Identifying carers' concern for older people at risk of falling at home

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A thesis submitted in fulfilment of the requirements

for the degree of

Doctor of Philosophy in Nursing

September 2019

This research was supported by an Australian Government Research Training Program (RTP) Scholarship

Statement of Originality

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This thesis is dedicated to my parents who have supported my decision to study abroad. I have never been away from my parents for such a long period of time before, and while they could not bear to see me leave, they believed in me and knew this would be the best for my future. Dear mum and dad, I am sorry for being away for so long. I know the photos of me everyday living here and photos of my meals I sent you are insufficient to allay your anxiety as I lived abroad away from you. I would also like to dedicate this thesis to my brother and sister-in-law. Thank you for accompanying mum and dad when I am not around and looking out for them. I would also like to dedicate this thesis to my best friend Samuel. Thank you for being there for me in Australia and accompanying me throughout. Thank you for sending me to the university every day and to the hospital for my recruitment. Without all of you, I wouldn't have been able to see my Ph.D. journey through to the end.

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- 7. **Ang, S. G. M.,** O'Brien, A. P., & Wilson, A. (2019). Development and validation of an instrument to measure carers' concern for older people at risk of falling at home. Under review by *International Journal of Older People Nursing*.

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Glossary

ABC Activities-specific Balance Confidence Scale

ACAT Aged Care Assessment Team

ADLs Activities of daily living

Carees Older people; older persons; elders; family members; loved ones

CFC/CFC-I Carers' fall concern instrument

CVI Content validity index

FES Falls Efficacy Scale

FES-I Falls Efficacy Scale-International

FDWs Foreign domestic workers

FIBS Fall-related Impulsive Behaviour Scale

GPs General Practitioners

HREC Human Research Ethics Committee

HMRI Hunter Medical Research Institute

Icon-FES Iconographical Falls Efficacy Scale

KMO Kaiser-Meyer-Olkin

MMAT Mixed Methods Appraisal Tool

NSW New South Wales

PRISMA Preferred Reporting Items for Systematic Reviews and Meta-analyses

REDCap Research Electronic Data Capture

SAFE Survey of Activities and Fear of Falling in Elderly

SD Standard deviation

SEM Standard error of mean

SSA Site-specific assessment

3G Three Generations

Abstract

Background

Informal carers such as family members and friends are crucial in providing assistance to older people (care recipients) and preventing them from falling at home. Many carers experience increased psychological distress and caregiving burden when looking after their care recipients who have fallen previously. However, there were no previous studies found about carers' concern for their care recipients at risk of falling, and there was no validated instrument for measuring this concern.

Aims

This thesis aims to: 1) explore the factors influencing carers' fall concern, 2) develop an instrument for measuring this concern, and 3) evaluate the psychometric properties of the Carers' Fall Concern Instrument (CFC-I).

Methods

The study was conducted over three phrases which include: 1) interviewing 22 carers about their fall concern, 2) exploring the content validity and reliability of the initial CFC-I on 32 carers, and 3) testing the construct validity and reliability of CFC-I on 143 carers. All participating carers were providing support for an older person aged 60 years and over and living at home.

Results

During Phase One, four themes were identified as influencing carers' fall concern. These included: 1) carers' perception of fall and fall risk, 2) care recipients' behaviour and attitude towards fall risk, 3) care recipient's health and function, and 4) care recipients' xxi

living environment. During Phase Two, a 46-item CFC-I was developed and tested with a resultant average content validity of 0.82. In Phase Three, the final 16-item CFC-I reported a Cronbach alpha of 0.93 and can discriminate carers looking after care recipients with or without falls.

Conclusion

The CFC-I is the first multi-item instrument designed for measuring carers' fall concern. Healthcare professionals are encouraged to use the CFC-I in future fall prevention programmes to determine the impact of fall risk on carers and to develop targeted interventions for managing their fall concern.

CHAPTER 1: OVERVIEW

1.1 Introduction

Previous studies have found that older people (care recipients) falling affects their carers' psychological health, caregiving burden, and ability to prevent falls. The Carers' Fall Concern Instrument (CFC-I) was specially developed to measure the concern of informal carers (i.e. family members) about the risk of falling among their care recipients living at home. This doctoral thesis which consists of seven refereed publications and conference paper aims to provide greater in-depth knowledge about carers' fall concern and raise awareness among healthcare professionals regarding the need to provide care for carers' wellbeing when developing fall prevention strategies. This chapter discusses the prevalence of falls and fear of falling among older people and the instruments commonly used for measuring fear of falling. The role of carers in providing support to their care recipients in daily activities and fall prevention, the potential effect of falls on carers, and the need for developing the CFC-I are described. The chapter concludes with an overview of the thesis and the focus of subsequent chapters.

1.2 Background

Prevalence of falls

A fall is defined by the World Health Organisation (2018b, para. 1) as "an event which results in a person coming to rest inadvertently on the ground or floor or other lower level." Falls are the leading cause of unintentional injury death, causing 646,000 deaths each year (World Health Organisation, 2018b). The risk of falling increases with age and people aged 65 and over had the highest number of fatal falls (World Health Organisation, 2018b). For example, in the United States, one in four older people reported falling in

2014 (Haddad, Bergen, & Luo, 2018) and the percentage of falls increased from 27% to 37% for older people aged between 65 and 74 years old, and those aged 85 years and above, respectively (Bergen, Stevens, & Burns, 2016). 2.8 million older people received treatment at the emergency department due to falls, and about 800,000 of these people required hospitalisation mostly due to head injuries, or hip fractures (Bergen et al., 2016; Centers for Disease Control and Prevention & National Center for Injury Prevention and Control, 2017).

In Australia in 2011-12, falls were also the most common cause of injury-related hospitalisations for people aged 65 and above, accounting for 96,000 cases (Tovell, Harrison, & Pointer, 2014). Twice as many women than men experienced a fall and people aged 85 and above had the highest proportion of cases (Tovell et al., 2014). Fractures were the most common form of fall injuries and twice as many people were hospitalised after experiencing a fall at home (50%) compared to those in the long-term care (23%) (Tovell et al., 2014).

Within New South Wales, Australia, a 2009 population study found 26% of the 5,681 community-dwelling older people aged 65 years and above fell in the previous year (Milat et al., 2011). Of the older people who had fallen, 39% experienced recurrent falls, 66% sustained an injury, and 20% were taken to the hospital (Milat et al., 2011). The number of falls is expected to increase in Australia as the population ages (Australian Institute of Health and Welfare, 2018). Older Australians are also more likely to live in their own homes, indicating a need to focus on fall prevention efforts in households.

Fear of falling among older people (care recipients)

Falls may result in psychological consequences such as fear of falling, or other fall-related concerns. Up to 85% of community-dwelling older people experience fear of falling, often resulting from a fall (Scheffer, Schuurmans, van Dijk, van der Hooft, & de Rooij, 2008). Some older people also experience fear of falling even if they have not fallen. The risk factors of fear of falling include female gender, old age, impaired physical function, and the use of a walking aid (Denkinger, Lukas, Nikolaus, & Hauer, 2015; Scheffer et al., 2008). Fear of falling is also associated with anxiety (Payette, Belanger, Leveille, & Grenier, 2016), depressive symptoms, neurotic personality traits, decreased executive functioning (Delbaere, Close, Brodaty, Sachdev, & Lord, 2010), and poor quality of life (Hughes, Kneebone, Jones, & Brady, 2015).

The relationship between fear of falling and activity avoidance is well established (Hughes et al., 2015). Older people with a higher level of fear of falling have more limitations in their activities of daily living (ADLs) and social participation, with these limitations continuing over time (van der Meulen, Rixt Zijlstra, Ambergen, & Kempen, 2014). Physical inactivity, due to fear of falling, can also lead to physical deconditioning and frailty (Hadjistavropoulos, Delbaere, & Fitzgerald, 2011). Cumming, Salkeld, Thomas, and Szonyi (2000) found that older people who were afraid of falling experienced more functional decline and were at a higher risk of falling, or admission to long-term care. A recent prospective cohort study also ascertained that fear of falling predicted functional disability among older people aged 65 and above (Auais et al., 2017).

Instruments used to measure fear of falling (care recipients)

There are many instruments designed to measure fear of falling. Fear of falling has been defined by Tinetti and Powell (1993, p. 36) as "a lasting concern about falling that leads to an individual avoiding activities that he/she remains capable of performing." Fear of falling was first measured using a single-item question asking whether the older person was afraid of falling. However, due to its lack of sensitivity in discriminating different levels of fear and concerns to different activities (Yardley et al., 2005), the first multi-item instrument known as the "Falls Efficacy Scale" (FES) was developed (Tinetti, Richman, & Powell, 1990).

The FES was developed using the self-efficacy theory by measuring the level of confidence in performing ten different ADLs without falling (Tinetti et al., 1990). As the FES comprised of only basic ADLs, it lacked sensitivity in measuring the concerns of more active older people (Yardley et al., 2005). Some of the FES items were also not applicable cross-culturally and did not include questions to measure concerns of performing social activities. Therefore, the Falls Efficacy Scale-International (FES-I) was developed by the Prevention of Falls Network Europe (ProFaNE) to address these limitations (Yardley et al., 2005).

The FES-I comprises of 16 items which assess the level of concern about falling when performing both basic and more physically demanding activities, and social activities (Yardley et al., 2005). Each item is measured using a four-point Likert scale of 1 being not at all concerned and 4 being very concerned. The initial FES-I validated on older people living in the community had an internal and test-retest reliability of 0.96. The FES-I has also been translated and tested cross-culturally on community-dwelling older people

living in Germany, The Netherlands and the UK (Kempen et al., 2007). The study reported a consistent Cronbach alpha of 0.90 and above across all three populations. Likewise, the FES-I validated on older people with cognitive impairment from the rehabilitation units also reported a Cronbach alpha of more than 0.90, but lower test-retest reliability (Hauer et al., 2010).

The FES-I was considered the gold standard for measuring fear of falling to date (Moore & Ellis, 2008). However, more recently, the Iconographical Falls Efficacy Scale (Icon-FES) was developed to include an even broader range of ADLs performed by older people in measuring their fear of falling (Delbaere, Smith, & Lord, 2011). The Icon-FES, which uses pictures to depict daily activities, has also been validated for use with cognitively impaired older people (Delbaere, Close, Taylor, Wesson, & Lord, 2013).

1.3 Role of Informal Carers

Carers providing daily care

Informal carers are crucial in providing support to people with disabilities, medical, and mental health conditions, or frailty to continue living at home (Australian Institute of Health and Welfare, 2015). Informal carers can be a family member, friend or neighbour, providing support based on pre-existing relationships with the care recipients. These carers are not usually paid for their assistance, but their care is necessary to complement the support provided by healthcare professionals. Around 2.7 million Australians identified as carers in 2015 and of these, 856,100 were primary carers (Australian Bureau of Statistics, 2018). A primary carer is defined as the person who provides the most informal assistance to a care recipient with a disability, or an older person aged 65 and above. The majority of primary carers are females (68%) and more likely to be partners

of the care recipients (40%) (Australian Bureau of Statistics, 2018). The assistance provided by carers is extensive and includes mobility (76%), self-care (59%), transport (86%), and cognitive and emotional support (79%) (Australian Bureau of Statistics, 2018).

Carers providing fall prevention

Besides the provision of daily care, carers can help to prevent older people from falling at home. However, this requires the active involvement of carers in deciding and implementing the most suitable fall prevention strategies with the help from healthcare professionals (Wilkinson et al., 2018). Healthcare professionals are encouraged to provide carers with information and training in identifying risk factors and taking action to prevent their care recipients from falling (World Health Organisation, 2007). A randomised controlled trial investigated the efficacy of a fall prevention programme which included education about hands-on nursing skills such as safe transfer, ambulation, and home environment safety for both carers and their care recipients with cancer (Potter, Pion, Klinkenberg, Kuhrik, & Kuhrik, 2014). The study found that care recipients from the intervention group were less likely to fall compared to those receiving usual fall prevention education. Both carers and care recipients demonstrated significant improvement in fall risk awareness and fall-prevention knowledge (Potter et al., 2014). Another study also found that care recipients receiving a home-based, carer-enhanced exercise programme demonstrated better balance, had lower fall-related concerns and increased planned physical activity (Taylor et al., 2017).

Social support from carers may contribute to the success of the fall prevention programmes. A previous qualitative study highlighted that the concern of family members, friends, and healthcare professionals about their care recipients falling could contribute

to the sense of caution in preventing falls among older people (care recipients) (Ward-Griffin et al., 2004). These family carers were also instrumental in providing psychosocial support to their care recipients to assist them to deal with their falls and fall injuries (Host, Hendriksen, & Borup, 2011). Another qualitative study found that care recipients with supportive family members expressed greater satisfaction in managing their fall risk and fear of falling (Huang, 2005). For example, they could provide support by listening to their care recipients about their fall concerns or acquiring walking aids for the care recipients to ease their disability. In contrast, care recipients who were unsupported by their family members were more likely to suffer from fear of falling and adopt negative coping strategies like activity avoidance (Huang, 2005).

Impact of falls among care recipients

Carers are affected by the falls of their care recipients with between 58 and 91% of carers expressing fear about their care recipients falling again (Faes et al., 2011; Liddle & Gilleard, 1995). After a fall, carers experienced a significant increase in stress (Forster & Young, 1995), anxiety (Liddle & Gilleard, 1995), and caregiving burden (Dow, Meyer, Moore, & Hill, 2013). Many carers were also worried about leaving their care recipients alone at home (Faes et al., 2010). Some carers reported having to change their daily routines in order to provide additional help and supervision to their care recipients (Dow et al., 2013). As a result, carers were often unable to engage in their own personal and social activities or get sufficient rest, which affected their quality of life (Dow et al., 2013).

Healthcare professionals are encouraged to pay greater attention to the psychological wellbeing of carers and their coping abilities before implementing any fall prevention strategies for their care recipients. A reliable and valid multi-item instrument to assess the

concern of carers regarding their care recipients' risk of falling could be valuable to future fall prevention programmes, especially those involving carers. An increase in fall concern indicates the need for individualised intervention, such as counselling or fall risk education, to assist carers in managing their fall concern. With lower fall concern, carers may be more confident in preventing their care recipients from falling, which could potentially improve the efficacy of fall prevention programmes.

1.4 Carers' Fall Concern Instrument

The problem statement

There is no multi-item instrument for measuring the concern of carers about their care recipients' risk of falling. The current multi-item instruments such as the FES and FES-I only measure the older people's (care recipients') fear of falling but not their carers. These instruments are limited to measuring the level of fear care recipients have when they perform daily activities (Honaker & Kretschmer, 2014). Fall concern among carers has only been assessed using a single-item question asking if carers are afraid of their care recipients falling again (Faes et al., 2011; Liddle & Gilleard, 1995).

Most research conducted on the fall concern of carers has been qualitative, focusing on the impact of falls among care recipients with a presumed higher risk of falling, such as those diagnosed with Parkinson's disease, dementia, or stroke, or with a history of falling. Little is known about the concern of carers looking after the general population of older people without falls. Other possible risk factors, such as environmental hazards, or individual perception of fall risk which may contribute to the fall concern of carers, have not been explored. In this study, Carers' Fall Concern was defined as "the concern of carers about the risk of falling among their care recipients", to encourage the

identification of other risk factors besides the consequences of falls. This definition also served to guide the development of the Carers' Fall Concern instrument (CFC-I).

The current study

The research questions for this study were:

- 1) What are carers' concerns for their care recipients at risk of falling?
- 2) What are the items used to form the instrument for measuring carers' fall concern?
- 3) Does the instrument constructed accurately measure the carers' fall concern?

The hypotheses of this study were:

- 1) The fall concern of carers is multi-dimensional comprising different factors
- 2) Carers of older people who had fallen will report a significantly higher level of fall concern than carers of older people without falls
- 3) The distribution of items scoring in the CFC-I (factors) will converge with themes from the qualitative interviews and literature

The aims of this study were:

- 1) To explore the factors influencing carers' fall concern (Phase One)
- 2) To develop an instrument for measuring carers' fall concern (Phase Two)
- 3) To evaluate the psychometric properties of the CFC-I (Phase Three)

Research design

This study used an exploratory sequential design, also known as the instrument development design, as there was limited knowledge about the fall concern among carers and no multi-item instrument to quantify this concern (Creswell & Clark, 2011). The

study began by qualitatively exploring the fall concern of carers. Building on the qualitative findings, a quantitative phase was conducted to develop and test an instrument to measure this concern. The exploratory design consisted of four steps which included:

1) collect and analyse the qualitative data, 2) develop the CFC-I and identify factors contributing to fall concern, 3) collect and analyse quantitative data, and 4) interpret and identify any connections between quantitative and qualitative data (Creswell & Clark, 2011). To ensure that the CFC-I was rigorously developed, the eight-step scale development guidelines by DeVellis (2017) was applied. The steps for developing the CFC-I were carried out over three phases (Table 1).

Table 1. Steps for developing the CFC-I

Study Phases	Steps in Exploratory Design	Steps in Scale Development
Phase 1	Collect and analyse qualitative result	Define carers' fall concern
Phase 2	Develop instrument and identify factors	Generate items for the instrument Determine the response format Expert review of the items Include validated items from other
Phase 3	Collect and analyse quantitative result Interpret quantitative and qualitative results	Administer the instrument Evaluate the instrument Modify the instrument

During Phase 1, an integrative review was conducted to synthesise available evidence related to carers' fall concern, followed by a descriptive qualitative study to explore their experience looking after care recipients at risk of falling. During Phase 2, items for the CFC-I were formulated from the integrative review and qualitative interviews. Experts with experience in aged care were involved in reviewing the CFC-I for content validity, followed by pilot testing the instrument on 32 carers. Items in the initial CFC-I were modified during each testing. During Phase 3, the revised CFC-I was tested on 143 carers to determine validity and reliability. Finally, the factors identified from the CFC-I were compared with themes from the qualitative interviews and literature for congruence.

Significance of the study

The proposed study served to develop an instrument for measuring the fall concern of informal unpaid carers (i.e. family members or friends) looking after older people living at home. The multi-item measure aimed to assist healthcare professionals more accurately identify carers with excessive fall concern and determine the situations in which they were most fearful of their care recipients being at risk of falling (Yardley et al., 2005). Targeted interventions such as counseling, or strategies to manage a care recipients' fall risk can then be provided to support carers in preventing their care recipients from falling at home. The CFC-I can also detect changes in the level of fall concern over time to assess the efficacy of fall prevention programme for carers looking after an older person at home.

Author's information

This study was conducted as part of a Doctor of Philosophy degree in Nursing at the University of Newcastle. Although the author initially hoped to carry out the study in Singapore, he was unable to gain support from local healthcare institutions. Some

publications in this thesis were written from his concern about the condition of older Singaporean people. These publications were developed on the study of Australian older people and their carers regarding falls, to project the situational context of the influence of falls on caregiving in Singapore. Nonetheless, his experience of conducting this study in Australia was fruitful and memorable. This included acquiring an understanding of the technical research procedures and protocols, experience with engaging ethics committees and multiple local healthcare agencies to obtain study approvals, and interaction with older people and their carers during data collection. This experience has also provided an opportunity for consideration of the data from different inherent cultural perspectives and outlooks.

1.5 Thesis Overview

Chapter One describes the rationale for undertaking this study. This chapter outlines the incidence of falls and fear of falling among older people (care recipients) and the importance of carers in fall prevention. It also highlights the potential impact of falls and fall risk of the care recipients on their carers and justifies the need for an instrument to measure the fall concern of carers.

Chapter Two consists of two papers which describe the significance of fall concern among carers. Paper 1 discusses fall concern from an Asian perspective while Paper 2 describes the association between the care recipients' fall risk and carers' fall concern.

Chapter Three consists of Paper 3, which presents an integrative review of the current evidence related to the fall concern of carers. The integrative review includes 15 studies discussing the fall concern of carers and the impact of this concern. The fall concern of

carers was assessed using a single-item instrument in three quantitative studies indicating the need for a comprehensive multi-item measure to better understand this concern.

Chapter Four consists of Paper 4, which presents the study protocol for developing the CFC-I. The paper presents the study design related to item construction, modification, and evaluation of the CFC-I. The data collection and analysis, and ethical considerations for the study are also reported.

Chapter Five consists of Paper 5, which presents the qualitative findings from the experiences of 22 participants caring for an older person living at home. This paper aimed to explore the concern of carers about their care recipients' risk of falling and the strategies they used to manage this risk. The paper also highlights different fall-related concerns among carers, regardless of whether their care recipients had previously sustained a fall. It concludes that external support from family members and friends could help carers cope with the management of their care recipients' fall risk, but not all carers receive such support.

Chapter Six consists of Paper 6, which presents the process of developing the Carers' Fall Concern Instrument (CFC-I). This paper identifies the factors contributing to carers' fall concern and tests the initial validity and reliability of the CFC-I in measuring the concern of carers regarding their care recipient being at risk of falling at home. An expert panel and 32 carers participated in the review of the initial 46-item CFC-I.

Chapter Seven consists of Paper 7, which presents the psychometric properties of the final 16-item CFC-I. This paper aimed to modify further and investigate the validity and

reliability of the CFC-I. A total of 143 carers completed the modified 17-item CFC-I. An additional item was removed to improve the internal consistency of the instrument in measuring the fall concern of carers.

Chapter Eight presents a general discussion of the overall study. The chapter presents a summary of the qualitative and quantitative findings and the challenges faced in this research leading to the development of the CFC-I. The chapter also discusses the implications for practice and future research directions for the use of CFC-I.

Chapter Nine concludes by providing a brief summary of the thesis. As this thesis comprises of individual papers submitted to different journals, there is some minor repetition in the content across the chapters. The issue around foreign domestic workers (FDWs) discussed in Paper 1 and Paper 3 is outside the scope of this thesis but served to highlight the caregiving challenges in the Singaporean community where the author is from. The references are located at the end of this thesis.

CHAPTER 2: COMMENTARIES

PAPER 1: Ang, S. G. M., O'Brien, A. P., & Wilson, A. (2018). Fall concern about older persons shifts to carers as changing health policy focuses on family, home-based care. *Singapore Medical Journal*, 59(1), 9-11. doi: https://doi.org/10.11622/smedj.2018005

PAPER 2: Ang, S. G. M., Wilson, A., & O'Brien, A. P. (2018). Concern of older people falling. *Australia Nursing and Midwifery Journal*, *25*(11), 36. Availability: https://search.informit.com.au/documentSummary;dn=664071853677710;res=IELHEA

2.1 Overview

This chapter comprises of two papers that extend the discussion on the significance of fall concern among carers. Paper 1 focuses on the potential influence of fall concern on carers in Singapore as health policies increasingly emphasise family-based care for older people. Due to limited community aged care facilities and support, many families engaged foreign domestic workers (FDWs) to care for their older people at home. This unique caregiving dynamic, especially among Asian households, highlights the need for healthcare professionals to refocus education and training to FDWs in the management of falls and fall concern.

Paper 2 explores the relationship between the level of fall concern in carers and the prevention of falls for older people. It hypothesises that excessive concern among carers could result in unnecessary restriction of activities among older people. Being unconcerned however, could indicate that carers are unaware of a fall risk, which potentially puts their care recipients at risk. A valid and reliable instrument to assess the level of concern of carers would allow healthcare professionals to determine if they have accurately appraised of their care recipients' fall risk.

2.2 Paper 1



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Fall concern about older persons shifts to carers as changing health policy focuses on family, home-based care

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ABSTRACT With the Singaporean population ageing at an exponential rate, home carers are increasingly becoming essential partners in fall prevention and care delivery for older persons living at home and in the community. Singapore, like other Asian countries, regards the family as the main support structure for the older person, and national policies have been implemented to support this cultural expectation. Family carers experience similar concerns as older persons with regard to fall risk, and identifying and addressing these concerns can potentially lower fall risk and improve fall prevention for older persons. It is timely to remind ourselves – as concern about falls in older persons begins to shift to carers – to incorporate the influence of Asian cultural values and unique family dynamics of outsourcing family caregiving, in the management of older persons' fall risk in the community.

Keywords: carers, fall concern, fall prevention, older persons, Singapore

INTRODUCTION

Singapore, like other Asian countries, regards the family as the main support structure for older people. (1,2) Recently, national policies have been implemented to encourage families to undertake the role of primary care provider. These policies, which address the distribution of financial responsibilities, have not been well studied for their societal impact and success. (1) Policies such as subsidised public housing, income tax relief for children staying with their parents and the Maintenance of Parents Act reinforce and support the cultural expectations that children are obligated and expected to look after their parents. (1,3) These expectations imply that the costs and burden of care for older people at risk of falls will be largely family-based. The family system must, therefore, be adequately prepared, supported and resourced to take on the challenges of caregiving with accessible community support. Shortages and the high cost of aged care community services that provide full-time care have led to many families having to engage foreign domestic workers (FDWs) to care for their dependents at home. (2,4) This shift in the provision of care at home for older people is evidenced in a recent national survey of Singaporeans, which indicated that up to 50% of families relied on FDWs. (4) The influence of Asian cultural values and the unique dynamics of extended family caregiving are important considerations in exploring the impact of carers' fall concerns in Singapore.

DOMESTIC FALLS AMONG OLDER PERSONS

Older persons experiencing domestic falls are an increasing concern in Singapore. Retrospective analyses of admissions to the emergency department suggest that 85.3% of the 720 elderly patients who were seen for injuries during a six-month study

period had sustained their injuries as a consequence of falls in their homes. (5) More than half (67.9%) of these presentations required hospitalisation. (5) Analysis of trauma cases admitted to an acute care Singapore hospital also found that older adults are more prone to falls that result in head injuries. (6) The impact of domestic falls was exacerbated by a 4% increase in the proportion of older persons experiencing a dwindling resident old-age support ratio (persons aged 20-64 years per resident aged \geq 65) from 7.8 to 5.4 between 2006 and 2016. (7) With the growing ageing population and the deleterious effect of fallrelated injuries, home carers are increasingly being recognised as essential partners in fall prevention and care delivery for older people in the community. In this climate of concern for older people's wellbeing, the priority is for health professionals to better understand the impact and effect of falls in older persons on their carers, and how this affects the way they might prevent and protect older persons from falls during their day-to-day care.

FALL CONCERN AMONG CARERS

Carers may experience similar fall concern as older persons with regard to the risk of falling. Due to the lack of local research on carers' fall-related concerns, inferences were made from overseas studies conducted in cities that are similar to Singapore. A prospective study of 96 pairs of carers and care recipients in Melbourne, Australia, found that carers reported a significant increase in caregiver burden after the older person had had their first fall. Similar results were also found in a large cross-sectional study of 1,874 community-dwelling older persons in Japan. In this study, a history of falls in the person being cared for was associated with increased caregiver burden, even after controlling for functional status and comorbidities. Carers of persons who had fallen subsequently changed their social and

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work engagements for fear of leaving their care recipients alone. (8) Older people can require higher levels of care following falls or progression of illness that causes falls. (8) Among Asian carers in general, societal expectations of filial piety can serve as both a motivator for caregiving and a cause of stress among those who feel that they are unable to fulfil this role. (10) In 2011, there were approximately 198,000 FDWs, mostly from the Philippines and Indonesia, working in Singapore, and this number is projected to increase to 300,000 in 2030. (11,12) As the country becomes increasingly dependent on FDWs for home caregiving, healthcare professionals need to take into account their understanding of falls and fall concern during the management of older persons' health and safety. Yet, understanding their concerns can be complex and challenging, as the FDWs have to cope with the responsibilities of being the homemaker and full-time family carer. (11)

CARERS PREVENTING FALLS

Increasingly, fall prevention programmes are designed to include carers because of their close involvement in delivery of care for older persons. One study on the efficacy of a fall prevention programme for cancer patients reported that involving family carers significantly improved fall risk awareness and fall prevention knowledge. (13) Another study assessing the impact of fear of falling among family caregivers on the functional recovery of hip fracture in older persons demonstrated that carers had significantly higher fall-related concerns than the older persons. (14) Furthermore, there was a significant correlation between a greater difference in fear of falling (between the carers and older persons) and a longer recovery period in the older persons. (14) Another study hypothesised that this outcome was due to overprotective carers who are excessively supportive, taking away the older person's independence. (15) This concept is supported by a longitudinal study that investigated the impact of professional carers' fear of falls on the residents' functional ability and falls in long-term care facilities. (16) In this study, the nurses' and nursing aides' fear of patients experiencing pain and falls was a significant predictor for the use of restraints or restrictions, which in turn led to functional deterioration and injurious falls. (16) While the study findings discussed here do not indicate causation and are not generalisable to other populations, there was a significant correlation between the impact of carers' fall concern and the quality of care. Therefore, addressing carers' fall concern is an important element in fall prevention among older persons. This is especially relevant in a climate of global ageing, where alternatives to placement in aged care facilities may be limited.

CONCLUSION

It appears that carers' fall concern plays an important role in the prevention of falls among older persons in the community. This concern may directly influence perceptions of fall risk among carers and older persons, and determine their motivation to progressively and continuously adopt preventive behaviours. The emphasis on filial piety care does not necessarily mean that the care burden falls on the family members, as FDWs are increasingly employed as surrogate caregivers for older persons at home. Yet,

this increasing reliance on FDWs for the delivery of care may indicate that families need more support from healthcare services, perhaps delivered directly to the home of the older persons who are at risk of falling. Given that carers could be affected by fall concern, the psychological impact on FDWs is substantial, if not even more significant. Being paid carers, FDWs may be caught in a dilemma between following the instructions of the older persons, who are often their employers, and executing adequate fall preventive measures. Yet, when the older persons fall, FDWs are likely to be accused of being negligent in the care provided. Rather than entrusting the entire delivery of care to families and, indirectly, to FDWs, the ministry and healthcare professionals need to ensure that adequate support is given to families caring for older persons at home. Such support can include increased funding to caring groups that support family caregiving, subsidies for utilisation of home nursing services, aged care community nurse support visits and rapid response services for carers looking after older persons at home. Identifying and addressing carers' needs in the delivery of community care could potentially reduce the reliance on institutional care facilities and allow older persons to age in the community.(17)

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2.3 Paper 2

ISSUES



By Seng Giap Marcus, Amanda Wilson and Anthony Paul O'Brien

Carers' falls concern is an important psychological factor associated with the care recipients' falling. Further, 90% of carers of older people are concerned about them falling again (Faes et al. 2011).

Few studies have been conducted to determine the impact on carers when older people fall, such as their physical, psychological, social health, and burden of care (Ang et al. 2018).

Besides these impacts, carers' concern about falls are also significantly associated with the older person's perception of fall risk (Ward-Griffin et al. 2004), and the strategies used to prevent falls (Ang et al. 2018).

Due to the complex nature of carers' falls concern and limited understanding about this phenomenon, it is not commonly included in falls prevention programs. Carers concerns about the older person falling have however, been associated objectively with caregiving burden (Dow et al. 2013; Kuzuya et al. 2006). This burden indicates that after the older person falls, carers can experience stress, anxiety and continuously worry about their care recipients falling again (Faes et al. 2010; Davey et al. 2004).

Excessive falls concern on fall risk

While carers' concern is associated with a sense of caution and fear of falling among community-dwelling elderly (Ward-Griffin et al. 2004), excessive concerns can lead to needless restrictions of older people's activities, including restricting access around the home. In a systematic review on restraints use in older people receiving home care, between 5 and 24.7% were subject to various types of restraint including body vests, seat belts, psychotropic medication, and seclusion (Scheepmans et al. 2017).

Another study found that carers who were less confident of their care recipients' balance were more likely to be overprotective and felt that they needed to provide more support to their care recipients (Honaker and Kretschmer 2014). These actions arguably lead to older people becoming increasingly dependent and

potential functional decline (Honaker and Kretschmer 2014).

A qualitative study on carers looking after family members with dementia identified strategies such as 'blocking' with furniture to restrict care recipients' movement in attempts to prevent further falls (Buri and Dawson 2000). Such strategies, although used with the best intention, may instead lead to increased falls risk due to physical deconditioning. Physical deconditioning is defined by a decreased level of physical fitness due to inactivity (Verbunt et al 2003). Decreased functional ability due to deconditioning among patients restrained was identified in a study of professional carers looking after older people with dementia in long-term care units (Fitzgerald et al. 2009). Inappropriate physical restriction can also cause psychological trauma and physical injury to the care recipients (Scheepmans et al. 2017).

Lack of falls concern about fall risk

Carers who underestimate falls risk can inadvertently jeopardise the safety of the care recipient. One study found many carers of people with Parkinson's disease felt it was normal for their care recipients to fall as the disease affects gait and balance (Abendroth et al. 2012). Families did not act to prevent the older person falling if they did not sustain any injury (Abendroth et al. 2012). However, when they sustained severe injuries from the fall, they often had to go into long-term care via an emergency department assessment and hospital admission (Abendroth et al. 2012).

Implication to practice

It is important for healthcare professionals to help carers in the home develop a realistic appraisal of their older people's fall risk, and to educate them on falls prevention strategies. Research is needed to increase the understanding of carers' falls concern and this should not just be limited to people with diseases like Parkinson's disease, or dementia, which are associated with a higher risk of falling. A validated uniform measurement for carers' falls concern is required to determine the level of both accurate and unfounded concerns about falling. Effectively addressing the range and scope of carers' falls concern could lower the burden of care, as well as preventing premature institutionalisation for the people they care for.

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CHAPTER 3: INTEGRATIVE REVIEW

PAPER 3: Ang, S. G. M., O'Brien, A. P., & Wilson, A. (2018). Carers' concern for older people falling at home: An integrative review. Accepted by *Singapore Medical Journal* on 1 July 2019.

3.1 Overview

This chapter consists of Paper 3, which provides a comprehensive synthesis of the current evidence and knowledge gaps related to the fall concern of carers. An integrative review method is used to explore the causes of concern regarding care recipients at risk of falling and the impact of these concerns on carers. Factors such as the threat of a care recipient falling, adverse consequences of a fall, and care recipients' unawareness of fall risk, can all increase the fall concern of carers. These concerns, if left unmanaged, have the potential to affect carers' physical, psychological and social health, increase their caregiving burden, and the ability to prevent falls. This integrative review has been recently accepted by the Singapore Medical Journal on 1 July 2019 (Appendix 1).

The issue of foreign domestic workers (FDWs) as carers of older persons in need of care monitoring and education has also been raised in this paper. The review identifies several important issues and gaps in care provision for older persons at home who are at risk of falling. The need for further research to prevent falls at home in the support of older person and their carers in the general aged population is highlighted. The review shows the need for healthcare professionals to assess the level of fall concern among carers providing care for older people at home, especially those who are at risk of falling.

Methodology update

Two authors (MA and OB) independently reviewed the titles and abstract of the studies identified from the search. Any disagreement related to the studies' eligibility was discussed with the third author (AW). The quality appraisal of the included studies was done by the first author (MA) using the Mixed Method Appraisal Tool (MMAT). While some researchers were concerned about the MMAT being incomplete in judging the methodological quality of a study, it is the only tool that allows concurrent appraisal of qualitative, quantitative and mixed method studies (Hong, Gonzalez-Reyes, & Pluye, 2018). Initial reliability testing on the MMAT also reported moderate to perfect agreement between reviewers (Pace et al., 2012). For the purpose of identifying additional factors related to carers' fall concern, no study was excluded due to poor methodological quality in this review.

3.2 Paper 3

ABSTRACT

Falls are the leading cause of injury and death among older people, which can have significant psychosocial impact on their carers. Carers play a crucial role in caring for the older person at home and preventing falls. This review aimed to identify carers' concern about older people falling and the impact of this concern. Fifteen studies were included. Findings identified that most carers expressed concerns about older people falling again, the unknown consequences of falling, and their care recipients' non-adherence to fall prevention advice. These concerns, in turn, affect the carers' physical/psychological health, lifestyle, caregiving burden, and fall prevention strategies used. The review highlights the importance of recognising carers' fall concern to identify their needs and awareness around preventing older people from falling at home. A greater awareness about carers' concern could facilitate the implementation of new strategies to manage the older person's fall risk and improve carers' wellbeing.

Keywords

Carers, fall concern, fall prevention, older people, integrative review

INTRODUCTION

Accidental falls are the leading cause of injury deaths globally, especially among older people (World Health Organisation, 2018b). Approximately 28 to 35% of older people aged 65 and over fall each year, with the incidence of falls increasing with age and frailty (World Health Organisation, 2007). Globally, 646,000 people die annually as a result of falls and another 37.3 million falls require medical attention (World Health Organisation, 2018b). Besides physical injury, falls have a significant psychological and social impact on older people, including a fear of falling, loss of confidence in their balance, and activity restriction (Denkinger et al., 2015).

As the world's ageing population increases, there are more carers needed to enable older people continue living in their own home (United Nations Department of Economic and Social Affairs Population Division, 2017). In 2011, there were around 6.5 million carers in the United Kingdom and that number is projected to increase to 9 million by 2037 (Carers UK, 2015). In the United States of America (USA), it is estimated that 34.2 million people provide unpaid care to people aged over 50 years (National Alliance for Caregiving & AARP Public Policy Institute, 2015). In Australia, almost 2.7 million Australians were identified as carers in 2015 (Australian Bureau of Statistics, 2018).

Unpaid carers, usually family or friends, contribute significantly in terms of time and effort in caring for older people in their homes. In many parts of Asia for example, it is a cultural norm for children to look after their parents (Mehta, 2006). For instance in Singapore, government housing grants were introduced since 1978 to encourage children to live with or near to their parents (Housing & Development Board, 2018; Teo, Mehta, Thang, & Chan, 2006), and about 10% of Singaporean households currently comprise

three generations (3G) or more families living together; such as, an elderly married couple living with their children and grandchildren (Ministry of Social and Family Development, 2015). Between 2000 and 2014, 3G households in Singapore with at least a member aged 65 years and above has increased from 62,800 to 82,100 (Ministry of Social and Family Development, 2015). The roles of caring for an older person are extensive and range from providing assistance in activities of daily living to the management of healthcare (Australian Bureau of Statistics, 2018). As people age, they experience concomitant physical (and cognitive) decline which increases the risk of a fall and the need for increased falls vigilance. Falls among older people at home generally increase a carer's burden. This is particularly the case as care needs increase and there is continued concern about the potential for ongoing falls (Davey, Wiles, Ashburn, & Murphy, 2004; Faes et al., 2010; Kuzuya et al., 2006).

Furthermore, carers are a trusted source of information and are well placed to negotiate, engage and initiate strategies to prevent the older person from falling at home (Mackintosh, Fryer, & Sutherland, 2007). A randomised controlled trial found carers who engaged in fall prevention programmes had significant improvement in falls risk awareness and fall prevention strategies for older adults with cancer (Potter et al., 2014). Another study on the efficacy of a home-based carer-enhanced exercise program found significant improvement in balance, fall concern, and physical activity among older people living with dementia (Taylor et al., 2017). Conversely, carers can inadvertently escalate the risk of older people falling. In attempts to prevent falls at home, carers may try to limit the older people's activities, leading to increased dependence (Honaker & Kretschmer, 2014). A longitudinal study in long-term care facilities found that professional carers' fall concern for residents with dementia was predictive of restraint

use, future functional ability, and injurious falls (Fitzgerald, Hadjistavropoulos, & MacNab, 2009).

While there is a growing body of evidence on the impact of carers' concern for older people falling, there is no integrated knowledge regarding this concern. A comprehensive overview of aspects influencing carers' concern for older people falling has the potential to improve future fall prevention programmes by tailoring preventive strategies to older people and their carers.

The search questions specific to this review are:

- 1) What are carers' concerns about older people falling?
- 2) What is the impact of fall concern on the carers and how does this concern influence fall prevention strategies?

METHODS

The evidence was synthesised using the integrative review method. This method combines different methodologies to provide a holistic understanding about carers' concern for older people falling and informs evidence-based practice regarding fall prevention at home (Whittemore & Knafl, 2005).

Search strategy

A systematic search was conducted in CINAHL, Embase, Medline, PsychINFO, Scopus, and Web of Science. Additional records were identified by hand searching reference lists of the selected studies. Search terms included "caregiver," OR "carer," OR "support person," AND "fall efficacy," OR "fear of falling," OR "worry of falling," OR "concern

of falling." Search strategies were modified according to individual databases. Proximity searches and truncation to identify terms in their adjectival form were used. The full search strategy for all databases is presented in the supplementary table.

Inclusion criteria for the review were empirical studies published in English between January 1993 and September 2018, exploring carers' concern for older people falling at home with a focus on the general older population, or those with age-related chronic illnesses. In this review, a 'carer' is defined as an individual providing informal ambulation support and activities of daily living assistance to an older person living at home. Studies that focused on professional carers, where falls occurred in the hospitals or nursing homes, or where falls were related to paediatric population were excluded from the literature search.

Search outcomes

The initial search yielded a total of 359 studies. After the removal of 220 duplicates, 143 studies, including four additional studies identified from the reference lists of the remaining studies, were reviewed using their title and abstract. Based on the inclusion criteria, 25 studies were selected for full-text review. Ten studies were excluded due to insufficient detail on carers' concern about their care recipients falling, such as evaluation of this concern, its causative factors, and its impact on the carers and older person. Fifteen studies were used for this integrative review. The search strategy and procedures were conducted according to the Preferred Reporting Items for Systematic Reviews and Metanalyses (PRISMA) framework (Fig. 1).

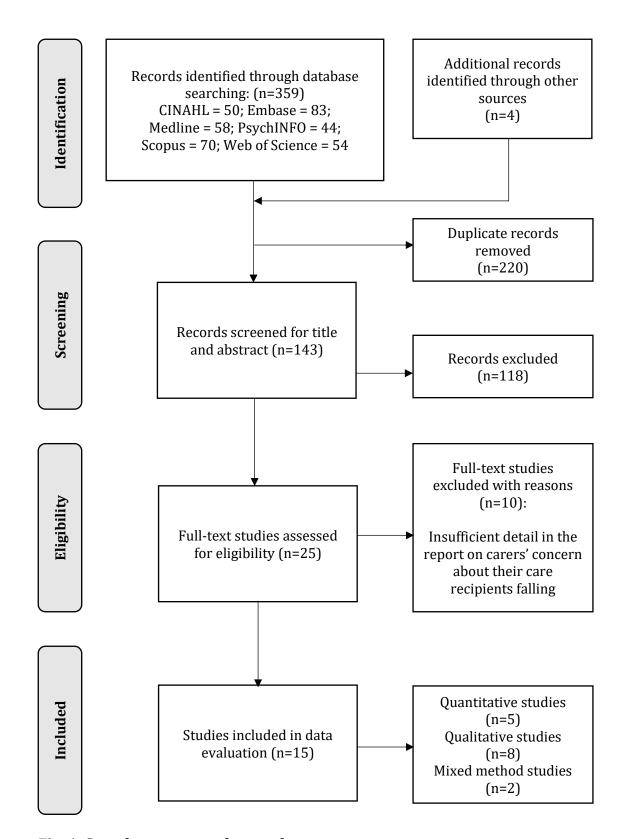


Fig. 1: Search strategy and procedures

Quality appraisal

The systematic search resulted in 15 studies: five quantitative, eight qualitative, and two mixed method studies relating to carers' concern for the older person falling. Methodological quality of the included studies was assessed using the 17-criteria Mixed Methods Appraisal Tool (MMAT) (Table 1) (Pluye et al., 2011). All 15 studies fulfilled the screening criteria by having research methodologies congruent to the study aims.

Among the qualitative studies, four applied grounded theory (Abendroth, Lutz, & Young, 2012; Buri & Dawson, 2000; Davey et al., 2004; Faes et al., 2010), three were descriptive designs (Habermann & Shin, 2017; Kelley et al., 2010; Peach et al., 2017), and one used focus groups (Stevenson & Taylor, 2018). All studies had relevant qualitative data sources and analysis, and appropriately addressed the study findings to the context. Only two studies appropriately considered potential researcher bias (Buri & Dawson, 2000; Kelley et al., 2010).

Of the five quantitative studies, one was a randomised controlled trial (Faes et al., 2011), two were cohort studies (Forster & Young, 1995; Liddle & Gilleard, 1995), and the rest used cross-sectional design (Kuzuya et al., 2006; Meyer et al., 2012). Methodological quality of the randomised controlled trial was robust, fulfilling all criteria related to randomisation description, blinding, completed outcome data >80%, and low dropout rate (Faes et al., 2011). The other four quantitative studies also achieved minimisation of selection bias, applied appropriate measurements, and recruited comparable participants. One study did not obtain an acceptable response rate of more than 60% as required by MMAT (Meyer et al., 2012). However, for the purpose of identifying additional factors

related to carers' concern, the study was included as it explored the relationship between care recipients' fall risk and caring burden.

Both mixed method studies used prospective longitudinal design for the quantitative component. For the qualitative component in the mixed method studies, one study applied a focus group (Dow et al., 2013), while the other study used face-to-face interviews (Honaker & Kretschmer, 2014). Methodological quality for individual quantitative and qualitative components were robust with both studies fulfilling most of the quality criteria. However, only one study demonstrated appropriate integration of qualitative and quantitative data (Honaker & Kretschmer, 2014).

Data extraction

A narrative analysis was used to review evidence related to the phenomenon of carers' fall concern. Data was extracted using a data reduction method to facilitate a systematic comparison of primary studies and an understanding of the relationship between each theme and the phenomenon of concern (Whittemore & Knafl, 2005). Seven studies were used to describe the causes for carers' concern about older people falling. Findings were extracted and grouped into two themes: prevalence and measurement of fall concern, and carers' concerns about falling. Thirteen studies provided findings on the impact of fall concern. These findings were pooled and categorised into four themes: impact on physical/psychological health, lifestyle changes, increased caregiving burden, and impact on fall prevention strategies used. A summary of these studies is provided in Table 2.

Table 1. Methodological quality of included studies

Study types	Qualitative						Randomised controlled trial	controlled Quantitative non-randomised			Mixed methods				
Quality criteria	Abendroth et al. 2012	Buri & Dawson 2000	Davey et al. 2004	Faes et al. 2010	Habermann & Shin 2017	Kelly et al. 2010	Peach et al. 2017	Stevenson & Taylor 2018	Faes et al. 2011	Forster & Young 1995	Kuzuya et al. 2006	Liddle & Gilleard 1995	Meyer et al. 2012	Dow et al. 2013	Honaker & Kretschmer 2014
Clear objectives	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$
Appropriate data collection	√	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	√	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	
Relevant data sources	√	$\sqrt{}$		$\sqrt{}$		$\sqrt{}$	$\sqrt{}$	√						$\sqrt{}$	V
Relevant data analysis	√	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$		$\sqrt{}$	$\sqrt{}$	√						$\sqrt{}$	
Appropriate setting	√	$\sqrt{}$		$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$						√	
Researcher influence considered	X	$\sqrt{}$	Х	X	X	$\sqrt{}$	X	X						Х	$\sqrt{}$
Clear randomisation description									√						
Blinding when applicable									$\sqrt{}$						
Outcome data (>80%)									$\sqrt{}$						
Dropout (<20%)									$\sqrt{}$						_
Minimise selection bias										$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	
Appropriate measurements										√	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	√	V
Comparable participants										$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	
Response rate (>60%)										√	$\sqrt{}$	$\sqrt{}$	X	√	V
Relevant research design														$\sqrt{}$	
Relevant mixed method integration														X	
Integration limitation considered														X	Х

Table 2. Summary of selected literature review related to carers' fall concern

Study	Study Aim	Qualitative study	Carer	Care Recipient	Related to Theme(s) in Review
Abendroth et al. 2012 United States	Understand carers' experience of caring for family member with Parkinson's disease, and decision for placement in a long-term care.	Grounded theory using semi-structured interviews	17 females and 3 males caring for spouse or parent	-	Increased caregiving burden
Buri & Dawson 2000 United Kingdom	Explore the perspective of fall risk among carers of elderly with dementia.	Grounded theory using focus group and one-to-one interviews	7 carers for focus group and 6 carers for one-to-one interview caring for spouse or parent	-	Impact on fall prevention strategies used
Davey et al. 2004 United Kingdom	Explore the views of informal carers of repeat fallers with Parkinson's disease.	Grounded theory using semi-structured interviews	11 females and 3 males caring for spouse, mean age 69.9 years	-	Carers' concerns about falling Impact on physical/ psychological health Lifestyle changes Impact on fall prevention strategies used
Faes et al. 2010 Netherlands	Explore the impact of fall for frail community-dwelling older persons and their family carers and define future fall prevention program.	Grounded theory using interviews	5 females and 5 males caring for spouse or parent, mean age 66.5 years	6 females and 4 males, mean age 78.5 years	Carers' concerns about falling Lifestyle changes Increased caregiving burden Impact on fall prevention strategies used
Habermann & Shin 2017 United States	Explore the needs, concerns, and preferences of couples with advanced stage Parkinson's disease.	Descriptive qualitative study using semi-structured interviews	7 females and 7 males caring for spouse, mean age 72.1 years	7 females and 7 males, mean age 73.3 years	Lifestyle changes Increased caregiving burden
Kelly et al. 2010 United States	Explore the lived experiences of stroke survivors and their spouses about falling and general mobility.	Qualitative study using semi-structured interviews	104 females and 29 males, caring for spouse, mean age 61.3 years	29 females and 104 males, mean age 65.4 years	Carers' concerns about falling Increased caregiving burden
Peach et al. 2017 United Kingdom	Explore the perceptions of older people with mild dementia/ cognitive impairment, and their family carers, about fall, fall risk and fall prevention.	Qualitative study using semi-structured interviews	21 relatives caring for spouse, parent, grandparent, or friend	7 females and 13 males mean age 70-93 years	Lifestyle changes Impact on fall prevention strategies used
Stevenson and Taylor 2018 Northern Ireland	Explore the experiences and concepts of risk from the perspective of family carers of older people with dementia.	Qualitative study using focus groups	16 females and 6 males caring for spouse or parent	-	Impact on fall prevention strategies used

Study	Study Aim	Randomised controlled trial	Carer	Care Recipient	Related to Theme(s) in Review	
Faes et al. 2011 Netherlands	Assess the efficacy of fall prevention program in preventing falls and fear of falling in frail older fallers and reducing caregiver burden.	Randomized, parallel- group, single-blind trial	19 females and 14 males caring for spouse, parent, or other	23 females and 10 males mean age 78.3 years	Prevalence and measurement of fall concern	
Study	Study Aim	Quantitative non- randomised study	Carer	Care Recipient	Related to Theme(s) in Review	
Forster & Young 1995 United Kingdom	Investigate the incidence and consequences of falls in elderly with stroke following discharge.	Cohort study follow up at 8 weeks and 6 months	74 carers, caring for spouse or relative	51 females and 57 males median age 70 years	Prevalence and measurement of fall concern Impact on physical/ psychological health Lifestyle changes	
Kuzuya et al. 2006 Japan	Determine the association between care recipients' falling and caregivers' burden.	Cross-sectional study using self-reported questionnaire	1478 carers caring for spouse, parent or others	1242 females and 632 males	Increased caregiving burden	
Liddle & Gilleard 1995 United Kingdom	Investigate the prevalence of a fear of falling among elderly admitted after a fall and their carers.	Cohort study follow up at 1 month	42 carers, caring for relative, friend or neighbour	62 females and 7 males mean age 83 years	Prevalence and measurement of fall concern	
Meyer et al. 2012 Australia	Investigate the association between frequency, circumstances and factors of falls risk for older care recipients, and their informal carers.	Cross-sectional study using self-reported questionnaire	66 females and 30 males caring for spouse, parent, sibling or friend, mean age 72 years	36 females and 60 males, mean age 78 years	Impact on physical/ psychological health Increased caregiving burden	
Study	Study Aim	Mixed methods	Carer	Care Recipient	Related to Theme(s) in Review	
Dow et al. 2013 Australia	Impact of care recipients' falls on carers	Prospective study and focus group	66 females and 30 males caring for spouse, parent, sibling or friend, mean age 71.8 years	36 females and 60 males, mean age 78.0 years	Carers' concerns about falling Impact on physical/ psychological health Lifestyle changes Increased caregiving burden Impact on fall prevention strategies used	
Honaker & Kretschmer 2014 United States	Investigate the impact of fear of falling on older patients with dizziness history and their carers	Mixed methods using phenomenological approach	8 females and 6 males caring for spouse or parent	9 females and 5 males, mean age 69.1 years	Lifestyle changes Impact on fall prevention strategies used	

RESULTS

Across all 15 studies, sample size for carers ranged from 10 to 1478 and care recipients ranged from 10 to 1874. Mean age for the carers ranged from 61.3 to 72.1 years and care recipients from 65.4 to 78.5 years old. In most studies, carers were either children or spouses of the care recipients (Abendroth et al., 2012; Buri & Dawson, 2000; Davey et al., 2004; Faes et al., 2010; Forster & Young, 1995; Habermann & Shin, 2017; Honaker & Kretschmer, 2014; Kelley et al., 2010; Stevenson & Taylor, 2018). Only one study was conducted in non-Western country (Kuzuya et al., 2006). Not all of the studies were conducted on the general older population, with three each focusing on carers of older people with Parkinson's disease (Abendroth et al., 2012; Davey et al., 2004; Habermann & Shin, 2017), and dementia (Buri & Dawson, 2000; Peach et al., 2017; Stevenson & Taylor, 2018), and two studies on carers looking after stroke patients (Forster & Young, 1995; Kelley et al., 2010).

Prevalence and measurement of fall concern

Three quantitative studies were reviewed to explore the prevalence of carers' concern about the older persons falling (Faes et al., 2011; Forster & Young, 1995; Liddle & Gilleard, 1995). Among older people with history of falls in the community, between 58% and 91% of the carers reported fear of their care recipients falling again (Faes et al., 2011; Liddle & Gilleard, 1995). In a quantitative study of older people with stroke, discharged from hospital, many carers were concerned about their care recipients falling regardless of whether they had fallen previously, with 57% (42/74) and 45% (33/74) of the carers continuing to experience this concern at 8 weeks and 6 months' follow-up (Forster & Young, 1995).

To measure carers' concern for their care recipients falling, three studies used a single-item question with 'yes' or 'no' response (Faes et al., 2011; Forster & Young, 1995), or three-point scale of 'no fear', 'some fear' and 'great fear' (Liddle & Gilleard, 1995). No aspects of validity and reliability were tested for any single-item measures.

Carers' concerns about falling

Two studies reported on the concerns of carers about the outcomes of their care recipients falling (Davey et al., 2004; Faes et al., 2010). While the possibility of older people falling was the main concern for carers, there is evidence suggesting that carers are equally distressed over other consequences of a fall. A qualitative study on carers whose spouses with Parkinson's disease experienced recurrent falls, found that their concerns exceeded the immediate consequences of the fall, with possible impact on the older person's quality of life and survival (Davey et al., 2004). Carers of frail older people also described fear about the unknown consequences of a fall, such as fractures or hospitalisation, regardless of the frequency of previous falls (Faes et al., 2010).

Four studies discussed carers' concern about the older person's lack of awareness for their fall risk and their continued engagement in high-risk activities, exposing them to the potential of falling (Davey et al., 2004; Dow et al., 2013; Faes et al., 2010; Kelley et al., 2010). A focus group with carers from the general elderly population found that care recipients forgetting, or not using mobility aids, were common causes for carers' concern (Dow et al., 2013). Similar concern was also highlighted by the spouses of stroke survivors when the older person chose to walk without their prescribed walking aids (Kelley et al., 2010).

Furthermore, Faes et al. (2010) also reported that carers of older people with cognitive impairment experienced emotional distress when their care recipients refused to adhere to their fall prevention advice. As a result, carers often felt that the falls were beyond their control and could not be prevented. Carers of older people with Parkinson's disease also attributed the causes of the fall and their concern to the care recipients' risk-taking behaviour, complicated by the older persons' desire for independence (Davey et al., 2004).

Impact on physical/psychological health

Only one study reported on carers who injured themselves while trying to stop their spouses falling, or helping them up from a fall (Davey et al., 2004). Due to the common occurrence of falls, some carers were reluctant to seek help, despite lacking the physical strength to lift their spouse up from a fall, which put the carers at further risk of personal injury (Davey et al., 2004).

The psychological impact of an older person's fall was explored in four studies (Davey et al., 2004; Dow et al., 2013; Forster & Young, 1995; Meyer et al., 2012). Forster and Young (1995) found that carers of older people with stroke were significantly more stressed if their care recipients had fallen six months after discharge. Among the general elderly population, carers of care recipients with a high fall risk expectation experienced higher levels of depression (Meyer et al., 2012). Another study revealed from the qualitative interviews that carers experienced mixed feelings of emotional and psychological consequences, such as anxiety, worry, fear, shock, anger, and frustration due to their care recipients' falling (Davey et al., 2004). Dow et al. (2013) concluded that some carers blamed themselves for not monitoring their care recipients closely enough.

Lifestyle changes

Seven studies discussed carers' social restriction related to the older person falling at home (Davey et al., 2004; Dow et al., 2013; Faes et al., 2010; Forster & Young, 1995; Habermann & Shin, 2017; Honaker & Kretschmer, 2014; Peach et al., 2017). Fear of older people falling meant carers needed to be constantly vigilant and avoided leaving the care recipient alone (Davey et al., 2004; Dow et al., 2013; Faes et al., 2010). One study reported that carers would only leave their spouses for brief periods, or when someone else was available to supervise them in their absence (Habermann & Shin, 2017). The reluctance to leave the older person alone limited the carers' opportunity to participate in individual, or social activities leading to social withdrawal (Davey et al., 2004; Faes et al., 2010; Forster & Young, 1995; Honaker & Kretschmer, 2014). Carers also reported changing their daily routines such as work arrangements and social engagements, to facilitate greater supervision of the older person after a fall (Dow et al., 2013; Peach et al., 2017).

Increased caregiving burden

The search identified seven studies discussing the carers' experience of increased burden related to caring for older people at risk of falling (Abendroth et al., 2012; Dow et al., 2013; Faes et al., 2010; Habermann & Shin, 2017; Kelley et al., 2010; Kuzuya et al., 2006; Meyer et al., 2012). Besides ensuring the care recipients' safety, some carers experienced a change in the level of care due to the older person requiring more help in mobility, or daily activities, and attending to their injuries after a fall (Dow et al., 2013). More time was needed to assist the older person and carers were often unable to complete their chores or get enough rest. This lack of time and energy was also explored in a qualitative study among spouses of stroke survivors (Kelley et al., 2010). The theme 'time is

constantly on my mind' emerged from the interviews as carers described difficulty fulfilling work and home responsibilities while looking after their spouses. According to Faes et al. (2010), carers of frail older people experienced increasing burden as they became more aware of their care recipients' dependence. Many carers also felt fatigue and were overwhelmed by the changes in caring role and duties (Faes et al., 2010).

The relationship between falls and caregiving burden was studied in two Australian quantitative studies finding a significant increase in general caregiving burden for carers looking after older people with a higher falls risk (Meyer et al., 2012), and those who had fallen once in 12 months (Dow et al., 2013). A Japanese study using a large cross-sectional sample of 1478 carers also found carers of older people who had fallen in the past six months had a significantly higher caregiving burden than those of non-fallers (Kuzuya et al., 2006).

When the burden of care exceeds their ability to provide adequate care, the care recipients who had experienced a fall often end up being placed in institutional care (Abendroth et al., 2012). Carers identified falls with severe injury as one of the main reasons for sending their family members with Parkinson's disease to long-term care. Yet, falls are an accepted part of Parkinson's disease progression, and carers do not always minimise the risk of their care recipients falling. To mitigate this burden, some carers turned to respite care for support. However, respite in the studies reviewed was sometimes met with reservations due to the carers' previous bad experience, or where the care recipients refused to accept the care (Dow et al., 2013; Habermann & Shin, 2017).

Impact on fall prevention strategies used

The influence of caregivers' fall concern on the strategies used for fall prevention at home was discussed in seven studies (Buri & Dawson, 2000; Davey et al., 2004; Dow et al., 2013; Faes et al., 2010; Honaker & Kretschmer, 2014; Peach et al., 2017; Stevenson & Taylor, 2018). Six studies described carers staying vigilant to prevent older people from falling (Buri & Dawson, 2000; Davey et al., 2004; Dow et al., 2013; Faes et al., 2010; Peach et al., 2017; Stevenson & Taylor, 2018). Findings included frequent telephoning, or visiting, monitoring care recipients' activities closely, constant reminders, and being aware of their individual fall risk. Other carers used strategies such as advising their care recipients on posture and walking, promoting physical activity, or attendance at rehabilitation clinics, encouraging the use of walking aid, and making changes to the home environment (Davey et al., 2004; Dow et al., 2013; Faes et al., 2010; Stevenson & Taylor, 2018). Besides preventing a possible fall, the modification of the home environment, such as installation of grab rails, sensor lights, and removing mats was also done to minimise the potential impact of a fall occurring (Davey et al., 2004).

Due to concerns about the older people's risk of falling, some carers chose to accompany their care recipients to social activities, or to assist them in their chores (Faes et al., 2010). However, one study found that carers of older people with dementia do not always want to undermine their care recipients' independence with over support (Peach et al., 2017). Stevenson and Taylor (2018) stated that carers generally do not wish to restrict their care recipients from participating in their daily activities, despite the risk involved. They further suggest that the risk would be worth it if their older care recipient could get out of the house, be mentally stimulated, or experience some enjoyment from being cared for in a flexible environment. Some carers, however tried to intervene by taking over, or by

restricting the activity perceived to be risk based (Stevenson & Taylor, 2018). Buri and Dawson (2000) advised that carers even attempted to control their care recipients with dementia by physically confining them in a controlled space, or by restricting their freedom to move around to reduce the likelihood of a fall occurring. While these preventive strategies appeared to reduce the risk of a fall occurring and served to increase the carers' feelings of control, they also potentially contribute to a greater dependence among older people (Honaker & Kretschmer, 2014).

DISCUSSION

This integrative review identified causes and impact of carers' concern about the older person falling at home. Six major themes were identified which included: 1) prevalence and measurement of fall concern, 2) carers' concerns about falling, 3) impact on physical/psychological health, 4) lifestyle changes, 5) increased caregiving burden, and 6) impact on fall prevention strategies used. To provide a comprehensive review of carers' fall concern, studies related to Parkinson's disease, dementia, and stroke were included in the review of the literature. Therefore, issues related to the carers' concern may be aligned with the care recipients' medical condition causing ambulation problems rather than ageing frailty leading to a fall. The findings of this integrative review are pertinent for healthcare professionals to investigate the psychological wellbeing and other needs of carers, as they are often the people in the front line preventing the older person from falling at home.

The majority of the carers in the studies reviewed reported having concern about their care recipients falling again (Faes et al., 2011; Liddle & Gilleard, 1995), and one study found that some carers were equally concerned even if the older persons had not fallen

(Forster & Young, 1995). This finding was similar to previous studies illustrating that the older care recipient with no history of falling, also experienced fear of falling, resulting in activity restriction, functional decline, and an increased risk of admission to institutional care (Cumming et al., 2000; Hughes et al., 2015; Scheffer et al., 2008). Future research could explore more deeply the possible burden associated with the carers' concern for non-fallers.

Most studies reviewed used a single-item instrument to measure carers' fall concern and none described the statistical rigour for these instruments (Faes et al., 2011; Forster & Young, 1995; Liddle & Gilleard, 1995). On the basis of what researchers have provided in their papers, it was not possible to determine the psychometric qualities associated with carers' concern. Since carers are essential partners in caring for the older person at home and falls have a significant impact on the carers' experience, a validated measure of carers' concern about the potential for the older persons falling could benefit falls surveillance (Ang, O'Brien, & Wilson, 2018b; Ang, Wilson, & O'Brien, 2018a).

In addition to the possibility of their care recipients falling, some carers were concerned about the older person's non-adherence to fall prevention advice (Davey et al., 2004; Dow et al., 2013; Faes et al., 2010; Kelley et al., 2010). It is possible that the older person fails to see the consequences of a fall (Lim et al., 2018), or feels that the advice to be careful about falling undermines their independence and freedom to engage in their normal activities (McMahon, Talley, & Wyman, 2011). Among carers, increased fall concern could be attributed to their lack of knowledge in preventing the older persons from falling. It can also be suggested that those carers who are overly concerned about falls may have inadvertently be restricting their care recipient's activity (Ang, Wilson, & O'Brien,

2018b). Therefore, measuring the level of carers' concern provides insight into whether their personal resources are being stretched when caring for an older person at risk of falling. This interval measure could serve as an intervention point for healthcare professionals to provide increased education and skills training and support for carers to help them more effectively manage or prevent falls at home.

The use of fall prevention strategies such as activity restriction and seclusion, indicated that carers may have limited knowledge about fall prevention. It also highlights a lack of effective fall prevention services provided to people caring for the older person at home who are at risk of falling. Although physical restrictions such as seclusion were used to ensure safety, these measures can potentially result in physical, psychological and social implications for the older person, as well as bringing about ethical issues related to human rights considerations (Scheepmans, Dierckx de Casterle, Paquay, & Milisen, 2017). Since the carers have a major role in looking after the older persons at home, particularly in managing falls, their lack of knowledge and inappropriate use of fall prevention strategies could potentially endanger their care recipients. It is important to address these ethical issues to improve carers' awareness of fall risk and to avoid premature institutionalisation due to preventable falls.

Implications for practice

Recognising carers' concern can be incorporated into caregiver training, rehabilitation and fall prevention programmes to assist healthcare professionals identify carers who might have difficulty managing falls at home. Interventions could then be tailored to the individual carer and the older person. For instance, a distressed carer may be referred to a medical social worker or psychologist for counselling to ameliorate excessive concern.

Information on access to resources and community services such as home care assistance, respite care, counselling support, or financial aids could also be provided.

It is also important for healthcare professionals to identify carers' concern during discharge planning and to provide targeted discharge advice for older people admitted for recurrent falls. In countries with inadequate community services (i.e. nurses) to assist home carers support the older person at risk of falling, it would be prudent to review community nursing and care coordinators involvement in the support of the carer living at home with the older person at risk of falling.

Recommendations for future research

Many studies have focused on older people with specific medical conditions, however future studies are needed to find out more about carers' concern for the general population of elderly experiencing functional decline due to aging placing them at risk of falling. A multi-item measure could be developed to effectively capture a comprehensive picture of the impact of an older person's fall and be used as an alternative outcome measure for fall prevention programmes (Moore & Ellis, 2008).

Many carers experience lifestyle changes during the care of older people, which can aggravate physical and emotional burden. More research into how families can be better supported, especially in countries where families are considered the main support structure for older people would be beneficial (Yeoh & Huang, 2009). In some parts of the world, for example, the family's children are juggling full time jobs in addition to the care of their parents, or other older family member. This situation often means they need to engage paid carers such as foreign domestic workers (FDW) to help them (Yeoh &

Huang, 2009). These FDWs are often lowly educated and poorly paid, regulated by only a work permit system binding them to an individual employer from one household (Yeoh & Huang, 2009). In this context, unlike a spouse, or children, the FDWs have a paid duty to provide care for the older person living at home. Further research about paid carers' fall concern, support, and how family carers can be equipped to support and complement the roles of FDWs are crucial in the continuing care of the older person.

The majority of studies regarding falls and fall concern have been conducted in Western developed countries. Future research is recommended to be conducted in Asian cultures to allow a detailed analysis of the potential cultural influences on carers' fall concern (Ang, Wilson, et al., 2018a). Such research could clarify and identify alternative approaches to the cultural care of older people living at home who are at risk of falling. Fall concern research in Asian cultures for example, could involve understanding filial responsibility and its profound influence on carers' concern and falls prevention. Studies including socio-economic and environmental considerations related to fall prevention could also be worthy of deeper investigation.

CONCLUSION

Carers' concern about their care recipient falling is a major under-reported problem, which potentially affects the carers' physical and psychological health, lifestyle, increasing their caregiving burden, and influencing fall risk management at home. This concern is more than just the possibility of the older person falling and includes fear of the consequences of falling and the older person's lack of awareness of their fall risk. The apprehension associated with carers' concern regarding their care recipients' risk of falling could also reflect their lack of knowledge and understanding in fall risk and

prevention. Evaluating carers' concern for their care recipients falling would provide an alternative perspective for healthcare professionals to understand the older person's fall risk and the carers' needs for further support at home.

Supplementary Table. Full search strategy and search terms used

No	Search	CINAHLa	Embase	Medline	PsyINFO	Scopus ^b	Web of Science ^c
1	caregiver*	53,513	93,852	64,582	51,194	92,895	61,032
2	support person*	5,467	1,553	1,234	1,234	2,764	1,573
3	carer*	11,441	18,732	12,692	9,318	19,464	14,327
4	fall* adj3 efficac*	564	1,160	797	480	1,075	895
5	fear* adj3 fall*	1066	2,182	1,496	673	1,981	1,753
6	worr* adj3 fall*	19	47	29	17	61	46
7	concern* adj3 fall*	278	501	345	188	996	612
8	1 or 2 or 3	65,151	106,244	73,812	58,153	108,584	73,776
9	4 or 5 or 6 or 7	1615	3,209	2,227	1,091	3,537	2836
10	8 and 9	52	86	60	47	75	56
11	Limit to English language	50	83	58	44	70	54

^aReplace adj3 with n3; ^bReplace adj3 with w/3; ^cReplace adj3 with near/3.

CHAPTER 4: METHODS

PAPER 4: Ang, S. G. M., O'Brien, A. P., & Wilson, A. (2018). Carers' concerns about their older persons (Carees) at risk of falling: A mixed-methods study protocol. *BMC Health Services Research*, 18:819. doi: https://doi.org/10.1186/s12913-018-3632-6

4.1 Overview

This chapter consists of Paper 4, which discusses the methodology for developing and validating the Carers' Fall Concern Instrument (CFC-I). The study consisted of three phases, including an integrative review and qualitative interview (Phase One), the development and pilot-testing of the initial CFC-I (Phase Two), and validation of the final CFC-I (Phase Three). The protocol paper included in this chapter describes the study design, data collection and analysis procedures for each phase. The ethical considerations and minor changes with Human Research Ethics Committee (HREC) approval to the study design during data collection are described below.

Ethical considerations

All research activities in this project adhere to the Australian National Statement on Ethical Conduct in Human Research 2007 (National Health and Medical Research Council, Australian Research Council, & Australian Vice-Chancellors' Committee, 2007). Ethics approval was obtained from the Hunter New England Health HREC (Appendix 2) and registered with the University of Newcastle HREC (Appendix 3). Permission to recruit from the Hunter Medical Research Institute (HMRI) Research Registry (Appendix 4) and the Carers NSW were sought and granted. To collect data at the John Hunter Hospital, a site-specific assessment (SSA) form for assessing the

suitability of the study site was also completed and approved by the nursing unit or service manager (Appendix 5).

Variations of ethics approval

Four variations of ethics approval were granted during the study. In the first variation, the Rankin Park Centre Day Hospital (Rehabilitation Centre) was included as the fourth recruitment site for Phase Two and Three due to recruitment challenges during Phase One (Appendix 6). The Rankin Park Centre Day Hospital provides day hospital programmes for patients who require rehabilitation and have the potential for functional improvement. These patients are usually referred from the local district hospital network, General Practitioners (GPs), specialists or the Aged Care Assessment Team (ACAT). Patients can enrol in the Day-only Programme, falls clinic, or Parkinson's Programme. The Day-only Programme includes physiotherapy, occupational therapy, speech pathology, social work, medical review, and nursing care. The Falls Clinic provides a six-week programme for older people that involves an initial assessment, exercise, and education. The Parkinson's Programme is an eight-week exercise and education programme for both the older people and their carers to teach strategies and methods used to cope with everyday activities. Site-specific authorisation was also granted for this site (Appendix 7).

The second variation involved recruiting participants from Phase One to increase the rate of participation for Phase Two and Three (Appendix 8). These participants were approached by text messaging the online survey link. Paid advertisements for the study was also used in an attempt to recruit from the wider population of carers living in New South Wales Australia. The study was advertised on the HMRI social media platforms

such as Facebook and Instagram. The first and second variations of ethics approval were registered with the University of Newcastle HREC (Appendix 9).

The third variation involved removing the follow-up survey after two weeks in Phase Three due to the low response rate from carers (Appendix 10). Participants were not required to provide written consent to participate as consent was assumed if they completed the anonymous survey.

The last variation was the inclusion of an online survey link in the Information Statement for Phase Three (Appendix 11). This meant participants did not need to contact the researchers in order to participate and could access the online survey at a time convenient to them. Reciprocal approval from the University of Newcastle HREC was obtained for the third and fourth variations of ethics approval (Appendix 12). Due to the proposed variations, the study documents such as information statements for participants, social media wordings, and data collection forms were revised several times and only the most updated documents are attached in this thesis (Appendices 13 to 24).

Informed consent

All participants received an information statement, which described the study purpose, procedures, potential risks and benefits, and the contact details of the researchers (Appendix 18, 20, and 21). Participants were given time to read the information statement and discuss any aspects of the study they may have with the researcher. Participants were required to provide written informed consent in the Phase One study (Appendix 19). Since there was no personal identifying information collected and foreseeable risk involved, implied consent was used for those who completed the online survey in Phase Two or

Three. All participants were informed that participant was voluntary and that they could withdraw from the study at any time without giving any reason. For Phase Two and Three, the participants could withdraw by anonymously exiting the website.

Privacy, confidentiality, and disclosure of information

All information collected during the study was confidential and only the research team had access to the study information. Research data including audio recordings were stored in the University of Newcastle password-protected cloud server. Hard copies of the research data were locked in the filing cabinet of the chief investigator's office. These data will be kept for at least five years at the university before being destroyed as per policy and protocol.

During Phase One, participants gave permission to audiotape the interview. Participants were requested not to identify themselves during the interviews. The names of the participants were replaced with pseudonyms in the thesis and publications to conceal their identity and maintain privacy. Transcripts were de-identified using number codes. For Phase Two and Three, the participants were not required to provide their name, or any other identifying information such as email address, or telephone number meaning it not possible to identify the participants who completed the online survey from the password protected Research Electronic Data Capture (REDCap) database.

Potential risks

There were no obvious risks associated with this study. Participants were told if they should experience any distressing or overwhelming feelings while answering the questions, they would be asked to stop the interview or survey. Any distressed participant

would also be referred to the support services stated on the information sheet if requested.

A senior member of the researcher team was expected to follow up with the affected participant within a few days, however throughout the study this was not required.

Minor changes to study design

Besides the proposed changes in design, two changes were made regarding the development of the CFC-I and data collection. Specifically, a five-point Likert scale of "being not at all concerned" to "extremely concerned" was selected for the item response. This was opposed to the seven-point Likert Scale of "strongly disagree" to "strongly agree" with a neutral score in the middle suggested in the protocol paper. Convergent validity of the CFC-I was not performed as the frequency of falls and injury sustained among care recipients were collected as an ordinal variable. Carers were not able to recall the exact number of falls/ injuries if their care recipients had experienced frequent falls. Therefore, carers were asked to select from five options: "no fall, one fall, two falls, three or more falls, or unsure" for the frequency of falls. Regarding injury sustained, carers could choose "no injury, minor injury did not require medical attention, minor injury require medical attention, severe injury or unsure". The study methodology is discussed in detail in the following published paper.

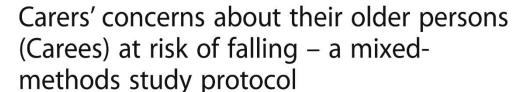
4.2 Paper 4

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BMC Health Services Research

STUDY PROTOCOL

Open Access





Seng Giap Marcus Ang^{*} Anthony Paul O'Brien and Amanda Wilson

Abstract

Background: When dependent older persons (carees) experience a fall at home, their carers worry that they will fall again. This ongoing concern affects the carers' wellbeing, perception of burden and can potentially change care arrangements. Previous research has focused on carers of high fall risk older persons with stroke, dementia or Parkinson's disease. However, little is known about the carers' concerns for carees at risk of falling generally; and there is no validated instrument to measure this concern. This study aims to explore carers' fall concern about carees at risk of falling and the development of an instrument to measure this concern.

Methods: This study utilises an exploratory sequential design in the development of an instrument to measure carers' concerns. Phase One will explore carers' fall concern using a descriptive qualitative approach. Phases Two and Three will involve expert review, pilot testing and field testing of the instrument. Twenty participants will be recruited by purposive sampling in phase one, and convenience sampling of 50 and 250 participants respectively, in Phases Two and Three. The participants will be recruited from research volunteer registers and local hospital outpatient clinics.

Participants will be 18 years old and older and the main carer of an older person. Participants will be interviewed about their concerns about falls. Inductive content analysis will be used to analyse interviews and develop items for the instrument. The psychometric properties of the raw instrument will be tested using an online survey. This study has received ethics approval from the Hunter New England Human Health Research Ethics Committee.

Discussion: This study aims to provide greater depth of understanding about the psychological concerns and emotional burden related to carees' falls for carers. Quantifying carers' concerns will provide a context for interventions to assist and support carers and in the greater vigilance of monitoring the falling incidence of carees.

Keywords: Carer, Older person, Fall concern, Fall risk, Fear of falling, Mixed methods

Background

In this paper, the term "caree" is used to refer to an older person, who is dependent on someone to assist them in their daily activities. This term is used to standardise the current variation of terms and euphemisms (such as older people, older persons, elders, family members, and loved ones).

Falls are the second leading cause of unintentional injury deaths internationally [1]. About 646,000 people die from falls each year with those aged above 65 suffering the

highest number of fatal falls [1]. Hospitalisations due to injuries sustained from falls are also common among carees. In Australia, 126,000 people aged 65 and above hospitalised due to injuries between 2011 and 2012 [2]. Of these, 77% sustained injuries due to a fall and the rate of injuries increased with age [2]. More than twice as many women than men were hospitalised, and majority of the falls occurred at home (49.6%), followed by residential institutions (22.5%) [2]. According to the Australian Bureau of Statistics, the proportion of people aged above 65 years increased from 11.9 to 15.0% between 1995 and 2015, and is projected to increase by another 1.1% by year 2020 [3]. With the population ageing, falls are an imminent public

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healthcare issue among carees, especially those living at home [4].

Falls can cause adverse psychological impact on carees, increased fear of falling again, decreased self-efficacy, and confidence in balance [5]. Up to 85% of carees living at home experience a fear of falling associated with activity restriction/avoidance [5-7], leading to decreased physical and mental performance and poorer quality of life [6, 8]. After a fall, carees with fear of falling can become more dependent, have a higher risk of falling, and are at increased risk of being admitted to long-term institutional care [6, 9]. The concepts of fear of falling in this group has been the subject of many studies looking to quantify it using different instruments [10]. However, these instruments are mostly designed to measure the psychological effect of falling among older people. The instruments are limited to questions about activity restriction, or the types of activities the respondents may perform, and do not provide an understanding about the burden that carees' fall risk imposes on carers [11].

Like carees, carers also experience fall concern and worry about their carees falling at home. Carers of spouses with Parkinson's disease expressed loss of confidence and fear when their carees fell [12]. Davey, Wiles, Ashburn and Murphy [12] reported that carers' concerns go beyond the immediate consequences of falls and encompass the potential impact on carees' quality of life and survival. Similarly, carers of stroke survivors have fears about their carees falling, especially when they refuse to use prescribed assistive devices [13]. In a grounded theory study, carers of frail carees, the majority suffering from mild cognitive impairment and dementia, expressed fear about them falling [14]. Although carers are generally concerned about carees at risk of falling, the causes of their concern vary across each of the carees' medical condition.

Falls have significant physical, psychological and social consequences for carers. Some carers reported injuring themselves while trying to prevent carees from falling, or when helping them to get up from the falls [12]. Despite this, carers were reluctant to seek help about their carees' frequent falling, which places both at further risk of injury [12]. Other carers experienced a significant increase in caregiving burden after their carees had fallen [15, 16]. They described having to change normal routines such as work or social engagements to avoid leaving carees alone at home. This placed the carers at risk of psychological distress and social isolation [16]. The issue of social withdrawal was highlighted among carers of frail carees due to constant worry, vigilance and reluctance to leave their carees alone at home [14]. A cross-sectional study of 96 carers in Australia showed that generally, carers experienced moderate caregiving burden, low self-rated health and poorer quality of life [17]. However, those who looked after carees with high

fall risk had significantly greater caregiving burden and depression [17].

Carers may have to change the level of care provided for carees who fall, as they require more assistance, supervision, or on-going care for their fall injuries [16]. The higher level of care needed as the result of falls and fall concern, further increases caregiving burden [13, 16]. When this burden exceeds the carer's ability to provide adequate care, carees often have no alternative but to be admitted to institutional care. This pathway was explored by Abendroth, Lutz and Young [18] who interviewed twenty primary carers of family members with Parkinson's disease. For carees who sustained severe injury from falls, this was the main reason for their placement in long-term care.

Most research in this area focuses on carers looking after people with Parkinson's disease, dementia or stroke, who are at high risk of falling due to functional or cognitive impairment. However, falls do not only affect high risk carees, so it is important to understand more about carers' concerns, especially those caring for people who are functionally independent but require some form of assistance due to age-related functional or cognitive decline.

There is little quantitative research around this concern. One possible reason is the absence of a reliable instrument to measure carers' concerns about falls. Studies have quantified the impact of carees' falling on carers by measuring caregiver burden [15–17], and others have measured the concern for carees falling using a single-item question with binary responses [19], or 10-point Likert scale on how afraid they are of their carees falling [20]. One mixed method study used open-ended questions to assess their perception for fear of falling as there were no validated questionnaires for measuring carers' fear of falling [11]. Based on the studies reviewed, there is a need for a comprehensive measure of carers' concern about the fear of carees falling, which includes psychosocial, mental health, quality of life and lifestyle restrictions.

Study aims and objectives

Aim

The aim of this study is to explore carers' fall concern and use this information to develop and test an instrument (Carers' Fall Concern Instrument [CFC]). As there is no definition for the term carers' fall concern, we define it as carers' fear of their carees falling.

Objectives

The study objectives are to:

- Identify and describe the different dimensions of carers' fall concern
- Develop a pilot instrument to measure these concerns

3) Test the pilot instrument and validate its psychometric properties

Methods

Design

This is a mixed method study using an exploratory sequential design to develop the CFC instrument [21]. The study will be conducted over three Phases, beginning with a qualitative approach to explore carers' fall concern. Building on the qualitative findings, a questionnaire will be constructed and validated. The study has been approved by the Hunter New England Health Human Research Ethics Committee.

Phase one

A descriptive qualitative study design will be used to explore the phenomena of carers' concern about carees at risk of falling. It is the method of choice for exploratory research because little is known about carers' fall concern [22]. This approach provides a comprehensive summary of daily activities using everyday terms and allows researchers to maintain the original data meanings with little interpretation, thus increasing the likelihood of usability and acceptability [23]. After analysis, statements and/or quotes related to carers' fall concern will be developed into items for the instrument [21]. The multi-item questionnaire will identify carers' fall concern. Each item will be ranked on a Likert scale of seven categories from strongly disagree, to strongly agree, and a neutral score at middle category [24].

Phase two

The raw instrument will be reviewed by an expert panel including geriatricians, nurses, allied health professionals and consumers for its face and content validity [25]. Problematic items will be identified for revision and the proposed scoring algorithm of using a seven-point Likert scale will be evaluated. The improved version will then be pilot tested among carers [24]. To ensure comprehensibility and relevance, the target population will involve carers looking after older persons at home with assumption that carers will experience different levels of fall concern. Instrument feasibility and acceptability will be assessed by carers being able to comprehend the questions and willingness to complete the survey [24].

Phase three

The CFC instrument will be field tested on a larger sample of carers. Exploratory factor analysis will be used to assess factor structure of the instrument [26]. The method consists of defining, extracting, and rotating factors for interpretability, and optimising the dimensionality [24]. Internal consistency (reliability) will be assessed using Cronbach's alpha to reduce the number of items and improve factor strength. Convergent and discriminant validity

will be assessed by comparing the instrument to frequency of carees falling over the past 12 months and injuries sustained to determine if the instrument is measuring what it is intended to measure [24]. Test-retest reliability will be assessed by re-administering the instrument to a subsample of carers two weeks later to ensure that scores received are consistent and stable over time [21]. The evaluation period is chosen to reduce content recall from baseline assessment and changes to events, such as carees' falling [25].

Study setting

Participants will be recruited from three study sites: 1) the Hunter Medical Research Institute (HMRI); 2) Carers NSW research register; and 3) the John Hunter Hospital. The HMRI research register is a central database of volunteers living in the Hunter New England Region, Australia, who are keen to participate in medical research as clinical controls [27]. Carers NSW is the peak non-government organisation for carers in New South Wales, Australia and focuses on improving the lives of carers through systemic advocacy and direct carer support [28]. Both databases provide a large cross-section to the general population of carers living in Australia. To enhance discriminatory ability of the CFC instrument, carers of patients from the Rheumatology Outpatient Clinic at John Hunter Hospital will also be recruited. Being the only trauma centre outside Sydney in New South Wales, John Hunter Hospital is a principal referral centre for the Hunter New England Region [29]. As part of osteoporosis re-fracture prevention, patients who are aged above 50 years and admitted to the emergency department for a fracture due to minimal trauma are referred to the Rheumatology Clinic for follow-up. Since most of these fractures are due to falls, the data set of participants from John Hunter Hospital will provide a unique group of carers looking after carees who have had a fall and sustained a fracture for comparison with the general population.

Sample size

During Phase One, an estimated twenty participants will be recruited using purposive sampling, which involves the deliberate selection of participants, to provide a complete understanding of carers' concerns [21]. Recruitment will cease upon data saturation. The literature suggests the instrument to be assessed by five to ten experts for its content validity [30]. Another fifty carers will be recruited via convenience sampling for the pilot testing of the CFC instrument [24]. At this stage, it is anticipated that the CFC instrument will contain 20 to 30 items developed from the key concerns shared in the qualitative interviews. The guidelines suggest four to ten participants are needed per item, with a minimum of 100 participants required for exploratory factor analysis [31]. Based on the proportion that 91% of carers were fearful of their carees falling again

[19], a sub-sample of 126 carers of carees with an injurious fall is needed for estimating the expected proportion with 5% absolute precision and 95% confidence. It is therefore estimated that 250 participants will need to be recruited during Phase Three, considering that there are carers looking after carees who had not fallen. This sample size is also adequate for eliminating subject variance and identifying adequacy of items in factor analysis [32]. Among the 250 participants, a random sample of fifty participants will be recruited for test-retest of the CFC instrument.

Inclusion and exclusion criteria

Participants will be eligible if they are: 1) aged above 18 years old; 2) the primary carer for family member or friend; and 3) providing support for at least one personal or instrumental activity of daily living (ADLs). Examples of personal ADLs include mobility, self-care and communication while instrumental ADLs include light housekeeping, transportation and meal preparation. The primary carer is defined in this study as the person who is most involved in caring for a person aged above 60 years old and living at home. The primary carer does not have to live with the caree. Exclusion criteria will include those who were: 1) paid carers or health care providers; 2) being unable to speak English; or, 3) provide informed consent.

Recruitment process

The coordinators from HMRI and Carers NSW will send out study invitations to their research registry members. At HMRI, those who wish to participate will reply to the HMRI coordinator via a Study Response Form and their contact information will then be forwarded to the researchers for contacting purposes. At Carers NSW, interested participants will need to contact the researchers directly. The study information will be published on HMRI and Carers NSW's social media such as Facebook page, website and email newsletter.

At the Rheumatology Clinic, the rheumatology nurses will distribute recruitment flyers to the patients for their carers to contact the researchers if they are interested in participating. The nurses will also gather information about carers from the patients and record contact details of patients who are willing to convey the study recruitment to their carers. The researcher will contact all participants to explain the study details, confirm their interest in participating and answer any questions about the research project.

Written Informed Consent will be obtained from Phase One participants. Participation in the survey implies consent for Phase Two and Three. All participants will receive the study information statement, consent form and reply-paid envelope (if applicable) by post or email.

Data collection methods

During Phase One, carers will be interviewed either face-to-face, or by telephone, depending on their preference, using a semi-structured interview guide. Telephone interview is chosen to allow flexibility for those who are keen to participate in the study, but unable to leave their carees alone at home. The topics to be discussed in the interview will include carers' concern about carees at risk of falling, factors facilitating care, problems faced during care, personal risks and support received to prevent and manage falls. Follow-up questions and prompts will be used to gain more insight about carers' fall concern. Demographic data, including age, gender, marital status, employment, care arrangement, history of falls and injury will also be recorded. Each interview session will take approximately one hour and will be audio-recorded. Reflective field notes will also be taken after the interview.

During Phase Two, experts in the area will be asked for their opinion about the accuracy and content relevance of the raw CFC instrument using open-ended questions. They will also rate each item on a four-point Likert scale with one being not relevant and four being very relevant to the construct. Their opinions will be incorporated into an instrument item revision. The revised instrument will then be piloted with 50 carers on-line using Research Electronic Data Capture (REDCap). REDCap is a secure, web-based application designed for building and managing online surveys [33]. It provides an intuitive interface for validated data entry, audit trails for tracking data manipulation and export procedures, automated export procedures for data downloads, and procedures for importing data from external sources [33].

An on-line survey allows carers to complete at their preferred time and provides access to a broad target audience from across the state of NSW. The survey will take approximately 30 min to complete. Participants will complete the CFC instrument and then asked their opinion on the item relevance, demographic questions and falls history of their carees. Findings from the pilot will be used to further refine the instrument. The hyperlink for the on-line survey will be sent to participants via email. For those without email access, the researcher will administer the survey by telephone. A reminder email will be sent to participants after one month to increase response rate.

During Phase Three, the third version of the CFC instrument will be administered to 250 participants. As with Phase Two, a hyperlink to the on-line survey on REDCap will be sent to the participants. The participants will complete the CFC instrument, demographic questions and falls history of their carees. The researcher will administer the survey by telephone for those without email. After two weeks, participants will complete the CFC instrument and report on recent falls history of their carees. A reminder

email will be sent if the participants did not complete the online survey after one month.

Data analysis

During Phase One, analysis of qualitative data will begin simultaneously with data collection to allow researchers to modify data treatment and accommodate new insights [23]. The interviews will be audio-recorded, transcribed verbatim and reviewed for transcription accuracy. An inductive content analysis approach will be applied as little is known about the research topic. The process consists of open coding, forming categories and abstraction [34]. The researcher will write notes and headings in the transcript while reading. Headings will be recorded in coding sheets and grouped to form categories. Repeated patterns in words, phrases, actions or events will identified. During abstraction, these categories are then compared and further categorised to form broader and higher level categories which will be developed into items to describe the hypothetical constructs of carers' fall concern [34]. Member checking will be conducted to ensure credibility of findings [21, 35].

Feedback regarding the representativeness of CFC instrument will be gathered using open-ended questions from the carers during Phase Two. Method triangulation will be applied to compare the interviews with reflective field notes collected. The researchers' background and possible influence on the participants' interaction will be acknowledged to address any potential role conflict. Dependability and confirmability will be ensured by keeping an audit trail which includes the audio recordings, interview transcripts, data analysis documents, and field notes to enhance transparency of research process [35]. To allow transferability, thick description will be used to provide comprehensive illustration of the research context [22].

Quantitative data will be entered into the Statistical Package for Social Science [36] and cleaned to ensure accuracy. The researchers will crosscheck the data with the completed questionnaires to identify any missing values. Frequency tests will be conducted to identify any abnormal values. The data sets will be assumed to be normally distributed.

During Phase Two, the Content Validity Index (CVI) of the proportion of experts rating three and above for each item in the raw CFC instrument will be calculated [25]. Items with CVI score of below 0.80 will be removed. The wordings of the remaining items will also be modified based on the experts' suggestions.

Descriptive statistics will be used to summarise carers' demographics, falls history, and data from the CFC instrument. Missing values and distribution item scores will be identified to improve the instrument. An item is considered acceptable if it has less than 3%, but no more than 15% of missing scores [24].

A questionnaire with several missing scores might indicate that participants do not understand the items, do not know the answers, are not willing to provide answers, or items are not applicable [24]. As for item scores distribution, a very high or low mean item score indicates most participants agree or disagree with the item, therefore reducing its power to discriminate. Items with a large percentage of missing scores or low standard deviation will be deleted. Cronbach alpha coefficient will be calculated to assess internal consistency of the raw instrument. Cronbach's alpha value of between 0.70 and 0.90 is recommended [24, 32]. A Cronbach's alpha of below 0.70 may indicate too few questions or lack of inter-items homogeneity, while items above 0.90 indicates redundancy of items [37].

During Phase Three, exploratory factor analysis will be conducted with the assumption of normality and homogeneity of variance [26]. Firstly, the suitability of data set for factor analysis will be explored. The use of factor analysis is appropriate if there are substantial numbers of items with a correlation coefficient of above 0.3 [26]. The factorability of data will also be determined by the Bartlett's test of sphericity and the Kaiser-Meyer-Olkin (KMO) measure of sample adequacy. A *P*-value of < 0.05 for Bartlett's test and minimum value of 0.6 for KMO show factor analysis to be appropriate [26].

Secondly, factors will be extracted using the principal factor method. The number of factors to be retained will be decided by the criteria of eigenvalue > 1, screen plot test, the proportion of cumulative variance accounted for and the overall interpretability of the factors [24]. Thirdly, factor rotation using either Orthogonal or an Oblique factor solution will be performed to facilitate interpretation of factors for loading closer to 1 or 0 [24]. The selected factors with related items loaded will be labelled [24] and items with a loading below the recommended threshold of 0.4 will be removed [24], as will items with high loadings onto more than one factor. Items will be deleted individually, and factor analysis will be performed after each deletion.

The decision to retain factors of item load with similar eigenvalues will depend on the researchers' subjective choices regarding content relevance and interpretability of factors. A minimum of three items contributing to each factor is recommended [24]. List-wise deletion will be the primary method of treating missing data, however, if this results in many responses being excluded (greater than 10% of the total sample size), alternative methods will be explored, such as utilising available cases (pairwise-deletion) and multiple imputation. Cronbach alpha coefficient for internal consistency of the instrument is also calculated. Spearman correlation will be used to assess the correlation between carers' concern and number of falls and severity of injuries sustained. A statistically significant correlation that exceeds 0.5 would suggest the instrument has convergent validity. Discriminant validity will be assessed by using independent T-test to examine group differences in total scores between carers of carees with or without falls and injuries sustained. Test—retest reliability will be assessed by intra-class coefficient between scores obtained during the initial survey and at two weeks' follow-up.

Discussion

While there is substantial research about carers' fall concern for carees suffering from Parkinson's disease, dementia and stroke, the full picture of carers' concerns for older people at risk of falling has not been investigated. There is no validated instrument which accurately measures or quantifies this concern. The primary purpose of this study is to develop and validate a measure for carers' fall concern. This study will explore the different dimensions of carers' fall concern affecting their physical, psychological and social health, and potentially influence care arrangements for carees.

To develop a self-reported instrument measuring carers' fall concern, this study will involve the general population of carers looking after older people at home. This will ensure that the items included in the instrument will be important and relevant to carers [38]. Unlike other instruments measuring the psychological impact of falling among older people, the operationalisation of carers' fall concern is not based upon any theoretical assumptions [39]. Therefore, the instrument will not be limited to activity-related deficits of carees such as in the case of adopting the Self-efficacy Theory. Validity and reliability of the instrument will be ensured by pilot testing with carers and obtaining feedback for modifications from carers and experts.

Several challenges are anticipated in this study. Since the majority of carers are female, there may be a disproportion in gender distribution among the sample population [40]. However, the use of purposive sampling in Phase One and recruitment from research registries will allow access to a diverse population representative of carers. As described in previous studies, most carers worry about leaving their carees alone, and therefore avoid going out of the house [14, 16]. To overcome potential low participation rates among carers, telephone interview will be used for data collection. This will minimise the need for travel and carers may feel more comfortable talking about their experiences and concerns due to the anonymity associated with telephone interview [41].

This study will provide insight into carers' concerns, promote greater awareness of the psychological impact of caregiving for people at risk of falling, and potentially enable tailored interventions based on carers' scores on the CFC instrument. As well as measuring carers' fall concern, the CFC instrument may serve as an alternative measure to predict older persons' falls risk, therefore overcoming the challenge to assess risk

of older people falling, especially those who have cognitive impairment.

A prospective study is proposed to determine if carers' fall concern would be sensitive to the frequency of carees falling or changes to their medical status and psychosocial health variables. The longitudinal design would also provide clear insight to the causal order between carers' concern and carees' subsequent falls. Furthermore, the CFC instrument could also be tested internationally to determine the potential cross-cultural influence of older people falling on carers' fall concern.

Abbreviations

ADL: Activity of daily living; Caree: Older person(s); CFC: Carers' Fall Concern; CVI: Content Validity Index; HMRI: Hunter Medical Research Institute; KMO: Kaiser-Meyer-Olkin; NSW: New South Wales; REDCap: Research Electronic Data Capture

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Availability of data and materials

Not applicable

Authors' contributions

SGMA drafted and revised the manuscript. AOB and AW reviewed and revised the manuscript. All the authors read and approved the final manuscript.

Ethics approval and consent to participate

The study protocol has received ethical approval from the Hunter New England Human Research Ethics Committee (ref. 17/09/20/4.03). Informed Consent will be obtained from all participants in Phase One. Participation in the survey implies consent for Phase Two and Three.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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CHAPTER 5: PHASE ONE RESULTS

PAPER 5: Ang, S. G. M., O'Brien, A. P., & Wilson, A. (2018). Understanding carers' fall concern and their management of fall risk among older people at home. *BMC Geriatrics*, 19:144. doi: https://doi.org/10.1186/s12877-019-1162-7

5.1 Overview

This chapter consists of Paper 5, which presents the findings for Phase One of the study. A descriptive qualitative design was used to explore the factors influencing the fall concern of carers and their management of fall risk at home. Twenty-two carers from two research registers and a large tertiary hospital were recruited and interviewed face-to-face, or by telephone. An inductive content analysis of the interviews revealed that carers' fall concern was affected by: 1) the carers' perception of fall and fall risk, 2) care recipients' behaviour and attitude towards fall risk, 3) care recipients' health and function, and 4) their living environment. Carers used different strategies to prevent their care recipients from falling depending on their level of fall prevention knowledge, physical ability, and availability of support. This study was conducted between October 2017 and February 2018.

5.2 Paper 5

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BMC Geriatrics

RESEARCH ARTICLE

Open Access

Understanding carers' fall concern and their management of fall risk among older people at home



Seng Giap Marcus Ang^{*} , Anthony Paul O'Brien and Amanda Wilson

Abstract

Background: Many older people (care recipients) experience long-term psychological distress due to the fear of falling again. Falls can affect carers due to concerns about their care recipients falling. Understanding carers' fall concern is crucial to determine if carers are coping with the provision of care or have adequate knowledge and support in preventing their care recipients from falling at home.

Methods: A descriptive qualitative study was conducted to explore carers' concern about their care recipients being at risk of falling and their management of fall risk at home. Twenty-two carers were recruited from two research registers and a large tertiary hospital in a regional centre of Australia. Carers were interviewed face-to-face, or by telephone using a semi-structured interview guide about their fall concern. The data was analysed using an inductive content analysis method.

Results: Eight major themes emerged from the interviews. Four themes described key factors influencing carers' fall concern which include: 1) carers' perception of fall and fall risk, 2) care recipients' behaviour and attitude towards fall risk, 3) care recipients' health and function, and 4) care recipients' living environment. Another four themes described the management of care recipients' fall risk which include: 5) fall prevention strategies used, 6) risk of preventing falls, 7) support from family and friends, and 8) support from healthcare professionals.

Conclusions: The findings from this qualitative study provide an insight into the carers' awareness of fall risk, knowledge, and the availability of support in preventing their care recipients from falling at home. Healthcare professionals are encouraged to include carers and address their fall concern to improve fall prevention programmes for care recipients at risk of falling at home.

Keywords: Carer, Older people, Fall concern, Fall risk, Fear of falling, Qualitative research

Background

Falls are a serious problem among older people which result in injuries, deaths, and long-term psychological consequences [1]. Globally, 28 to 35% of people aged 65 and above fall each year with the rate of falls increasing with age and frailty [2]. There were 98,704 older people hospitalised for injuries sustained by falling in Australia between 2012 and 2013; an increase of 24,000 cases over 10 years [3]. A common complication of a fall is the fear of falling again, which affects between 3 and 85% of the older people [4]. This psychological concern about

falling can pose a significant threat to an older person's autonomy resulting in self-imposed activity restriction and a loss of confidence in their ability to ambulate safely [5].

Like older people (care recipients), falls can also affect their carers [6]. Previous research has highlighted that after a fall has occurred, most carers experience increased concern about their care recipients falling again [7, 8]. This concern is significantly associated with increased psychological distress, social restriction, and caregiving burden among carers [8–11]. Concerns about their care recipients falling have resulted in many carers adopting various strategies to prevent falls, including, increased vigilance and not leaving them alone at home

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[12–15]. However, such approaches often lead to carers not having enough time for themselves, or to fulfil other social and work duties.

Carers are an essential part of the caring support network for older people which enables them stay at home longer, delaying institutional care if they (older people) should deteriorate with their physical health [11]. Previous fall prevention programmes that included carers have found significant improvement in fall risk awareness and knowledge among cancer patients at risk of falling [16], and better balance and fall efficacy among older people living with dementia [17]. However, carers who are overly supportive and prevent their care recipients from engaging in their daily activities, can inadvertently increase care recipients' dependence [18]. Such outcomes have been attributed to the loss of confidence in their care recipients' balance, and the need to constantly provide assistance to the care recipients in their daily activities also restrict carers from participating in their personal or social activities [18].

Carers are closely involved in the care of older people and are important for the successful implementation of fall prevention strategies at home. However, there is no published research on the perceived impact of fall risk among older people (with and without falls) on carers. Previous qualitative studies of carers' perspectives have focused on care recipients who have fallen or diagnosed with medical conditions such as Parkinson's disease or cognitive impairment which places them at a higher risk of falling [12, 14, 15]. In addition, there is no evidence regarding the common fall prevention strategies used by carers looking after care recipients from the general population of older people.

The aims of this study were to explore 1) carers' concern for the risk of falling among care recipients, known as carers' fall concern, and 2) their management of fall risk at home. The outcomes of this study have implications for future improvements of fall prevention programmes targeting carers' fall concern, while reducing falls and fall risk of the care recipients living at home under their care. The findings from this study will facilitate healthcare professionals to assess how carers are coping with the provision of care and if they have appropriate access to support, or relevant knowledge in preventing their care recipients from falling at home.

Methods

Design

This study was conducted between October 2017 and February 2018. A descriptive qualitative design was applied because little is known about the topic of carers' fall concern [19]. The method of data collection and analysis in a descriptive qualitative study allows researchers to stay close to the data by presenting a

comprehensive summary of everyday events using simple language to increase agreement among researchers and carers [20].

Participants

Participants were recruited from three study sites: 1) Hunter Medical Research Institute (HMRI) (research register and Facebook Page), 2) Carers New South Wales (Carers NSW) (membership register), and 3) the Rheumatology outpatient clinic at a large regional teaching hospital in NSW. The study sites provided access to carers living in metropolitan and regional New South Wales, Australia [21]. At HMRI and Carers NSW, study invitations were sent to the registry members by the research coordinators. Participants who were keen to participate responded to the HMRI coordinator by completing a study response form containing their contact information, which was then forwarded to the researchers for contacting purposes. Other interested participants who received study information from the HMRI Facebook page or Carers NSW contacted the researchers directly regarding their interest. In the outpatient clinic, the rheumatology nurses assisted with distributing the study flyers to carers who had accompanied their family members for follow-up appointments. Interested participants could either contact the researchers directly or approach the nurses who would then refer them to one of the researchers.

The inclusion criteria consisted of people currently providing care for a family member or friend aged 60 years and over and living at home. The carer did not have to live with the care recipient, however participants who were aged below 18 years old, or working as professional or paid carers were excluded. As the study intended to explore the fall concern of the general population of carers, the recruitment was not restricted to carers looking after care recipients with an increased risk of falling. In addition, carers of care recipients with and without the use of professional support services were also included. The study was approved by the Hunter New England Health Human Research Ethics Committee [17/09/20/4.03]. All participants were provided with the study details and written consent was taken before the interview.

Twenty-two participants were recruited using purposive sampling, which involved a deliberate selection of participants to obtain a complete understanding of carers' fall concern [19]. The carers differed in terms of age, gender, and the care recipients' frequency of falls and severity of injury sustained. These factors have been associated with older people's fear of falling which could potentially affect carers' fall concern [5]. The relationship between carer and care recipient was also considered as the type of caregiving relationship, such as carers

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caring for their spouses versus carers caring for their parents may affect the fall prevention strategies used [22]. The recruitment continued until no new themes were emerging from the qualitative data.

Data collection

Face-to-face or telephone interviews were conducted using a semi-structured interview guide by one researcher (MA, first author) who was a registered nurse with experience in caring for older people. The face-toface interviews occurred at a convenient and quiet place, such as an unused office, or quiet area close to the outpatient department. The option of telephone interview was provided to encourage participation from carers who were unable to leave their care recipients alone at home because they were afraid of their care recipients falling when unsupervised. Examples of the interview questions were: 1) can you tell me about your concerns caring for your family member and their risk of falling, 2) what helps you care for a family member/friend at risk of falling, 3) have you encountered any problems during your caring, 4) are there any risks in preventing your family member/friend from falling, and 5) have you received any advice, or support regarding fall prevention and from whom? Socio-demographic details such as age, relationship to the care recipient, time spent caring and the care recipients' number of falls in the last 12 months were also collected.

As agreed by the carers, the interviews were audiorecorded. The researcher avoided interrupting the carers to allow them to speak freely about their concerns regarding their care recipient's fall risk. However, the researcher would lead the carers back to the subject if they deviated from the topic, for example sharing only about the general caregiving burden. Sometimes, the questions were repeated, and probes were used to gain more insight or to find out if the carers understood what was being asked. The interviews lasted between 10 and 30 min.

Data analysis

The audio-recorded interviews were transcribed verbatim and analysed by the first author MA using inductive content analysis [23]. Before the analysis, the transcripts were reviewed and verified against the audio recordings. The researcher first immersed himself in the data by reading the transcripts several times [24]. Codes describing content related to the study aims and interview questions were written in the transcripts during open coding [25]. These codes were transferred to the coding sheets and grouped to form categories. Similar categories were further combined to form higher order categories/ themes [24]. The first author met with two senior researchers (OB and AW) in the team every 2 weeks to review and refine the codes and themes formulated from

the transcripts. The codes and themes were revised continuously as the study progressed to ensure that they fit the study data and addressed the study aims. After the interviews were completed, all transcripts were recoded using the final coding scheme. Summaries of the themes and sub-themes are illustrated in Tables 1 and 2.

Trustworthiness of the study findings was ensured following four criteria suggested by Lincoln and Guba which include credibility, transferability, dependability, and confirmability [26]. Confidence in the truth of study findings known as credibility was ensured by having two researchers (OB and AW) independently reviewing the congruence between selected content and themes generated. Any disagreement in the themes was discussed among the three researchers to reach consensus. Transferability, which refers to the applicability of study findings to other settings was determined by providing a detailed description of carers' account for each theme and recruiting participants of different socio-demographic and caring relationships [25]. Dependability, which refers to stability of the findings was ensured by keeping an audit trail of the audio recordings, interview transcripts, coding sheets, and socio-demographic questionnaires to keep track of coding decisions and changes made to the codes during analysis [25]. To maintain objectivity of the findings known as confirmability, only carers willing to share about their concerns were recruited and the data were critically analysed by all three researchers.

Results

The socio-demographic details of the carers are presented in Table 3. Of the 22 carers, 16 were females and 6 were males. Twelve were caring for their spouses, nine were caring for their parents, and one cared for a friend. The mean age of carers was 68 years (55 to 88) and care recipients was 81 years (61 to 99). The average length of caring was 7 years. Only eight carers had care recipients who had not fallen during the past year. Six carers reported that their care recipients sustained minor injuries, while six had sustained severe injuries, such as fractures, from the falls. Two care recipients had not sustained any injury. The carers were numbered C1-22 in this study. From the data analysis, four themes highlighted the causes of carers' fall concern which include 1) carers' perception of fall and fall risk, 2) care recipients' behaviour and attitude towards fall risk, 3) care recipients' health and function, and 4) care recipients' living environment. Another four themes described the management of care recipients' fall risk which include 5) fall prevention strategies used, 6) risk of preventing falls, 7) support from family and friends, and 8) support from healthcare professionals.

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Table 1 Summary of themes and sub-themes (Causes of fall concern)

Example of related sentences/phrases	Codes	Sub-themes	Themes
'I guess I am always worried. She is always careful. I guess I am a bit worried that she may trip over a shoe or a floor mat' (C17)	Concern about care recipient's risk of fall	Possibility of fall	Carers' perception of fall and fall risk
'If he does fall, like you say like causing more damage to himselfbreaking bonesmaking them pain' (C15)	Concern about the consequence of fall	Consequence of fall	
'Just a few bruises and scraped knees. There was nothing major, so we were fine' (C14)	Little concern about minor injuries	Minor injuries	
'I don't worry much now because in the house he is using the walker…I feel that he's got more stability' (C4)	Confidence in care recipients' balance	Confidence in balance	
'If she wants to use it (the walker), she uses it. But I have told her if she had another fall, she will be going into care' (C7)	Non-compliant to walking aid	Not listening to carers' advice	Care recipients' behaviour and attitude towards fall risk
The biggest challenge is getting through to both, they shouldn't be lifting heavy weights' (C9)	Continued with risky activities	Taking risks	
'So, if I say things too often to her she gets cranky and says stop pushing her in doing things' (C16)	Upset with repeated reminders	Upset with repeated reminders	
'My biggest concern is her not realising that she is getting olderShe can't do things like she used to be able to do' (C7)	Unaware of fall risk	Unaware of fall risk	
'My husband has starting to get a bit slower in his actions and his memorydue to his Parkinson's disease' (C13)	Cognitive and functional decline	Cognitive and functional decline	Care recipients' health and function
Because she has arthritis in her knees and when she turns quickly her knees didn't sort of go with her and she fell' (C20)	Impaired gait and poor balance	Impaired gait and poor balance	
She is very good using her walker. Only that if she just gets up to answer the phonea little quick, she might fall' (C21)	Risk of falling when rushing to do things	Rushing to do things	
But our house is very flat now. Used to have a 2-storey house but luckily, we sold it last year. So, it's all flat' (C19)	Risk of falling when using the stairs	Presence of stairs	Care recipients' living environment
'He likes to just go out the street to get out of the house, I can't let him go on his own' (C10)	Risk of falling when going out alone	Going out alone	
I am only away for half an hour an hour, no problem. But any longerwe get a friend come in look after her' (C19)	Risk of falling when alone at home	Alone at home	
'Knowing that there is a close neighbour, it is very helpful because I think there's always another person around' (C9)	Feel reassured with support from neighbours	Support from neighbours	

Causes of fall concern

Theme 1: Carers' perception of fall and fall risk

The perception of fall and fall risk varied among carers regardless of whether their care recipients had fallen previously. Many carers were constantly worried about the possibility of their care recipients falling again. For example, one older male carer whose wife had fallen more than three times over the past year commented that 'You spend a lot of time worrying about where she is, if she is going to fall down the stairs, or fall in the shower...' (C3). Another female carer also expressed concerns for her mother's fall risk even though she had not fallen: 'I guess I am always worried. She is always

careful. I guess I am a bit worried that she may trip over a shoe or a floor mat' (C17).

A few carers were concerned about the consequences of the fall causing additional harm to their care recipients and bringing an end to their independent living. This concern was illustrated by one female carer looking after her husband: '...if he does fall, like you say like causing more damage to himself, with arthritis and everything like that, breaking bones, or making them worst, and making them pain' (C15).

In contrast, few carers were unconcerned about their care recipients sustaining minor injuries such as bruises and abrasions from the fall. When asked about the care Ang et al. BMC Geriatrics (2019) 19:144 Page 5 of 12

Table 2 Summary of themes and sub-themes (Management of care recipients' fall risk)

to prevent. That's why I like to be around a lot more" (C18) To de telephone. Checking on her most of the days. I visit maybe three times a week" (C17) We really don't go out much and leave each other. We do go shopping together, we prepare the meals together" (C11) We have got raillings outside the house for the steps to prevent falling, in the house we had modifications to the shower" (C4) It happened so quickly. Out of the sudden she fell. It happened so quickly that you didn't have time to support her" (C2) I don't try to assist because I could be injured as well. You should just let them fall, if they are going to fall" (C4) We have friends who put up rails at front and back for us. With the steps, and they made the steps smaller" (C15) I's wear friends who put up rails at front and back or us. With the steps, and they made the steps smaller" (C10) When he had his first operation, the nurse in the emergency gave me a piece of paper with what to do if the falls over" (C6) We were advised by the hospital about how to break Advice on fall prevention Telephone to check on care recipient recipient Pleiphone to check on care recipient Calling the care recipient Doing things together reduce fall risk Doing things together recipient Doing things together recipient Doing things together recipient Doing things together recipient Doing things together reduce fall risk Telephone to check on care recipient reduce fall risk Doing things together reduce fall risk Doing things together reduce fall risk Doing things together reduce fall risk Telephone to the sudden she fell. Thome modifications Plan and of getting insk Plan and and some of physical limitation Pleon friends Supp				
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Visit maybe three times a week' (C17) recipient	to prevent. That's why I like to be around a lot	Being around care recipient	Increase supervision	Fall prevention strategies used
We do go shopping together, we prepare the meals together (C11) We have got railings outside the house for the steps to prevent falling. In the house we had modifications to the shower (C4) It happened so quickly. Out of the sudden she fell. It happened so quickly that you didn't have time to support her (C2) I don't try to assist because I could be injured as well. You should just let them fall, if they are going to fall' (C4) My daughter and some of the grandchildren, they help out at times. Especially with the yard and the bigger jobs' (C8) We have friends who put up rails at front and back for us. With the steps, and they made the steps smaller' (C15) It's very tiring for mewe have the kids always promising to come in and helpand they got their own life' (C10) When he had his first operation, the nurse in the emergency gave me a piece of paper with what to do if he falls over' (C5) As part of the rehabilitation, there was physiotherapist instruction on what to do to make sure you don't fall' (C6) We were advised by the hospital about how to break reduce fall risk Home modification falls Home modification Aware of physical limitation Aware of physical limitation Aware of physical limitation Aware of physical limitation Support from family friends Support from friends Support from friends Fall is unexpected Afraid of getting injured when help injured when helping Aware of physical limitation Aware of physical limitation Support from family friends Support from family friends Support from friends Fall is unexpected Area of getting injured when help injured when helping Support from family friends Support from family friends Support from friends Fall is unexpected Area of physical limitation Aware of physical limitation Aware of physical limitation Aware of physical limitation Fall is unexpected Area of physical limitation Aware of physical limitation Aware of physical limitation Aware of physical limitation Fall is unexpected Area of physical limitat			Calling the care recipient	
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happened so quickly that you didn't have time to support her' (C2) 'I don't try to assist because I could be injured as well. You should just let them fall, if they are going to fall' (C4) 'My daughter and some of the grandchildren, they help out at times. Especially with the yard and the bigger jobs' (C8) We have friends who put up rails at front and back for us. With the steps, and they made the steps smaller' (C15) 'It's very tiring for mewe have the kids always promising to come in and helpand they got their own life' (C10) When he had his first operation, the nurse in the emergency gave me a piece of paper with what to do if he falls over' (C5) 'As part of the rehabilitation, there was physiotherapist to do if all' (C6) We were advised by the hospital about how to break Afraid of getting injured when help as Advice on fall prevention Aware of physical limitation Support from family a friends Support from family and friends Support from family and friends Support from friends Support from friends Support from friends Support from healther professionals	to prevent falling. In the house we had modifications		Home modification	
well. You should just let them fall, if they are going to fall' (C4) 'My daughter and some of the grandchildren, they help out at times. Especially with the yard and the bigger jobs' (C8) We have friends who put up rails at front and back for us. With the steps, and they made the steps smaller' (C15) 'It's very tiring for mewe have the kids always promising to come in and helpand they got their own life' (C10) When he had his first operation, the nurse in the emergency gave me a piece of paper with what to do if he falls over' (C5) 'As part of the rehabilitation, there was physiotherapist instruction on what to do to make sure you don't fall' (C6) We were advised by the hospital about how to break helping Help in manual activities by family members Support from family a friends Support from friends Support from friends Support from friends Support from family a friends	happened so quickly that you didn't have time to	Fall is unexpected	Did not encounter such risk	Risk of preventing falls
help out at times. Especially with the yard and the bigger jobs' (C8) We have friends who put up rails at front and back for us. With the steps, and they made the steps smaller' (C15) It's very tiring for mewe have the kids always promising to come in and helpand they got their own life' (C10) When he had his first operation, the nurse in the emergency gave me a piece of paper with what to do if he falls over' (C5) As part of the rehabilitation, there was physiotherapist instruction on what to do to make sure you don't fall' (C6) We were advised by the hospital about how to break Mome modifications by friends Support from friends Lack of support Lack of support Lack of support Information on fall prevention professionals Support from healthcore professionals Support from allied healthcare professionals Support from allied healthcare professionals	well. You should just let them fall, if they are		Aware of physical limitation	
for us. With the steps, and they made the steps smaller' (C15) 'It's very tiring for mewe have the kids always promising to come in and helpand they got their own life' (C10) 'When he had his first operation, the nurse in the emergency gave me a piece of paper with what to do if he falls over' (C5) 'As part of the rehabilitation, there was physiotherapist instruction on what to do to make sure you don't fall' (C6) 'We were advised by the hospital about how to break Lack of support Lack of support Information on fall prevention prevention Support from healthcore professionals Support from allied healthcare professionals Advice on fall prevention Received support only after	help out at times. Especially with the yard and the		Support from family	Support from family and friends
promising to come in and helpand they got their own life' (C10) When he had his first operation, the nurse in the emergency gave me a piece of paper with what to do if he falls over' (C5) 'As part of the rehabilitation, there was physiotherapist instruction on what to do to make sure you don't fall' (C6) We were advised by the hospital about how to break Given brochure on fall prevention allied healthcare professionals Support from healthcare professionals Support from allied healthcare professionals Received support only after	for us. With the steps, and they made the steps	Home modifications by friends	Support from friends	
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instruction on what to do to make sure you don't fall' (CG) We were advised by the hospital about how to break Advice on fall prevention Received support only after	emergency gave me a piece of paper with what		Information on fall prevention	Support from healthcare professionals
	instruction on what to do to make sure you			
X. Y. S.	We were advised by the hospital about how to break the fallAnyway, these were only after the fall' (C2)			

recipient's fall injuries, one female carer looking after her mother, who had sustained more than three falls in the past 1 year, replied that: '...just a few bruises and scraped knees. There was nothing major, so we were fine' (C14). Many carers believed that their care recipients had a low risk of falling because they had employed paid home carers to assist them in their daily activities or with the household chores. The majority of carers highlighted that the presence of assistive devices such as walkers, shower chairs, and grab bars gave them confidence in helping with their care recipients' balance. For instance, one older female spouse carer said that: 'I don't worry much now because in the house he is using the walker and he walks around he uses that all the time now. And when we go out shopping, he has another walker that he uses. So, I feel that he's got more stability' (C4). Another female spouse carer (81 years old) said that: 'When he (her husband) is walking with his walker, he is very good. But if he holds onto the furniture and tries to walk, he could fall over then' (C5).

Theme 2: care recipients' behaviour and attitude towards fall risk

Theme 2 describes carers' perception of their care recipients' fall risk including actions which may increase carers' fall concern. Carers, especially those looking after their parents said they had difficulty communicating fall risk to their care recipients. Several carers were concerned about the care recipients not listening to their fall prevention advice. This often resulted in feelings of frustration, stress, and helplessness. For example, one female carer, whose mother had sustained a fracture from her recent fall, commented that: 'She should look after herself. If she wants to use it (the walker), she uses it. But I have told her if she had another fall, she will be going into care (institutional care) or I won't be caring for her shoulder. She will hopefully use the walker' (C7). Another female carer said that her parents refused to seek help when needed and continued with activities against advice, which put them at increased risk of falling: 'The biggest challenge is getting through to both,

Table 3 Socio-demographic details of Carers

Carrer Age range Gender Marital status Employment status Relationship to CR Living with CR Time spent Age range Gender 1 70–79 Female married not working spouse yes 5–9 70–79 female 8 3 70–79 Male married not working spouse yes 5–9 70–79 female 8 4 70–79 Female married not working spouse yes 0–4 80–89 female 9 50–69 Female married not working spouse yes 0–4 80–89 female 1 50–69 Female married not working spouse yes 0–4 80–89 female 1 6 50–69 Female married not working spouse yes 0–4 80–89 female 1 60–69 Female married not working spouse yes<	Interview	Carer ii	Carer information							Care recipient (CR) information	nt (CR) infor	mation	
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3 70–79 Male married not working spouse yes 5–9 70–79 female 4 70–79 Female married not working spouse yes 5–9 80–89 male 5 80–89 Female married not working spouse yes 0–4 80–89 male 7 50–59 Female married not working children no 7–7 6–69 female male 10 60–69 Female married not working spouse yes 0–4 80–89 male 11 80–89 Female married not working spouse yes 0–4 80–89 male 11 80–89 Female married not working spouse yes 0–4 80–89 male 12 70–79 Female married not working spouse yes 0–4 80–89 female	Telephone	2	69-09	Male	married	not working	spouse	yes	0-4	69-09	female	-	severe injury
4 70–79 Female married not working spouse yes 5–9 80–89 male 5 80–89 Female married not working spouse yes 0-4 80–89 male 7 70–79 Male married not working children no 210 70–79 female 8 80–89 Female married not working children no 0-4 80–89 female 10 60–69 Female married not working spouse yes 0-4 80–89 female 11 80–89 Female married not working spouse yes 0-4 90–99 female 12 70–79 Male divorced not working spouse yes 0-4 90–99 female 13 70–79 Female married not working spouse yes 0-4 90–99 female 14 60–69 <td< td=""><td>Face-to-face</td><td>3</td><td>70-79</td><td>Male</td><td>married</td><td>not working</td><td>spouse</td><td>yes</td><td>5-9</td><td>70–79</td><td>female</td><td>KI N</td><td>minor injury</td></td<>	Face-to-face	3	70-79	Male	married	not working	spouse	yes	5-9	70–79	female	KI N	minor injury
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12 70–79 Male divorced not working friend no 60–69 female 13 70–79 Female married not working spouse yes 5–9 80–89 male 14 60–69 Female divorced not working children no 5–9 80–89 female 15 60–69 Female divorced casual children no 5–9 80–89 female 17 50–59 Female Naver married part-time children no 0–4 80–89 female 18 50–59 Female not working spouse yes 0–4 80–89 female 19 70–79 Male married not working spouse yes 0–4 80–89 female 20 60–69 Female not working part-time children no 5–9 90–99 female 21 60–69 F	Telephone	1	80-89	Female	married	not working	spouse	yes	>10	68-08	male	0	no injury
13 70–79 Female matried not working spouse yes 5–9 80–89 male 14 60–69 Female divorced not working children no 0–4 90–99 female 15 60–69 Female divorced casual children no 5–9 80–89 female 17 50–59 Female married part-time children no 0–4 80–89 female 18 50–59 Female Naver married casual children no 0–4 80–89 female 18 70–79 Male married not working spouse yes 0–4 70–79 female 20 60–69 Female Never married part-time children no 5–9 90–99 female 21 60–69 Female Never married full-time children no 5–9 90–99 female	Telephone	12	70–79	Male	divorced	not working	friend	no	0-4	69-09	female	0	no injury
14 60–69 Female not working children not working children not working children not working spouse yes 210 60–69 female 15 50–59 Female divorced casual children no 5–9 80–89 female 18 50–59 Female not working spouse yes 0–4 80–89 female 19 70–79 Male married not working spouse yes 0–4 70–79 female 20 60–69 Female not working spouse yes 0–4 70–79 female 21 60–69 Female Never married full-time children no 5–9 90–99 female 22 60–69 Female Never married full-time children yes 5–9 90–99 male	Telephone	13	70-79	Female	married	not working	spouse	yes	5-9	80-89	male	0	no injury
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17 50–59 Female married part-time children no 5–9 80–89 female 18 50–59 Female Never married casual children no 0–4 70–79 female 20 60–69 Female married part-time children no 5–9 90–99 female 21 60–69 Female Never married full-time children ves 5–9 90–99 male	Telephone	16	50-59	Female	divorced	casual	children	no	5-9	80-89	female	0	no injury
18 50–59 Female Never married casual children no 0–4 80–89 female 19 70–79 Male married not working spouse yes 0–4 70–79 female 20 60–69 Female married part-time children no 5–9 90–99 female 21 60–69 Female Never married full-time children yes 5–9 90–99 male	Face-to-face	17	50-59	Female	married	part-time	children	no	5-9	68-08	female	0	no injury
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20 60–69 Female married part-time children no ≥10 90–99 female 21 60–69 Male Never married part-time children s-9 90–99 female 22 60–69 Female Never married full-time children yes 5–9 90–99 male	Face-to-face	19	70–79	Male	married	not working	spouse	yes	0-4	70-79	female	-	severe injury
21 60–69 Male Never married part-time children no 5–9 90–99 female 22 60–69 Female Never married full-time children yes 5–9 90–99 male	Telephone	70	69-09	Female	married	part-time	children	no	>10	66-06	female	-	severe injury
22 60–69 Female Never married full-time children yes 5–9 90–99 male	Telephone	21	69-09	Male	Never married	part-time	children	no	5-9	66-06	female	0	no injury
	Telephone	22	69-09	Female	Never married	full-time	children	yes	5-9	66-06	male	<u>K</u>	minor injury

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they shouldn't be lifting heavy weights. Mum chops wood sometimes and getting up on ladders' (C9). Only one female spouse carer (C10) discussed about the difficulty of communicating fall risk to her husband. Instead, the majority of carers of spouses had concerns related to their care recipients' health and functional status, and environmental risk factors.

In some cases when the care recipients were repeatedly reminded about their fall risk, they became upset and felt that their carers were trying to control them. One female carer looking after her mother (85 years old) said that: 'So if I say things too often to her, oh what about doing this? What about doing that? Then she gets cranky and says stop pushing her in doing things' (C16). There were several reasons suggested by carers about why the care recipients would not adhere to their fall prevention advice. Some carers believed that the care recipients were aware of their fall risk but resisted acknowledging their physical limitations by being dependent. This was explained by the previous carer that: 'I think it's the dignity thing that they still want their independence but it's disappearing on them because of age and some of them can't accept it where others their age accept it' (C16). Another female carer felt her mother (79 years old) was unaware of her fall risk and therefore did not take any measures to protect herself: '...my biggest concern is her not realising that she is getting older. I must keep reminding her she is getting older. She can't do things like she used to be able to do then' (C7).

Theme 3: care recipients' health and function

The care recipients' cognitive and functional decline leading to an increased risk of falling was highlighted when carers discussed fall concern. This was often associated with issues of ageing, or other pre-medical conditions, such as dementia and Parkinson's disease. For example, one older female carer (C13) noticed that her husband (84 years old) had started to 'get a bit slower' in his actions and memory due to his Parkinson's disease. A younger female carer (C16), was extremely concerned about her mother (85 years old) falling, as she realised that her mother was starting to lose her memory and would forget what she was saying, or supposed to be doing. One female carer, looking after her mother (99 years old), described the issue of cognitive decline as unavoidable and likely to worsen over time: 'I think that will pretty go on for as long as she lives because she just forgets, forgets more with some things' (C14).

Impaired gait and poor balance were emphasised by several carers when talking about their care recipients' fall risk. In some instances, it was also the main reason for the fall. One female carer, who was looking after her mother (92 years old), described an event that: 'She

turned quickly and her knees kind of didn't because she has arthritis in her knees and when she turns quickly her knees didn't sort of go with her and she fell broke her hip' (C20).

Furthermore, a few daily activities such as showering, getting up from bed, or a chair, and using the stairs, were highlighted by carers as potential risks in causing a fall. This prompted carers to try to supervise and assist their care recipients in these activities. There were also concerns that the care recipients rushed to do things, or forgot to use their walking aid, especially when carers were not around to remind them, resulting in a fall. One male participant caring for his mother commented that: 'She is very good using her walker, which is, you know is great. Only that if she just gets up to answer the phone, or something and is a little quick, that's all, that she might fall in her unit' (C21).

Besides increasing carers' fall concern, the issue of the care recipients' health and function may affect the overall caregiving process and level of support required. This was illustrated in one female carer's account: 'Since mum has dementia, I have become more involved with her care. I don't just think of her risk of falling, but I actually think of everything else and that she's safe' (C18).

Theme 4: care recipients' living environment

Several carers discussed concern regarding their care recipients using stairs and falling at home. This concern was often associated with the care recipients' health issues such as syncope or functional decline. One female carer mentioned that: 'if she (her mother) is going to have another one of these episodes where she blacks out a little bit, if she is going to be going down the stairs, that's a big risk and there is no hand rails' (C16). A few carers also expressed relief that there were no stairs at home, especially after their care recipients had sustained an injury from a fall. One older male carer whose wife had broken her hip from a fall said that: 'But our house is very flat now. Used to have a 2-storey house but luckily, we sold it last year. So, it's all flat' (C19). Other concerns expressed by carers included tripping over uneven floors, or objects, walking on a slope, or a wet surface. This was highlighted in one female carer's account: 'my bathroom is lower than the floor. About a good 6 inches lower than the floor. So, you're not only stepping into a bath, you step into a drop (C10)'.

The concerns about care recipients falling outside the home were similar to those in the home. Nevertheless, these outdoor concerns were often considered inevitable and difficult to control. For example, one female carer whose mother (92 years old) was living alone said that: 'we have taken all the precaution we need to, like removing mats and making the house as safe as possible. But there's probably not a lot we can do especially when she

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is going out of the house and unless she avoids using the steps at all' (C20). A few carers were even reluctant to let their care recipients to go out alone. For instance, one female carer whose husband had fallen twice last year added that: 'I won't put him alone no, and I won't let him go anywhere on his own, no. Like if he wants to go. He likes to just go out the street to get out of the house, I can't let him go on his own' (C10).

Many carers expressed concern about their care recipients falling when alone at home. A few carers would only leave their care recipients alone for a short period of time or get someone else to look after them. Others could not leave their care recipients alone at all. For carers who were not living with their care recipients, many were reassured that they are living near to them, or their care recipients have had neighbours to look out for them. This was highlighted by one female carer who was looking after her mother: 'Knowing that there is a close neighbour, it is very helpful because I think there's always another person around' (C9).

Management of care recipients' fall risk Theme 5: fall prevention strategies used

Carers identified various strategies to prevent their care recipients from falling which included increasing supervision, assisting with daily activities, providing support during mobility, or encouraging physical activity. Close monitoring of the care recipients was the most commonly used method in situations such as making sure that they use their walking aid and being around when they shower. For example, one female carer chose to spend more time with her mother who was suffering from dementia because of the lack of fall prevention knowledge: 'Maybe I don't know everything that could be done, to prevent. That's why I like to be around a lot more' (C18).

Most carers regularly called to check on their care recipients if they were not living with them. For example, one female carer said that: 'I do telephone. Checking on her (her mother) most of the days. I visit maybe three times a week and that will generally include an outing, we go out like the social occasion, coffee or lunch' (C17) . Another female carer looking after her father with mobility impairment also said that: 'I ring him several times a day to make sure he's okay' (C22). Additionally, one female carer (C16) had encouraged her mother with an impaired gait to carry a phone with her at home, just in case she fell and needed to call someone. A majority of carers also mentioned helping out with the difficult chores such as preparing meals, doing grocery shopping, cleaning the house, and doing laundry in an effort to reduce the fall risk of their care recipients.

Several carers, who were looking after their spouses, were at risk of falling themselves. This group described

strategies such as looking out for each other's risk, planning and doing things together. For instance, one older female spouse carer said that: '...we really don't go out much and leave each other. We do go shopping together, we prepare the meals together, and we do the dishes together. So, we were 85% of the time we were in our own home' (C11). However, regardless of the caring relationship, the majority of carers discussed about making changes to the environment to prevent their care recipients from falling. This included installing handrails, replacing the bathtub with a shower, levelling the floor, and removing of carpets or mats. This was highlighted in one female spouse carer's account: '...we have got railings outside the house for the steps to prevent falling. In the house we had modifications to the shower and railings in the shower' (C4).

Theme 6: risk of preventing falls

When asked about the risks of preventing their care recipients from falling, only one carer (C1) mentioned sustaining an injury (i.e. sprain) while trying to assist her husband get up from the fall. Most carers claimed they had not encountered this problem. For example, one younger male spouse carer mentioned that: 'It happened so quickly. Out of the sudden she fell. It happened so quickly that you didn't have time to support her or anything like that' (C2). A few carers were aware of their physical limitation and the risk of sustaining an injury when assisting their care recipients during the fall. For instance, one older female spouse carer said that: 'I don't think he would be able to get up on his own. I don't try to assist because I could be injured as well. You should just let them fall, if they are going to fall' (C4). Another female carer who was looking after her mother when the fall occurred said that: 'I can't hold her if she falls. I think there was one fall which I was holding onto her arm. I had to let go because when she fell, it was dead weight and I would have landed on top of her' (C14).

Theme 7: support from family and friends

Several carers received support from their family and friends in fall prevention, which included assistance in activities requiring manual handling, monitoring of care recipients, and home modification. As previously mentioned, some older spouse carers were also at risk of falling due to functional decline and increasing age. Support in undertaking complex activities may help these older carers better manage their care, minimise the risk of falling for both carers and their care recipients, and alleviate their fall concern. For example, one female spouse carer said that: 'My daughter and some of the grandchildren, they help out at times. Especially with the yard and the bigger jobs' (C8). Another female carer looking after her mother mentioned that: 'Since the fall,

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I visit my mother every day, my sister does some nights, my niece does some nights, and another niece does some nights' (C14). One female spouse carer (C15) said that her friends came to install hand rails and modify the stairs (made smaller steps) in her house. This support helped mitigate her disappointment with the delay in professional help from the hospital and community disability services.

In contrast, some carers expressed frustration with the lack of support from their family members in the general provision of care and activities which may be beyond the physical limitation of carers and were potential falling risks. For example, one female spouse carer (67 years old) said that: 'It's very tiring for me. So, it's a bit of everything. He doesn't listen, we have the kids always promising to come in and help, mow the lawn, and things like that, and they got their own life' (C10). Similarly, another younger female carer looking after her mother also said that: 'My sister and her children sometimes visit. But they just go and have a chit chat and leave, while I used to spend the whole day there and do stuff' (C16).

Theme 8: support from healthcare professionals

The majority of carers did not receive any fall prevention information from healthcare professionals. Among those who had received advice on the management of their care recipients' fall risks, information was delivered in the form of brochures provided by nurses in the hospital. For example, one older female spouse carer said: 'When he had his first operation, the nurse in the emergency took me into a quiet room and she gave me a piece of paper with what to do if he falls over and what to do if he's disoriented. That was very helpful' (C5). A few carers also reported that their care recipients had received services from occupational therapists for home assessment and modification, and physiotherapists for body strengthening exercises to prevent falls. For instance, one male spouse carer said that: 'As part of the rehabilitation, there was physiotherapist instruction on what to do and how to look after yourself and what muscles to build up to make sure you don't fall' (C6).

While the majority of carers who had received advice and support on fall prevention from healthcare professionals were satisfied with these services, one male carer whose wife had sustained multiple fractures from a fall felt that this advice had come too late: 'We were advised by the hospital about how to break the fall if things like that were to happen again, like if it is possible. Anyway, these were only after the fall' (C2). He added that: 'My wife, prior the hospitalisation only had two falls. She had talked to the doctor about it. The doctor said well that happens when you get old. That wasn't very good advice'. Another female carer (C17) wanted to know more

about fall prevention but did not know who to seek advice from since her mother has not fallen.

Discussion

This study explores the complex relationship between carers and their concerns for their older care recipients who were at risk of falling at home. The findings contribute to the literature in two major ways. First, the study reveals four main themes contributing to carers' fall concern, which include carers' perception of fall and fall risk, care recipients' behaviour and attitude towards fall risk, their health and function, and living environment. Second, the findings highlight the carers' level of knowledge and strategies used in preventing their care recipients from falling. Since carers such as family members and friends are often the main support person for older people at home, these findings could create the potential for collaboration between healthcare providers and carers to develop a comprehensive fall prevention programme tailoring to both the care recipients and their carers.

A systematic review and meta-analysis of exercise interventions found that exercises including Tai Chi, yoga, balance training, strength and resistance training have only small to moderate short-term effect in reducing fear of falling among older people, but no significant longterm effect [27]. Therefore, the inclusion of carers in fall prevention programmes; improving their understanding of fear of falling and providing strategies to appropriately support their care recipients, could potentially reduce care recipients' fear of falling and maintain this effect over time. This hypothesis is supported by a study where care recipients reported greater satisfaction in managing the fear of falling, especially when strategies to minimise their fall risk and fear of falling were supported by family members [28]. These strategies included providing instrumental support such as installing handrails and obtaining assistive devices to increase their independence, or emotional support such as discussing fall concern with the care recipients. Another study found that care recipients with lower social support demonstrated significant increase in falls self-efficacy after a fall prevention programme (including group exercises) and at 5-months follow-up [29].

The findings from this study provide an understanding of how carers see potential contributory factors to the risk of their care recipients falling at home. Previous research shows carers of fallers are concerned about the likelihood of their care recipients falling again [8, 9, 12, 14]. This study shows that carers of non-fallers are equally concerned about the risk of their care recipients falling. Moreover, carers' concern for their care recipients' risk of falling is not only due to ageing and intrinsic factors such as cognitive and functional decline,

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impaired gait, and poor balance [14]. Factors, such as the presence of stairs, the care recipients living alone, or support from neighbours can either increase or mitigate their concern.

A small group of carers in this study were not concerned about their care recipients sustaining minor injuries as a result of the falls. This finding corresponds with another study, which found that carers have little concern about their care recipients with Parkinson's disease falling, as it was accepted as part of the disease progression [30]. However, care recipients were at risk of entering long-term care if they sustained severe injuries from the falls. Therefore, it is important for healthcare professionals to assist carers in developing accurate appraisals of their care recipients' fall risk [31].

Another finding is the possible influence of the caring relationship on carers' fall concern and strategies used to prevent their care recipients from falling. As with other studies, carers reported difficulty communicating fall risk to their care recipients as they refused to follow carers' advice [14], walked without their walking aid [13, 32], and took risks by not seeking help [12]. This concern was mainly discussed by carers looking after their parents. It seems that carers in the child-parent relationship may have a greater disparity in appraisals of fall risk compared to those in spousal relationships. Carers who were looking after their spouses were about the same age and may have similar fall risk as their care recipients. Therefore, they could be unaware of their fall risk and were less likely to take appropriate measures to prevent their care recipients from falling.

In addition to differences in perceptions of fall concern among carers, the choice of fall prevention strategy also varied among carers who were looking after their parents and those looking after their spouses. Our study revealed that supervision in the form of close monitoring, regular visiting and contacting their care recipients by telephone are commonly used by female carers looking after their parents to prevent a fall. This finding is different from another study, which found that sons but not the daughters took on a more 'protective' role of supervision in preventing their mothers from falling [22]. The latter study also found that daughters were involved in working together with their parents to provide falls supervision. In contrast, the fall prevention strategies used by spouse carers in our study tended to be more collaborative, such as looking out for each other's fall risk and doing things together. The difference in fall prevention strategies used may be attributed to the power imbalance between carers and their care recipients, with younger carers having more control in the caring relationship. However, future research is needed to ascertain the difference in management of fall risk between spouse carers and those caring for their parents.

This study found that support from family and friends is important for carers to cope with the management of their care recipients' fall risk. However, not all carers had external support and some also did not have adequate knowledge about preventing falls. As found in other studies, the use of inappropriate strategies such as over-protection and increased supervision could lead to stress, exhaustion, and social isolation among carers [12-14]. These strategies may also increase the risk of care recipients falling. For example, calling the care recipients several times per day could be a fall risk if care recipients with mobility impairment try to answer the telephone. Therefore, it is important that carers are supported when implementing fall prevention strategies for their care recipients such as improving their awareness of fall risk and providing them with strategies to prevent falls.

Implications for practice

The increasing onus on carers for the implementation of sustainable fall prevention interventions at home [33] means it is important that healthcare professionals develop fall prevention programmes which are inclusive of carers. To date, fall prevention strategies are designed only for care recipients (older people) targeting falls [34] and their fear of falling [27]. An individualised approach for carers when implementing fall prevention strategies is recommended. This would mean identifying the impact of care recipients' fall risk on their carers and their management strategies in preventing care recipients from falling. Healthcare professionals could assist carers to recognise their care recipients' fall risk, provide counselling for fall concern, and discourage potentially harmful strategies such as increasing supervision or restricting outings. Positive strategies already in use, such as doing household chores together (with care recipients) and seeking help from family and friends should be reinforced. Future fall prevention programmes should also cater to carers whose care recipients have not fallen so that they are aware of their care recipients' risk of falling.

Regarding implications for research and practice, this study has generated a pool of measurable items which will be used to develop an instrument for assessing carers' fall concern. This instrument will allow healthcare professionals to better understand the impact of fall risk on carers and identify the association between fall concern and other psychological factors. For example, if anxiety and depression are

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associated with increased carers' fall concern, healthcare professionals need to be mindful of this during the assessment of care recipients' fall risk before developing an individualised fall prevention programme for carers and their care recipients. The multiple factors associated with carers' fall concern also highlights the need for a multidisciplinary team to manage the physical, psychological and social needs of carers and their care recipients when preventing falls at home.

Limitations

There are several limitations of this study. One of the limitations was the length of the interviews lasted only between 10 and 30 min. However, we stopped recruiting when no new themes emerged from the qualitative data. The study was conducted with a small sample of carers in one state of Australia and is not representative of the larger population of carers, such as those living in nearby Asia, or the rest of Australia. Nevertheless, it is likely that the findings would be common to other carers looking after older people at home. The use of telephone interviews prevents direct observation of carers' gestures and actions which could be used for comparison with the interview data during analysis to determine the accuracy of information shared [35]. Furthermore, the lack of prolonged engagement and personal contact in telephone interviews may also prevent the researcher from building trust and rapport with carers, which is important for obtaining meaningful information. However, we found that this option gave carers more flexibility to participate in the interview at a time of their convenience and allowing them to feel more relaxed and to share their private concerns freely [35].

The researcher who conducted the interviews was also involved in the data analysis. To ensure trustworthiness of the findings, investigator triangulation was achieved by the involvement of two other researchers (OB and AW) to validate the categories derived [26]. This study was motivated by the first author's experience of working with older people who were admitted to the hospital for recurrent falls and interaction with their anxious carers. His prior experience interviewing carers to develop discharge plans for their care recipients (older people) may strengthen his ability to probe in-depth about carers' concern. However, this experience may also affect the researcher's objective interpretation of the findings [36].

Conclusion

This study reveals that concern about care recipients at risk of falling may be attributed to four themes (i.e. carers' perception of fall and fall risk) involving carers and their care recipients. Different strategies were used for managing the care recipients' fall risk, and some carers had extra support from family and friends, or healthcare professionals in falls prevention. An individualised fall prevention programme catering to carers is encouraged in assisting carers to accurately identify their care recipients' fall risk, cope with fall concern, and implement strategies for preventing falls. This could potentially improve carers' confidence in managing their care recipients' fall risk and, potentially reduce the incidence of falling among older people, and allowing them to stay at home longer.

Abbreviations

Carers NSW: Carers New South Wales; HMRI: Hunter Medical Research Institute

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Authors' contributions

SGMA drafted and revised the manuscript. AOB and AW reviewed and revised the manuscript. All the authors read and approved the final manuscript.

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Availability of data and materials

The data generated during the current study are not available due to ethics requirement that the interview transcripts are to be kept in password protected files and accessible only by the researchers.

Ethics approval and consent to participate

The study protocol has received ethical approval from the Hunter New England Human Research Ethics Committee (ref. 17/09/20/4.03). Written informed consent was obtained from all participants before the interviews.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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CHAPTER 6: PHASE TWO RESULTS

PAPER 6: Ang, S. G. M., Wilson, A., & O'Brien, A. P. (2019). Developing the carers' fall concern instrument. Conference paper presented at 7th Annual Worldwide Nursing Conference 2019, Hotel Fort Canning, Singapore, 15-16 July 2019. Availability: http://dl4.globalstf.org/products-page/proceedings/wnc/developing-the-carers-fall-concern-instrument/

6.1 Overview

This chapter consists of Paper 6, which describes the steps of developing the initial Carers' Fall Concern Instrument (CFC-I). Forty-six items derived from the integrative review and qualitative interviews were used to construct the CFC-I. As with the qualitative findings, these items measure four domains that include: 1) carers' perception of fall and fall risk, 2) care recipients' behaviour and attitude towards fall risk, 3) care recipients' health and function, and 4) care recipients' living environment. Some questions from the Falls Efficacy Scale-International and the Fall-related Impulsive Behaviour Scale were modified and included in the CFC-I, as described in the following conference paper. Ten experts in aged care evaluated the items for content validity. The initial CFC-I was then modified as suggested by the experts and pilot tested on 32 carers. The revised CFC-I with 17 items retained provided an instrument with Cronbach's alpha coefficient of 0.94 and an average inter-item correlation of 0.50. This study was conducted between March 2018 and May 2018.

7th Annual Worldwide Nursing Conference (WNC 2019)

Developing the Carers' Fall Concern Instrument

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Abstract-This paper describes the development of the Carers' Fall Concern Instrument (CFC-I) which measures carers' concern about their older people (carees) at risk of falling. Carers play an important role in preventing falls at home and the risk of a caree falling can potentially affect the carers' physical and psychosocial health, burden of care, and complicate fall prevention strategies. Currently, there is no validated instrument to measure carers' fall concern. Step One in the development of the CFC-I was to identify factors contributing to carers' fall concern using evidence from an integrative literature review and semi-structured qualitative interview. Step Two involved constructing items and selecting an appropriate response format for measuring carers' fall concern. Step Three established the content validity of the CFC-I by an expert panel and Step Four examined the reliability of the CFC-I by piloting the new instrument with carers of older people living at home. Forty-six items were generated measuring four domains: carers' perception of fall and fall risk; carees' behaviour and attitude towards fall risk; carees' health and function; and, carees' living environment. Initial validation of the CFC-I revealed excellent content validity and reliability with an average-item content validity index of 0.82 and Cronbach's Alpha of 0.94.

Keywords-carer; older people; fall concern; fall risk; fear of falling

I. INTRODUCTION

In this study, the term caree describes an older person, aged 60 years and over, being cared for at home. The revised nomenclature related to care recipient serves to standardise the different terms used in the literature (such as, older person, elderly, family member, and loved one) [1]. Fear of falling can be a consequence of, or a risk factor for falling among carees [2]. Up to 85% of carees experience fear of falling [3] and this concern is often associated with increased psychological distress, activity restriction, and poorer quality of life [4]. Many carees with fear of falling also experience functional decline, increased fall risk, and risk early admission to long-term care [5-7].

There are several instruments available to measure carees' fear of falling, which have served as an important benchmark for the efficacy of fall prevention programmes [8]. These include the Falls Efficacy Scale (FES) [9], Activities-specific Balance Confidence Scale (ABC) [10], the Survey of Activities and Fear of Falling in Elderly (SAFE) [11], and the Falls Efficacy Scale-International (FES-I) [12]. These instruments have been validated on carees and do not take a family-centred approach in addressing the fall concern of carers [13]. Furthermore, the questions in these instruments are limited to

investigating activity restriction and the types of activities performed by carees [11].

Informal carers, such as family members and friends, are important in allowing carees to continue living at home by providing support in daily activities such as mobility, self-care (i.e. dressing, showering, and toileting) and communication [14]. Previous studies show that carers could assist their carees to implement strategies in reducing their fall risk and fear of falling [15, 16]. For example, carees seek help from their family members in regard to transport, household activities, home modification, or getting assistive devices to prevent falls and improve home safety. The inclusion of carers significantly improves the efficacy of fall prevention programmes by reducing fall incidence, increasing physical activity, and providing greater awareness of fall risk and prevention among carees [17-19].

A recent commentary in Singapore highlighted that carers experience similar fall concern to their carees [20]. After a fall, carers can experience increased stress, anxiety and depression related to the possibility of their carees falling again and sustaining an injury [21-24]. These concerns in turn affect carers' psychological wellbeing, lifestyle, quality of life, and burden of care [21, 24, 25].

Health care professionals need to better understand and acknowledge the impact of carees' risk of falling on carers. One way of achieving this is by quantifying carers' concern. Carers' fall concern has been previously measured using a single-item question, such as answering 'yes' or 'no' to whether the carer is worried about their carees falling, or using a Likert scale to identify their level of fall concern [22, 23, 26]. However, no study has reported on the psychometric properties of these single-item instruments used. Carers' fall concern appears to be a multi-dimensional construct which means the use of a single-item measurement may significantly underestimate prevalence [11]. A comprehensive measurement to assess carers' fall concern is important as it would provide deeper insight into carers' awareness of fall risk and their specific needs in preventing a fall. Therefore, interventions could be targeted to reduce the concern of carers and improve fall prevention efforts at home.

II. AIMS

The aims of this study were to identify the factors contributing to carers' fall concern and to test the initial validity and reliability of the Carers' Fall Concern Instrument (CFC-I) in measuring carers' concern of older people at risk of falling at home.

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III. METHODS

A. Design

This study was conducted between October 2017 and May 2018 and was approved by the local health district Human Research Ethics Committee (HREC) [17/09/20/4.03] and the University of Newcastle HREC. To ensure a reliable and valid instrument, the CFC-I was developed following the four-step guidelines by Davis [27]. Step One was to determine the factors which CFC-I measure using evidence from an integrative review and qualitative interview. Step Two focused on selecting items and responses. Step Three involved investigating the face and content validity of the items using an expert panel. The initial CFC-I was then modified and tested on 32 carers in Step Four.

B. Study Settings

In Step One, carers looking after older people from the general population were recruited from a local research institute volunteer register and a non-government state organisation for carers (membership list). Carers of carees who had sustained a fall resulting in a fracture were also recruited from the rheumatology outpatient clinic at a regional teaching hospital [1]. Carers were recruited from the same institutes during the testing of CFC-I in Step Four. Recruitment was extended to a regional rehabilitation day hospital for patients with a potential for functional improvement. These patients, who are usually referred by the hospitals, General Practitioners (GPs), Specialists, or Aged Care Assessment Teams, were enrolled in a day-only programme, Falls Clinic, or Parkinson's programme. The recruitment information was also published on the research and carers institutes' Facebook pages, websites, and newsletters.

Carers were eligible if they were aged 18 years and above and providing support for an older person living at home with at least one activity of daily living (ADL). The ADLs consisted of personal activities such as mobility, self-care, and communication, or instrumental activities, such as housekeeping, transportation, or meal preparation. Exclusion criteria were paid or professional carers and those looking after carees below 60 years of age.

IV. STEP ONE

A. Integrative Review

During Step One, an integrative review was conducted to identify the factors contributing to carers' fall concern and to search for any existing instruments measuring this concern [28]. The review defined carers' fall concern as the concern among carers about their carees at risk of falling. No multi-item screening instruments measuring carers' fall concern was found. In the studies reviewed, family carers were concerned about the possibility of their carees falling again, sustaining injuries, and being hospitalised as a result of a fall [29]. Some carers were concerned about the long-term impact of the fall, such as decreased functional ability, poorer quality of life and admission to long-term care [24, 30]. Few studies have reported on the concerns of carees' non-adherence to carers' fall prevention advice [24, 25, 29, 31]. Carers described this as

the carees' lack of awareness of their physical limitations, leading them to engage in dangerous activities, such as walking without an assistive device which increased their risk of falling.

B. Qualitative Interview

A qualitative interview was conducted with 22 carers to determine whether the factors described in the literature were similar to carers' actual concerns of falling [28]. The input from carers also helped to improve the usability and acceptability of the instrument being developed. The interviews were conducted face-to-face or by telephone using a semistructured interview guide. Carers were asked for their concerns about carees' risk of falling, strategies used to manage fall risk, and support received in fall prevention. Data were analysed using inductive content analysis which included open coding, forming sub-themes and themes, and abstraction [32].

Four themes were derived from the qualitative interviews regarding causes of carers' fall concern, including carers' perception of fall and fall risk, carees' behaviour and attitude towards fall risk, carees' health and function, and carees' living environment. Similar concerns were identified in both the review and the interviews. However, some carers were not overly concerned about their carees sustaining minor injuries. Other concerns included carees' cognitive and functional decline, risk of falling when performing daily activities, environmental hazards, and availability of support. The qualitative evidence suggested that fall concern affects carers of high fall risk older people, as well as those looking after the general population of older people.

V. STEP TWO

The initial CFC-I was developed using analysis and synthesis of the literature and qualitative findings. It comprised 46-items in four thematic domains (See Table 1). Items were generated using quotes from the interviews, applied short sentences, or words, and used only one issue or activity in each statement for consistency and clarity [33]. Carers were asked to indicate their level of concern about carees' risk of falling for each statement using a five-point Likert Scale: 'not at all concerned, slightly concerned, somewhat concerned, moderately concerned, and extremely concerned'. The number of response options were selected to increase variability for each item and a central point of 'somewhat concerned' was intended to discriminate between carers having high and low level of concerns [33].

Twelve items from the FES-I were modified for use in the carers' context to explore their concerns about carees' risk of falling when performing daily activities. With high internal and test-retest reliability (Cronbach's alpha = 0.96, intra-class coefficient = 0.96), the FES-I is the gold standard and most updated instrument for measuring an older person's fear of falling [12]. The FES-I contained 16 items assessing concern about physical activities at home and outside home on a four-point scale of '1' being not at all concerned and '4' being very concerned.

TABLE I. CONTENT VALIDITY INDEX FOR INDIVIDUAL ITEMS

Theme 1: Carers' Perception of Fall and Fall Risk	CVIa	Decision
Falling at home	1.0	Keep
Being at risk of falling	0.8	Keep
Falling again	0.6	Delete
4. Getting minor injuries (bruises/ grazes) from a fall	0.7	Delete
5. Getting severe injuries (breaking bones) from a fall	1.0	Keep
Not recovering from a fall	0.9	Keep
7. Requiring more care after a fall	0.8	Keep
8. Requiring more care than I can provide after a fall	0.9	Delete
Theme 2: Carees' Behaviour and Attitude towards Fall Risk		
Not taking my advice about fall risk	0.7	Keep
10. Being unconcerned of fall risk	0.8	Keep
11. Being unconcerned of own safety	0.7	Delete
12. Not seeking help about fall risk	0.7	Delete
13. Refusing to be assessed for fall risk	0.9	Keep
14. Refusing to have home checked for safety	0.9	Keep
15. Refusing to have home modified for safety	0.9	Keep
	-	
16. Refusing to go for rehabilitation	0.5	Keep
17. Forgets to use the walking aid (i.e. walker)	0.9	Keep
Theme 3: Carees' Health and Function		
18. Falling due to poor health	0.7	Delete
19. Falling due to old age	0.4	Delete
20. Falling due to pain occurring	0.7	Delete
21. Falling due to poor balance	0.9	Delete
22. Falling due to dizziness	0.9	Delete
23. Falling due to unsteady gait	0.9	Delete
24. Cleans the house (e.g. sweep, vacuum, dust) ^b	0.4	Keep
25. Gets dressed or undressed ^b	0.8	Keep
26. Prepares simple meals ^b	0.6	Keep
27. Takes a bath or shower ^b	1.0	Keep
28. Gets in and out of a chair ^b	1.0	Keep
29. Reaches for something above their head or on the ground ^b	0.7	Keep
 Goes to answer the telephone before it stops ringing^b 	0.7	Delete
31. Rushes to do things	0.7	Keep
Theme 4: Carees' Living Environment		
32. Goes up or down stairs ^b	1.0	Keep
33. Goes to the toilet at night	1.0	Keep
34. Being alone at home	1.0	Keep
35. Goes out alone	1.0	Keep
36. Walks on a slippery surfaces (e.g. wet or icy) ^b	0.6	Keep
37. Walks in a place with crowds ^b	0.7	Keep
38. Walks on an uneven surface (e.g. rocky ground,	0.7	Keep
poorly maintained pavement) ^b	0.7	кеер
39. Walks up or down a slope ^b	0.7	Keep
	1.0	
40. Nobody being there to help me if a fall occurs	-	Keep
 Hurting myself when helping my care recipient to get up from a fall 	0.9	Keep
	0.7	Keep
42. Not having enough knowledge to stop a fall		Delete
43. Not being with my care recipient when he/she	0.8	Defete
43. Not being with my care recipient when he/she needs me		
43. Not being with my care recipient when he/she	0.8 0.4 0.7	Delete Delete

a. CVI: Content Validity Index. b. Items from Falls Efficacy Scale-International (FES-I).

VI. STEP THREE

A. Content Validity

The initial 46-items CFC-I was evaluated by ten experts: three research fellows in nursing and physiotherapy, one professor of aged care services, two gerontologists, three clinical nurse consultants (older person acute care,

rheumatology, rehabilitation), and a registered nurse from the aged care services emergency team. Individual emails invited the experts to rate each item for the content relevance using a four-point scale of '1 = not relevant to 4 = very relevant', provide comments on the items and instructions, and suggest additional items for the CFC-I.

The content validity index (CVI) for individual item was calculated with the number of experts giving a rating of 3 and above, divided by the total number of experts [34]. Twenty-four of 46 items in the CFC-I achieved CVI of 0.80 and above, 15 items had CVI of 0.70, and seven items with less than 0.70 (See Table 1). For face validity, all experts agreed that the items were measuring carers' fall concern. However, a few experts felt that the initial CFC-I was too long, and several items were repeated.

B. Modification of Instrument

To achieve reasonable item-representation of CVI above 0.80 [35], eleven items (item 3, 4, 11, 12, 18-20, 30, 44-46) with CVI of 0.70 and below were deleted. However, five items with CVI of 0.80 and above were also deleted because item 8 was similar to item 7, items 21 to 23 asked about the carees' underlying medical conditions and were not directly related to fall concern, and item 43 was considered to be 'guilt-laden' by the experts. The remaining items were revised according to the experts' qualitative inputs to improve the instrument's validity. After eliminating 16 items, the average CVI for each item increased from 0.78 to 0.82.

Other suggestions included having the response of 'not applicable' and replacing 'care recipient' with 'the person I am caring for'. As suggested, one additional item 'trying to walk without help when asked not to' from the Fall-related Impulsive Behaviour Scale (FIBS) was also included to improve the CFC-I representation in the theme for carees' behaviour and attitude towards fall risk [36]. The FIBS was developed to assess impulsive fall risk behaviour among home care residents and has good internal reliability of 0.77 and test-retest reliability of 0.93. After the evaluation of content validity by the experts, 31-items remained in the CFC-I.

VII. STEP FOUR

A. Pilot Testing

The researchers recruited a convenience sample of 32 carers for the pilot testing of the revised 31-item CFC-I. The CFC-I was administered face-to-face using structured interview and/or an online survey. Implied consent was assumed for those who agreed to participate. During the survey, the carers were asked about their fall concern by completing the revised CFC-I. Each statement in the CFC-I was assessed using a five-point scale (1 = not applicable/not at all concerned, 5 = extremely concerned). They were also asked for their opinion regarding the relevance of the survey items, frequency of experiencing this concern, and their preferred naming of their care recipients. In addition, demographic information, care arrangement, carees' history of falling, and injuries sustained, were also collected from the carers.

B. Data Analysis

Data was analysed inferentially using the Statistical Package for Social Sciences version 24.0 [37]. Descriptive statistics summarised the demographic information and other study variables. Distribution of item scores was identified from the means and standard deviations. Items with very high, or very low mean item score and having a small standard deviation indicated poor discrimination of the population and were deleted [38]. The internal consistency of the CFC-I was assessed by calculating the Cronbach's alpha coefficient [38]. The 'item-total correlations' and 'alpha coefficient after each item was deleted' were also calculated for further modifications of the CFC-I.

C. Results

Table 2 illustrates the demographic characteristics of carers. The mean age of carers was 67 years (SD 11.1) and 24 (75.0%) were female. The majority of carers (n=25; 78.1%) were living with their carees, 14 (43.8%) carers reported providing care for more than 70 hours per week, and 8 (25.0%) had been caring for their carees for 10 years or more. The mean age of carees was 80 years (SD 10.4) and 17 (53.1%) were female. Twenty-four carees (75.0%) had fallen during the previous year and 20 of these (83.3%) had sustained an injury. The mean total CFC-I score was 87.3 (SD 27.5) with scores ranging from 42 to 141.

TABLE II. DEMOGRAPHIC CHARACTERISTICS OF CARERS

Characteristic (N=32)		Carer	Caree
Administration format, n (%)	Face-to-face	17 (53.1)	
	Online	15 (46.9)	
Age (years), mean (SD)		67 (11.1)	80 (10.4)
Gender of carer, n (%)	Male	8 (25.0)	15 (46.9)
	Female	24 (75.0)	17 (53.1)
Employment status, n (%)	Not working	20 (62.5)	
20 SSH	Working	12 (37.5)	
Relationship to caree, n (%)	Spouse	19 (59.4)	
	Parent	10 (31.3)	
	Friend	1 (3.1)	
	Others ^b	2 (6.3)	
Living with caree, n (%)	No	7 (21.9)	
	Yes	25 (78.1)	
Hours spent caring per week, n	≤ 70	18 (56.3)	
	> 70	14 (43.8)	
Years spent caring, n (%)	< 10	24 (75.0)	
	≥ 10	8 (25.0)	
Falls in past year, n (%)	No		8 (25.0)
	Yes		24 (75.0)
Injury from falls, n (%)	No		4 (16.7)
	Yes		20 (83.3)
Number of chronic illness, n (%)	< 2		24 (75.0)
* * **	≥2		8 (25.0)

a. Information of Carees provided by Carers. b. Grandmother/ Mother-in-law

Table 3 illustrates the distribution of items scoring, itemtotal correlation, and alpha coefficient if item deleted. Internal consistency for the CFC-I was 0.95. However, not all items contributed positively to the reliability of the scale with mean inter-item correlations of r=0.36 (range -0.16 to 0.91). Only three carers (9.4%) felt that the survey items did not accurately capture their concerns about the person they care for at risk of

falling. Their reasons were 'some questions appeared to ask about my own concerns of falling instead of the concerns for my care recipient', 'the concerns for my care recipient falling changes every now and then, depending on their medical condition, and it is difficult for me to determine', and 'some questions do not seem to apply to people who were wheelchair bound'. While the majority of carers felt that the survey items were relevant, the authors noted that few carers sought clarification of whether the questions were asking about their concern of falling, or the concern for their carees falling when completing the survey.

Most carers (N = 23, 71.9%) said that they experienced fall concern every day, followed by six (18.7%) who said, 'last week', and one (3.1%) 6 months ago. Two carers (6.3%) felt their level of concern changed with the type of activities performed by their carees. On the scale where 1 is the least preferred and 5 the most preferred, 29 carers responded to the question asking for their preferred way for naming their 'care recipient'. Sixteen carers (55.2%) chose 'loved one' as most preferred term, followed by thirteen (44.8%) choosing 'family member', and ten (34.5%) choosing 'person I am caring for'. Only six (20.7%) preferred the term 'caree', four (13.8%) preferred 'care recipient', and two (6.9%) chose 'my dependent' as the most preferred term.

D. Modification of Instrument

To ensure that all items measured the same underlying characteristics, nine items (item 1, 2, 6, 9-14) with corrected item-total correlation of 0.50 and below were deleted (See Table 3) [39]. With consensus from the authors, items 29 to 31 were removed as they were frequently misinterpreted by carers as assessing their own concern of falling during the pilot test. Items 3 and 7 were also removed because they measured the same content as items 4 and 8 respectively. After eliminating 14 items, Cronbach alpha coefficient of the remaining 17 items (See Fig. 1) was 0.94 with all items contributing positively to the instrument's internal consistency. The inter-item correlation averaged 0.50, ranging from 0.17 to 0.91.

VIII. DISCUSSION

There has been growing recognition of carers' role of providing care to older people and preventing them from falling at home. However, there is no multi-item instrument, which objectively measures the impact of carees' falling on carers' fall concern, which could significantly affect carers' psychological wellbeing and ability to consistently provide care. This study has taken a systematic approach in defining the carers' fall concern construct, developing and validating the measure known as Carers' Fall Concern Instrument (CFC-I).

The CFC-I is the first multi-item scale to identify carers' concern about carees at risk of falling across different situations, such as the performance of daily activities, environmental hazards, behaviour and attitude towards fall risk. Unlike most fear of falling instruments where items are generated by health professionals or researchers [40], carers' input was used in the development and modification of the CFC-I to ensure its comprehensibility, relevance and completeness [38]. The inclusion of carers looking after carees

with and without a history of falling, also provides a wider perspective in assessing their fall concern. Other advantages such as using modified items from the well-validated FES-I and FIBS measures, a multi-disciplinary expert review, and pilot testing of the initial CFC-I have helped to further establish the instrument's validity.

TABLE III. DISTRIBUTION OF ITEMS SCORING, ITEM-TOTAL CORRELATION, AND ALPHA COEFFICIENT IF ITEM DELETED

Items	Mean	Item-total	Alpha
	(SD ^a)	correlation	if item
1 Folling at home	3.53	0.50 ^b	deleted 0.95
1. Falling at home	(1.24)	0.50	0.93
2. Being at risk of falling	3.59	0.48 ^b	0.95
	(1.10)	1823975-7	10000000
3. Sustaining a severe injury from a fall	3.94	0.60 ^b	0.94
e.g. fracture	(1.34)		
4. Not recovering from a fall	3.88	0.68	0.94
5. Requiring extra care and support after	3.50	0.70	0.94
a fall	(1.41)	0.70	0.94
6. Not being concerned about falls	2.75	0.42b	0.95
C contract of C	(1.69)	3803037775	
7. Being unaware about his/her fall risk	2.91	0.58 ^b	0.94
	(1.59)		
8. Doesn't want to be assessed for fall	1.91	0.60	0.94
risk 9. Doesn't want to have a health	(1.35)	0.50 ^b	0.95
9. Doesn't want to have a health professional assess his/her home for fall	(1.08)	0.30	0.93
risk	(1.00)		
10. Doesn't want to have his/her home	1.53	0.47 ^b	0.95
modified to decrease fall risk	(1.02)	100000000	100000000
11. Won't accept that he/she is at risk of	1.81	0.34 ^b	0.95
falling	(1.15)		
12. Falling when he/she cleans the house	1.66	0.21 ^b	0.95
13. Falling when he/she gets dressed or	(1.04)	0.48 ^b	0.95
undressed	(1.33)	0.46	0.93
14. Falling when he/she prepares meals	1.69	0.39 ^b	0.95
3 1 1	(1.06)		1000000000
15. Falling when he/she takes a bath or	2.91	0.69	0.94
shower	(1.57)	. = 4	0.01
16. Falling when he/she gets in and out of a chair or bed	2.78 (1.50)	0.74	0.94
17. Falling when he/she uses the stairs	2.91	0.70	0.94
17. Faming when he she uses the stans	(1.63)	0.70	0.54
18. Falling when he/she reaches for	2.63	0.66	0.94
something above his/her head or on the	(1.41)		12.00.0 100
ground			Terriero.
19. Falling when he/she rushes to do	2.75	0.65	0.94
things 20. Falling when he/she goes to the toilet	(1.61)	0.70	0.94
at night	(1.34)	0.70	0.74
21. Falling when he/she is alone at home	3.31	0.78	0.94
	(1.60)	200000	50.000 7,9
22. Falling when he/she goes out alone	2.81	0.62	0.94
	(1.64)	0.75	0.01
23. Falling when he/she walks on a	3.50	0.75	0.94
slippery surface 24. Falling when he/she walks in	(1.46)	0.61	0.94
crowded places	(1.49)	0.01	0.54
25. Falling when he/she walks on an	3.50	0.70	0.94
uneven surface	(1.37)		
26. Falling when he/she walks up or	3.31	0.63	0.94
down a slope	(1.49)	0.55	0.0-
27. Falling when he/she walks without	2.47	0.57	0.95
his/her walking aid e.g. walker	(1.67)	l	

28. Falling when he/she tries to walk without help when asked not to	2.78 (1.58)	0.55	0.95
29. Nobody being there to help me if a fall occurs	3.19 (1.79)	0.53 ^b	0.95
30. Hurting myself when helping the person I am caring for getting up from a fall	2.81 (1.62)	0.61 ^b	0.94
31. Not being able to prevent the person I am caring for from falling	3.81 (1.49)	0.61 ^b	0.94
Overall scale	87.25 (27.53)	0.36	

a. SD: Standard Deviation. b. Items were Deleted.

Based on the experts' validation, the average CVI for each item was 0.82 achieving the minimum recommended level of agreement of 0.80 [35]. Internal consistency of the 17-item CFC-I was excellent (Cronbach's alpha = 0.94) and comparable to other instruments measuring fall-related psychological difficulties among older people such as FES-I (Cronbach's alpha = 0.96) [12], SAFE (Cronbach's alpha = 0.91)[11], and ABC (Cronbach's alpha = 0.96)[10]. The findings support the initial validity and reliability of the CFC-I in quantifying carers' concern regarding their carees' risk of falling. The CFC-I would help health professionals to evaluate whether carers are coping with the care of their carees with a falling risk, and their awareness and level of competence in managing falls following fall prevention programmes.

There are some limitations which warrant attention. During the pilot study, carers who completed the survey face-to-face were often accompanied by their carees. This may have resulted in under-reporting of their concerns as some carers could have been afraid of letting their carees know how they felt, or there may have been social desirability bias of giving the impression that they were coping with their care [34]. To minimise the effects of bias in future, several strategies were put in place, including removing items which appeared to portray carees in a negative light and retaining 'subtle' items measuring the same traits or behaviour (i.e. item 3 and 4 in Table 3)[34]. Wording of items was also revised, and similar items removed to make the survey quicker and easy to be self-administered.

The sample was recruited by convenience sampling. It is possible that carers with a higher level of concern did not have time to participate in the survey. To ensure generalisability, items of the CFC-I were generated from both qualitative interviews and integrative review findings. Finally, carers recruited in the qualitative interview and pilot study were primarily looking after high functioning carees. Therefore, items developed for the CFC-I were found not applicable in assessing carers' concern for carees who were wheelchair-bound or bedbound.

Future studies are recommended to ascertain the factor structure of the CFC-I and its relationship to other fall risk variables using a larger sample of carers. It is also important to determine the predictive validity of the CFC-I to carees' fall risk and its sensitivity to change after interventions. As the CFC-I is the only multi-item scale in measuring carers' fall concern, it could potentially serve as an important endpoint in future fall prevention programmes that include carers. The CFC-I should also be tested across different languages and

cultures to determine its psychometric properties and crosscultural influence on carers' concern.

IX. CONCLUSION

With an increasing recognition of the carers' role in the prevention of falls among older people at home, health professionals and researchers are encouraged to incorporate the carers' fall concern instrument when planning future fall prevention programmes to reduce the risk of future falls. Unlike other instruments measuring the older people's fear of falling, the concept of carers' fall concern was not based upon any theoretical assumptions; therefore, the items developed were not restricted to the activities performed by carees. Instead, a systematic evidence-based approach was applied in defining the carers' fall concern construct and development of items for the CFC-I.

Carers' Fall Concern for Older Persons Questionnaire For each statement, please indicate the level of concern you might have for the person you care for being at risk of falling. There are no right or wrong answers.				
How concerned are you about [the person you care for] not recovering from a fall	□ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned			
[the person you care for] requiring extra care and support after a fall	□ Moderately concerned □ Extremely concerned □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned			
[the person you care for] not wanting to be assessed for fall risk	□ Extremely concerned □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned			
[the person you care for] falling when taking a bath or shower	□ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned			
[the person you care for] falling when getting in and out of a chair or bed	□ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned			
[the person you care for] falling when using the stairs	□ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned			
[the person you care for] falling when reaching up or for something on the ground	□ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned			
[the person you care for] falling when rushing to do things	□ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned			
[the person you care for] falling when going to the toilet at night	□ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned			

[the person you care for] falling	□ Not applicable/ not at all concerned
when at home alone	□ Slightly concerned
	□ Somewhat concerned
	□ Moderately concerned
	□ Extremely concerned
[the person you care for] falling	□ Not applicable/ not at all concerned
when going out alone	□ Slightly concerned
	□ Somewhat concerned
	□ Moderately concerned
	□ Extremely concerned
[the person you care for] falling	☐ Not applicable/ not at all concerned
when walking on a slippery surface	□ Slightly concerned
	□ Somewhat concerned
	□ Moderately concerned
	□ Extremely concerned
[the person you care for] falling	☐ Not applicable/ not at all concerned
when walking in crowded places	□ Slightly concerned
	□ Somewhat concerned
	□ Moderately concerned
	□ Extremely concerned
[the person you care for] falling	□ Not applicable/ not at all concerned
when walking on an uneven surface	□ Slightly concerned
	□ Somewhat concerned
	□ Moderately concerned
	□ Extremely concerned
[the person you care for] falling	☐ Not applicable/ not at all concerned
when walking up or down a slope	□ Slightly concerned
	□ Somewhat concerned
	□ Moderately concerned
	□ Extremely concerned
[the person you care for] falling	□ Not applicable/ not at all concerned
when walking without a walking	□ Slightly concerned
aid e.g. walker	□ Somewhat concerned
	□ Moderately concerned
	□ Extremely concerned
[the person you care for] falling	☐ Not applicable/ not at all concerned
when trying to walk without help,	□ Slightly concerned
when asked not to	□ Somewhat concerned
	□ Moderately concerned
	□ Extremely concerned
Figure 1 17-items Carers	' Fall Concern Instrument (CFC-I)

Figure 1. 17-items Carers' Fall Concern Instrument (CFC-I)

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CHAPTER 7: PHASE THREE RESULTS

PAPER 7: Ang, S. G. M., O'Brien, A. P., & Wilson, A. (2019). Development and validation of an instrument to measure carers' concern for older people at risk of falling at home. Under review by *International Journal of Older People Nursing*.

7.1 Overview

This chapter consists of Paper 7, which presents the psychometric properties of the CFC-I including reliability, distribution of item scoring, and construct validity. A cross-section of 143 carers from four recruitment sites completed the 17-item CFC-I developed in Phase Two. During reliability analysis, one item was removed as it did not appear to assess carers' fall concern. The remaining 16-item CFC-I reported a Cronbach's alpha of 0.93. Factors analysis identified three factors related to the care recipients' health and function, living environment, and carers' perception of fall and fall risk. The CFC-I was also found to discriminate between carers looking after care recipients with and without falls. This phase of the study was conducted between June 2018 and November 2018.

7.2 Paper 7

ABSTRACT

Aims

This study aimed to develop and validate an instrument for measuring carers' concern for their care recipients (older people) at risk of falling.

Background

Family carers are crucial in preventing older people from falling at home. Their concerns for older people at risk of falling also have severe implications on carers' psychological wellbeing and ability to prevent falls; however there are no validated instruments for measuring this concern.

Methods

The new Carers' Fall Concern instrument (CFC-I) was developed to measure the impact of falls and fall risk on carers and to identify their needs in fall prevention. Carers looking after older people living at home completed the 17-item CFC-I and provided information about care arrangements and their care recipients' fall history.

Results

143 carers completed the survey either by face-to-face or online. After deleting one item with item-total correlation of below 0.3, the remaining 16-item CFC-I reported a Cronbach's alpha of 0.93. Construct validity was supported by strong item-total correlations (0.51-0.76), mean inter-item correlations (0.47), and factor loadings (0.557-0.809). Factor analysis suggested a single factor with three dimensions assessing concerns about care recipients' health and function, living environment, and carers' perception of

fall and fall risk. The 16-item CFC-I discriminates between carers of older people with and without recurrent (fallen 3 or more times) falls.

Conclusions

The 16-item CFC-I is a valid and reliable scale for measuring carers' concern for their care recipients' risk of falling. Future analysis of test-retest reliability and inter-rater reliability of the instrument will further support its clinical use for carers.

Implications for practice

The newly developed multi-item CFC-I can be used to quantify the carers' level of fall concern and inform targeted interventions for carers when managing the fall risk of older people.

Keywords

Carers, older people, falls, fall concern, fall risk, fear of falling

SUMMARY STATEMENT OF IMPLICATIONS FOR PRACTICE

What does this research add to existing knowledge in gerontology?

- 1. Family carers are concerned about their care recipients being at risk of falling at home.
- 2. The Carers' Fall Concern instrument is valid and reliable for measuring carers' fall concern.
- Three factors identified contributing to carers' fall concern: care recipients' health
 and function, care recipients' living environment, and carers' perception of fall
 and fall risk.

What are the implications of this new knowledge for nursing care with older people?

- 1. Health care professionals need to consider carers' fall concern when developing fall prevention strategies for older people at home.
- 2. An individualised fall prevention programme for carers is needed to support carers in managing their care recipients' fall risk and fall concern.

How could the findings be used to influence policy or practice or research or education?

- 1. The 16-item CFC-I is recommended to be used as an end-point measure to evaluate the efficacy of fall prevention programme for carers.
- 2. As a multi-item instrument, the CFC-I can assist health care professionals to prescribe targeted intervention based on the needs of carers.

INTRODUCTION

Fear of falling is a crucial fall risk factor among older people that is associated with increased functional disability (Auais et al., 2017), and a higher risk of admission to long-term care institutions (Cumming et al., 2000). While fear of falling often affects older people after a fall, it can also occur in those who have not fallen (Murphy, Dubin, & Gill, 2003). Many instruments are found measuring older people's fear of falling. The 'Falls Efficacy Scale' (FES) was the first fear of falling instruments developed to measure older people's confidence in performing daily activities without falling (Tinetti et al., 1990). Subsequently, researchers modified the FES to develop other instruments such as the Falls Efficacy Scale-International (FES-I), which assesses both physical and social activities (Yardley et al., 2005), and the Iconographical Falls Efficacy Scale (Icon-FES), which includes pictures in the assessment of fear of falling (Delbaere et al., 2011).

Falls among older people (care recipients) can also cause significant psychological distress for their carers (Forster & Young, 1995; Liddle & Gilleard, 1995), and are associated with increased caregiver burden (Dow et al., 2013; Kuzuya et al., 2006). Many carers feel they need to monitor their care recipients more closely to prevent falls, which impact their own time for resting or socialising (Dow et al., 2013; Faes et al., 2010; Habermann & Shin, 2017). Falls resulting in a severe injury are directly related to the care recipient being placed in long-term care because the carer was unable to continue providing care at home (Abendroth et al., 2012). The term "carers' fall concern" coined in this study describes carers' fear of their care recipients' risk of falling (Ang, O'Brien, & Wilson, 2018a).

Some carers fear the uncertainty and consequences of the fall. Others are concerned about their care recipients' non-adherence to fall prevention advice or engaging in activities with a higher risk of falling (Davey et al., 2004; Dow et al., 2013; Faes et al., 2010). Carers of care recipients with medical conditions such as Parkinson's disease or dementia had increased fall concerns because these conditions could lead to a gradual loss of cognitive, mobility or functional abilities (Faes et al., 2010). Carers' fall concerns could affect the fall risk of the care recipients and potentially undermine fall prevention efforts at home (Ang, O'Brien, et al., 2018b). Excessive fall concern can lead to the unnecessary restriction of the care recipients' activity to prevent falls. However, lack of concern can result in carers underestimating their care recipients' fall risk and not preventing them from falling (Ang, Wilson, et al., 2018b).

In a literature review, only two studies explored the prevalence of carers' fall concern and reported that 58% to 91% of the carers were fearful of their care recipients falling again (Faes et al., 2011; Liddle & Gilleard, 1995). However, the conceptualisation of instruments for measuring carers' fall concern in terms of methodology and design were not described in both studies. Specifically, these studies measured carer's fall concern using a single-item questionnaire (Faes et al., 2011), or a Likert scale (Liddle & Gilleard, 1995) which were not able to detect the variation in the level of concern based on different situations. Therefore, the Carers' Fall Concern Instrument (CFC-I) was developed to address these limitations. The CFC-I is a multi-item instrument specifically designed to assess carers' concern of their care recipients at risk of falling. The objectives of this study were to develop, modify, and investigate the validity and reliability of the CFC-I.

METHODS

Development of the CFC-I

An integrative review and semi-structured interviews with twenty-two carers generated the items for the CFC-I. Four themes: 1) carers' perception of fall and fall risk, 2) care recipients' behaviour and attitude towards fall risk, 3) care recipients' health and function, and 4) care recipients' living environment categorised the items which increased carers' fall concern. The description for each theme was reported in another paper (Ang, O'Brien, & Wilson, 2019). To ensure broad coverage of different situations and to improve the validity of the instrument, twelve items were referred from the Falls Efficacy Scale-International (FES-I) and modified to assess carers' concern for their care recipients' health and function, and risk of falling in the living environment (Yardley et al., 2005). The FES-I is the gold standard for measuring fear of falling among older people and reports a Cronbach's alpha and intra-class correlation of 0.96 (Yardley et al., 2005). These items comprised of activities of daily living which carers from the semi-structured interviews believed may put their care recipients at risk of falling, therefore requiring their assistance.

The initial instrument comprising 46 items, was reviewed by a team of ten expert researchers and clinicians specialising in aged care for content and face validity (Acknowledgements). As recommended by the experts, 16 items that were not relevant to measuring carers' fall concern, or where they repeated some content in other items were deleted. The remaining 30 items produced an average content validity index of 0.82. One item from the Fall-related Impulsive Behaviour Scale (FIBS) assessing impulsive falls risk behaviour among older people, was also suggested to be included in the instrument, giving a total of 31 items (Whitney, Jackson, Close, & Lord, 2013). The

revised 31-item CFC-I was then pilot-tested on a convenience sample of 32 carers. 14 items, which were negatively correlated with other items, or were ambiguous and misinterpreted by the carers for measuring their own fear of falling, were removed. After item analysis, the remaining 17-item CFC-I reported good internal consistency (Cronbach's alpha = 0.94) above the minimally recommended value of 0.90 and had an average inter-item correlation of 0.50, within the suggested range of 0.30 to 0.70 (DeVon et al., 2007). The supplementary table presented the item development process for the initial CFC-I.

Participants

Carers providing support for their care recipients in at least one activity of daily living (ADL) who were aged 60 years and above living at home were recruited. However, those who were: 1) paid or professional carers, 2) looking after a care recipient aged below 60 years old, or 3) caring for a care recipient who was wheelchair- or bed-bound were excluded. The study was approved by the Hunter New England Health Human Research Ethics Committee (HREC) with reciprocal approval from the University of Newcastle HREC.

The carers were recruited from four main study sites: 1) a local research institute volunteer register, 2) a non-government state organisation for carers (membership list), 3) a rheumatology outpatient clinic, and 4) a day rehabilitation centre in a regional hospital. Both the registry and membership list had provided the researchers access to the general population of carers living in New South Wales, Australia. Another two study sites had carers looking after older people who were likely to have had a fall at home. The study recruitment information was also published on Facebook pages, websites, and newsletters.

The sample size was estimated following the guidelines of four to ten carers per item and a minimum of 100 carers required to conduct factor analysis (Kline, 2000). Based on the pilot study of 32 carers, difference in CFC-I scores between 24 carers looking after care recipients who had fallen in the past year (mean = 91.42, standard deviation (SD) = 27.67) and 8 carers looking after care recipients who did not fall (mean = 74.75, SD = 24.56) had a medium effect size (d = 0.64) (Cohen, 1988). In this study, a fall was defined as the unintentional coming to rest on the floor or lower level (World Health Organisation, 2007). With this effect size, a sub-sample of 40 carers from each group (fallers and non-fallers) would achieve 80% power with a significance level of 0.05 using a two-tailed test (Soper, 2019).

Data collection

Consenting carers were asked to complete the 17-items CFC-I either by face-to-face interviews, or online surveys. The carers were asked to rate the level of their concern about their care recipients' risk of falling using a five-point Likert scale with "1 being not applicable/not at all concerned" to "5 being extremely concerned" for each statement. They also provided their socio-demographic information including age, gender, employment status, relationship to care recipients, history of falls and injury in the past 12 months, and medical history.

Data analysis

The analyses were performed using SPSS for Windows (Version 24.0, IBM Corp, Armonk, NY, USA). Descriptive statistics were used to describe the socio-demographic characteristics. The internal consistency of the CFC-I was analysed using Cronbach's and overall structure of the modified CFC-I was explored by factor analysis using principal

component analysis with Varimax rotation. Distinct factors of the CFC-I were identified based on the eigenvalue of more than one (Williams, Onsman, & Brown, 2010). The validity of the CFC-I was assessed using independent t-tests to examine between-group differences in total scores according to the study variables. ANOVA with Bonferroni post hoc tests was also used to examine score differences in scores among carers of care recipients who had not fallen, fallen once, twice, and three, or more times.

RESULTS

Socio-demographic characteristics

One hundred and forty-three carers completed the survey. The mean age of the carers was 65.52 years (SD = 12.08), and 107 were females (74.8%). The majority of the carers were caring for their spouses (n = 75, 52.4%), followed by caring for their parents (n = 52, 36.4%). The mean age of the care recipients was 78.63 years (SD = 9.21), and 75 (52.4%) were females. 102 carers (71.3%) reported that their care recipients had fallen in the previous year and 86 (84.3%) sustained an injury from the fall. 110 carers (76.9%) completed the survey face-to-face, while 33 carers (23.1%) completed the online survey. Carers who completed the survey face-to-face were significantly older than those who completed the survey online (mean age = 66.98 versus 60.59 years, P = 0.008).

Reliability

The overall internal consistency of the 17-item CFC-I was high with a Cronbach's alpha coefficient of 0.93 and the mean inter-item correlation of 0.43 ranging from -0.01 to 0.74. Item 3 with an item-total correlation of below 0.3 indicated that it could be measuring something different from the overall scale was deleted (Table 1). The Cronbach's alpha

for the remaining items was 0.93 with an improved inter-item correlation of 0.47 (range 0.15-0.74).

Table 1. Mean, standard deviation (SD), item-total correlation, and alpha coefficient if item deleted

Items	Mean (SD)	Item-total correlation 17-item	Alpha if item deleted 17-item	Item-total correlation 16-item	Alpha if item deleted 16-item
1. Not recovering from a fall	3.50 (1.32)	0.51	0.93	0.51	0.93
2. Requiring extra care and support after a fall	3.41 (1.34)	0.52	0.93	0.52	0.93
3. Not wanting to be assessed for fall risk ^a	1.97 (1.32)	0.19	0.93	-	-
4. Falling when taking a bath or shower	2.58 (1.46)	0.65	0.92	0.64	0.93
5. Falling when getting in and out of a chair or bed	2.44 (1.35)	0.72	0.92	0.72	0.93
6. Falling when using the stairs	2.58 (1.47)	0.59	0.92	0.59	0.93
7. Falling when reaching up or for something on the ground	2.81 (1.36)	0.71	0.92	0.71	0.93
8. Falling when rushing to do things	2.90 (1.40)	0.69	0.92	0.69	0.93
9. Falling when going to the toilet at night	2.50 (1.41)	0.75	0.92	0.75	0.93
10. Falling when at home alone	3.09 (1.42)	0.74	0.92	0.73	0.93
11. Falling when going out alone	2.58 (1.58)	0.52	0.93	0.53	0.93
12. Falling when walking on a slippery surface	3.57 (1.30)	0.72	0.92	0.72	0.93
13. Falling when walking in crowded places	2.76 (1.38)	0.71	0.92	0.71	0.93
14. Falling when walking on an uneven surface	3.61 (1.26)	0.77	0.92	0.76	0.93
15. Falling when walking up or down a slope	3.30 (1.43)	0.69	0.92	0.69	0.93
16. Falling when walking without a walking aid e.g. walker	2.83 (1.66)	0.61	0.92	0.62	0.93
17. Falling when trying to walk without help, when asked not to	2.74 (1.63)	0.64	0.92	0.64	0.93
Overall scale		0.43 ^b (-0.01 - 0.74)	0.93	0.47 ^b (0.15 - 0.74)	0.93

^aItem was deleted; ^bmean inter-item correlation (range).

Overall Structure

Based on the eigenvalue above one, the initial factor analysis identified three factors from the 16-item CFC-I, which converged with three of the four hypothetical themes derived from the semi-structured interviews (Table 2). Items assessing concerns about the care recipients' health and function loaded highly onto the first factor which explained 27.0% of the variance. Items assessing concerns about the care recipients' living environment loaded highly onto the second factor which explained 26.1% of the variance. Two items, that assessed carers' perception of fall and fall risk, loaded highly onto the third factor explaining 13.2% of the variance. However, when a one-factor solution was specified, all items were also found to load highly onto a single dimension (50.6% variance).

Distribution

The mean total 16-item CFC-I score was 47.20 (SD = 16.07) with scores ranging from 19 to 80. The distribution of the CFC-I which was close to normal has a skewness of 0.319 (standard error of mean [SEM] 0.203) and kurtosis of -0.823 (SEM 0.403). The carers used every response such as one to five of the Likert scale in the 16-item CFC-I. Three carers (2.1%) gave the maximum score of 80, and none gave the minimum score of 0 which indicates an absence of floor or ceiling effect.

Table 2. Factor loadings of the 16-item CFC-I

Item		Three factor solution			One factor solution
		Factor 1	Factor 2	Factor 3	
1.	Not recovering from a fall			0.797	0.557
2.	Requiring extra care and support after a fall			0.801	0.564
3.	Falling when taking a bath or shower	0.743			0.698
4.	Falling when getting in and out of a chair or bed	0.750			0.766
5.	Falling when using the stairs	0.663			0.647
6. gro	Falling when reaching up or for something on the und	0.713			0.760
7.	Falling when rushing to do things	0.786			0.745
8.	Falling when going to the toilet at night	0.618	0.463		0.792
9.	Falling when at home alone	0.533	0.446		0.778
10.	Falling when going out alone		0.671		0.578
11.	Falling when walking on a slippery surface	0.452	0.661		0.766
12.	Falling when walking in crowded places	0.518	0.629		0.759
13.	Falling when walking on an uneven surface	0.449	0.656		0.809
14.	Falling when walking up or down a slope		0.762		0.740
	Falling when walking without a walking aid e.g. lker		0.707	0.407	0.667
	Falling when trying to walk without help, when ed not to		0.763		0.685

Validity

The carers looking after care recipients with a history of falls reported significantly higher CFC-I scores than carers of care recipients who did not fall indicated that the 16-item CFC-I has good construct validity (Table 3). Carers who completed the survey online and were below the age of 66 years old also reported significantly higher CFC-I scores. The significant difference in total CFC-I scores obtained by face-to-face interviews and an online survey was probably due to older age carers recruited from the outpatient clinic and day rehabilitation centre at the regional hospital. After controlling for age (partial eta squared = 0.038, p = 0.021), the methods of administration have no effect on CFC-I scores (partial eta squared = 0.021, p = 0.091). Other variables did not reveal any significant differences in CFC-I scores.

Analysis of variance with Bonferroni post hoc tests was used to examine between-group differences in CFC-I scores according to the frequency of falls (Table 4). Significant differences in CFC-I scores were reported between carers of care recipients who did not fall (mean = 40.74, SD = 13.97), fallen once (mean = 42.53, SD = 15.05), fallen twice (mean = 45.78, SD = 13.87), or fallen three or more times (mean = 56.20, SD = 15.68) over the past year (F_{3,137} = 9.578, p < 0.001). Post-hoc comparisons using the Bonferroni test revealed that the CFC-I scores for carers of care recipients who fell three or more times were significantly different from carers of care recipients who did not fall or fall less than three times in the previous year.

Table 3. Mean and standard deviation (SD) of the 16-item CFC-I for subgroups based on sociodemographic characteristics (N = 143)

Variables	Group 1	Number	Mean (SD)	Group 2	Number	Mean (SD)	P-value
Administration format	Face-to- face	110	45.65 15.92	Online	33	52.36 15.75	0.035
Age of carer (years) ^a	<66	70	51.43 15.08	≥66	70	43.10 16.02	0.002
Gender of carer	Male	36	46.53 17.47	Female	107	47.43 15.66	0.772
Employment status	Not working	99	45.76 16.31	Working	44	50.45 15.22	0.107
Caring relationship ^b	Spouse	75	45.83 15.99	Parent	52	49.38 16.15	0.222
Hours spent caring per week	≤70	58	48.88 15.17	>70	85	46.06 16.66	0.305
Years spent caring	<8	105	47.50 15.44	≥8	38	46.37 17.90	0.710
Living with care recipient	No	38	49.53 15.88	Yes	105	46.36 16.14	0.300
Age of care recipient (years)	<79	68	47.24 15.90	≥79	75	47.17 16.34	0.982
Gender of care recipient	Male	68	47.56 16.67	Female	75	46.88 15.62	0.802
Previous falls ^c	No	39	40.74 13.97	Yes	102	49.83 16.22	0.002
Injury from the fall	No	16	47.38 13.01	Yes	86	50.29 16.77	0.512
Number of chronic illness	<2	68	45.34 16.99	≥2	75	48.89 15.11	0.188

^a3 carers did not report their age; ^b16 carers not included (3 caring for siblings, 5 caring for friend, 3 caring for partner, 3 caring for mother-in-law, 1 caring for grandparent, and 1 caring for older child); ^c2 carers were not sure if their care recipients had fallen.

Table 4. Bonferroni-adjusted mean differences of the 16-item CFC-I based on frequency of falls among care recipients

Mean difference	No fall	1 fall	2 falls	3 or more falls
No fall	-	-1.79	-5.04	-15.46***
1 fall	1.79	-	-3.25	-13.67**
2 falls	5.04	3.25	-	-10.42*
3 or more falls	15.46***	13.67**	10.42*	-

^{*}p < 0.05, **p = 0.001, ***p < 0.001.

DISCUSSION

The 16-item CFC-I is the first multi-item instrument developed to measure carers' concern for their care recipients at risk of falling. Compared with the existing single-item questionnaire, the 16-item CFC-I provides more detail about the carers' level of fall concern in different situations, ranging from the care recipients' performance of daily activities to the indicators of dangerous environments. Initial validation of the 17-item CFC-I reported internal reliability of 0.93. However, one item measuring carers' concern regarding their care recipients "not wanting to be assessed for fall risk" was removed because it had an item-total correlation of 0.19, which was below the recommended value of 0.3 (DeVon et al., 2007). It is possible that the poor fit of this item is due to the carers in this study were mainly recruited from the outpatient clinic and day rehabilitation centre where their care recipients have had their fall risk assessed. After deleting this item, the Cronbach's alpha of the remaining 16-item CFC-I maintained at 0.93 but reported an improved mean inter-item correlation of 0.47. Overall, the 16-item CFC-I demonstrated good construct validity with item-total correlations above the recommended range of 0.3 (0.51-0.76) and factor loadings of more than 0.40 (0.557-0.809) (DeVon et al., 2007).

From the factor analysis, only three factors were identified from the 16-item CFC-I that assessed concerns related to the care recipients' health and function, living environment, and the carers' perception of falls and fall risk. This is opposed to four factors conceptualised from the qualitative findings. Two items: "falling when walking without a walking aid" and "falling when trying to walk without help" which were thought to assess concerns related to the care recipients' behaviour and attitude towards fall risk, were found loading onto the factor for the living environment. It was hypothesised that the care recipients' behaviour and attitude towards fall risk could be dependent on their environmental awareness. The care recipients may be unable to take advance precautions if they do not foresee the risks in the environment (Stevenson & Taylor, 2018). While the CFC-I could measure three factors, the instrument was suggested to be used as a single unitary entity due to cross loading of items and higher factor loadings in a one-factor solution.

The 16-item CFC-I was able to discriminate between carers looking after care recipients with no falling history and those with recurrent falls. This finding is consistent with previous studies which found most carers worry their care recipients will fall again (Faes et al., 2011; Liddle & Gilleard, 1995). In this study, the level of fall concern is only significantly higher for carers of care recipients who have sustained three or more falls over the past year and among younger carers. In contrast, a previous study had found older people were more likely to develop a fear of falling (Murphy et al., 2003).

Other advantages of the 16-item CFC-I include the non-significant difference in the level of fall concern to caregiving arrangements, normal distribution, and stability across different modes of administration. These advantages show that the instrument is sensitive

to the carers' concern about the potential of their care recipients falling. An increase in fall concern may indicate the need for professional intervention for carers, such as fall concern counselling, education on risk identification and strategies in managing falls. The use of CFC-I could encourage the active involvement of carers in implementing suitable fall prevention strategies to effectively reduce the fall rates among older people at home (Wilkinson et al., 2018).

Implications for practice

The CFC-I is suitable as an end-point measure to evaluate the efficacy of the fall prevention programme for carers. As a multi-item instrument, the CFC-I can identify different situations contributing to the concern of carers which allow the prescription of targeted interventions based on the specific needs of carers. For example, healthcare professionals may refer carers who are concerned about their care recipients' living environment for home assessment or assistance in home modification. The assessment of carers' fall concern may also reveal other underlying issues such as increased caregiving burden, psychological distress, lack of fall risk awareness, or inadequate knowledge in preventing falls. The multiple issues associated with carers' fall concern also indicate a need for a multidisciplinary healthcare team to manage the needs of carers and their care recipients during fall prevention.

Future studies are recommended to determine the relationship of carers' fall concern with other fall risk variables among care recipients such as gait/ balance, fear of falling, or medications (Rubenstein, Vivrette, Harker, Stevens, & Kramer, 2011). Therefore, healthcare professionals can ascertain if carers have an accurate appraisal of fall risk and take appropriate actions to prevent their care recipients from falling (Ang, Wilson, et al.,

2018b). There is also a need to assess the impact of carers' fall concern on other psychological factors such as anxiety and depression among carers, which may have implications on their ability to prevent falls. Lastly, the psychometric properties and feasibility of the CFC-I could be explored in different populations or settings to determine possible cultural influences.

Limitations

A limitation of this study was the inability to conduct test-retest reliability and inter-rater reliability for the instrument. However, internal consistency reliability was calculated to determine the correlation of items. The authors also acknowledge that the causes of carers' fall concern are not limited to the items in the CFC-I. However, these 16 items were the most common causes identified by carers for increasing their fall concern in this study. The CFC-I was developed using carers of a general population of care recipients who were living independently at home with some form of assistance. The findings may not be generalisable to carers of people with lower functioning abilities who are wheelchair-or bed-bound.

CONCLUSION

Carers' fall concern is a multi-dimensional construct which is affected the care recipients' health and function, living environment, and carers' perception of fall and fall risk. The CFC-I has been found to provide a simple, yet reliable scale for measuring carers' concern for their care recipient's risk of falling. Currently, there is no multi-item instrument for measuring carers' fall concern. In providing targeted and effective interventions to prevent falls among older people, healthcare professionals are encouraged to assess the fall concern of carers who are looking after their care recipients at home. Addressing their

fall concern would also help to prevent sequelae of adverse outcomes such as adopting harmful strategies to prevent falls, increased caregiving burden, and putting their care recipients at risk of falling.

Supplementary Table. Process of item development

Generation of items (46 items)	Content evaluation (31 items)	Pilot test (17 items)
Theme 1: Carers' perception of fall and fall risk		
Falling at home	Falling at home	Deleted
Being at risk of falling	Being at risk of falling	Deleted
Falling again	Deleted	Deleted
Getting minor injuries (bruises/ grazes) from a fall	Deleted	Deleted
Getting severe injuries (breaking bones) from a fall	Sustaining a severe injury from a fall e.g. fracture	Deleted
Not recovering from a fall	Not recovering from a fall	Not recovering from a fall
Requiring more care after a fall	Requiring extra care and support after a fall	Requiring extra care and support after a fall
Requiring more care than I can provide after a fall	Deleted	Deleted
Theme 2: Care recipient's behaviours and attitude	es towards fall risk	
Not taking my advice about fall risk	Not being concerned about falls	Deleted
Being unconcerned of fall risk	Being unaware about his/her fall risk	Deleted
Being unconcerned of own safety	Deleted	Deleted
Not seeking help about fall risk	Deleted	Deleted
Refusing to be assessed for fall risk	Doesn't want to be assessed for fall risk	Not wanting to be assessed for fall risk
Refusing to have home checked for safety	Doesn't want to have a health professional assess his/her home for fall risk	Deleted
Refusing to have home modified for safety	Doesn't want to have his/her home modified to decrease fall risk	Deleted
Refusing to go for rehabilitation	Won't accept that he/she is at risk of falling	Deleted
Forgets to use the walking aid (i.e. walker)	Falling when he/she walks without his/her walking aid e.g. walker	Falling when walking without a walking aid e.g. walker
-	Falling when he/she tries to walk without help when asked not to ^b	Falling when trying to walk without help, when asked not to
Theme 3: Care recipient's health and function		
Falling due to poor health	Deleted	Deleted

Falling due to old age	Deleted	Deleted
Falling due to pain occurring	Deleted	Deleted
Falling due to poor balance	Deleted	Deleted
Falling due to dizziness	Deleted	Deleted
Falling due to unsteady gait	Deleted	Deleted
Cleans the house (e.g. sweep, vacuum, dust) ^a	Falling when he/she cleans the house	Deleted
Gets dressed or undressed ^a	Falling when he/she gets dressed or undressed	Deleted
Prepares simple meals ^a	Falling when he/she prepares meals	Deleted
Takes a bath or shower ^a	Falling when he/she takes a bath or shower	Falling when taking a bath or shower
Gets in and out of a chair ^a	Falling when he/she gets in and out of a chair or bed	Falling when getting in and out of a chair or bed
Reaches for something above their head or on the ground ^a	Falling when he/she reaches for something above his/her head or on the ground	Falling when reaching up or for something on the ground
Goes to answer the telephone before it stops ringing ^a	Deleted	Deleted
111151115		
Rushes to do things	Falling when he/she rushes to do things	Falling when rushing to do things
	Falling when he/she rushes to do things	Falling when rushing to do things
Rushes to do things	Falling when he/she rushes to do things Falling when he/she uses the stairs	Falling when rushing to do things Falling when using the stairs
Rushes to do things Theme 4: Care recipient's living environment		
Rushes to do things Theme 4: Care recipient's living environment Goes up or down stairs ^a	Falling when he/she uses the stairs	Falling when using the stairs
Rushes to do things Theme 4: Care recipient's living environment Goes up or down stairs ^a Goes to the toilet at night	Falling when he/she uses the stairs Falling when he/she goes to the toilet at night	Falling when using the stairs Falling when going to the toilet at night
Rushes to do things Theme 4: Care recipient's living environment Goes up or down stairs ^a Goes to the toilet at night Being alone at home	Falling when he/she uses the stairs Falling when he/she goes to the toilet at night Falling when he/she is alone at home	Falling when using the stairs Falling when going to the toilet at night Falling when at home alone
Rushes to do things Theme 4: Care recipient's living environment Goes up or down stairs ^a Goes to the toilet at night Being alone at home Goes out alone	Falling when he/she uses the stairs Falling when he/she goes to the toilet at night Falling when he/she is alone at home Falling when he/she goes out alone	Falling when using the stairs Falling when going to the toilet at night Falling when at home alone Falling when going out alone
Rushes to do things Theme 4: Care recipient's living environment Goes up or down stairs ^a Goes to the toilet at night Being alone at home Goes out alone Walks on a slippery surface (e.g. wet or icy) ^a	Falling when he/she uses the stairs Falling when he/she goes to the toilet at night Falling when he/she is alone at home Falling when he/she goes out alone Falling when he/she walks on a slippery surface	Falling when using the stairs Falling when going to the toilet at night Falling when at home alone Falling when going out alone Falling when walking on a slippery surface
Rushes to do things Theme 4: Care recipient's living environment Goes up or down stairs ^a Goes to the toilet at night Being alone at home Goes out alone Walks on a slippery surface (e.g. wet or icy) ^a Walks in a place with crowds ^a Walks on an uneven surface (e.g. rocky ground,	Falling when he/she uses the stairs Falling when he/she goes to the toilet at night Falling when he/she is alone at home Falling when he/she goes out alone Falling when he/she walks on a slippery surface Falling when he/she walks in crowded places	Falling when using the stairs Falling when going to the toilet at night Falling when at home alone Falling when going out alone Falling when walking on a slippery surface Falling when walking in crowded places
Rushes to do things Theme 4: Care recipient's living environment Goes up or down stairs ^a Goes to the toilet at night Being alone at home Goes out alone Walks on a slippery surface (e.g. wet or icy) ^a Walks in a place with crowds ^a Walks on an uneven surface (e.g. rocky ground, poorly maintained pavement) ^a	Falling when he/she uses the stairs Falling when he/she goes to the toilet at night Falling when he/she is alone at home Falling when he/she goes out alone Falling when he/she walks on a slippery surface Falling when he/she walks in crowded places Falling when he/she walks on an uneven surface	Falling when using the stairs Falling when going to the toilet at night Falling when at home alone Falling when going out alone Falling when walking on a slippery surface Falling when walking in crowded places Falling when walking on an uneven surface

Not having enough knowledge to stop a fall	Not being able to prevent the person I am caring for from falling	Deleted
Not being with my care recipient when he/she needs me	Deleted	Deleted
Not keeping an eye on my care recipient	Deleted	Deleted
Not having enough time for myself	Deleted	Deleted
Not having anyone to help me with the care	Deleted	Deleted

 $^{{}^{}a}Items\ modified\ from\ the\ Falls\ Efficacy\ Scale-International\ (FES-I);\ {}^{b}Item\ from\ the\ Fall-related\ Impulsive\ Behaviour\ Scale\ (FIBS).}$

CHAPTER 8: GENERAL DISCUSSION

8.1 Overview

The overarching aim of this study was to develop and validate an instrument for measuring the concern of carers about their care recipients' risk of falling. In this chapter, the findings are discussed in terms of how they answer the research questions outlined in Chapter One. The chapter also addresses the study conceptualisation, challenges, strengths, and limitations. The chapter concludes with the study implications and recommendations for future research.

Fear of falling is a common issue among older people, which can lead to activity restriction, social isolation, and a reduction in quality of life (Hughes et al., 2015; van der Meulen et al., 2014). Older people's fear of falling could predict future falls, functional disability, and an increased risk of admission to long-term care (Auais et al., 2017; Cumming et al., 2000). Informal carers such as family and friends are crucial to help older people cope with their fear of falling (Host et al., 2011; Huang, 2005). However, the lack of support from family members may result in older people adopting negative strategies such as activity restriction to avoid falling (Huang, 2005).

Carers are important partners in the delivery of care and fall prevention for older people at home. While there is a large body of research around fear of falling among older people, few studies have explored the significance of this fear (concern) among carers. This knowledge is necessary for healthcare professionals to provide support for carers when preventing their older people (care recipients) from falling. Healthcare professionals

supporting carers ensure that the fall prevention strategies developed for older people are acceptable and achievable at home (Wilkinson et al., 2018).

An exploratory sequential design was used to address the research questions in this study. During Phase One, an integrative review (refer to Paper 3) and descriptive qualitative study (refer to Paper 5) were conducted to explore the concern of carers about their care recipients' risk of falling. During Phase Two, the list of items generated in Phase One was used to construct an instrument for measuring the fall concern of carers (refer to Paper 6). An expert panel and carers assisted with reviewing the carers' fall concern instrument (CFC-I). During Phase Three, the CFC-I was reviewed for construct validity and compared with the qualitative findings from Phase One (refer to Paper 7).

What are the carers' concerns for their care recipients' risk of falling?

The integrative review highlighted that most previous research focused on the concern of carers looking after care recipients at high risk of falling. This includes care recipients with a history of falls or diagnosed with medical conditions that affect their functional mobility like Parkinson's disease and stroke. The possibility of care recipients falling is a common concern among carers, as is the potential consequence of falling and the care recipients' lack of awareness of their fall risk. No validated multi-item instrument designed to measure the fall concern of carers. The knowledge gaps identified in this review led to the qualitative study which explored the experience of carers looking after older people regarding their falls and fall risk.

In the descriptive qualitative study conducted as part of this doctoral research, the fall concern of some carers was influenced by their perception of fall and fall risk. Others

were concerned about the care recipients not listening to fall prevention advice and taking risks in performing daily activities. The majority of carers discussed their care recipients' old age and chronic illnesses which contributed to cognitive, and functional decline, and an increased risk of falling. Regarding environmental risk factors, many carers were especially concerned about care recipients living alone and falling when using the stairs.

What are the items used to form the instrument for measuring carers' fall concern? After collecting and analysing the qualitative findings, the CFC-I was constructed using quotes from the interviews. These quotes were grouped into four main themes such as 1) the carers' perception of fall and fall risk, 2) care recipients' behaviour and attitude towards fall risk, 3) health and function, and 4) living environment. The CFC-I also included items modified from the Falls Efficacy Scale International (FES-I) and the Fall-related Impulsive Behaviour Scale (FIBS). An expert panel reviewed the questions for the initial CFC-I for its content validity. The revised 31-item CFC-I was then completed by 32 carers in a pilot test to assess for the initial validity and reliability.

Does the instrument constructed accurately measure the carers' fall concern?

The revised 31-item CFC-I demonstrated good initial validity and reliability during Phase Two. Most of the carers (90.6%) felt that the questions accurately capture the concerns about their care recipients' risk of falling. A decision to remove nine items with an itemtotal correlation of 0.50 and below ensured all items contributed positively to the instrument's internal consistency. Another five items that carers had difficulty understanding or repeated (in the content) were removed. The remaining 17-item CFC-I reported a Cronbach alpha of 0.94 and an improved average item correlation of 0.5.

Phase Three extended the evaluation of the CFC-I psychometric properties to 143 carers. An additional item with item-total correlation below the recommended value of 0.3 was subsequently removed (DeVon et al., 2007). The final instrument reported excellent internal reliability and demonstrated that the level of concern among carers increased with the number of falls sustained by the care recipients. Post hoc analysis suggested that only carers of care recipients having recurrent falls had significantly higher levels of fall concern than those carers of care recipients with two and fewer falls.

8.2 Study Conceptualisation

As a registered nurse who had worked extensively with older patients, the candidate is passionate about the research into fear of falling among older people. This study began as a quantitative investigation into the disparity in the level of fear of falling between care recipients and their carers and its impact on fall risk. However, the candidate discovered that there was little research on carers about their fear of falling and no instrument to measure this fear. With support from supervisors, it was decided to change the study topic to the fall concern of carers. The findings from this thesis will contribute to the expansion of knowledge around the experience and concern of carers related to their care recipients or loved ones falling and fall prevention at home.

8.3 Challenges

A major challenge was defining the boundaries of fall concern among carers. The author had to remind himself that the instrument is neither measuring the burden of care, nor assessing the physiological health of care recipients (older people). During the qualitative interview in Phase One, the author also realised that participants tend to discuss their caregiving burden, instead of the concern about falls. He was required to respectfully

remind participants when they deviated from the questions to refocus on the issue about concern and not the burden of caring.

In this study, a carer was defined as an individual who provides unpaid care, such as support in daily activities to an older person aged 60 and above living at home. Some people who fulfilled the role of a carer do not identify themselves as carers and were therefore reluctant to participate in this study. Furthermore, there is a large proportion of older people living alone in Australia without any form of carer (De Vaus & Qu, 2015). This demographic characteristic was unfamiliar to the candidate since children are encouraged to live with their parents in Singapore, so there is a relatively low proportion of older adults living alone as they age (Linton, Gubhaju, & Chan, 2018).

8.4 Strengths

The qualitative component of this thesis has helped to fill the research gap related to the experiences of carers at home caring for the general population of older people who are at risk of falling. The qualitative study provided insight into common fall prevention strategies used by carers and the support they receive in preventing their care recipients from falling. This finding is crucial for healthcare professionals to recognise the knowledge needs of carers concerning the identification of fall risk and introduction of strategies to prevent falls in the home environment. It also provides a reference point for nurses and other healthcare professionals to direct interventions necessary to support carers in managing the fall risk of their care recipients.

The CFC-I is the first multi-item instrument developed to measure the concern of carers about the risk of falling among their care recipients. Of significance, the items were

constructed from the experiences and perspectives of carers, before consulting the experts of related fields for further modification. The qualitative interviews showed that carers' fall concern might involve other issues such as the risk of falling, the potential consequences of falls, and non-compliance to safety. These concerns were in contrast to the fear of falling among older people, which were mainly related to their physiological function and the restriction in activities (Huang, 2006). The construction of the CFC-I also supports the hypothesis that the fall concern of carers is multi-dimensional.

Another major strength of this study was the use of an evidence-based and systematic approach in developing the CFC-I. The study was conducted using an exploratory sequential design and followed steps recommended for instrument development. The qualitative research and use of expert opinions ensured that the CFC-I sampled a comprehensive range of attributes related to the fall concern of carers. Furthermore, the CFC-I included items modified from two previously validated instruments, the FES-I and FIBS, which measure fall-related issues among older people (Whitney et al., 2013; Yardley et al., 2005). The development process was rigorous as items of the CFC-I went through multiple rounds of review and revision during Phase Two and Three. The initial psychometric analysis showed that CFC-I is a reliable and valid instrument.

During the item development process, priority considerations on the instrument design were made to ensure the questionnaire was short and easy to understand. First, the consistency of wording for each statement was ensured so that a higher score denotes a higher level of concern (DeVellis, 2003). Second, a five-point Likert scale with "1 being not applicable/ not at all concerned" to "5 being extremely concerned" was used for the instrument's response as the response format can discriminate different levels of fall

concern, but it is not too complicated for carers to identify the differences. This is important since most carers are older, and often have limited education. Thirdly, repeated items with similar meanings were removed to ensure that the instrument was concise. Questions with low item-scale correlation, or which had been perceived by the experts as not accurately measuring the fall concern of carers were also excluded.

The sample size of 143 participants were sufficient for factor analysis with a significant Bartlett's test of sphericity of <0.001 and Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy of 0.88, which is above the required value of 0.6 (Pallant, 2011). This sample size has also achieved a minimum of five participants per question in the 16-item CFC-I required for factor analysis (DeVon et al., 2007).

Lastly, the distribution of CFC-I scores was close to normal meaning it is likely to be sensitive to change after an intervention (Delbaere, Close, Mikolaizak, et al., 2010). It was further hypothesised that the CFC-I is suitable for use by carers with a higher level of concern, such as those looking after older people with a higher disability, or risk of falling.

8.5 Limitations

The main limitation of this study was the inability to conduct test-retest reliability for the CFC-I. As mentioned in Chapter Four of this thesis, the follow-up survey was removed due to poor participants' response in Phase One and Two studies. It was not possible to follow-up with the participants since most carers were recruited from the outpatient clinic at John Hunter Hospital. These carers had accompanied their care recipients for the outpatient ambulatory care appointment, which only occurred once every few months. It

was also anticipated that the need for written consent to obtain contact details from carers could potentially limit their interest to participate in this study, particularly when they were in the waiting room expecting to be called to their appointment at any moment.

The cut-off scores to differentiate between carers with higher and lower levels of concern were not established because the CFC-I was not designed to be a diagnostic or screening tool. Instead the multi-item CFC-I was intended to provide an alternative to the existing single-item instrument, and to assist healthcare professionals in identifying specific situations which could contribute to the fall concern of carers. It is also difficult to establish the validity of cut-points for the CFC-I with the lack of a gold standard measure for the impact of the care recipients' fall risk on their carers (Delbaere, Close, Mikolaizak, et al., 2010).

The assessment for fall concern was limited to 16 questions in the CFC-I. Carers choosing the option of "not applicable" for items in the CFC-I does not necessarily mean they have no concern about their care recipients' risk of falling. There could be other factors which contribute to the fall concern of carers. However, these factors are considered the most common issues affecting carers related to the risk of falling among older people.

The CFC-I has not been tested beyond the targeted population of family carers looking after the general population of older people living at home. As mentioned in Papers 6 and 7, some activity-related questions in the CFC-I are not applicable for carers of older people with a lower functional ability, such as those using wheelchairs or who are bedbound. Likewise, the CFC-I is not validated for professional carers of institutionalised older people as the questions assume that the care recipients are living in the community.

The CFC-I may be limited in assessing the fall concern of professional carers looking after older people at home. For instance, professional carers may experience greater psychological distress as they could be accused of negligence if the care recipients fall while under their care (Ang, O'Brien, et al., 2018b).

In some Asian countries, foreign domestic workers (FDWs) are commonly employed as surrogate carers for older people in their homes (Ang, Wilson, et al., 2018a). The CFC-I is not validated to measure fall concern of FDWs. Unlike professional carers (i.e. nurses), FDWs face many challenges in providing care to older people who are often their employers. These challenges include FDWs being in a subservient position which prevents them effectively initiating fall prevention strategies at home, lacking of formal aged care training, and having to complete other household responsibilities such as cooking and cleaning (Ang, Wilson, et al., 2018a).

8.6 Implications for practice

Carers are crucial in providing care and preventing their care recipients from falling at home. The qualitative component of this doctoral study revealed that the care recipients' falls and risk of falling can adversely affect their carers. It has also highlighted the need to provide greater health service or home care support for carers when implementing fall prevention strategies at home. Healthcare professionals are encouraged to ensure that carers demonstrate adequate awareness of fall risk and confidence in initiating appropriate fall prevention strategies for their care recipients. A deeper understanding of fall concern enables healthcare professionals to recommend fall prevention plans that are specifically tailored for older people and their carers. Such process could reduce the incidence of older people falling at home and admission to emergency care due to the fall.

Another significant contribution of this study was the development of CFC-I. This newly developed instrument allows healthcare professionals to measure the psychological impact of falling on carers and can be used to assess the efficacy of a fall program designed for carers. The multiple factors associated with carers' concern also indicate a need for interdisciplinary collaboration between healthcare professionals to mitigate the fall risk of older people. Healthcare professionals such as the Aged Care Assessment Team, community nurses and discharging nurse are encouraged to incorporate the CFC-I into the assessment of older people when determining the type of services, they need. For example, they may refer carers with concerns related to environmental risk factors to the occupational therapist for ergonomic assessment of the home environment.

8.7 Recommendations for Future Research

As instrument development is an iterative process, more studies are needed to ascertain the psychometric integrity of the CFC-I. Specifically, researchers are encouraged to investigate the test-retest and inter-rater reliability of the CFC-I. These tests are crucial to determine if the CFC-I consistently measures the fall concern of carers.

Another step in the validation of the CFC-I is to examine the predictive validity of the instrument. Researchers may determine the association between changes in CFC-I scores and the frequency of falls. By confirming the predictive validity, healthcare professionals can assess the fall risk of older people who cannot report or articulate their fall risk from the report of the carers' fall concern.

Besides investigating the psychometric properties of the CFC-I, prospective studies are needed to examine the association of fall concern with other health determinants of carers and their care recipients. For example, future researchers may investigate the relationship between the fall concern of carers and psychological factors such as anxiety and depression. A significant association between both variables would require healthcare professionals to attend to the mental health of carers when providing support for older people with the risk of falling. Likewise, studies could assess caregivers' burden and quality of life and its effects on the level of concern among carers.

It is also useful to determine the availability of support services in mitigating the fall concern of carers. As discussed in the qualitative interviews during Phase One, not all participants received support from the healthcare professionals, or their family members and friends. However, it appears that carers with external support have a lower level of concern and greater confidence in managing their care recipients' risk of falling. Therefore, the availability of the CFC-I would provide a means of quantifying this relationship.

Finally, future studies may validate the CFC-I in a different population of carers to determine the effect of cultural influence and health conditions of care recipients. Being the only multi-item instrument developed for measuring the fall concern of carers, researchers may translate and validate the CFC-I in other languages.

8.8 Summary

In order to seek the support from carers in implementing fall prevention strategies for older people, it is crucial to know the carers' level of fall concern in different circumstances related to their care recipients' risk of falling. The 16-item CFC-I was specially designed to measure the level of concern among carers regarding their care

recipients' risk of falling. The instrument was developed progressively and sequentially over three phases, which included conducting an integrative review and qualitative interview, piloting the CFC-I, and then applying to a larger sample after improving internal consistency. The CFC-I is a multi-item and multi-dimensional instrument measuring three factors: carers' perception of fall and fall risk, care recipients' health and function, and their living environment.

CHAPTER 9: CONCLUSION

With a global aging population, older people are expected to live in their own homes (World Health Organisation, 2018a). Family carers are crucial in providing support in daily activities and preventing their older people (care recipients) from falling at home (Ang, Wilson, et al., 2018a). However, there is limited research about the experiences of carers looking after the general population of older people specifically in regard to their risk of falling.

A comprehensive search revealed that carers are affected by their care recipients falling. The psychological impact of falls can influence the physical and psychosocial health and increase caregiving burden for carers (Davey et al., 2004). Despite its significance, only three studies have attempted to quantify the concern of carers regarding the risk of their care recipients falling (Faes et al., 2011; Forster & Young, 1995; Liddle & Gilleard, 1995) and none of these studies describe the psychometric attributes of the single-item instruments used. Most studies focused on the experiences of carers looking after care recipients with a history of falls or suffering from chronic conditions such as Parkinson's disease that put them at a higher risk of falling. This thesis explored the concern of carers looking after the general population of older people about their fall risk and developed a multi-item instrument to measure this concern.

The qualitative study revealed that carers are concerned about their care recipients falling even when they have not fallen. Causes of concern vary between carers and include the consequences of falls, the older person being non-receptive to fall prevention advice, and environmental factors. The quantitative study led to the development of the Carers' Fall

Concern Instrument (CFC-I) to measure the level of concern of carers about the risk of their care recipients falling.

The final CFC-I comprises 16 questions assessing issues related to carers' perception of fall and fall risk, the care recipients' health and function, and their living environment (Appendix 25). The carers rated their level of concern for each statement using a five-point Likert scale from 1 being "not applicable/not concerned at all" to 5 being "extremely concerned." The level of fall concern is calculated by the total score for all 16 questions with higher score indicating higher level of concern. The initial analysis of the CFC-I provided good validity and reliability. Most importantly, the CFC-I scores are able to discriminate between carers looking after older people with and without a history of recurrent falls, which is a significant predictor of fall risk (American Geriatrics Society & British Geriatrics Society, 2011).

Since the psychometric data obtained from the CFC-I in this study are preliminary, the researchers recommend further research on the predictive validity of this instrument and its applicability in different cultural settings. As the only multi-item instrument available to measure carers concern, the CFC-I provides a quick screening instrument to measure the psychological impact on carers about their care recipients' risk of falling.

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APPENDICES

Appendix 1. Documentation for Paper 3 Acceptance

15/08/2019

Mail - Seng Giap Marcus Ang - Outlook

Your Submission

em.singaporemedj.0.6447c4.2b55056e@editorialmanager.com on behalf of

Singapore Medical Journal <em@editorialmanager.com>

Mon 1/7/2019 8:20 PM

To: Seng Giap Marcus Ang <SengGiapMarcus.Ang@uon.edu.au>

Dear Mr. Ang,

Tracking No.: SMJ-2018-182R3

Manuscript Title: Carers' concern for older people falling at home: An integrative review

Singapore Medical Journal

I am pleased to inform you that the above-referenced paper has been favourably reviewed, and has been accepted for publication in the Singapore Medical Journal, on Jun 28, 2019.

The editorial team will copyedit your article shortly and will contact you with queries, if any, to make the manuscript more readable and to conform to the Journal's house style.

Congratulations on having your work accepted by the Singapore Medical Journal.

With kind regards,

A/Prof Poh Kian Keong Editor-in-Chief Singapore Medical Journal

Comments from the Editors and Reviewers (if any):

In compliance with data protection regulations, you may request that we remove your personal registration details at any time. (Use the following URL:

https://www.editorialmanager.com/singaporemedj/login.asp?a=r). Please contact the publication office if you have any questions.

Appendix 2. Hunter New England Human Research Ethics Committee Approval



5 October 2017

Prof Anthony O'Brien Faculty of Health and Medicine School of Nursing and Midwifery University of Newcastle

Dear Professor O'Brien

Re: Carers concerns about the older persons (17/09/20/4.03)

HNEHREC Reference No: 17/09/20/4.03 NSW HREC Reference No: HREC/17/HNE/419

Thank you for submitting the above application for single ethical review for a multi-centre study. This project was first considered by the Hunter New England Human Research Ethics Committee at its meeting held on 20 September 2017. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review. The Committee's Terms of Reference are available from the Hunter New England Local Health District website.

I am pleased to advise, the Hunter New England Human Research Ethics Committee has determined that the above protocol meets the requirements of the National Statement on Ethical Conduct in Human Research and following acceptance of the requested clarifications and revised Information Statement and Consent Form by Dr Nicole Gerrand Manager, Research Ethics & Governance, under delegated authority from the Committee, grants ethical approval of the above project.

The National Statement on Ethical Conduct in Human Research (2007), which the Committee is obliged to adhere to, include the requirement that the Committee monitors the research protocols it has approved. Ethics Approval will be ongoing subject to the following conditions:

- A report on the progress of the above protocol is to be submitted at 12 monthly intervals. A proforma for the annual report will be sent at the beginning of the month of the anniversary of approval. Your review date is October 2018.
- > All variations or amendments to this protocol must be forwarded to, and approved by, the Hunter New England Human Research Ethics Committee prior to their implementation.
- A final report must be submitted at the completion of the above protocol, that is, after data analysis has been completed and a final report compiled.
- Adherence to the safety reporting requirements of the with the NHMRC Safety Monitoring and Reporting Guidance for Therapeutic Goods Trials (November 2016) available at

Hunter New England Research Ethics & Governance Office

Locked Bag No 1 New Lambton NSW 2305

Telephone: (02) 49214950 Email: HNELHD-HREC@hnehealth.nsw.gov.au

https://www.nhmrc.gov.au/ files nhmrc/file/publications/16469 nhmrc - ahec position statement-web.pdf

If for some reason the above protocol does not commence (for example it does not receive funding); is suspended or discontinued, please inform Dr Nicole Gerrand as soon as possible.

The following documentation has been reviewed and approved by the Hunter New England Human Research Ethics Committee:

Document	Version	Date
NEAF [Locked Code AU/1/9E4038]	-	-
Cover invitation letter	1	22 September 2017
Master Information for Participants Phase 1	2	22 September 2017
Master Participant Consent Form Phase 1	2	22 September 2017
Master Information for Participants Phase 2	2	22 September 2017
Master Information for Participants Phase 3	3	2 October 2017
Recruitment flyer	-	undated
Data Collection Form Phase 1	3	3 October 2017
Data Collection Form Phase 2	2	22 September 2017
Data Collection Form Phase 3 – Baseline	2	22 September 2017
Email for online survey	1	22 September 2017
Reminder Email	2	22 September 2017
Social media wordings for HMRI/Carers NSW website	2	22 September 2017

Approval has been granted for this study to take place at the following sites:

- Hunter Medical Research Institute
- John Hunter Hospital

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained.

A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

Should you have any concerns or questions about your research, please contact Dr Gerrand as per the details at the bottom of the page. The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Please quote 17/09/20/5.03 in all correspondence.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For: Ms M Hunter

Chair

Hunter New England Human Research Ethics Committee

Hunter New England Research Ethics & Governance Office
Locked Bag No 1
New Lambton NSW 2305
Telephone: (02) 49214950
Email: HNELHD-HREC@hnehealth.nsw.gov.au

Appendix 3. University Human Research Ethics Committee

Registration 1

RESEARCH INTEGRITY UNIT



Registration of External HREC Approval

To Chief Investigator or Project Supervisor:

Cc Co-investigators / Research Students:

Mr Seng Giap Marcus Ang
Doctor Amanda Wilson

Re Protocol: Carers concerns about the older persons

 Date:
 17-Oct-2017

 Reference No:
 H-2017-0343

 External HREC Reference No:
 17/09/20/4.03

Thank you for your **Initial Application** submission to the Research Integrity Unit (RIU) seeking to register an External HREC Approval in relation to the above protocol.

Your submission was considered under an Administrative Review by the Ethics Administrator.

I am pleased to advise that the decision on your submission is External HREC Approval Noted effective 17-Oct-2017.

As the approval of an External HREC has been noted, this registration is valid for the approval period determined by that HREC.

Your reference number is H-2017-0343.

PLEASE NOTE:

As the RIU has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University's RIU, via RIMS.

Linkage of ethics approval to a new Grant

Registered External HREC approvals cannot be assigned to a new grant or award (ie those that were not identified in the initial registration submission) without confirmation from the RIU.

Best wishes for a successful project.

Mr Alan Hales

Manager, Research Compliance, Integrity and Policy

For communications and enquiries:

Human Research Ethics Administration

Research & Innovation Services Research Integrity Unit The University of Newcastle

Appendix 4. Hunter Medical Research Institute Approval



ABN 27 081 436 919 Locked Bag 1000 New Lambton NSW 2305

> 1300 993 822 P info@hmri.org.au E hmri.org.au W

Professor Anthony O'Brien School of Nursing and Midwifery Faculty of Health and Medicine University of Newcastle CALLAGHAN NSW 2308

Dear Professor O'Brien,

I would like to inform you of the HMRI Research Register Management Committee's decision to approve your request for volunteers from the Research Register to participate in the study "Carers concerns about the older persons"

The Register will approach up to 200 selected members by mail on your behalf, inviting them to participate in the study. This letter will include an invitation to participate in the study, a copy of the participant information sheet, and a Study Response Form. It should be noted that the study consent form will not be included. It is the responsibility of the researcher to gain consent from study participants.

Register members will be asked to respond to the invitation by ticking a box on the Study Response Form and returning this to the Register in a pre-paid envelope. Members who wish to participate in the study will be told to expect a phone call from the research group within the following two weeks.

The names and contact details of those wishing to participate in the study will be forwarded to the researcher involved in organizing study participation.

Please note: The researcher is expected to inform the Register of the names of those who accept the conditions of the study and participate, decline, are ineligible, complete the study or withdraw.

Researchers accessing participants via the HMRI Research Register are required to provide the Register with an annual progress report and a final report. The information from these reports will be used in the HMRI Annual Report and to update information about current HMRI affiliated research activities in the HMRI Research Register newsletter and website, as a means of maintaining members' interest in research activities. Individual researchers will have the opportunity to preview this material before publication.

If you have any further questions, please contact the HMRI Research Register Coordinator on 40420587.

Yours sincerely,

Trisha D'Accione Coordinator, HMRI Research Register P: 40420587 F: 40420001 E: trisha.daccione@hmri.com.au

cc: Seng Giap Marcus Ang

In partnership with our Community





I FADING BESEARCH FOR LIFE CHANGING RESULTS

hmri.org.au

Appendix 5. Site-Specific Assessment Authorisation



18 October 2017

Prof Anthony O'Brien Faculty of Health and Medicine School of Nursing and Midwifery University of Newcastle

Dear Professor O'Brien

Re: Carers concerns about the older persons (17/09/20/4.03)

HNEHREC Reference No: 17/09/20/4.03 NSW HREC Reference No: HREC/17/HNE/419

SSA Reference No: SSA/17/HNE/420

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

- **Hunter Medical Research Institute**
- John Hunter Hospital

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

- 1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
- 2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer;
- 3. Annual Report submitted to the lead HREC for review and the acknowledgment, are copied to the research governance officer;
- 4. Final Report submitted to the lead HREC for review and the acknowledgement, are copied to the research governance officer.

Yours faithfully

Dr Nicole Gerrand Research Governance Officer **Hunter New England Local Health District**

Hunter New England Research Ethics & Governance Office

Locked Bag No 1 New Lambton NSW 2305 Telephone: (02) 49214950

Email: HNELHD-HREC@Inhehealth.nsw.gov.au/ethics/Pages/Research-Ethics-and-Governance-Unit.aspx

Appendix 6. Variation 1



12 December 2017

Prof Anthony O'Brien Faculty of Health and Medicine School of Nursing and Midwifery University of Newcastle

Dear Professor O'Brien

Re: Carers concerns about the older persons (17/09/20/4.03)

HNEHREC Reference No: 17/09/20/4.03 NSW HREC Reference No: HREC/17/HNE/419 SSA Reference No: SSA/17/HNE/420

Thank you for submitting a request for an amendment to the above project. This amendment was reviewed by the Hunter New England Human Research Ethics Committee. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review.

I am pleased to advise that the Hunter New England Human Research Ethics Committee has determined the variation meets the requirements of the National Statement on Ethical Conduct in Human Research and has granted ethical approval for the following amendment requests:

Document	Version	Date
Data Collection Form Phase 1	4.0	24 November 2017
Data Collection Form Phase 2	3.0	24 November 2017
Data Collection Form Phase 3 – Baseline	3.0	24 November 2017

- For the addition of Rankin Park Centre Day Hospital as recruitment site

Approval has been granted for this study to take place at the following sites:

- **Hunter Medical Research Institute**
- John Hunter Hospital
- **Rankin Park Centre**

The National Statement on Ethical Conduct in Human Research (2007), which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. Ethics Approval will be ongoing subject to the following conditions:

Hunter New England Research Ethics & Governance Office

Locked Bag No 1 New Lambton NSW 2305 Telephone: (02) 49214950

Email: HNELHD-HREC@hnehealth.nsw.gov.au http://www.hnehealth.nsw.gov.au/ethics/Pages/Research-Ethics-and-Governance-Unit.aspx

- A report on the progress of the above protocol is to be submitted at 12 monthly intervals. A proforma for the annual report will be sent at the beginning of the month of the anniversary of approval. Your review date is October 2018.
- All variations or amendments to this protocol must be forwarded to and approved by the Hunter New England Human Research Ethics Committee prior to their implementation.
- > A final report must be submitted at the completion of the above protocol, that is, after data analysis has been completed and a final report compiled.
- Adherence to the safety reporting requirements of the NHMRC Safety Monitoring and Reporting Guidance for Therapeutic Goods Trials (November 2016) available at https://www.nhmrc.gov.au/ files nhmrc/file/publications/16469 nhmrc.gov.au/ files nhmrc - ahec.position.gov.au/ files nhmrc - nhmrc - nhmrc/file/publications/16469 nhmrc/file/publications/16469 nhmrc/file/publications/16469 nhmrc/file/publications/16469 https://ahec.position.gov.au/ nhmrc/file/publications/16469 nhmrc/file/publication.gov.au/ nhmrc/file/publication.gov.au/ nhmrc
- If for some reason the above protocol does not commence (for example it does not receive funding); is suspended or discontinued, please inform Dr Nicole Gerrand as soon as possible.

The Hunter New England Human Research Ethics Committee also has delegated authority to approve the commencement of this research on behalf of the Hunter New England Local Health District. This research may therefore commence.

Should you have any queries about your project please contact Dr Nicole Gerrand as per the contact details at the bottom of the page. The Hunter New England Human Research Ethics Committee Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Hunter New England Local Health District website.

Please quote 17/09/20/5.03 in all correspondence.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For: Ms M Hunter Chair

Hunter New England Human Research Ethics Committee

Appendix 7. Site-Specific Assessment Authorisation for Rankin Park Centre



19 December 2017

Prof Anthony O'Brien Faculty of Health and Medicine School of Nursing and Midwifery University of Newcastle

Dear Professor O'Brien.

Re: Carers concerns about the older persons (17/09/20/4.03)

HNEHREC Reference No: 17/09/20/4.03 NSW HREC Reference No: HREC/17/HNE/419 SSA Reference No: SSA/17/HNE/610

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

Rankin Park Centre

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

- 1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
- 2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer;
- 3. Annual Report submitted to the lead HREC for review and the acknowledgment, are copied to the research governance officer;
- Final Report submitted to the lead HREC for review and the acknowledgement, are copied to the research governance officer.

Yours faithfully

Dr Nicole Gerrand Research Governance Officer Hunter New England Local Health District

> **Hunter New England Research Ethics & Governance Office** Locked Bag No 1 New Lambton NSW 2305 Telephone: (02) 49214950 Email: HNELHD-HREC@hnehealth.nsw.gov.au http://www.hnehealth.nsw.gov.au/ethics/Pages/Research-Ethics-and-Governance-Unit.aspx

Appendix 8. Variation 2



7 May 2018

Prof Anthony O'Brien Faculty of Health and Medicine School of Nursing and Midwifery University of Newcastle

Dear Professor O'Brien

Re: Carers concerns about the older persons (17/09/20/4.03)

HNEHREC Reference No: 17/09/20/4.03 NSW HREC Reference No: HREC/17/HNE/419 SSA Reference No: SSA/17/HNE/420

Thank you for submitting a request for an amendment to the above project. This amendment was reviewed by the Hunter New England Human Research Ethics Committee. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review.

I am pleased to advise that the Hunter New England Human Research Ethics Committee has determined the variation meets the requirements of the National Statement on Ethical Conduct in Human Research and has granted ethical approval for the following amendment requests:

Document	Version	Date
Data Collection Form Phase 2	4.0	26 April 2018
Data Collection Form Phase 3 – Baseline	4.0	26 April 2018
Social media wordings for HMRI/Carers NSW website	3.0	26 April 2018
SMS message	1	4 May 2018

- To include paid advertising of the study via HMRI social media platform;
- For changes to social media wording for HMRI/Carers NSW website; and
- To SMS participants from Phase 1 to participate in Phases 2 and 3 as recruitment method

Approval has been granted for this study to take place at the following sites:

- **Hunter Medical Research Institute**
- John Hunter Hospital
- **Rankin Park Centre**

Hunter New England Research Ethics & Governance Office

Locked Bag No 1 New Lambton NSW 2305

Telephone: (02) 49214950

Email: HNELHD-HREC@Innehealth.nsw.gov.au/ethics/Pages/Research-Ethics-and-Governance-Unit.aspx

The National Statement on Ethical Conduct in Human Research (2007), which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. Ethics Approval will be ongoing subject to the following conditions:

- A report on the progress of the above protocol is to be submitted at 12 monthly intervals. A proforma for the annual report will be sent at the beginning of the month of the anniversary of approval. Your review date is October 2018.
- > All variations or amendments to this protocol must be forwarded to and approved by the Hunter New England Human Research Ethics Committee prior to their implementation.
- > A final report must be submitted at the completion of the above protocol, that is, after data analysis has been completed and a final report compiled.
- Adherence to the safety reporting requirements of the NHMRC Safety Monitoring and Reporting Guidance for Therapeutic Goods Trials (November 2016) available at https://www.nhmrc.gov.au/ files https://www.nhmrc.gov.au/ files nhmrc - ahec position statement-web.pdf
- If for some reason the above protocol does not commence (for example it does not receive funding); is suspended or discontinued, please inform Dr Nicole Gerrand as soon as possible.

The Hunter New England Human Research Ethics Committee also has delegated authority to approve the commencement of this research on behalf of the Hunter New England Local Health District. This research may therefore commence.

Should you have any queries about your project please contact Dr Nicole Gerrand as per the contact details at the bottom of the page. The Hunter New England Human Research Ethics Committee Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Hunter New England Local Health District website.

Please quote 17/09/20/5.03 in all correspondence.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For: Ms M Hunter

Chair

Hunter New England Human Research Ethics Committee

Appendix 9. University Human Research Ethics Committee

Registration 2

RESEARCH INTEGRITY UNIT



Registration of External HREC Approval

To Chief Investigator or Project Supervisor:

Cc Co-investigators / Research Students:

Mr Seng Giap Marcus Ang
Doctor Amanda Wilson

Re Protocol: Carers concerns about the older persons

 Date:
 15-May-2018

 Reference No:
 H-2017-0343

 External HREC Reference No:
 17/09/20/4.03

Thank you for your **Variation** submission to the Research Integrity Unit (RIU) seeking to register an External HREC Approval in relation to the above protocol.

Variation 1 - Approval obtained on 12 December 2017 1) Addition of Rankin Park Centre Day Hospital as recruitment site 2) Changes to demographic question on data collection form for Phase 1, 2 and 3 Variation 2 - Approval obtained on 7 May 2018 1) To sms participants from Phase 1 to participate in Phases 2 and 3 as recruitment method 2) To include paid advertising of the study via HMRI social media platform 3) Changes to social media wording for HMRI/Carers NSW website 4) Changes to questions on data collection form for Phase 2 and 3

Your submission was considered under an Administrative Review by the Ethics Administrator.

I am pleased to advise that the decision on your submission is External HREC Approval Noted effective 15-May-2018.

As the approval of an External HREC has been noted, this registration is valid for the approval period determined by that HREC.

Your reference number is H-2017-0343.

PLEASE NOTE:

As the RIU has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University's RIU, via RIMS.

Linkage of ethics approval to a new Grant

Registered External HREC approvals cannot be assigned to a new grant or award (ie those that were not identified in the initial registration submission) without confirmation from the RIU.

Best wishes for a successful project.

Mr Alan Hales

Manager, Research Compliance, Integrity and Policy

Appendix 10. Variation 3



5 June 2018

Prof Anthony O'Brien Faculty of Health and Medicine School of Nursing and Midwifery University of Newcastle

Dear Professor O'Brien

Re: Carers concerns about the older persons (17/09/20/4.03)

HNEHREC Reference No: 17/09/20/4.03 NSW HREC Reference No: HREC/17/HNE/419 SSA Reference No: SSA/17/HNE/420

Thank you for submitting a request for an amendment to the above project. This amendment was reviewed by the Hunter New England Human Research Ethics Committee. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review.

I am pleased to advise that the Hunter New England Human Research Ethics Committee has determined the variation meets the requirements of the National Statement on Ethical Conduct in Human Research and has granted ethical approval for the following amendment requests:

Document	Version	Date
Master Information for Participants Phase 3	4	29 May 2018
Data Collection Form Phase 3	5.0	29 May 2018
Social media wordings for HMRI/Carers NSW website	4.0	29 May 2018
Email for online survey	2.0	29 May 2018

- To remove the follow-up after 2 weeks during Phase 3 data collection

Approval has been granted for this study to take place at the following sites:

- Hunter Medical Research Institute
- John Hunter Hospital
- Rankin Park Centre

The National Statement on Ethical Conduct in Human Research (2007), which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. Ethics Approval will be ongoing subject to the following conditions:

Hunter New England Research Ethics & Governance Office
Locked Bag No 1
HRMC NSW 2300
Telephone: (02) 49214950
Email: HNELHD-HREC@hnehealth.nsw.gov.au

Email: HNELHD-HREC@hnehealth.nsw.gov.au http://www.hnehealth.nsw.gov.au/ethics/Pages/Research-Ethics-and-Governance-Unit.aspx

- > A report on the progress of the above protocol is to be submitted at 12 monthly intervals. A proforma for the annual report will be sent at the beginning of the month of the anniversary of approval. Your review date is **October 2018**.
- All variations or amendments to this protocol must be forwarded to and approved by the Hunter New England Human Research Ethics Committee prior to their implementation.
- > A final report must be submitted at the completion of the above protocol, that is, after data analysis has been completed and a final report compiled.
- Adherence to the safety reporting requirements of the NHMRC Safety Monitoring and Reporting Guidance for Therapeutic Goods Trials (November 2016) available at https://www.nhmrc.gov.au/ files https://www.nhmrc.gov.au/ files nhmrc - ahec position statement-web.pdf
- If for some reason the above protocol does not commence (for example it does not receive funding); is suspended or discontinued, please inform Dr Nicole Gerrand as soon as possible.

The Hunter New England Human Research Ethics Committee also has delegated authority to approve the commencement of this research on behalf of the Hunter New England Local Health District. This research may therefore commence.

Should you have any queries about your project please contact Dr Nicole Gerrand as per the contact details at the bottom of the page. The Hunter New England Human Research Ethics Committee Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Hunter New England Local Health District website.

Please quote 17/09/20/5.03 in all correspondence.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For: Ms M Hunter

Chair

Hunter New England Human Research Ethics Committee

Appendix 11. Variation 4



19 July 2018

Prof Anthony O'Brien Faculty of Health and Medicine School of Nursing and Midwifery University of Newcastle

Dear Professor O'Brien

Re: Carers concerns about the older persons (17/09/20/4.03)

HNEHREC Reference No: 17/09/20/4.03 NSW HREC Reference No: HREC/17/HNE/419 SSA Reference No: SSA/17/HNE/420

Thank you for submitting a request for an amendment to the above project. This amendment was reviewed by the Hunter New England Human Research Ethics Committee. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review.

I am pleased to advise that the Hunter New England Human Research Ethics Committee has determined the variation meets the requirements of the National Statement on Ethical Conduct in Human Research and has granted ethical approval for the following amendment requests:

Document	Version	Date
Master Information for Participants Phase 3	5	17 July 2018

Approval has been granted for this study to take place at the following sites:

- **Hunter Medical Research Institute**
- John Hunter Hospital
- Rankin Park Centre

The National Statement on Ethical Conduct in Human Research (2007), which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. Ethics Approval will be ongoing subject to the following conditions:

A report on the progress of the above protocol is to be submitted at 12 monthly intervals. A proforma for the annual report will be sent at the beginning of the month of the anniversary of approval. Your review date is October 2018.

Hunter New England Research Ethics & Governance Office

Locked Bag No 1 HRMC NSW 2300 Telephone: (02) 49214950

Email: HNELHD-HREC@hnehealth.nsw.gov.au/ethics/Pages/Research-Ethics-and-Governance-Unit.aspx

- All variations or amendments to this protocol must be forwarded to and approved by the Hunter New England Human Research Ethics Committee prior to their implementation.
- > A final report must be submitted at the completion of the above protocol, that is, after data analysis has been completed and a final report compiled.
- Adherence to the safety reporting requirements of the NHMRC Safety Monitoring and Reporting Guidance for Therapeutic Goods Trials (November 2016) available at https://www.nhmrc.gov.au/ files nhmrc/file/publications/16469 nhmrc.gov.au/ files <a href="
- If for some reason the above protocol does not commence (for example it does not receive funding); is suspended or discontinued, please inform Dr Nicole Gerrand as soon as possible.

The Hunter New England Human Research Ethics Committee also has delegated authority to approve the commencement of this research on behalf of the Hunter New England Local Health District. This research may therefore commence.

Should you have any queries about your project please contact Dr Nicole Gerrand as per the contact details at the bottom of the page. The Hunter New England Human Research Ethics Committee Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Hunter New England Local Health District website.

Please quote 17/09/20/5.03 in all correspondence.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For: Ms M Hunter

Chair

Hunter New England Human Research Ethics Committee

Appendix 12. University Human Research Ethics Committee Registration 3

RESEARCH INTEGRITY UNIT

Registration of External HREC Approval

To Chief Investigator or Project Supervisor: Professor Tony O'Brien
Cc Co-investigators / Research Students: Mr Seng Giap Marcus Ang

Re Protocol: Carers concerns about the older persons

 Date:
 08-Aug-2018

 Reference No:
 H-2017-0343

 External HREC Reference No:
 17/09/20/4.03

Thank you for your **Variation** submission to the Research Integrity Unit (RIU) seeking to register an External HREC Approval in relation to the above protocol.

Variation 3 - Approval obtained on 5 June 2018

- 1) Remove follow-up of participants after 2 weeks in Phase 3 data collection
- 2) Changes to Master Information for Participants in Phase 3, data collection form for Phase 3, social media wordings for HMRI/Carers NSW website, and email for online survey.

Variation 4 - Approval obtained on 19 July 2018

1) Include online survey link on Master Information for Participants Phase 3

Your submission was considered under an Administrative Review by the Ethics Administrator.

I am pleased to advise that the decision on your submission is External HREC Approval Noted effective 08-Aug-2018.

As the approval of an External HREC has been noted, this registration is valid for the approval period determined by that HREC.

Your reference number is H-2017-0343.

PLEASE NOTE:

As the RIU has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University's RIU, via RIMS.

Linkage of ethics approval to a new Grant

Registered External HREC approvals cannot be assigned to a new grant or award (ie those that were not identified in the initial registration submission) without confirmation from the RIU.

Best wishes for a successful project.

Mr Alan Hales

Appendix 13. Recruitment Flyer

Mr. Seng Giap Marcus Ang (Student Researcher)

School of Nursing and Midwifery Faculty of Health and Medicine, University of Newcastle Callaghan NSW 2308 Australia Telephone +61 0478 696 149; Fax +61 2 492 16301

Email: senggiapmarcus.ang@uon.edu.au



CARERS' FALLS CONCERN FOR OLDER PERSONS

Are you over the age of 18 years?

Are you the primary carer for a family member/ friend?

Is your family member/ friend over the age of 60 years?

Does your family member/ friend need help with their daily activities i.e. mobility, self-care, housekeeping?



ESEARCH

WE NEED YOU!

This University of Newcastle based project aims to provide understanding about your concern for older people at risk of falling at home and to develop a questionnaire to measure this concern. The study will consist of three phases. Phase one involves you being interviewed about your concern for older people at risk of falling. At phase two and three, you will complete an online survey to answer a questionnaire developed from phase one.

For more information about the study please contact:

Seng Giap Marcus Ang: senggiapmarcus.ang@uon.edu.au 0478 696 149 Prof Anthony Paul O'Brien: tony.obrien@newcastle.edu.au (02) 4985 4368 Dr. Amanda Wilson: amanda.wilson@newcastle.edu.au (02) 4921 6635

Complaints about this research

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference [17/09/20/4.03]. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Manager, Research Ethics and Governance Unit, Hunter New England Human Research Ethics Committee, Hunter New England Local Health District, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, email https://district.new.gov.au

Appendix 14. Social Media Wordings for HMRI/ Carers NSW

https://hmri.org.au/participate-research

Carers' falls concern for older persons

Are you a carer?

Researchers are seeking volunteers to understand about the carers' concern for older people at risk of falling at home.

Click here to find out more

https://hmri.org.au/participate-research/carers-fall-concern

Carers' falls concern for older persons

Are you a carer?

Researchers are seeking volunteers to understand more about carers' concern for older people at risk of falling at home.

Why is the research being done?

The purpose of the research is to develop an understanding about carers' concern for older people at risk of falling at home and to develop a questionnaire to measure this concern. After a fall, carers have been found to be afraid of their family members falling again. We think this may potentially affect carer's health and further care provided. We do not know if this concern affects the risk of older people falling again.

The study will consist of three phases. Phase one of the study is now completed. Phase two and three will require participants to complete an online survey asking about your concern for older people at risk of falling.

Who can participate in the research?

- You must be over the age of 18 years.
- You must be the primary carer for a family member/ friend.
- Your family member/ friend must be over the age of 60 years.
- Your family member/ friend need help with their daily activities e.g. mobility, self-care, housekeeping.

What would you be asked to do?

Participate in at least one of the three phases in the study.

- For phase one, undertake an audio recorded interview face-to-face at the University of Newcastle or over the telephone or at another place of your convenience.
- 2. For phase two, complete an online survey to assess your level of falls concern and provide feedback about the questionnaire in the survey.
- 3. For phase three, complete an online survey which assesses your level of falls concern.

The online surveys are anonymous and will take about 15 minutes to complete.

Click here to download the Participant Information Statement

Click here to access the online survey and participate in this study

If you have any queries, please contact Marcus Ang – email senggiapmarcus.ang@uon.edu.au or call 0478 696 149.

Social Media Wording (all posts will link to appropriate landing page on HMRI website or to the appropriate online survey and will be used on HMRI social media platforms as organic and paid advertising)

- 1) Researchers are seeking volunteers to develop a better understanding about carers' concerns for older people at risk of falling at home. Complete a 15 minute online survey.
- 2) Researchers are looking for carers to participate in a research study on falls. Can you spare 15 minutes to complete an online survey?
- 3) Complete a 15 minute online survey to help researchers identify the concerns of carers for older people at risk of falling at home.
- 4) Carers needed to complete a 15 minute online survey about the risk of falling for older people.
- 5) Help researchers understand your concerns as carers for older people at risk of falling at home. Volunteer today and complete a 15 minute online survey.
- 6) Are you a carer? Researchers are seeking volunteers to understand carers' concern for older people at risk of falling at home. Complete a 15 minute online survey today.
- 7) Are you a carer? We want to understand carers' concern for older people at risk of falling at home. Help researchers by completing a 15 minute online survey today.
- 8) Are you a carer? Complete an online survey to help researchers identify the concerns of carers for older people at risk of falling at home.
- 9) Are you a carer? Complete an online survey to help researchers identify the fall concerns of carers.
- 10) Are you a carer? Complete an online survey to help researchers identify the fall concerns of carers for older people.
- 11) Are you a carer? Volunteers needed to complete research into the concerns of carers for older people at risk of falling at home. Complete a 15 minute online survey
- 12) Are you a carer? Help researchers understand your concerns for older people at risk of falling at home. Volunteer today and complete an online survey.





Source: https://www.flickr.com/photos/68716695@N06/29609193412



Source: https://pixabay.com/en/hands-skin-holding-hands-elderly-578918/





Appendix 15. Email for Online Survey

Project Title: Carers' falls concern for older persons

Dear [First Name],

Thank you for accepting our invitation to participate in the online survey aimed to provide understanding about the carers' concern for older people at risk of falling at home.

The survey is entirely anonymous. We will know that you have completed the survey (thus ensuring that you don't receive reminders) but we are unable to tell which survey is yours. The survey will take approximately 30 minutes to complete. All survey responses are aggregated for analysis.

You may participate by completing the online survey at [SurveyLink]. The survey will be available until [date].

Your participation is greatly appreciated.

If there are any queries please feel free to contact Marcus Ang – email senggiapmarcus.ang@uon.edu.au or call 0478 696 149.

Kind Regards,

Marcus Ang

Please note: If you do not wish to receive further emails from us, please click the link below, and you will be automatically removed from our survey participant list.

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Appendix 16. Reminder Email

Project Title: Carers' falls concern for older persons

Dear [First Name],

Our online survey has been running now for 1 month and we have received many responses. However, we still need more responses to ensure comprehensive answers

to our project questions about the carers' concern for older people at risk of falling at

home.

If you have completed the online survey, the project team would like to thank you for

taking the time to do so. If you haven't completed the online survey, we'd like to stress

the importance of this project and the valuable contribution you can make by completing

the survey.

The survey is entirely anonymous. We will know that you have completed the survey

(thus ensuring that you don't receive reminders) but we are unable to tell which survey

is yours. The survey will take approximately 30 minutes to complete. All survey

responses are aggregated for analysis.

You may participate by completing the online survey at [SurveyLink]. The survey will be

available until [date].

Your participation is greatly appreciated.

If there are any queries please feel free to contact Marcus Ang – email

senggiapmarcus.ang@uon.edu.au or call 0478 696 149.

Kind Regards,

Marcus Ang

Please note: If you do not wish to receive further emails from us, please click the

link below, and you will be automatically removed from our survey participant list.

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Appendix 17. SMS Message

SMS Message to recruit participants from Phase 1 to participate in Phase 2 and 3

The SMS message will be as follows:

Thank you for participating in my study "Carers' Concerns about the Older Persons." There is a second/third part of the study, which involves completing an online survey. The survey will take approximately 15 minutes to complete. If you are happy to participate in this next part of the study please click on this link and it will take you to the survey:

Click here to access the online survey and participate in this study

Appendix 18. Master Information for Participants Phase One



CARERS' FALLS CONCERN FOR OLDER PERSONS – PHASE ONE INFORMATION FOR PARTICIPANTS

Please read this information sheet carefully before deciding whether or not to participate.

What is the research about?

This project aims to gather information about the concerns of people caring for older people who are at risk of falling.

Who can participate in the research?

We need people over 18 years of age who are the main carers for an older family member or friend.

What Choice do you have?

Taking part in this study is up to you. If you decide not to take part, there will be no disadvantage of any kind. You may withdraw from the project at any time without giving a reason.

If you are identified as being of Aboriginal/ Torres Strait Islander background, you may choose to have a hospital Aboriginal Liaison Officer/ friend/ relative with you during the consent taking process.

What would you be asked to do if you agree to participate?

We would like to interview you about your role as a carer and in particular, any concerns you have about the person you care for having a fall. Interviews will be either in person or via the telephone. The face-to-face interview will be held at the University of Newcastle, the John Hunter Hospital, or another place of convenience to you. The interview will take approximately 1 hour and will be audio-recorded.

What are the risks and benefits of participating?

Risks

There is no anticipated risk associated with this study. In the event that you experience any feelings that are distressing or overwhelming while answering questions, we will stop the interview and restart it when you are ready. We can also refer you to the support services stated on this information sheet if requested. A senior member of the research team will follow up with you within a few days.

Benefits

If you participate in this study, you may benefit from an increased awareness of the importance of fall prevention.

Will the study cost you anything?

Participation in this study will not cost you anything, nor will you be paid.

How will your privacy be protected?

All information collected will be securely stored and only the researchers will have access to it. Raw data on which the results of the project depend will be kept in secure storage for five years and then destroyed.

Further Information

If you have any questions please contact Marcus Ang on 0478 696 149 or email senggiapmarcus.ang@uon.edu.au

Thank you for considering this invitation.

Mr. Seng Giap Marcus Ang

Co-investigator/ student researcher

Professor Anthony Paul O'Brien

Principal investigator/ project supervisor

Dr. Amanda Wilson

Co-investigator/ project co-supervisor

Complaints about this research

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference [17/09/20/4.03].

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Manager, Research Ethics and Governance Unit, Hunter New England Human Research Ethics Committee, Hunter New England Local Health District, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, email hnehealth.nsw.gov.au

Resources and referral information

If you would like support following this interview, talking with your GP is a good start. He or she can assist you find help that is suited to you. If you don't have a GP, there are some online services locators to help you find a GP or other services:

- https://healthengine.com.au/
- https://www.healthdirect.gov.au/australian-health-services
- https://www.beyondblue.org.au/get-support/find-a-professional

There are several phone lines available if you need help, get a referral, or just want to talk to someone:

Lifeline: 13-11-14. Available 24 hours. Provides counselling, professional support and local referrals. Online crisis chat service is also available at set times. Visit https://www.lifeline.org.au/ for more info.

Carers NSW: 1800-242-636. Available 9am to 5pm. Provides carer information, support and counselling. For carers wanting emergency respite to call 1800-052-222. Visit https://www.carersnsw.org.au/ for more info.

Appendix 19. Consent Form



CARERS' FALLS CONCERN FOR OLDER PERSONS - PHASE ONE PARTICIPANT CONSENT FORM

I, _______name] of

Appendix 20. Master Information for Participants Phase Two



CARERS' FALLS CONCERN FOR OLDER PERSONS – PHASE TWO INFORMATION FOR PARTICIPANTS

Please read this information sheet carefully before deciding whether or not to participate.

What is the research about?

This project aims to gather information about the concerns of people caring for older people who are at risk of falling.

Who can participate in the research?

We need people over 18 years of age who are the main carers for an older family member or friend.

What Choice do you have?

Taking part in this study is up to you. If you decide not to take part, there will be no disadvantage of any kind. You may withdraw from the project at any time without giving a reason.

What would you be asked to do if you agree to participate?

You will be asked by email to complete an online survey. If you do not have access to email and the internet, a study team member will to complete the survey with you over the telephone.

The survey is about the concerns carers have when looking after someone at risk of having a fall. There will also be some demographic questions including age, gender, marital status, employment and relationship to the care recipient. It will take approximately 30 minutes to complete.

What are the risks and benefits of participating?

Risks

There is no anticipated risk associated with this study. In the event that you experience any feelings that are distressing or overwhelming while answering questions, we strongly encourage you to stop the survey and make use of the support services stated on this information sheet.

Benefits

If you participate in this study, you may benefit from an increased awareness of the importance of fall prevention.

Will the study cost you anything?

Participation in this study will not cost you anything, nor will you be paid.

How will your privacy be protected?

All information collected will be securely stored and only the researchers will have access to it. Raw data on which the results of the project depend will be kept in secure storage for five years and then destroyed.

Further Information

If you have any questions please contact Marcus Ang on 0478 696 149 or email senggiapmarcus.ang@uon.edu.au

Thank you for considering this invitation.

Mr. Seng Giap Marcus Ang

Co-investigator/ student researcher

Professor Anthony Paul O'Brien

Principal investigator/ project supervisor

Dr. Amanda Wilson

Co-investigator/ project co-supervisor

Complaints about this research

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference [17/09/204.03].

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Manager, Research Ethics and Governance Unit, Hunter New England Human Research Ethics Committee, Hunter New England Local Health District, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, email hnehealth.nsw.gov.au

Resources and referral information

If you would like support following this interview, talking with your GP is a good start. He or she can assist you find help that is suited to you. If you don't have a GP, there are some online services locators to help you find a GP or other services:

- https://healthengine.com.au/
- https://www.healthdirect.gov.au/australian-health-services
- https://www.beyondblue.org.au/get-support/find-a-professional

There are several phone lines available if you need help, get a referral, or just want to talk to someone:

Lifeline: 13-11-14. Available 24 hours. Provides counselling, professional support and local referrals. Online crisis chat service is also available at set times. Visit https://www.lifeline.org.au/ for more info.

Carers NSW: 1800-242-636. Available 9am to 5pm. Provides carer information, support and counselling. For carers wanting emergency respite to call 1800-052-222. Visit https://www.carersnsw.org.au/ for more info.

Appendix 21. Master Information for Participants Phase Three



CARERS' FALLS CONCERN FOR OLDER PERSONS – PHASE THREE INFORMATION FOR PARTICIPANTS

Please read this information sheet carefully before deciding if you want to participate.

What is the research about?

This project looks at the concerns of people caring for older people who are at risk of falling.

Who can participate in the research?

You can take part if you are 18 years of age or older and the main person caring for a family member or friend aged over 60 years.

What choice do you have?

Taking part in this study is up to you. If you decide not to take part, there will be no disadvantage of any kind. You may withdraw from the project at any time without giving a reason.

What would you be asked to do if you agree to participate?

We will send you an email with a link to an online survey. If you do not have access to email or the internet, a study team member will contact you to complete the survey over the telephone or in person.

The survey is about the concerns people have when looking after someone at risk of having a fall. There are also questions about you including age, gender, marital status, employment and your relationship to the care recipient. This information is anonymous and confidential. The survey will take around 15 minutes to complete.

What are the risks and benefits of participating?

Risks

There are no obvious risks associated with this study. If you should experience any distressing or overwhelming feelings while answering questions, we would ask you to stop the survey and contact the support services listed on this information sheet.

Benefits

While there are no benefits from participating in this study, you may gain from an increased awareness of the importance of fall prevention.

Will the study cost you anything?

There are no costs or payments for participation in this study.

How will your privacy be protected?

All information collected will be securely stored and only the researchers will have access to it. Data will be kept for five years and then destroyed.

Further Information

If you have any questions please contact Marcus Ang on 0478 696 149 or email senggiapmarcus.ang@uon.edu.au

Thank you for considering this invitation.

Mr. Seng Giap Marcus Ang

Co-investigator/ student researcher

Professor Anthony Paul O'Brien

Principal investigator/ project supervisor

Dr. Amanda Wilson

Co-investigator/ project co-supervisor

Complaints about this research

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference [17/09/20/4.03].

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Manager, Research Ethics and Governance Unit, Hunter New England Human Research Ethics Committee, Hunter New England Local Health District, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, email hnehealth.nsw.gov.au

Resources and referral information

If you would like support following this interview, talking with your GP is a good start. He or she can assist you find help that is suited to you. If you don't have a GP, there are some online services locators to help you find a GP or other services:

- https://healthengine.com.au/
- https://www.healthdirect.gov.au/australian-health-services
- https://www.beyondblue.org.au/get-support/find-a-professional

There are several phone lines available if you need help, get a referral, or just want to talk to someone:

Lifeline: 13-11-14. Available 24 hours. Provides counselling, professional support and local referrals. Online crisis chat service is also available at set times. Visit https://www.lifeline.org.au/ for more info.

Carers NSW: 1800-242-636. Available 9am to 5pm. Provides carer information, support and counselling. For carers wanting emergency respite to call 1800-052-222. Visit https://www.carersnsw.org.au/ for more info.

After having read the participant information statement you can access the survey by following the link provided below. You will then be prompted to provide your informed consent to participate in the survey. Thank you for your interest in this research.

https://is.gd/carerfallconcern

Appendix 22. Data Collection Form Phase One

To protect your privacy, please don't identify yourself during the interview recording. Once the interview is completed, a pseudonym will be used to protect your identity. Your name will not be used in any data collection document. If you are now ready to start the interview, please let me know.

Case Index No:				
Demographic Data				
Date of birth (dd/mm/yy)				
Gender	☐ Male☐ Female☐ Other (specify):			
What is your present marital status?	 Never married Widowed Divorced Separated but not divorced Married Defacto 			
Are you working?	☐ Full-time☐ Part-time☐ Casual☐ Not working			
What is your relationship to the care recipient?	 □ Spouse □ Children □ Sibling □ Friend □ Others (specify): 			
Are you living with your care recipient?	□ Yes □ No			
How many hours do you spend caring per week?	 □ 0-10 hours □ 11-20 hours □ 21-30 hours □ 31-40 hours □ 41-50 hours □ 51-60 hours □ 61-70 hours □ More than 70 hours 			
How many years have you been providing care?				
Date of birth for care recipient (dd/mm/yy)				

Gender for care rec	pient		Male Female Other (specify):
	Fall i	nforma	tion of older people
How many falls did your care recipient have in the past 12 months?			No falls 1 fall 2 falls 3 or more Unsure
Did your care recipient sustain any injury in any of the fall/s in the past 12 months?			No Minor injury, did not require medical attention
(Rate most severe injury due to a fall)			Minor injury, did require medical attention Severe injury (fracture, etc.) Unsure
Does your care recipient have any chronic medical condition/s?			Yes (specify): No
(Example Dementia, Parkinson's disease)			
	Int	erview	Questions
Venue			
Date			
Time	me		
 Tell me about your concerns caring for your family member or friend related to their risk of falling What helps you care for a family member or friend at risk of falling? Have you encounter any problems in your caring? Are there any risks in preventing your family member or friend from falling? Have you received any advice or support regarding falls and from whom? 			

We have reached the end of the interview and I have stopped recording. If you wish to review your recording, please let me know and I will send it to you as a typed transcript for your review. Thank you for your participation.

Appendix 23. Data Collection Form Phase Two

Case Index No:	
1. Do you wish to participate in the Carers' Falls Concern Survey? Selecting yes above will be taken as your informed consent to participate.	□ Yes □ No
	Demographic Data
How did you find out about this study?	 Advertisement on HMRI Facebook page Email from HMRI research registry Email from Carers NSW Nurse from John Hunter Hospital Nurse from Rankin Park Day Hospital
Your Date of birth (dd/mm/yyyy)	
Your Gender	MaleFemaleOther (please specify):
Are you?	 Never married Widowed Divorced Separated but not divorced Married Defacto
Are you working?	Full-timePart-timeCasualNot working
Who are you caring for?	□ Spouse□ Parent□ Sibling□ Friend□ Other (please specify):
Are you living with the person you care for?	□ Yes □ No
How many hours do you spend caring per week?	 0-10 hours 11-20 hours 21-30 hours 31-40 hours 41-50 hours 51-60 hours

	61-70 hoursMore than 70 hours
How many years have you been providing such care?	
Year of birth for the person whom you are caring for (yyyy)	
Gender for the person you care for	MaleFemaleOther (please specify):
Fall	information of the Older Person
How many falls did the person you care for have in the past 12 months?	 No falls 1 fall 2 falls 3 or more falls Unsure
Did the person you care for sustain any injury in any of the fall/s in the past 12 months? (Select most severe injury due to a fall)	 □ No □ Minor injury, did not require medical attention □ Minor injury, did require medical attention □ Severe injury (fracture, etc.) □ Unsure
Does the person you care for has any chronic medical condition/s?	☐ Yes (please specify):☐ No
(Example Dementia, Parkinson's disease)	
Perc	ception of Questionnaire
Did the statements in the previous page accurately capture concerns about the person you care for falling?	☐ Yes☐ No (please provide additional comments)
Can you think of any other types of fall concerns that should be in the previous page?	Yes (please specify):No
How often do you have these concerns?	 Every day Last week 1 month ago 6 months ago Other (please specify)

What would be your preferred format for completing this questionnaire?	□ P[□ W	nline DF ord docume her (please			
There is currently no standardised term for a person being cared for by others e.g. care recipient. Therefore, we would like to find out what is your most preferred way of naming them.					
From a scale of 1 to 5, with 1 be term/phrase, please choose a reterms.	-	•		-	•
Person I am caring for	1	2	3	4	5
Care recipient	1	2	3	4	5
My dependent	1	2	3	4	5
Loved one	1	2	3	4	5
Family member	1	2	3	4	5
Caree	1	2	3	4	5
Are there any other terms you know of which are not listed above?					

Appendix 24. Data Collection Form Phase Three

Case Index No:			
Do you wish to participate in the Carers' Falls Concern Survey? Selecting yes above will be taken as your informed consent to participate.			Yes No
	Den	nograpl	nic Data
How did you find o study?	ut about this		Advertisement on Hunter Medical Research Institute (HMRI) Facebook page Email from Hunter Medical Research Institute (HMRI) research registry Email from Carers NSW Nurse from John Hunter Hospital Nurse from Rankin Park Day Hospital Other (please specify):
Your date of birth ((dd/mm/yyyy)		
Your gender			Male Female Other (please specify):
Are you?			Never married Widowed Divorced Separated but not divorced Married Defacto
Are you working?			Full-time Part-time Casual Not working
Who are you carin	g for?		Spouse Parent Sibling Friend Other (please specify):
Do you live with the care for?	e person you		Yes No
How many hours a spend with this per	•		0-10 hours 11-20 hours 21-30 hours

	 31-40 hours 41-50 hours 51-60 hours 61-70 hours More than 70 hours 	
How many years have you been caring for this person?		
Year of birth for the person whom you are caring for (yyyy)		
Gender for care recipient	□ Male□ Female□ Other (please specify):	
Fall information of the Older Person		
How many falls did the person you care for have in the past 12 months?	 No falls 1 fall 2 falls 3 or more Unsure 	
Did the person you care for sustain any injury in any of the fall/s in the past 12 months? (Select most severe injury due to a fall)	 No Minor injury, did not require medical attention Minor injury, did require medical attention Severe injury (fracture, etc.) Unsure 	
Does the person you care for has any medical condition/s?	☐ Yes (please specify):☐ No	
(Example Cognitive impairment, Dementia, Parkinson's disease, Stroke)		
For the purposes of this survey, what do you call the person you care for?		
Example Mum, John, Marion. We won't keep this information.		
Please use "the person you care for" if you prefer not to say.		

Appendix 25. 16-item Carers' Fall Concern Instrument

Carers' Fall Concern for Older Persons Questionnaire For each statement, please indicate the level of concern you might have for the person you care for being at risk of falling. There are no right or wrong answers. How concerned are you about		
1.[the person you care for] not recovering from a fall	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned 	
2.[the person you care for] requiring extra care and support after a fall	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned 	
3.[the person you care for] falling when taking a bath or shower	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned 	
4.[the person you care for] falling when getting in and out of a chair or bed	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned 	
5.[the person you care for] falling when using the stairs	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned 	
6.[the person you care for] falling when reaching up or for something on the ground	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned 	
7.[the person you care for] falling when rushing to do things	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned 	
8.[the person you care for] falling when going to the toilet at night	□ Not applicable/ not at all concerned□ Slightly concerned□ Somewhat concerned	

	□ Moderately concerned
	□ Extremely concerned
9.[the person you care for] falling when at home alone	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned
10.[the person you care for] falling when going out alone	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned
11.[the person you care for] falling when walking on a slippery surface	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned
12.[the person you care for] falling when walking in crowded places	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned
13.[the person you care for] falling when walking on an uneven surface	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned
14.[the person you care for] falling when walking up or down a slope	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned
15.[the person you care for] falling when walking without a walking aid e.g. walker	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned
16.[the person you care for] falling when trying to walk without help, when asked not to	 □ Not applicable/ not at all concerned □ Slightly concerned □ Somewhat concerned □ Moderately concerned □ Extremely concerned