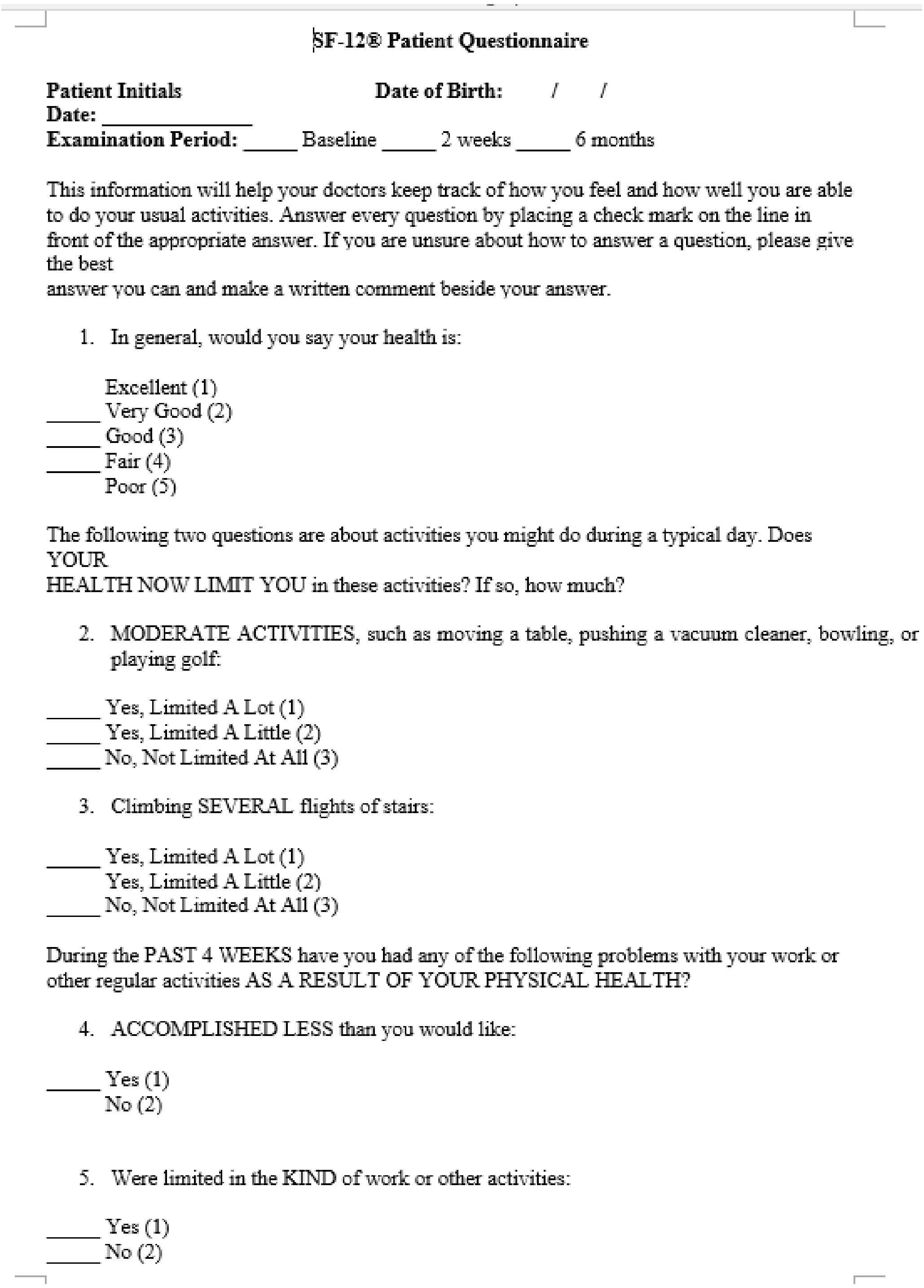
2. For HBRA studies, the witness may be a member of the team carrying out the research only if a participant or the participant's legal representative is able to read, sign and date on the consent form.

Investigator's Statement

I, the undersigned, certify to the best of my knowledge that the participant / participant's legal representative signing this consent form had the study fully explained and clearly understands the nature, risks and benefits of his/her / his ward's / her ward's participation in the study.

Name of Investigator / Person obtaining consent	Signature	Date

Appendix F: License to use SF-12 Health Survey (SF-12) and SF 12 Questionnaire



SF-12® Patient Questionnaire

Patient Initials **Date of Birth:** / /
Date: ______________
Examination Period: _____ Baseline _____ 2 weeks _____ 6 months

This information will help your doctors keep track of how you feel and how well you are able to do your usual activities. Answer every question by placing a check mark on the line in front of the appropriate answer. If you are unsure about how to answer a question, please give the best
answer you can and make a written comment beside your answer.

1. In general, would you say your health is:

Excellent (1)
_____ Very Good (2)
_____ Good (3)
_____ Fair (4)
Poor (5)

The following two questions are about activities you might do during a typical day. Does YOUR
HEALTH NOW LIMIT YOU in these activities? If so, how much?

2. MODERATE ACTIVITIES, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf:

_____ Yes, Limited A Lot (1)
_____ Yes, Limited A Little (2)
_____ No, Not Limited At All (3)

3. Climbing SEVERAL flights of stairs:

_____ Yes, Limited A Lot (1)
Yes, Limited A Little (2)
_____ No, Not Limited At All (3)

During the PAST 4 WEEKS have you had any of the following problems with your work or other regular activities AS A RESULT OF YOUR PHYSICAL HEALTH?

4. ACCOMPLISHED LESS than you would like:

_____ Yes (1)
No (2)

5. Were limited in the KIND of work or other activities:

_____ Yes (1)
_____ No (2)

During the PAST 4 WEEKS, were you limited in the kind of work you do or other regular activities AS A RESULT OF ANY EMOTIONAL PROBLEMS (such as feeling depressed or anxious)?

6. ACCOMPLISHED LESS than you would like:

_____ Yes (1)
_____ No (2)

7. Didn't do work or other activities as CAREFULLY as usual:

_____ Yes (1)
_____ No (2)

8. During the PAST 4 WEEKS, how much did PAIN interfere with your normal work (including both work outside the home and housework)?

Not At All (1)
_____ A Little Bit (2)
_____ Moderately (3)
_____ Quite A Bit (4)
Extremely (5)

The next three questions are about how you feel and how things have been DURING THE PAST 4 WEEKS. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST 4 WEEKS –

9. Have you felt calm and peaceful?

All of the Time (1)
_____ Most of the Time (2)
_____ A Good Bit of the Time (3)
_____ Some of the Time (4)
A Little of the Time (5)
_____ None of the Time (6)

10. Did you have a lot of energy?

_____ All of the Time (1)
_____ Most of the Time (2)
_____ A Good Bit of the Time (3)
Some of the Time (4)
_____ A Little of the Time (5)
_____ None of the Time (6)

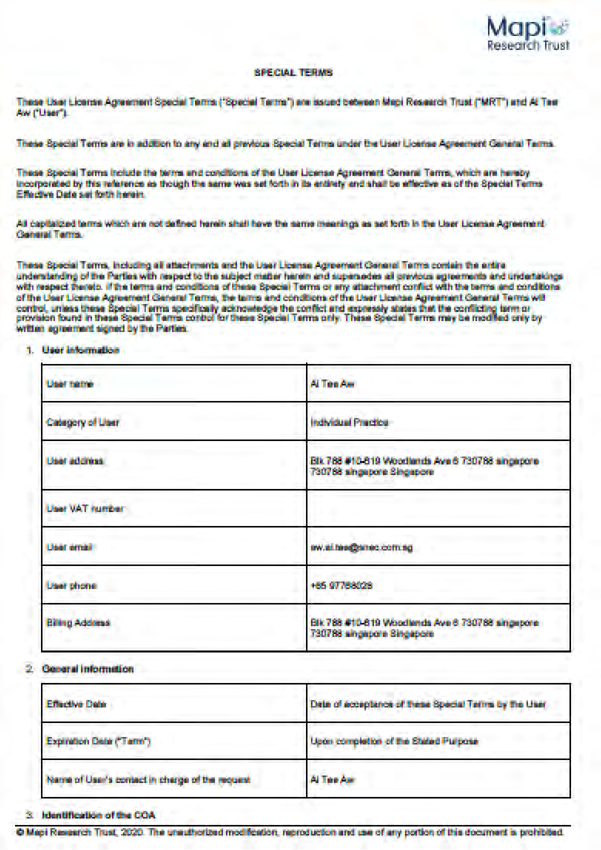
11. Have you felt downhearted and blue?

All of the Time (1)
_____ Most of the Time (2)
_____ A Good Bit of the Time (3)
_____ Some of the Time (4)
A Little of the Time (5)
_____ None of the Time (6)

12. During the PAST 4 WEEKS, how much of the time has your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your social activities (like visiting with friends, relatives, etc.)?

_____ All of the Time (1)
Most of the Time (2)
_____ A Good Bit of the Time (3)
_____ Some of the Time (4)
_____ A Little of the Time (5)
None of the Time (6)

Appendix G: License to Use ZBI and ZBI Questionnaire



SPECIAL TERMS

These User License Agreement Special Terms ("Special Terms") are issued between Mapi Research Trust ("MRT") and Ai Tee Aw ("User").

These Special Terms are in addition to any and all previous Special Terms under the User License Agreement General Terms.

These Special Terms include the terms and conditions of the User License Agreement General Terms, which are hereby incorporated by this reference as though the same was set forth in its entirety and shall be effective as of the Special Terms Effective Date set forth herein.

All capitalized terms which are not defined herein shall have the same meanings as set forth in the User License Agreement General Terms.

These Special Terms, including all attachments and the User License Agreement General Terms contain the entire understanding of the Parties with respect to the subject matter herein and supersedes all previous agreements and undertakings with respect thereto. If the terms and conditions of these Special Terms or any attachment conflict with the terms and conditions of the User License Agreement General Terms, the terms and conditions of the User License Agreement General Terms will control, unless these Special Terms specifically acknowledge the conflict and expressly states that the conflicting term or provision found in these Special Terms control for these Special Terms only. These Special Terms may be modified only by written agreement signed by the Parties.

1. **User information**

User name	Ai Tee Aw
Category of User	Individual Practice
User address	Blk 788 #10-619 Woodlands Ave 6 730788 singapore 730788 singapore Singapore
User VAT number	
User email	aw.ai.tee@smec.com.sg
User phone	+65 97788028
Billing Address	Blk 788 #10-619 Woodlands Ave 6 730788 singapore 730788 singapore Singapore

2. **General information**

Effective Date	Date of acceptance of these Special Terms by the User
Expiration Date ("Term")	Upon completion of the Stated Purpose
Name of User's contact in charge of the request	Ai Tee Aw

3. **Identification of the COA**

Name of the COA	ZBI - Zarit Burden Interview
Author	Zarit SH
Copyright Holder	Zarit Steven H and Zarit Judy M
Copyright notice	Copyright 1980, 1983, 1990 Steven H Zarit and Judy M Zarit
Bibliographic reference	ZBI-22 Zarit SH, Reever KE, Bach-Peterson J. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. Gerontologist. 1980;20(6):649-55 Zarit SH, Orr NK, Zarit JM. The hidden victims of Alzheimer's disease: Families under stress. New York: New York University Press, 1985 Anthony-Bergstone CR, Zarit SH, Gatz M. Symptoms of psychological distress among caregivers of dementia patients. Psychol Aging. 1988 Sep;3(3):245-8 (PubMed abstract) Zarit SH, Zarit JM. The Memory and Behavior Problems Checklist and the Burden Interview. Gerontology Center, Penn State University. 1990 ZBI-12 Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The Zarit Burden Interview: a new short version and screening version. Gerontologist. 2001 Oct;41(5):652-7 (PubMed Abstract)
Modules/versions needed	ZBI-22

4. **Context of use of the COA**

The User undertakes to use the COA solely in the context of the Stated Purpose as defined hereafter.

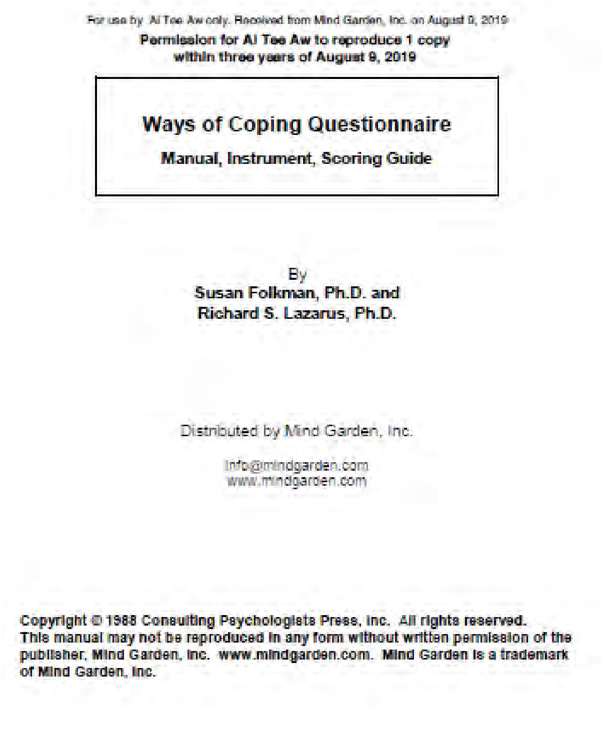
THE ZARIT BURDEN INTERVIEW

Please circle the response the best describes how you feel. Never	Rarely	Sometimes	Quite Frequently	Nearly Always	Always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4

16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4
Total Score (out of 88)					

Interpretation of Score:
0 – 21 little or no burden
21 – 40 mild to moderate burden
41 – 60 moderate to severe burden
61 – 88 severe burden

Appendix H: License to use Ways of Coping Questionnaire (WOC) and WOC Questionnaire



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Ways of Coping Questionnaire

Manual, Instrument, Scoring Guide

By
Susan Folkman, Ph.D. and
Richard S. Lazarus, Ph.D.

Distributed by Mind Garden, Inc.

info@mindgarden.com
www.mindgarden.com

WAYS OF COPING (Revised)*

Please read each item below and think about how you generally have coped with stressful encounters that you have experienced. Using the following rating scale, to what extent did you generally use the strategies listed below.

Not Used	**Used Somewhat**	**Used Quite A Bit**	**Used A great deal**
0	**1**	**2**	**3**

_____ 1. Just concentrated on what I had to do next – the next step.

_____ 2. I tried to analyze the problem in order to understand it better.

_____ 3. Turned to work or substitute activity to take my mind off things.

_____ 4. I felt that time would make a difference – the only thing to do was to wait.

_____ 5. Bargained or compromised to get something positive from the situation.

_____ 6. I did something which I didn't think would work, but at least I was doing something.

_____ 7. Tried to get the person responsible to change his or her mind.

_____ 8. Talked to someone to find out more about the situation.

_____ 9. Criticized or lectured myself.

_____ 10. Tried not to burn my bridges, but leave things open somewhat.

_____ 11. Hoped a miracle would happen.

_____ 12. Went along with fate; sometimes I just have bad luck.

_____ 13. Went on as if nothing had happened.

_____ 14. I tried to keep my feelings to myself.

_____ 15. Looked for the silver lining, so to speak; tried to look on the bright side of things

_____ 16. Slept more than usual.

_____ 17. I expressed anger to the person(s) who caused the problem.

_____ 18. Accepted sympathy and understanding from someone.

_____ 19. I told myself things that helped me to feel better.

_____ 20. I was inspired to do something creative.

_____ 21. Tried to forget the whole thing.

_____ 22. I got professional help.

_____ 23. Changed or grew as a person in a good way.

_____ 24. I waited to see what would happen before doing anything.

_____ 25. I apologized or did something to make up.

_____ 26. I made a plan of action and followed it.

_____ 27. I accepted the next best thing to what I wanted.

_____ 28. I let my feelings out somehow.
_____ 29. Realized I brought the problem on myself.
_____ 30. I came out of the experience better than when I went in.
_____ 31. Talked to someone who could do something concrete about the problem.
_____ 32. Got away from it for a while; tried to rest or take a vacation.
_____ 33. Tried to make myself feel better by eating, drinking, smoking, using drugs or meds.
_____ 34. Took a big chance or did something very risky.
_____ 35. I tried not to act too hastily or follow my first hunch.
_____ 36. Found new faith.
_____ 37. Maintained my pride and kept a stiff upper lip.
_____ 38. Rediscovered what is important in life.
_____ 39. Changed something so things would turn out all right.
_____ 40. Avoided being with people in general.
_____ 41. Didn’t let it get to me; refused to think too much about it.
_____ 42. I asked a relative or friend I respected for advice.
_____ 43. Kept others from knowing how bad things were.
_____ 44. Made light of the situation; refused to get too serious about it.
_____ 45. Talked to someone about how I was feeling.
_____ 46. Stood my ground and fought for what I wanted.
_____ 47. Took it out on other people.
_____ 48. Drew on my past experiences; I was in a similar situation before.
_____ 49. I knew what had to be done, so I doubled my efforts to make things work.
_____ 50. Refused to believe that it had happened.
_____ 51. I made a promise to myself that things would be different next time.
_____ 52. Came up with a couple of different solutions to the problem.
_____ 53. Accepted it, since nothing could be done.
_____ 54. I tried to keep my feelings from interfering with other things too much.
_____ 55. Wished that I could change what had happened or how I felt.
_____ 56. I changed something about myself.
_____ 57. I daydreamed or imagined a better time or place than the one I was in.
_____ 58. Wished that the situation would go away or somehow be over with.
_____ 59. Had fantasies or wishes about how things might turn out.
_____ 60. I prayed.

_____ 61. I prepared myself for the worst.

_____ 62. I went over in my mind what I would say or do.

_____ 63. I thought about how a person I admire would handle this situation and used that as a
model.

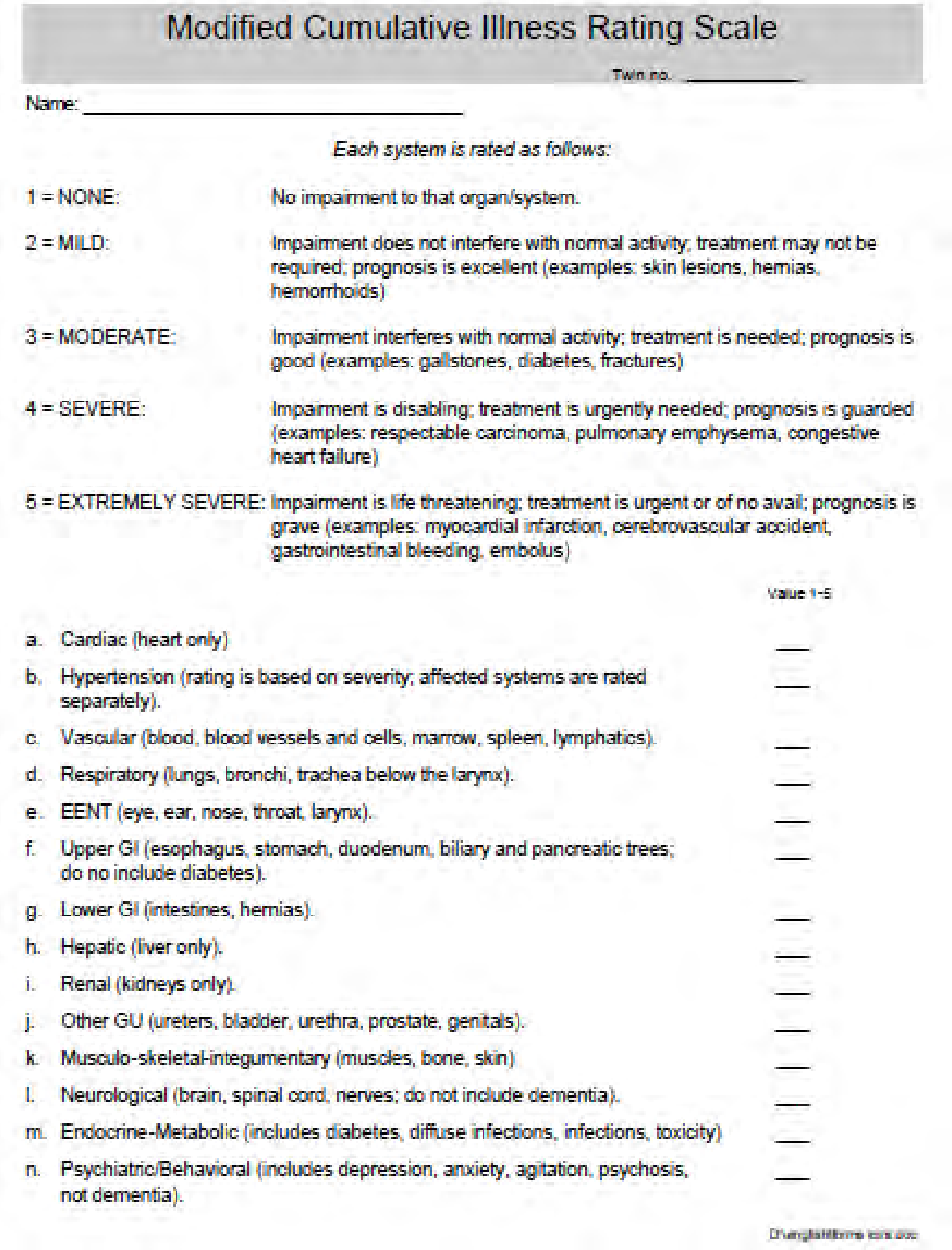
_____ 64. I tried to see things from the other person's point of view.

_____ 65. I reminded myself how much worse things could be.

_____ 66. I jogged or exercised.

*Adapted from Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. (1986). The dynamics of a stressful encounter: Cognitive appraisal, coping and encounter outcomes. Journal of Personality and Social Psychology, 50, 992-1003.

Appendix I: Cumulative Illness Rating Scale (CIRS) Questionnaire



Modified Cumulative Illness Rating Scale

Twin no. ____________

Name: ____

Each system is rated as follows:

1 = NONE:	No impairment to that organ/system.
2 = MILD:	Impairment does not interfere with normal activity; treatment may not be required; prognosis is excellent (examples: skin lesions, hernias, hemorrhoids)
3 = MODERATE:	Impairment interferes with normal activity; treatment is needed; prognosis is good (examples: gallstones, diabetes, fractures)
4 = SEVERE:	Impairment is disabling; treatment is urgently needed; prognosis is guarded (examples: respectable carcinoma, pulmonary emphysema, congestive heart failure)
5 = EXTREMELY SEVERE:	Impairment is life threatening; treatment is urgent or of no avail; prognosis is grave (examples: myocardial infarction, cerebrovascular accident, gastrointestinal bleeding, embolus)

		Value 1-5
a.	Cardiac (heart only)	___
b.	Hypertension (rating is based on severity; affected systems are rated separately).	___
c.	Vascular (blood, blood vessels and cells, marrow, spleen, lymphatics).	___
d.	Respiratory (lungs, bronchi, trachea below the larynx).	___
e.	EENT (eye, ear, nose, throat, larynx).	___
f.	Upper GI (esophagus, stomach, duodenum, biliary and pancreatic trees; do no include diabetes).	___
g.	Lower GI (intestines, hernias).	___
h.	Hepatic (liver only).	___
i.	Renal (kidneys only).	___
j.	Other GU (ureters, bladder, urethra, prostate, genitals).	___
k.	Musculo-skeletal-integumentary (muscles, bone, skin)	___
l.	Neurological (brain, spinal cord, nerves; do not include dementia).	___
m.	Endocrine-Metabolic (includes diabetes, diffuse infections, infections, toxicity)	___
n.	Psychiatric/Behavioral (includes depression, anxiety, agitation, psychosis, not dementia).	___

Appendix J: Health Utilisation Questionnaire

Instructions: Please answer all questions.

1. During the past month have you been hospitalised?

☐No
☐Yes How many days?___________________

Instructions: When answering the following questions please think only of the days you were at home during the past month.

2. In the past month have you:

Visited your doctor? ☐No ☐ Yes How many times? _____________________
Been visited at home by a doctor? ☐No ☐ Yes How many times?____________
Telephoned a doctor for advice? ☐No ☐ Yes How many times? ____________

3. In the past month have you received any treatment or care form any of the following health professionals?

TCM ☐No ☐ Yes How many times?______________________________________
Physiotherapist ☐No ☐ Yes How many times?_________________________
Dietician ☐No ☐ Yes How many times?______________________________
Radiographer ☐No ☐ Yes How many times?______________________________
Nurse ☐No ☐ Yes How many times?______________________________________
Surgeon ☐No ☐ Yes How many times?_____________________________
Masseuse ☐No ☐ Yes How many times?_______________________________
Counsellor ☐No ☐ Yes How many times?_______________________________

4. During the past month, did you, in connection with your health receive:

Help in the home ☐No ☐ Yes How many times? __________________________
Paid domestic help ☐No ☐ Yes How many times?__________________________
If you have a live-in maid, does the maid assist with caregiving tasks? ☐No ☐ Yes
Home nursing service ☐No ☐ Yes How many times?__________________________
Care from family and friends ☐No ☐ Yes How many times?___________________

5. During the past month, in connection with your own health did you receive:

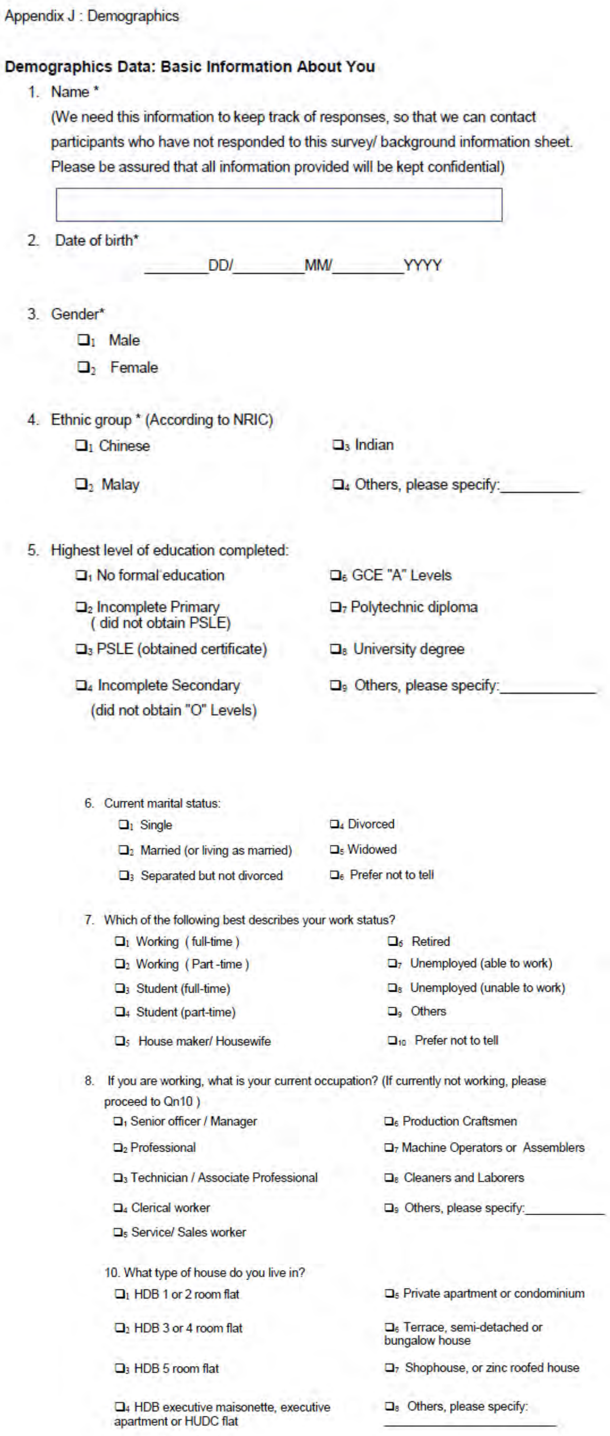
Medication ☐No ☐ Yes
Special food ☐No ☐ Yes
Assistive devices (eg. Wheelchair/stick) ☐No ☐ Yes
Care products (eg. Incontinence aids) ☐No ☐ Yes

6. In general, would you say your health is:..(Circle one)

Excellent..............................1
Very good............................2
Good...................................3
Fair......................................4
Poor.....................................5

Any additional comments?-

Appendix K: Demographics Questionnaire



Appendix J : Demographics

Demographics Data: Basic Information About You

1. Name *
   (We need this information to keep track of responses, so that we can contact participants who have not responded to this survey/ background information sheet. Please be assured that all information provided will be kept confidential)

2. Date of birth*
   _______DD/________MM/________YYYY

3. Gender*
   - ☐1 Male
   - ☐2 Female

4. Ethnic group * (According to NRIC)
   - ☐1 Chinese
   - ☐2 Malay
   - ☐3 Indian
   - ☐4 Others, please specify:__________

5. Highest level of education completed:
   - ☐1 No formal education
   - ☐2 Incomplete Primary (did not obtain PSLE)
   - ☐3 PSLE (obtained certificate)
   - ☐4 Incomplete Secondary (did not obtain "O" Levels)
   - ☐6 GCE "A" Levels
   - ☐7 Polytechnic diploma
   - ☐8 University degree
   - ☐9 Others, please specify:____________

6. Current marital status:
   - ☐1 Single
   - ☐2 Married (or living as married)
   - ☐3 Separated but not divorced
   - ☐4 Divorced
   - ☐5 Widowed
   - ☐6 Prefer not to tell

7. Which of the following best describes your work status?
   - ☐1 Working (full-time)
   - ☐2 Working (Part -time)
   - ☐3 Student (full-time)
   - ☐4 Student (part-time)
   - ☐5 House maker/ Housewife
   - ☐6 Retired
   - ☐7 Unemployed (able to work)
   - ☐8 Unemployed (unable to work)
   - ☐9 Others
   - ☐10 Prefer not to tell

8. If you are working, what is your current occupation? (If currently not working, please proceed to Qn10)
   - ☐1 Senior officer / Manager
   - ☐2 Professional
   - ☐3 Technician / Associate Professional
   - ☐4 Clerical worker
   - ☐5 Service/ Sales worker
   - ☐6 Production Craftsmen
   - ☐7 Machine Operators or Assemblers
   - ☐8 Cleaners and Laborers
   - ☐9 Others, please specify:____________

10. What type of house do you live in?
   - ☐1 HDB 1 or 2 room flat
   - ☐2 HDB 3 or 4 room flat
   - ☐3 HDB 5 room flat
   - ☐4 HDB executive maisonette, executive apartment or HUDC flat
   - ☐5 Private apartment or condominium
   - ☐6 Terrace, semi-detached or bungalow house
   - ☐7 Shophouse, or zinc roofed house
   - ☐8 Others, please specify: ____________________

11. Whom do you stay with? Tick as many as apply.

☐1. Staying alone
☐2 Spouse
☐3 Children
☐4 Parents
☐5 Siblings
☐6 Extended family members
☐7 Landlord and/or flat mate
☐8 Friend
☐9 Others, specify: ___________

Health Status

12. Do you have any of the following medical conditions? (Please *tick as may apply)*

☐1	Diabetes
☐2	Hypertension
☐3	High cholesterol / Lipid disorders
☐4	Heart diseases
☐5	Stroke
☐6	Lung/breast/colon cancer
☐7	Osteoarthritis
☐8	Asthma
☐9	Chronic Obstructive Pulmonary Disease (COPD) / Lung Disease
☐10	Benign Prostate Hyperplasia
☐11	Neprosis/Nephritis
☐12	Anxiety
☐13	Major depression
☐14	Migraine
☐15	Parkinson's Disease
☐16	Vision disorders
☐17	Adult-onset hearing loss
☐18	Others, please list: ______________________________
☐19	None of the above

13. Have you have had any significant experience with poor health or illness?

☐1 **Yes, I have/had a significant experience**

Please specify condition(s) (e.g. fractured arm):______________________________
Please specify duration (e.g. 3 months): ______________________________

☐2 **No, I do not have a significant experience**

14. Have you provided care to a family member or relative with chronic illness?

☐1 **Yes,** I am /were the **main** caregiver

Please specify relationship to patient (e.g. grandmother):

____

Please specify patient's condition(s) (e.g. cancer) :

____

Please specify the duration of care provided:

____

☐2 **No,** I am/was not the **main** caregiver

Thank you for your time and effort in taking part in this survey. ☺

Appendix L : The caregiver interview guide

1. Tell me about your usual day of caregiving
2. How do you feel about your role as a caregiver
3. What are the barriers to your role
4. What sort of things would make caregiving easier for you?
5. Tell me what you don’t like about your caregiving role?
6. Tell me what you like about your caregiving role?
7. What do you think is important to help caregivers?
8. Please, tell me how does caregiving affect you?
9. How does your caregiving affect your family?
10. How does caregiving affect your social life?
11. Where do you go or who do you see to talk about caregiving or for help?

Appendix M: Transcript A Sample of Interview Transcript of Non-Sighted Participant

Participant Code P2

Interview Length: 60 minutes

R: Researcher P: Participant

R: What is your usual caregiving?

P: I am a caregiver to my wife. I am working as braille transcriber. I work at 7am back by 6pm. Sometimes I buy dinner after work. Marketing done by neighbour who pay for this job. This neighbour will buy for the whole week. My wife will cook. sometimes. I don't cook. I do the housekeeping once a while. My wife does the house work most of the time?

R: Who accompany your wife to see doctor?

P: I am the one who accompanied her medical review because she cannot find her way.

R: What types of medical appointment you have to accompany her?

P: I will bring my wife for dental and medical check-ups at polyclinic.
We make the appointment on the same day for medical check-up so we don't need to go twice. We go polyclinic to see her hypertension and my epilepsy.
We go to the General Practitioner behind the block for common flu and cough.

R: Please, tell me how does caregiving affect you?

P: It is enjoyable as a caregiver. But there is good times and bad times, and enjoyable… help each other is a success when we achieve is enjoyable.

R: What types of activities you do together?

P: We go church together on weekend. Either take bus or take a lift from church friend. Normally we come back on back on our own.

R: How to cope with challenges of caregiving?

P: Over the eyes my vision has deteriorates, sometimes go to new places that I am not familiar the barriers will be we cannot see we need to ask around ..when there is nobody around for us to ask on the block number. Difficult to go certain places. I will try my very best first. Will find who are going to the same events. We give ourselves early time and ask for help. Maybe 1 hour to 45 mins earlier to this place and hopefully can ask people will help.

R: Can taking a cab helps?

P: Take a cab sometime but does not solve the problem. The cab can drop at places you still don't know. Going the venue early in hope to get help.

R: What social aspect can we provide the caregivers to make caregiving easier?

P: Wah …I don't want to be demanding… I don't want to sound demanding. The touch community (*this is Welfare Volunteer Organization in Singapore*) is a good help can call for help there is the volunteer service.

The frustration part is the supermarket the items keeping moving to different shelves. We will approach the staff to ask for help but sometimes no one is around. It will be good to have volunteer in supermarket to provide help.

R: What are the things you don't like to do in caregiving?

P: There is nothing particular …. What I like in caregiving is to achieve the other party need… But I cannot fulfil I feel bad I cannot achieve.

R: Do you talk with your wife how to make things better?

P: We do discuss…how to sort certain issues.

R: How does caregiving affecting your social life?

P: No it doesn't. . Doesn't affect my social life.. we try to make it family affair whatever we do. For example, tomorrow is mother day I will bring my mom back from Nursing home and bring to my sister's place to celebrate. We just go there to celebrate. We went on a cruise with family last year.

R: Any of family members come by to visit you two?

P: In fact, we are the ones to visit siblings we go to their homes for Chinese new year visiting or housewarmings. We try to go there is always a first time.

R: Do you both travel or go outings?

P: Once while we go short trip… because we cannot see …we cannot go ourselves …we must go with friends and family members. We went on cruise with family last year. Two of us will eat out sometime. We will visit my mom in Nursing homes. I just go and see her yesterday. We will plan and go together.

R: Where do you work?

P: I have been working at SAVH (*Singapore Association of Visually Handicapped*) for 41 years…my department has 8 of us. I work as Braille transcriber transcribing for Singapore association library. That's something I have not serious think of retire. What is purpose retiring, keeping working till I can't work. I think my peripheral visual field is narrowing. SAVH is aware of my eye condition. My nature of my work does not need vision. I can still work but same pay for many years.

R: Your son aware of your vision?

P: My son is aware whether he takes my condition seriously I don't know. He does not ask much. Generally, boys are not so caring.

R: Do you need help from other family member?

P: Actually to be frank… my siblings are older than me and need more help. There is something I have been thinking for quite long time, my son is the caregiver for us, who will love to a 24/7 caregiver… everyone runs away. I don't expect my son to look after us. He is doing final year in chemical degree. My wife and I don't earn much… even my son education I need to look for a sponsor… I don't have much in my saving for medical fees…My son needs funds to study degree I asked from donors.

R: What are social needs to support caregiving?

P: Financial help for housing grant will be good. There is no priority for disable person in applying government flat. A group of touch community is good the service has hotline (helpline) for help. This will be a way to help the low vision caregivers. In the supermarket there station an usher for low vision people. The supermarket keeps the placing of the goods and we cannot see is not easy to find the goods.

Appendix N: A Sample of Interview Transcript of Sighted Participant

Participant Code P6

Interview Length: 50 minutes

R: Researcher P: Participant

R: Can you share how long have you looking after your husband?

P: I have been looking after my husband ever since he has low vision for 4 years.

R: Are you working previously?

P: No no I am not working. Now I can't work because he is not only partially blind and also deaf, I have to be his caregiver I cannot go to work. He has glaucoma when we were used to stay overseas Hong Kong. When he has glaucoma and we are not citizen of Hong Kong we had to pay a lot for his medical fees. We decided had to come back to Singapore.

R: What types of caregiving role are you involved?

P: I need to put eyedrop and sorting out his medication. I need to clean him after shower and dress him. Showering he can do himself using grab bars installed by government housing board. He used the walking stick to walk to toilet. I need to prepare 3 meals for him. At night I need to put a pail for him to pee.

R: Can you share your usual caregiving activities?

P: Every Monday, Wednesday and Friday he go day care, he came back by 4pm. Before he goes to day care in the morning, I have to wake up at 4am to prepare breakfast, put eye drop for him, take his blood sugar and blood pressure…he is on pills. Lunch he had in day care. When I prepare meals for him, must tell him what are the food on left and right side of the table, on the centre is white rice. The vegetable has to cut into small size.

R: Any helper, family or children giving you any help?

P: No maid helping. My siblings never come by. My husband sister is older and dementia and stay in nursing home. We do not have kids. If he has to go hospital I have to push him on wheelchair. This is a hard time for me. I myself had brain tumour with operation in 2015.

R: How do you bring your husband for medical appointment?

P: I bring down him to take a cab and when we reach the hospital to borrow the wheelchair from the hospital. I can't bring his wheelchair to the taxi.

R: How is your husband usual behavioural?

P: Most of time he is depressed. As a caregiver I have also have my temper. It is not easy to be a caregiving it is very taxing.

R: Please, tell me how does caregiving affect you?

P: It is burden as caregiver when you go out you have to think you need to rush back to pick him back because he cannot see he cannot walk back home by himself. That why I have to wake up early as 4am as I have sent him down at 7am to wait for the transport from the day care.

R: What about any barriers you have as a caregiver?

P: Communication. He is deaf so communication is the biggest barrier. He doesn't use the hearing aid because of disturbing sounds from hearing aid. He could not take the noise and he does not use the heard aid. I don't want to make him unhappy. In good mood he will speak and talk to me. He can be quite demanding and he wants him to things done it immediately. I think sick person is demanding.

R: How to cope with challenges of caregiving?

P: One of niece who stays nearby once a while will call me. We keep in touch. Once a while I go church but I don't go with him. My husband Is a Buddhist he does not goes to church.

R: Have you consider placing you husband in day care whole week?

P: The Day care can only accept him for three times a week as the day care has no slots for daily service. I also feel unfair to put him in the day care whole day there from 830am to 3pm. The transport sends back home about 4pm.

R: What are social needs to support caregiving?

P: A helpline will be useful for me to talk to someone. But the most important the government can support to caregiver should be transportation. My husband has monthly appointment at eye centre. The transportation to eye centre from 9am -10am peak hours the taxi trip costs $40. He could not see we cannot take train to eye centre, it is not convenient to take train or bus. Every taxi trip to and forth to eye clinic is $60. The waiting time in the eye clinic is long till evening time. By the time when the eye clinic ends already 5pm. There is 25%

surcharge for each taxi trip after 630pm.

We have no children, no other income. Our income is from eldershield insurance paid out of $400 per month. The government should give voucher for taxi transport. The day care is free service and medical social worker applied for mean testing.

R: What you don't like about your caregiving role?

P: My husband is stubborn. Even he cannot but he wants things to do according to his way how the slippers are placed next to the bed. And how the air condition is going on and off because the door must be closed… he is fussy over trivial things. I get stress up with these things.

Many friends encourage me to put him at home. But because of financial burden I cannot afford to do so. Since we are old couple in good times he took care of me… now in hard time it is my duty to take care of him.

R: Any enjoyable time caregiving moments?

P: Sometimes we are in good mood he will talk to me nicely we don't quarrel so often. He has to look after me and I have to look after him. We talked and don't quarrel… we prayed hard if you pass away first easier for him and me.

R: How does caregiving affect your social life?

P: Off course. For this long weekend holidays my friend going for short trip they invited me. I told them. cannot join them. Even leaving home for only 2 days I cannot go. No one can take care of him.

R: Can your neighbour help?
Even good neighbour is hard to find. I cannot ask someone to look after my husband. People may think I am away for holidays and expect someone to help. Not everyone will help.

I cannot bring him out for social program because I have problem to push him to handicapped toilet. I am so worried if he is jammed inside the public toilet. I end up going with him he doesn't know how to lock the toilet. I cannot follow him to the male toilet unless there is a handicapped toilet which I can go inside with him.

R: Is caregiving affect your health?

P: Well, I have high blood pressure and I go to polyclinic to collect my medicine. I always go traditional Chinese medicine (*TCM*) for my knee pain. This knee pain can be due to constant pushing the wheelchair uphill for every month medical review. Every month practically I see the traditional Chinese medicine for acupuncture and massage. The TCM helps the pain relief but expensive. My blood pressure is under control.

I will follow up my blood pressure at the polyclinic walking distance from my flat. In 2015 I had tumour and surgery done in Singapore and still having follow up. There is side effect of this brain operation, I tend to forget things… I left the door gate open, the house key is left in the door …I forgot to off the stove I leave my house. I cannot cook as the pots are burned. The medical social worker from eye centre applied free meals from the church to my place. But the free meal from church is not available on weekends.
Weekends I will do my marketing and cooking as I need to cook.

R: Do you have enough rest?

P: Lately I could not sleep well because of financial worries. We have savings from working but every month the increase expenses we will lose our saving. I worried about this.

When I thought of finance, I worried the money is getting lesser is there is less subsidised when my husband passes on. How I can have survived and I cannot sleep. To apply for subsides our bank account cannot exceed $10k. Not everyone has less than $10k in my savings. In eye centre, I am not eligible to apply for transport fees.

R: How can we help you in caregiving?

P: I don't know who to go to. No medical social worker come by visit me and my husband. If I need to buy talking clock or white cane I will call the medical social worker for help. The medical social worker teaches me how to put the food to guide him to feel himself.

Appendix O: Process of Thematic Analysis

Question 1	Please, tell me how does caregiving affect you?				
Sighted caregiver	Verbatim	Codes	Sub-themes	Themes	Core Themes
P5	My role as caregiver is tired because I work part time cleaner and rush back home to look after him.	Time constraints	Lack of vitality	Negative Impact on quality of life	Effects on mental and physical aspects of quality of life.
P9	I am tired as I also have to work.. too tired to go out for any events.	Physically tired	Lack of vitality	Negative Impact on quality of life	
P6	Most of the time he is depressed. I have temper and very taxing for me.	Emotional burden	Emotional distress	Negative Impact on quality of life	
P7	I couldn’t sleep because of my daughter and no one to turn to.	Lack of formal support	Deprivation of sleep	Negative Impact on quality of life	
P10	Social life was affected as I cannot go out alone. I must accompany him all the time.	Given up social activities	Constant worry of uncertainty	Negative Impact on quality of life	
P11	It is difficult for me to image her vision loss. I can be worried of her safety I	Concern over the safety of care recipient	Constant worry of uncertainty	Negative Impact on quality of life	

	would call her to check on her.				

Question 2	How does caregiving affect your social life?				
Sighted caregiver	Verbatim	Codes	Sub-themes	Themes	Core Themes
P9	I am tired as I also have to work.. too tired to go out for any events.	Physically tired	Lack of vitality	Negative Impact on quality of life	Effects on mental and physical aspects of quality of life.
P10	Social life was affected as I cannot go out alone. I must accompany him all the time.	Given up social activities	Constant worry of uncertainty	Negative Impact on quality of life	
Low vision caregiver					
P2	Caregiving does not affect my social life we try to make as family affair. Tomorrow is my mom’s birthday. We are going to bring my mom back from nursing home and bring her to my sister’s place to celebrate. We go church together.	Attempt to connect with extend family and attend religious event	Good social network	Positive impact on quality of life	Effects on mental and physical aspects of quality of life.
P12	I just went out yesterday with my colleagues for	Took effort to have social interactions	Maintain good social interactions	Positive impact on quality of life	Effects on mental and physical

	steamboat. there were 3 blind and 2 sighted colleagues				aspects of quality of life.

Question 3	How to cope with challenges of caregiving?				
	Verbatim	Codes	Sub-themes	Themes	Core Themes
P7	I visited the dinning in the dark to understand.	Trying to understand how it feels to be low vision	Proactive in problem-solving	Caregivers proactively seeking solution	Coping Patterns
P11	On my day off I will bring my mother out.	Specially arranged activity	Proactive in problem-solving	Caregivers proactively seeking solution	
Low vision caregiver					
P2	We went on cruise with family last year.	Active coping.	Proactive in problem-solving	Caregivers proactively seeking solution	
P3	I accompanied her to see the doctor roughly understand how diabetes has impact the eye and kidney.	A sense of empowerment	Proactive in problem-solving	Caregivers proactively seeking solution	
Sighted caregiver					
P11	When I go business trip I will have to arrange my sister to come over to place.	Taking control	Seeking family social support	Caregivers proactively seeking support to solve caregiving issues	Coping Patterns

P4	I asked my brother to help if I cannot make it.	Seeking siblings support	Seeking family social support	Caregivers proactively seeking support to solve caregiving issues	
P7	My sisters would take care of my daughter when I visited them.	Secondary caregivers supporting in caregiving	Seeking family social support	Caregivers proactively seeking support to solve caregiving issues	
P8	The daughters will buy dinner for us.	Secondary caregivers supporting in caregiving	Seeking family social support	Caregivers proactively seeking support to solve caregiving issues	
P9	My daughter and son-in-law will fetch us out every week.	Secondary caregivers supporting in caregiving	Seeking family social support	Caregivers proactively seeking support to solve caregiving issues	
P1	The children come back to see us once a week.	Secondary caregivers supporting in caregiving	Seeking family social support	Caregivers proactively seeking support to solve caregiving issues	
P2	We cannot see we must go with family.	Seeking help from family	Seeking family social support	Caregivers proactively seeking support to solve caregiving issues	
Sighted caregiver					

P10	I was proud of him .	Positive emotion	Positive reappraisal	Caregivers reframing perception	Coping Patterns
P4	Caregiving made me more patient and calm.	Refine character to be a better person	Positive reappraisal	Caregivers reframing perception	
P9	Caregiving is a positive experience for me.	Caregiver satisfaction	Positive reappraisal	Caregivers reframing perception	
P8	The caregiving journey is good. Because of his handicapped the children come by every week.	Positive caregiving experience	Positive reappraisal	Caregivers reframing perception	
Low vision caregiver					
P2	What I like about caregiving in giving to the other party. Help each other is success.	Master the skills of caregiving	Positive reappraisal	Caregivers reframing perception	Coping Patterns
Sighted caregiver					
P4	He is my father, my family so it is our responsibility to stand by each other.	Fulfillment of the duty of children.	Accept responsibility	Accepting care responsibility	Coping Patterns
P5	My role... very tired because I am working and have to do my role as a wife.	Fulfillment of the duty of a wife.	Accept responsibility	Accepting care responsibility	

P8	I am not seeing myself as caregiver.	Obligation as spouse.	Accept responsibility	Accepting care responsibility	
Low vision caregiver					
P1	I don’t feel like a caregiver.	Don’t see himself as caregiver because of obligation as husband	Accept responsibility	Accepting care responsibility	Coping Patterns
P2	It is enjoyable as a caregiver.	Caregiver satisfaction	Accept responsibility	Accepting care responsibility	
P12	I don’t see myself as caregivers. We are companions as we have the same eye condition.	Companion than caregiver	Accept responsibility	Accepting care responsibility	
P11	I cannot say I don’t like it. My sisters are married my mother has to stay with me.	Obligation as daughter	Accept responsibility	Accepting care responsibility	
Low vision caregiver					
P1	Take care of handicapped people one has to be very patience and very calm.	Trying to main harmony	Self-control	Caregiver adapting and managing negative emotions	Coping Patterns

Question 4	What are social needs to support caregiving?				
Sighted participant	Verbatim	Codes	Sub-themes	Themes	Core Themes
P11	We need a support group to come together to share our journey.	Want to speak to someone with same experience	Support from peer with similar identity	Lack of social support	Challenges in caregiving journey.

P5	Helpline for caregiver will be useful when we are free we can chat.	Need to find a balance	Support from peer with similar identity	Lack of social support	
P6	A helpline will be useful for me to talk to someone.	Wanted an emotion outlet	Support from peer with similar identity	Lack of social support	
Low vision participant					
P3	I shared with my social worker how I cope when I am not happy.	Unhappy events that need emotion support	Unmet needs of tangible support	Lack of health care support	Challenges in caregiving journey.
P2	A group of touch community is good the service has hotline (helpline) for help. This will be a way to help the low vision Caregivers.	Touch community is a welfare organization from Church. The church provides helpline services. The caregiver deemed that this service is beneficial for Low vision caregivers.	Unmet needs of tangible support	Lack of health care support	
P12	Hotline (helpline) for caregivers will be good.	Want to have more resource		Lack of health care support	
Sighted participant	Verbatim	Codes	Sub-themes	Themes	
P5	.. money or allowance from government will be helpful for caregivers… I am 64 and working part time for 16 years	Taking up the low wage job to sustain in caregiving role. Age is issue as caregiver	Unmet needs of financial support	Lack of health care support	Challenges in caregiving journey.

	now. I have been doing this job (cleaner) to finance the family…This work has no Central Provident fund and annual leave.	passed the retirement age and still has no sufficient savings.			
P6	I could not sleep well thinking of financial support. I worried the money is lesser how can I survived. Not everyone has S$10k in savings. The transport to bring him for day care and medical appointment is by taxi and the trip is not cheap cost S$60 for return trip.	The transportation fees is a concern as there is not government support for transportation for medical appointment. Caregiver has not sufficient savings for pay for additional transportation.	Unmet needs of financial support	Lack of healthcare support	
Low vision participant					
P1	I have no Central Provident Fund and my also use up her medical savings...without my daughter giving is money… how to survive.	Low vision caregivers are not earning sufficient to save for their retirement and health care needs.	Unmet needs of financial support	Lack of health care support	Challenges in caregiving journey.
P2	My wife and I don't earn much… even my son education I need to look for a sponsor… I don't have much in my saving for medical fees…My	Low vision caregivers are not earning well to even to support their son for education.	Unmet needs of financial support	Lack of health care support	

	son needs funds to study degree I asked from donors. Financial help for housing grant will be good. There is no priority for disable person in applying government flat.	Low vision caregivers are not given any special priority for applying government housing.			
P3	The magnification software for reading and printing text to speech costs S$2000. My wife installs herself to the work desk computer in the company, the company may not trust the software.	The caregivers required additional financial support to purchase IT software in order to be employable.	Unmet needs of financial support	Lack of health care support	
P8	I am not seeing myself as a caregiver.. Caregiving is nothing difficult	Caregivers do not perceived their role of “caregiver” to be a natural responsibility of adult life.	Social identity	Lack of social support	Challenges in caregiving journey.
P9	I am not sure I am considered as caregiver.	Caregivers do not perceived their role of “caregiver” to be a natural responsibility of adult life.	Social identity	Lack of social support	
P10	To be disable is not a choice for my husband.. we	Moral obligation of a	Social identity	Lack of social support	

	need to face it.. it is my responsibility to take care of my family.. I have to do it.	wife and familism.			
Low vision participant					
P12	We don’t see ourselves as caregivers. We are companions as we have the same eye condition. There is no barrier in caregiving	Caregivers see themselves as life partners.	Social identity	Lack of social support	