

**SELF-MANAGEMENT AND
ADHERENCE WITH
EXERCISE-BASED FALLS
PREVENTION PROGRAMMES FOR
OLDER PEOPLE WITH
LONG-TERM CONDITIONS: A
FRAMEWORK FOR
PHYSIOTHERAPY PRACTICE**

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ABSTRACT

Introduction

This study aimed to work with older people attending a regional falls and syncope service, older people with the falls-associated chronic liver disease primary biliary cirrhosis, relatives and local physiotherapy practitioners to develop a framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.

Methods

Focus groups were conducted with older people attending a regional falls and syncope service (3 groups, total 12 participants), relatives (1 group, total 4 participants) and local physiotherapists (4 groups, total 18 participants). Participants were asked to propose strategies to promote self-management and adherence with an exercise-based falls prevention programme. These strategies were tested and refined in an experimental case-series for 10 older people with primary biliary cirrhosis.

Findings

The older people participating in the focus group research expressed a long-term commitment to exercise-based falls prevention programmes. They valued approaches that promoted self-efficacy and self-management. The physiotherapists indicated that the older people they came into contact with were poorly motivated to

participate in an exercise-based falls prevention programme. They demonstrated a limited awareness of strategies to promote self-efficacy and self-management.

Visual analysis of the experimental case-series data revealed unstable baselines and fluctuations throughout the treatment and follow up phases in keeping with variations in disease-specific quality of life measures, suggesting that long-term conditions interact with measures that predict and monitor falls-risk and self-efficacy. The exercise-based falls prevention programmes had perceived benefit for older people with primary biliary cirrhosis. However, this was not evident in the measures selected, many of which demonstrated a ceiling effect in the population group under investigation. The self-management strategies had low levels of perceived acceptability. Participants indicated that they lacked the necessarily skills to monitor their progress with an exercise-based falls prevention programme on completion of the experimental case-series.

Conclusion

This study demonstrated that self-management does not sit comfortably within the philosophy of routine clinical practice. The framework for physiotherapy practice developed during the course of the current study has the potential to empower physiotherapists and older people with long-term conditions identified as being at increased risk of falling to work in partnership to challenge existing approaches to clinical service delivery.

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I owe a debt of gratitude to the older people, relatives and physiotherapy practitioners who gave up their time so readily to participate in this study and to my multi-disciplinary colleagues at the Falls and Syncope Service and Biomedical Research Centre in Ageing for their unwavering friendship and encouragement.

Special thanks to Lynne Alberts who performed the role of assistant moderator, Elsbeth Henderson who delivered the standard intervention and Jane Newman who completed the independent assessments. I am also indebted to Elizabeth Milne and Linda Jobling for transcribing the qualitative data and to James Frith for his technical support and expertise.

Finally, I would like to dedicate this thesis to Neil Joyce – there definitely would have been more tantrums without you. Thank you for your continuing love and patience.

DECLARATION

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Approval for the focus group research has been sought and granted by the School Ethics Committee on 16.8.06, the Primary Care Trust Clinical Governance Department on 3.9.06, the Acute Trust Research and Development Department on 28.9.06, and the Local Research Ethics Committee on 29.9.06. Approval for the experimental case-series has been sought and granted by the School Ethics Committee on 22.12.08, the Acute Trust Research and Development Department on 26.3.09, and the Local Research Ethics Committee on 10.3.09.

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CHAPTER 1. INTRODUCTION AND LITERATURE REVIEW

1.1. Overview of chapter

The purpose of the opening chapter of this thesis is to situate the current study within the context of the relevant and contemporary literature. The chapter will begin by setting out the background to, and rationale for, the study. The author's clinical and academic roles within a regional falls and syncope service and biomedical research centre in ageing will be discussed to establish the scope and focus of the thesis. To provide the theoretical framework underpinning the current study, the concept of self-management for long-term conditions will be examined from a political, psychosocial and biomedical perspective. These three approaches to self-management will be used to critically review the falls prevention literature to identify areas where current knowledge is lacking or conflicting. The chapter will conclude by identifying specific areas for future inquiry and intervention.

1.2. Background to and rationale for study

The author of this thesis is a practising physiotherapist, based in a regional falls and syncope service, and has over 10 years experience delivering exercise-based falls prevention programmes for older people at risk of falling in a variety of clinical environments. This thesis will chart the research processes and outcomes that led to the development of a framework for physiotherapy practice to promote self-

management and adherence with an exercise-based falls prevention programme for older people with a long-term condition. This section will discuss the key concepts of falls, adherence, long-term conditions and self-management. It will introduce the auto-immune falls-associated chronic liver disease primary biliary cirrhosis as the specific long-term condition in which the phenomena of self-management and adherence with an exercise-based falls prevention programme will be investigated.

In the context of an ageing population, falls in later life represent a significant and increasing public health concern worldwide. Between one third and one half of community-dwelling older people fall each year (Gillespie et al., 2009), and approximately 50% of those who fall do so repeatedly (Tinetti et al., 1998). Falls are associated with considerable mortality, morbidity, reduced functioning and increased dependency (Masud & Morris, 2001), and carry a huge cost to health and social services, individuals, families and carers. Scuffham et al (2003) conducted an analysis of national databases to estimate the number of accident and emergency attendances, admissions to hospital and associated care costs as a result of unintentional falls in older people, and discovered that falls cost the British Government approximately £981 million per annum. To put this figure in context, it equated to 20% of the total National Health Service expenditure on pharmaceuticals and 3.3 times the total National Health Service funding earmarked for mental health, coronary heart disease, cancer and primary care services in England. Most of these costs (66%) were attributable to falls in those aged 75 years and above. The major cost driver was in-patient admissions, accounting for 49.4% of the total cost of falls.

Long-term care costs were the second highest, accounting for 41% of government expenditure.

The last 10 years have seen a marked expansion in falls research, meta-analyses and local and national management guidelines, reflecting an increased multi-disciplinary professional awareness of falls and falls prevention strategies (Davison & Marrinan, 2007). A simple distinction is often made between single and multi-factorial interventions. Clinical guidelines advocate a multi-factorial approach to falls prevention incorporating: identification of falls history; assessment of gait, balance, mobility and muscle weakness; osteoporosis risk; perceived functional ability; fear of falling; visual and cognitive impairment; urinary incontinence; home hazards; neurological and cardiovascular assessment; and medication review (National Institute for Health and Clinical Excellence, 2004). However, a meta-regression comparing single and multi-factorial interventions demonstrated that single interventions can be as effective at reducing falls as those with multiple components (pooled rate ratios 0.77, 95% confidence interval 0.67 – 0.89 and 0.68 – 0.89 respectively) (Campbell & Robertson, 2007).

Exercise-based falls prevention programmes have been shown to reduce falls-rate and falls-risk when delivered as a multiple-component group exercise (rate ratio 0.78, 95% confidence interval 0.71 – 0.86; risk ratio 0.83, 95% confidence interval 0.72 – 0.97) or individually-prescribed multiple component home-exercise (rate ratio 0.66, 95% confidence interval 0.53 – 0.82; risk ratio 0.77, 95% confidence interval 0.61 – 0.97) (Gillespie et al., 2009). Despite the growing body of high-quality

research evidence to support the efficacy of exercise-based falls prevention programmes, however, clinical experience and a review of the academic literature would suggest that their impact is often limited by poor uptake and adherence, particularly in the long-term. Participants in research trials are highly selected, yet refusal rates in excess of 50% are commonly reported (Campbell et al., 2001), and uptake of simple exercise interventions in the community as low as 10% have been documented (Fabacher et al., 2002). Further attrition, through drop out and non-adherence, are frequently reported as studies progress. Twelve months into a commonly-cited randomized controlled trial evaluating a general practice programme of home-exercise to prevent falls in older women, for example, only 42% of participants were still completing the exercise programme 3 times per week as instructed (Campbell et al., 1997). These findings would suggest that older people at risk of falling may be reluctant to participate in and / or experience difficulties maintaining a long-term commitment to exercise-based falls prevention programmes.

In the United Kingdom, approximately 17.5 million people are currently living with one or more long-term condition (Department of Health, 2004a). Over the next 50 years the number of people aged 60 years and over is estimated to more than triple and, in developed countries, will account for almost one third of the total population (Department of Health, 2005). Associated with this rise will be an increase in the prevalence of long-term conditions such as diabetes, asthma, arthritis and heart disease (Newman et al., 2004). Long-term conditions currently account for more than half the global disease burden and have been described as a primary challenge

for 21st century healthcare systems (World Health Organization, 2005). Already, 30% of the population with long-term conditions account for 70% of National Health Service expenditure (de Silva, 2011). In the United Kingdom, approximately 80% of general practice consultations, 60% of days spent in hospital and 70% of emergency admissions are related to long-term conditions (Department of Health, 2004). Identifying effective approaches to clinical service delivery that reduce dependency on healthcare professionals and encourage individuals with long-term conditions to increase their sense of control and well-being is imperative to cope with the escalating healthcare costs associated with an ageing population (Newman et al., 2004; de Silva, 2011).

It is prevalent in both research and clinical practice to use the term self-management to describe the variety of ways in which healthcare professionals support individuals with long-term conditions to manage their care in the community (Lau-Walker & Thompson, 2009). There are a wide range of initiatives to support self-management. These can be categorized on a continuum of interventions, with basic information provision about healthy behaviours and other technical topics at one end of the spectrum and initiatives that actively seek to support behaviour change and increase self-efficacy at the other (de Silva, 2011). Self-management support has been found to be consistently associated with improved health outcomes in a variety of long-term conditions (Corben & Rosen, 2005), and most practitioners would agree that self-management is an important aspect of contemporary healthcare delivery (Hughes, 2004). Despite such observations, however, the contradictions and challenges associated with actualizing the concept of self-management for

individuals with long-term conditions means that a huge gulf still exists between political rhetoric and the realities of routine clinical practice (Newman et al., 2004; de Silva, 2011).

The current study was conducted under the auspices of a biomedical research centre in ageing (liver theme). Established in 2007, and funded by the National Institute of Health Research, the centre is composed of seven themes: dementia and neurodegenerative ageing, stroke and cardiovascular ageing; mitochondrial abnormalities in ageing and age-related diseases; ageing and type II diabetes; liver disease in ageing; musculoskeletal disease in ageing; vision and ageing. Clinical and academic roles within a regional falls and syncope service and biomedical research centre in ageing provided a unique opportunity to:

1. Involve local stakeholder groups with experience of prescribing and participating in an exercise-based falls prevention programme in the development of strategies to promote self-management and adherence.
2. Test and refine these strategies in a small sample of older people with primary biliary cirrhosis as part of a larger programme of activities to define the burden of chronic liver disease and to develop improved clinical services for older people living with this long-term condition.

Primary biliary cirrhosis is a progressive auto-immune cholestatic liver disease that predominantly affects women (Kaplan & Gershwin, 2005). There is no specific cure, with 5% of individuals ultimately requiring liver transplantation (Heathcote, 2000).

The mean age of onset is 50 years, with 50% of cases presenting over the age of 65 (Talwalkar & Lindor, 2003). Primary biliary cirrhosis affects all races, yet seems to cluster within specific geographical areas (Prince et al., 2001) Epidemiological research suggests that primary biliary cirrhosis affects up to 30 per 100, 000 of the population (James et al.,1999), and 1 in 700 women over the age of 40 (Metcalf et al., 1997). The most common symptoms associated with primary biliary cirrhosis are fatigue, pruritis (itch), dry eyes and mouth, and cognitive impairment (Jones & Newton, 2005). The ageing demographic of the general population and improvements in the medical management of chronic liver disease have led to increased numbers of older people with primary biliary cirrhosis presenting to auto-immune liver clinics in secondary healthcare facilities (Newton et al., 2000). In addition to the liver-related clinical features outlined above, it is now recognized that older people with primary biliary cirrhosis suffer from a range of co-morbid processes (Frith et al., 2010). These are not directly linked to the severity of the underlying liver disease, but present a unique set of challenges for older people with primary biliary cirrhosis and the healthcare professionals responsible for delivering their care.

Several studies have demonstrated that autonomic dysfunction, which is a significant risk factor for falls, is highly prevalent in primary biliary cirrhosis at all stages of the disease process (Hendrickse & Triger 1992; Kempler et al.,1994; Keresztes et al., 2007). Abnormalities in skeletal muscle function, demonstrated using magnetic resonance spectroscopy, might also predispose individuals with primary biliary cirrhosis to falling (Hollingsworth et al., 2008). The potential impact of falls could,

in turn, be increased by the high prevalence of osteoporosis associated with this long-term condition (Talwalkar & Lindor, 2003). To identify the prevalence and sequelae of falls in primary biliary cirrhosis and to identify modifiable risk factors, our research team undertook a cross-sectional geographical population census of primary biliary cirrhosis and two control groups: primary sclerosing cholangitis (another cholestatic chronic liver disease), and a community-dwelling population without chronic liver disease from the same geographically-defined area (Frith et al., 2010). Self-assessment tools completed by the three cohorts determined the prevalence of falls, injuries and associated symptoms, such as postural dizziness and fear of falling. To establish the prevalence of established falls-risk factors, all participants were invited to attend for multi-disciplinary falls assessment regardless of whether or not they had previously fallen.

Significantly more of the primary biliary cirrhosis cohort had fallen (72%, $P < 0.001$) than both control groups. Fifty five percent had fallen in the last year ($P < 0.001$) and 22% more than once in the last year ($P < 0.01$). Seventy percent of fallers had fractured a bone and 19% were admitted to hospital, both significantly more than controls. Postural dizziness was significantly worse in fallers with primary biliary cirrhosis ($P < 0.001$), as was balance ($P < 0.001$) and lower limb muscle strength ($P < 0.002$). Lower limb muscle strength was independently associated with number of falls in the previous year ($\beta = 0.184$, $P < 0.001$).

This study demonstrated for the first time that falls are common in older people with primary biliary cirrhosis, and occur significantly more often than in a matched non-

liver disease community-dwelling population and biliary-disease control group. Despite such observations, however, this patient group had not previously had access to an exercise-based falls prevention programme in the local region. After conducting a series of focus groups with local stakeholder groups to identify the factors influencing uptake and adherence with an exercise-based falls prevention programme, it was with this novel population of older people identified as being at increased risk of falling that the thesis author chose to test and refine acceptable strategies to promote self-management. The findings from both of these approaches were used to inform a framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition, and this will be presented in the final chapter of this thesis.

1.3. Clarification of terminology

The World Health Organization define adherence as ‘the extent to which a person’s behaviour – taking medication, following a diet, and / or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider’ (Sabate, 2003 p. 3). Authors across all healthcare disciplines frequently consider the terms and phenomena of adherence and compliance as synonymous and use them interchangeably (Bissonnette, 2008). However, compliance implies that patients must abide obediently by a prescribed treatment regime and is often associated with blame, on the part of patients or healthcare professionals, if the process is unsuccessful (Sabate, 2003). Adherence, on the other hand, places the emphasis on

understanding a patient's complex and fluctuating healthcare needs and promotes their role as active partners in the planning and implementation of a treatment programme (Clemson et al., 1999). In keeping with the philosophical principles underpinning the current study, adherence will be the preferred term throughout this thesis.

It is widely acknowledged that adherence is a primary determinant of the effectiveness of a healthcare intervention, since poor adherence attenuates optimum clinical benefit (Sabate, 2003). A variety of healthcare interventions with established efficacy in randomized controlled trials are less effective (and cost effective) in clinical practice as a result of non-adherence (Yardley & Donovan-Hall, 2007). The research focus of this dissertation is self-management and adherence with exercise-based falls prevention programmes for older people with long-term conditions. However, it would appear that poor adherence with healthcare interventions is a global phenomenon. In developed countries, a number of rigorous reviews have identified that adherence with clinical interventions amongst individuals suffering from a variety of chronic health complaints averages only 50% (Sabate, 2003). In keeping with other forms of healthcare, physiotherapy is not immune to the problem of poor adherence. Bassett (2003) identified that up to 65% of individuals were either non-adherent or only partially-adherent with a home-based exercise programme, and that 10% typically failed to complete a prescribed course of treatment.

Self-management support has been defined as ‘the assistance caregivers give patients with chronic disease in order to encourage daily decisions that improve health-related behaviours and clinical outcomes’ (Bodenheimer et al., 2005 p. 4). For self-management support to be effective it must encompass the ability to monitor one’s condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life (Barlow et al., 2002). These definitions would imply that self-management is more than simple adherence with treatment guidelines. In addition it incorporates the psychological and social implications of living with a long-term condition (Newman et al., 2004).

By focussing simply on adherence, Paterson (2001) believes that healthcare professionals negate an individual’s ability to make choices and decisions regarding how best to manage their care. Such observations inevitably raise the question: should individuals with long-term conditions adhere to a plan of treatment that they did not contribute to equally, or should healthcare professionals adhere to the needs and wishes of individuals with long-term conditions (Hughes, 2004)? It has been suggested that an emphasis on self-management support may provide the key to promoting active long-term participation with clinical interventions, such as exercise-based falls prevention programmes, for individuals with a long-term condition (Department of Health, 2005).

To provide the theoretical framework underpinning the current study, the concept of self-management for long-term conditions will be examined from a political, psychosocial and biomedical perspective.

1.4. Self-management: a political perspective

Medical and technological advances over the last 50 years have presented health systems throughout the developed world with a new challenge – how best to support an ageing population with long-term conditions (Wilson et al., 2005). It is perhaps not surprising, therefore, that the Labour Government (1997 – 2010) placed self-management support at the heart of their drive to modernize the National Health Service. Expert patient initiatives seek to empower individuals with long-term conditions to take control of their own healthcare, but also recognize the importance of ongoing professional support and expertise in managing that independence (Hughes, 2004). Building upon the white papers *Saving Lives: Our Healthier Nation* (Department of Health, 1999) and *The NHS Plan: A Plan for Investment, A Plan for Reform* (Department of Health, 2000), *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century* (Department of Health, 2001a) recommended action over a six year period to introduce user-led self-management for long-term conditions to all areas of the National Health Service by 2007.

Based on the principle that individuals who are more confident in their ability to manage their long-term condition are more likely to have better health outcomes (Donaldson, 2003), the mainstay of the Expert Patient Programme was a six-week self-management training course offering support in life skills such as decision-making, coping with pain and fatigue, and managing relationships with healthcare professionals (Tattersall, 2002). Delivered by individuals who were themselves living with a chronic health complaint, these courses were generic rather than

condition-specific and open to anyone with a long-term condition (Jordan & Osborne, 2007).

A variety of methods were used to evaluate the pilot phase of the Expert Patient Programme. A randomized controlled trial involving 629 individuals with self-defined long-term conditions identified that the six week programme increased patients' self-efficacy by a moderate amount, but had a relatively small impact on the amount of energy people reported (energy was selected as the health status outcome relevant to the majority of individuals living with a long-term condition). There was no change in health service utilization (sum of general practice consultations, practice nurse appointments, accident and emergency attendances, and out-patient visits), although overnight hospital stays and use of day care facilities were reduced in the intervention group. A health economics analysis indicated that Expert Patient Programmes had the potential to be cost effective as the overall reduction in service utilization offset the cost of delivering these interventions (Rogers et al., 2006).

Despite such observations, however, a qualitative personal experience survey identified that Expert Patient Programmes often reinforced the value and salience of individual's pre-existing self-care activities, rather than initiating alternative behavioural changes (Rogers et al., 2006). These findings were explained by the fact that such initiatives often draw in people who are already committed to self-management and who tend to be white, middle class and well-educated (Jordan & Osborne, 2007), leading critics to suggest that Expert Patient Programmes increased

social inequalities by failing to target those with limited education and low economic resources (Foster et al., 2003). There was also observed to be a lack of integration with other initiatives aimed at individuals with long-term conditions and clinical services received from primary and secondary healthcare facilities, making it difficult for healthcare professionals to reinforce the learning gained as a result of attending these programmes (Tattersall, 2002). The authors concluded that recruiting sufficient people to make an impact at a public health level would prove problematic. Rather than being concentrated on a single programme, it was suggested that central resources for self-management support should be directed towards a variety of systems and interventions that would be better placed to meet the wide range of needs of individuals living with long-term conditions (Rogers et al., 2006).

During their election campaign, the Labour Government pledged to move away from the Conservative's focus on the internal market and competition, and concentrate instead on supporting the principle of partnership working (Forster & Gabe, 2008). During their first three years in power, however, the Labour Government continued the consumerist discourse favoured by their Conservative predecessors. NHS Direct, a nurse-led telephone helpline, was introduced in 1998 to provide faster advice and information about health, illness and the National Health Service so that individuals were better able to care for themselves and their families. Similarly, NHS walk-in centers were introduced to widen access to primary care facilities by offering no-appointment consultations in the evenings and at weekends as well as during traditional office hours. In both cases, the message was that the National Health

Service was accessible, convenient and, above all, customer-focused (Ilfie & Munroe, 2000).

In 2000, the Labour Government broke away from the previous government's expenditure plans and initiated a programme of National Health Service investment at a level (annual budget increases of 7%) and for a period (seven years) unequalled in any other healthcare system (Department of Health, 2000). However, this substantial increase in healthcare spending and investment in workforce and infrastructure was accompanied by a tightening of central control and regulation through the introduction of a framework for performance targets and assessment which included: enhanced regulation of clinical standards; quality-based contracts for doctors; and increased management accountability (Lewis & Gillam, 2001). Whilst the Labour Government continued to talk about the role of the individual consumer, this spending increase represented a move towards a more collectivist approach to healthcare delivery (Foster & Gabe, 2008).

The government's funding increase of 2000 was an historic opportunity to change the culture of National Health Service reform, and commentators have acknowledged that clinical services did improve for patients (Maynard & Street, 2006). However, healthcare in the United Kingdom does not exist as a single-system, but rather as a collection of locally-based systems that are influenced as much by their own idiosyncratic features and local histories as they are by larger national forces (Gallagher et al., 2008). Such observations have led critics to suggest that, by concentrating on national targets for activity and service delivery, the

Labour Government's spending plans diverted attention away from the real task of modernizing and improving the National Health Service (Wilson et al., 2005).

Over the last 30 years, governments have repeatedly attempted to undertake structural reorganizations of both the National Health Service and Department of Health (Smith et al., 2001). This reorganization has often been cyclical, with new governments or ministers reinventing structural arrangements that their predecessors abolished, seemingly unaware or uninterested in past reorganizations (Walsh, 2010). Few National Health Service reorganizations have been properly evaluated, but a recent study (National Audit Office, 2010) identified more than 90 reorganizations of central government departments and agencies between 2005 and 2009. Although it is considered a substantial underestimate, the cost of 51 of these reorganizations for which data were available was found to be in excess of £780 million. The report concluded that the benefits of many of these reorganizations were unclear, that the process was often poorly managed, and that their impact had a mainly adverse effect on performance.

In their seminal white paper *Equality and Excellence: Liberating the NHS* (Department of Health, 2010), the Coalition Government (2010 – date) also emphasize the importance of placing patients at the heart of the National Health Service. Through an information revolution and greater choice and control, their mantra 'no decision about me without me' highlights the importance of involving patients fully in their own care. However, despite having promised to 'stop the top-down reorganizations of the NHS that have got in the way of patient care' (HM

Government, 2010), the secretary of state for health, Andrew Lansley, announced plans to abolish strategic health authorities and primary care trusts, create about 500 new general practice consortiums to handle healthcare commissioning, hand over public responsibilities to local authorities, strip the Department of Health of many of its functions, force all National Health Service providers to apply for foundation trust status, and restructure the arrangements for healthcare regulation (Walsh, 2010). To reconcile bottom-up local processes and top-down policy initiatives, it would appear that healthcare professionals will be increasingly required to demonstrate that they support self-management whilst remaining accountable for the clinical decisions they make.

1.5. Self-management: a psychosocial perspective

There is overwhelming evidence that changing an individual's health-related behaviour can have a major impact on some of the largest causes of mortality and morbidity (National Institute for Health and Clinical Excellence, 2007). The Wanless reports *Securing Our Future Health: Taking a Long-Term View* (Department of Health, 2002) and *Securing Good Health for the Whole Population: Final Report* (Department of Health, 2004b) highlighted the massive growth in healthcare costs facing the British Government if they did not invest in reducing demand for clinical services as well as improving supply. The reports outline a position in the future in which levels of public engagement with health are high and the use of preventative and primary care services optimized, helping individuals with long-term conditions to remain healthy. Much of the current discussion surrounding

self-management in contemporary healthcare is based on a model of empowerment, in which individuals with long-term conditions are considered equal partners in the clinical decision-making process (Holmstrom & Roing, 2010). Identified as the best option for the future organization of healthcare delivery, this fully-engaged scenario requires behavioural change and its social, economic and environmental context to be placed at the heart of all disease prevention strategies (National Institute for Health and Clinical Excellence, 2007).

Justification for the study of health behaviours is based on two assumptions: that in developed countries a substantial proportion of mortality from the leading causes of death is due to particular behaviour patterns; and that these behaviour patterns are modifiable (Conner & Norman, 2005). This ‘psychological malleability’ (O’Brien-Cousins, 2000 p. 284) may provide the key to promoting self-management and adherence with a variety of clinical interventions for older people with a long-term condition. Epidemiological studies have found considerable variations in the personal characteristics of individuals who perform health behaviours. Approaches taken to understand these behaviours have been many and varied and represent a rapidly expanding sub-discipline of health psychology (Ballinger & Payne, 2002). A broad distinction is often made between factors intrinsic to the individual (socio-demographic factors, personality, social support, cognitions) and factors extrinsic to the individual (taxing tobacco and alcohol, subsidizing sports facilities). The former have received most attention from health psychologists and, within these intrinsic factors, cognitive variables have been focused on as the most proximal determinants of behaviour and behaviour change (Connor & Norman, 2005).

Models of how these cognitive factors produce various behaviours are referred to as social cognition models and have been widely used by health psychologists. Social cognition models are recognized to have contributed to our understanding of who performs health behaviours and how extrinsic factors may produce behaviour change. Justification for focussing on social cognitive factors is twofold: firstly, they are assumed to be important causes of behaviour which mediate the effects of other determinants (such as social class); and secondly, they are considered to be more open to change than other factors (such as personality) (Connor & Norman, 2005).

At present, there is no strategic approach to behaviour change across government, the National Health Service or other sectors, and many different models, methods and theories being used in an uncoordinated way. The National Institute for Health and Clinical Excellence (2007) published public health guidelines on the most appropriate generic and specific interventions to support attitude and behaviour change at population, community and individual levels. Whilst these guidelines acknowledge the extensive body of psychological literature supporting social cognition models of health behaviour and behaviour change, the research evidence evaluating the use and relevance of these models was found to be inconsistent. Although the academic literature does not currently support any particular theoretical approach to behaviour change, three social cognition models and their constructs (the theory of planned behaviour, social cognitive theory and the transtheoretical or stages of change model) have had a particular effect on the development of self-management strategies for older people with long-term conditions and warrant further exploration within the context of the current study.

1.5.1. Theory of planned behaviour

According to Ajzen's (1991; 2002) theory of planned behaviour, the intention to perform a particular behaviour is the most important factor in actually engaging in that behaviour. Intention is formed through an appraisal of:

- **Attitude** – an evaluation of the positive and negative consequences of performing the behaviour (coping appraisals versus threat appraisals).
- **Subjective norm** – an evaluation of whether relevant others (such as family or friends) would approve of the behaviour.
- **Perceived behavioural control** – an evaluation of whether it is easy or difficult to carry out the behaviour.

Discussing the risks and benefits of clinical interventions or care options is becoming an increasingly important aspect of modern healthcare delivery and is a vital component of self-management support (McPherson & Siegert, 2007). It has been suggested that the way information is presented by healthcare professionals can have a significant effect on the decisions made by older people with long-term conditions regarding the care they receive and the self-management strategies they choose to adopt (Edwards et al., 2001). Whilst there is a paucity of evidence in this field, it would appear that individuals are more willing to take risks when faced with the potential costs of a decision but more risk-averse when faced with the potential benefits of a decision (McCaul et al., 2002). Rothman and Salovey (1997) labelled

messages addressing the costs of not taking action as loss-framed messages and those addressing the benefits of taking action as gain-framed messages. As a general rule it would appear that gain-framed appeals encourage individuals to perform behaviours involving minimal risk, such as preventative behaviours; whereas loss-framed messages encourage individuals to perform behaviours involving some degree of risk, such as detection behaviours (McCaul et al., 2002).

Open and immediate online access to health information has reshaped the boundaries between healthcare professionals and individuals with long-term conditions (Thompson et al., 2009). The paternalistic approach to clinical service delivery in which healthcare professionals make all the treatment decisions and closely monitor the patient's progress is now considered inappropriate (Kennedy, 2005). Contemporary healthcare has placed individualization at the heart of clinical practice, and the primary task of the healthcare professional is to work from a common core of knowledge to promote participatory decision-making (Sandman & Munthe, 2010). This involves not only presenting the evidence to support or refute a particular intervention, but also encouraging individuals with long-term conditions to reflect on the options presented and relate these options to the values they place on benefit and harm (Muir-Gray, 2008). Whilst it would appear that self-efficacy and social support play an important role in the effects of message framing when the targeted behaviour requires a reasonable level of self-competence (Williams & Clarke, 2001), more research is needed to adequately address this issue within the fully-engaged scenario of self-management for long-term conditions.

1.5.2. Social cognitive theory

In Bandura's (1977; 2001) social cognitive theory, human motivation and action are based on three types of expectancies:

- **Situation-outcome** – beliefs about which consequences will occur without interfacing personal action. Susceptibility to a health threat would constitute a situation-outcome expectancy.
- **Action-outcome expectancy** – the belief that a given behaviour will or will not lead to a given outcome. For example the belief that quitting smoking will lead to a reduction in the risk of lung cancer.
- **Self-efficacy expectancy** – the belief that a behaviour is, or is not, within an individual's control. A belief that an individual is, or is not, capable of performing a particular behaviour, such as exercising regularly, would constitute a self-efficacy expectation.

One of the earliest attempts to incorporate self-management support into routine clinical practice involved an educational approach. Individuals with long-term conditions were provided with information in a traditional didactic format, with the expectation that greater knowledge would lead to appropriate changes in health behaviour (Newman et al., 2004). It is now widely acknowledged, however, that effective self-management support needs to address an individual's confidence (self-efficacy) in their ability to manage specific activities rather than simply convincing

them of the value of these activities (Lau-Walker & Thompson, 2009). An individual may, for example, believe that adopting a particular behaviour will improve his or her future health (high outcome expectancy). However, they may still dismiss this strategy because they do not see themselves being able to commence the behaviour or believe themselves incapable of sustaining it over time (low self-efficacy).

Self-efficacy is important to understand within the context of contemporary healthcare delivery because it has proved amenable to clinical intervention (Gallagher et al., 2008). Expectations of self-efficacy are currently considered to be the most powerful determinants of behaviour change since self-efficacy beliefs determine the initial decision to perform a given behaviour, the effort to be expended, and persistence in the face of adversity (Bandura, 1997). It should be pointed out, however, that self-efficacy is not a personality characteristic that operates independently of contextual factors; rather it relates to beliefs about capabilities of performing specific behaviours in particular situations (Bandura, 1997). An individual's efficacy expectations will vary greatly depending on the particular task and context in which they are required. It is, therefore, inappropriate to characterize an individual as having high or low self-efficacy without reference to the specific behaviour and circumstance with which the efficacy judgement is associated (Cheal & Clemson, 2001).

A precise understanding of the theoretical basis underpinning self-efficacy and outcome expectation would enable healthcare professionals and researchers to be more specific in the design and application of acceptable strategies to support self-

management for individuals with long-term conditions, and more able to differentiate and explain the separate elements of these complex health behaviours within the context of specific clinical interventions (Lau-Walker & Thompson, 2009).

1.5.3. The transtheoretical model

Developed by Prochaska and DiClement (1983) to explain intentional behaviour change, the transtheoretical model is based on the premise that an individual will move through a series of five stages when attempting to change their behaviour:

- **Pre-contemplation** – no intention to change behaviour in the foreseeable future or denial of need to change.
- **Contemplation** – intention to change within next 6 months.
- **Preparation** – serious intention to change within next 30 days
- **Action** – engaged in behavioural change at required level
- **Maintenance** – sustaining behavioural change for 6 months or more

Movement through these stages may occur in a linear fashion. However, more commonly, individuals are observed to move through these stages repeatedly, in a cyclical manner, leaving and re-entering the continuum at varying points before

maintenance is finally achieved (Burbank et al., 2000). The transtheoretical model recognizes that behavioural change is a dynamic process and that individuals often make many initial attempts to modify their behaviour, only to lapse again within a few days or weeks (Marcus & Simkin, 1993). The stages of change outlined above are integrated with decisional balance (the pros and cons of adopting a given behavioural change) and self-efficacy. The benefits (pros) of making a health-related behaviour change are said to increase and the costs (cons) decrease as an individual progresses along the continuum from pre-contemplation to maintenance (Burbank et al., 2000).

One of the most promising suggestions for supporting behavioural change in clinical practice is to tailor the intervention to suit the individual's readiness to change (Connor & Norman, 2005). In this approach, the emphasis on self-management support becomes more intensive with increasing readiness to change. A pre-contemplator may, for example, simply be given information about the behaviour; the contemplator given the opportunity to weigh up the pros and cons of the behaviour; and those in the preparation stage engaged in a discussion about how to proceed with changing their behaviour (Rollnick et al., 1993). Individuals in the action stage are considered to have already made significant changes in their behaviour and the goal at this stage would be to reaffirm commitment and social supports; whilst for those in the maintenance stage, the aim would be to encourage active problem solving to prevent future relapse (Burbank et al., 2000).

Prochaska et al (1992) have demonstrated that the amount of progress people make with a programme is directly related to the stage they were at prior to commencing the initiative. The majority of individuals accessing healthcare interventions are said to be in the contemplation stage, where ambivalence is a central problem (Rollnick et al., 1993). Rather than making a simple dichotomous distinction about whether or not a particular health behaviour is being practiced, the development of strategies to deal with this ambivalence in a constructive manner may support individuals with long-term conditions to move through the incremental stages of behaviour change more effectively (Burbank et al., 2000).

1.6. Self-management: a biomedical perspective

Despite the existence of policy directives in the United Kingdom supporting self-management, the increased prevalence of long-term conditions continues to expose significant limitations in the dominant models of healthcare delivery, which remain reactive, curative and focussed on the management of acute episodic illness (Department of Health, 2007). In these established models of healthcare delivery, patients' reports of illness are taken to indicate the existence of disease processes. To this end, the individual's condition is reduced to a set of signs and symptoms which are investigated and interpreted within a traditional positivist biomedical framework. Accurate diagnosis of the pathology permits selection of appropriate therapies which restore the disease processes to (or near to) normal, thus curing (or improving) the patient's illness (Mead & Bower, 2000).

It is often perceived that healthcare professionals have power by virtue of their knowledge (Hughes, 2004). Traditional clinical practices have tended to categorize, label and judge individuals with long-term conditions, and medical diagnoses have historically been used in a negative way to create dependency on the part of individuals with long-term conditions and the need for expertise on the part of healthcare professionals (Wilson-Thomas, 1995). Within the dominant models of clinical service delivery, healthcare professionals diagnose and treat the problem whilst the individual is considered the source of the problem and deemed responsible if the clinical intervention is unsuccessful (Sabate, 2003).

Clinical encounters between individuals with long-term conditions and healthcare professionals provide a critical juncture for the exchange of information to promote patient empowerment and participatory decision-making (Finset, 2008). It is now widely recognized that the extent to which healthcare professionals are able to instigate and participate in effective communication during the clinical encounter is likely to influence the extent to which individuals with long-term conditions adopt self-management strategies outside of the healthcare setting (Kennedy et al., 2005). Healthcare professionals who adopt empowering practices respect an individual's ability to make decisions, value their input in such decisions and are able to relinquish control if an individual decides to reject the advice given (Holmstrom & Roing, 2010). All too often, however, practitioners assume the language of empowerment, including statements that patient participation in treatment decisions is welcome, whilst at the same time behaving in a manner that implies professional dominance (Mead & Bower, 2000). Although some healthcare professionals may

support empowerment as a goal of patient participation, it has been suggested that their socialization to the practitioner-as-expert model of clinical service delivery is so deeply rooted that they proffer patient participation largely as an extension of their power base, rather than as a truly collaborative venture (Mayes, 2009).

It is through language that the structures of power relations are maintained and ideologies are internalised (Wilson-Thomas, 1995). To understand the paradoxes that currently exist surrounding self-management support for individuals with long-term conditions, more research is needed regarding the overt and covert ways that practitioners cling to professional dominance and impede participatory decision-making (Paterson, 2001).

1.7. Literature review

In keeping with the philosophical principles underpinning self-management for long-term conditions, continued participation with an exercise-based falls prevention programme has the potential to reduce demands on the healthcare delivery system by encouraging older people at risk of falling to play an active role in improving their mobility and physical functioning as well as preventing future falls (Yardley et al., 2007). However, within falls prevention, healthcare professionals have traditionally adopted an actuarial approach to clinical service delivery (Rubenstein, 2006; Swift, 2006). In the 1980s, various risk factors associated with falls were identified and evidence from prospective community-based studies demonstrated that an individual's risk of falling increases dramatically in relation to the number of risk

factors present (Tinetti et al., 1988). Although there is no reliable and agreed classification system, falls-risk factors are often described as being intrinsic or extrinsic to the individual. Over 400 recognised risk factors for falls have been identified in the academic literature. Table 1.1 details the most commonly-cited independent falls-risk factors.

**Table 1.1. Summary of the most commonly cited independent falls-risk factors
(Adapted from Davison & Marrinan, 2007)**

Intrinsic risk factors	Extrinsic risk factors
<p>Muscle weakness</p> <p>Abnormal gait and / or balance</p> <p>Visual impairment</p> <p>Cognitive decline</p> <p>Concomitant illness:</p> <ul style="list-style-type: none"> • Arthritis • Depression • Peripheral neuropathy • Parkinson’s disease • Stroke <p>Age > 80 years</p>	<p>Walking aids</p> <p>Inappropriate footwear</p> <p>Home / environmental hazards</p> <p>Polypharmacy (> 4 medications)</p> <ul style="list-style-type: none"> • Benzodiazepines • Antidepressants • Antipsychotics

Although exercise-based falls prevention programmes have been shown to reduce falls in those who take part, they can only prove effective at a population level if participation rates are high (Yardley et al., 2007). There is increasing recognition in

the academic literature that, by focussing on the identification and reduction of physical risk factors, current models of clinical service delivery fail to recognize the perceived threat that falls and falls prevention strategies pose to older people's personal and social identities (Ballinger & Payne, 2002). These observations may help to explain the low levels of uptake and adherence reported in the academic literature and witnessed in routine clinical practice.

In 2007, the Prevention of Falls Network Europe published guidelines for promoting the engagement of older people in activities to prevent falls (Yardley et al., 2007). Initially developed from a review of the academic literature, the clinical experience of core group members, and subsequent qualitative and quantitative studies of older people's views, these recommendations were refined through a consultation process with members of the falls-prevention community which drew on Delphi survey and nominal group techniques. The final recommendations are summarized in Table 1.2.

Table 1.2. Recommendations for promoting the engagement of older people in activities to prevent falls (Based on Yardley et al., 2007)

1.	Raise awareness in the general population that undertaking specific physical activities has the potential to improve balance and prevent falls.
2.	When offering or publicizing interventions, promote immediate benefits that fit with positive self-identity.
3.	Use a variety of forms of social support to engage older people in interventions.
4.	Ensure that the intervention is designed to meet the needs, preferences and capabilities of the individual.
5.	Encourage confidence in self-management rather than dependence on professionals, by giving older people an active role.
6.	Draw on validated methods for promoting and assessing the processes that maintain adherence, especially in the longer term.

Much of the research evaluating the impact of exercise-based falls prevention programmes published in the academic literature to date has employed an experimental design. These studies tend to focus on quantitative measures, such as reduction in falls-rate and falls-risk, and do not overtly acknowledge the concerns or agendas of older people at risk of falling or their family members. The recommendations presented in Table 1.2 were informed by substantial qualitative and quantitative research which targeted the views of a wide range of older people, and prompted reviews by Nyman and Ballinger (2007; 2008) which explored how these recommendations could be implemented in routine clinical practice. Despite the existence of such publications, however, there is little indication that researchers and healthcare professionals are currently supporting older people at risk of falling

and their families to play a major role in determining what kind of interventions are relevant and what kind of outcomes are desirable (Gzil et al., 2007).

A review of the falls prevention literature was undertaken prior to commencing the current study. This review was initially performed in May 2006, revisited throughout the course of the study in response to the focus group and experimental case-series findings, and comprehensively updated in September 2011. After consulting a typology of reviews (Grant & Booth, 2009), it was decided that a critical review of the falls prevention literature would be most in keeping with the philosophical and methodological principles underpinning the current study. A critical review attempts to demonstrate that the writer has extensively reviewed the relevant literature by presenting, analysing and synthesizing material from a diverse range of sources. Typically narrative in style, a critical review enables the writer to take stock by establishing what is of value within a particular body of work, and often provides the launch pad for a new phase of conceptual thinking (Grant & Booth, 2009). Rather than being subjected to a formalized quality assessment, the literature presented in a critical review is evaluated according to its conceptual contribution and often results in a completely new interpretation of the existing data.

Relevant theoretical and empirical literature was identified from searches of electronic databases (Cinahl, Psych Articles and Web of Science). In addition to academic articles, relevant policy documents were identified by searching appropriate government websites. Further literature was identified by selecting publications from the reference lists of relevant papers. To maintain a contemporary

focus to the discussion, searches were restricted to English language, peer-reviewed papers published between 2000 and 2011. The search strategy employed in the current study is illustrated in Table 1.3.

Table 1.3. Search strategy

Fall* OR Accidental falls
AND
Aware* OR Understand* OR Perception* OR Expectation* OR Recogni* OR Perspective*
AND
Prevent*

To understand the complexities surrounding uptake and adherence with an exercise-based falls prevention programme, it is necessary to consider the wider historical, economic, cultural and social contexts underpinning modern healthcare delivery. Extending the work of Yardley et al (2007) and Nyman and Ballinger (2007; 2008), the identified literature will be presented under six thematic headings informed by the recommendations set out in Table 1.2 and interrogated using the theoretical framework of self-management for long-term conditions presented in Sections 1.4, 1.5 and 1.6 of this thesis.

1.7.1. Recommendation 1: Raise awareness in the general population that undertaking specific physical activities has the potential to improve balance and prevent falls

Although most falls do not result in physical injury, it has been estimated that around one in five will require medical attention (Gillespie et al., 2009). Fall-related injuries become more common with increasing age. Approximately 2% of men and 4% of women in their sixties will suffer a fall-related injury. However, these figures rise to 15% and 16% respectively by the eighth decade of life (Kannus et al., 1999). The most serious fall-related injury is undoubtedly the fractured neck of femur. Whilst only 1% of falls result in hip fracture (Nevitt et al., 1989), the consequences for an older person can be devastating. It has been suggested that 20% of older people will be dead within 12 months of hip fracture and, of those who do survive, many will require assistance with activities of daily living (Cumming et al., 2000). Marottoli et al (1992) analysed the functional outcomes of 120 older people presenting with fractured neck of femur over a 6 year period. Pre-fracture, 86% were able to dress independently, 75% could mobilise independently, and 63% could climb a flight of stairs. Six months post-fracture, these figures had fallen to 49%, 15% and 8% respectively. It is perhaps not surprising, therefore, that more than 80% of women over 75 years of age surveyed by Salkeld et al (2000) expressed a preference for death rather than the loss of independence and quality of life that could result from a fall resulting in a fractured neck femur.

Despite several high profile health promotion campaigns over recent years to promote awareness in the general population that participating in an exercise-based falls prevention programme has the potential to improve balance and prevent falls, it would appear that many older people remain unaware of their risk of falling (Yardley & Todd, 2005) and that opportunities to prevent falls are often overlooked, with risk factors only becoming evident after an injurious fall has occurred (American Geriatrics Society & British Geriatrics Society, 2011). In support of these observations, Whitehead et al (2006) conducted semi-structured interviews with 60 older people attending the Accident and Emergency Department of a district general hospital in Adelaide, South Australia, following an injurious fall. Their findings revealed that, whilst 45 (75%) participants considered falls to be a concern for their age group, only 33 (55%) believed falls were preventable and, more importantly, only 31 (52%) had been invited to participate in an exercise-based falls prevention programme after experiencing a fall. Reasons for choosing not to take part in an exercise-based falls prevention programme included: lack of time and interest; perceiving they were already doing enough physical activity; difficulties with transport, leaving the house or partner; an inability to perform the exercises due to old age; and believing they were unlikely to fall again in the future.

Building upon these findings, Yardley et al (2006) conducted focus groups and semi-structured interviews with 66 older people between 61 and 91 years of age. Of those participating in the study, 33 (50%) had never fallen, 18 (27%) had experienced one fall, and 15 (23%) two or more falls. Thematic analysis revealed that participants viewed falls prevention primarily as a means of hazard reduction,

using mobility aids and reducing activities. Only one participant was aware that falls could be prevented by carrying out specific activities to improve strength and balance. Falls advice was typically regarded as useful in principle, but not personally relevant or appropriate. The information provided was often considered to be common sense, only necessary for older or more disabled individuals, and potentially patronizing or distressing.

Healthcare professionals working with older people in a variety of clinical environments have an important role to play in the prevention of falls and injuries through screening and referral to appropriate falls prevention services (Dickinson et al., 2011). It is recommended that older people in contact with healthcare professionals should be asked routinely whether they have fallen in the past year and asked about the frequency, context and characteristics of the falls (National Institute of Health and Clinical Excellence, 2004). Older people are the predominant users of healthcare services (Reed et al., 2006). However, studies have shown that this patient group do not receive as much health education and prevention advice as younger generations (Callahan et al., 2007). This represents a missed opportunity to promote awareness of falls in later life and to encourage older people at risk of falling to participate in exercise-based falls prevention programmes.

Communication is a two-way process and most effective in exchanges with others with whom we share an understanding of language, values, beliefs and accepted ways of behaving (Gallagher et al., 2008). Although researchers have been attempting to define a fall since the 1980s (Kellogg International Work Group on the

Prevention of Falls by the Elderly, 1987; Lach et al., 1991; Nevitt et al., 1991; Lord et al., 2001; Lamb et al., 2005), it would appear that falls continue to be conceptualized differently by older people, healthcare professionals and the wider academic research community.

Zecevic et al (2006) carried out telephone interviews with 477 community-dwelling older people aged over 75 and 31 healthcare professionals. Participants were asked to define a fall and provide reasons for falling. The authors identified that, whilst the research literature focussed mainly on the description of a falls event, older people and healthcare professionals tended to associate falls more with antecedents and consequences. The reasons for falling most commonly cited by older people included; poor balance; the weather; inattention; medical conditions; indoor obstacles; outside surface hazards; slips, trips or stumbles; dizziness; attitude; and muscle weakness. The order of the most frequently-cited reasons for falling amongst healthcare professionals differed somewhat and included: medical conditions; poor balance; medication; indoor obstacles; vision; attitude; the weather; assistive devices; inattention; and slips, trips or stumbles. Only two healthcare professionals associated falls with psychosocial factors, and no older people and only one healthcare professional provided a definition of a fall as specified in the research literature.

By focussing on the consequences of falls, there is a risk that non-injurious falls will be disregarded by older people and healthcare professionals, negating the opportunity for early intervention and reducing the likelihood of preventing more

serious falls in the future. To promote awareness of exercise-based falls prevention programmes and to make them more accessible and relevant to the entire population, researchers and healthcare professionals must move away from reductionist definitions of falls and falls prevention strategies and consider alternative explanations that emphasize opportunity and valued social identity.

1.7.2. Recommendation 2: When offering or publicizing interventions, promote immediate benefits that fit with positive self-identity

Risk is frequently invoked in contemporary accounts of ill health, but its construction is often constrained by a rationalist perspective which focuses on physical causes and functional outcomes, and that presents risk as external to the self and predictable (Ballinger & Payne, 2002). Whilst healthcare professionals are often orientated to the management of physical falls-risk, there is increasing evidence to suggest that older people are more concerned with the risk to their personal and social identities, leading to further dissonance in the clinical encounter.

Ballinger and Payne (2000) conducted semi-structured interviews with 20 healthcare professionals (10 physiotherapists and 10 occupational therapists), and 8 older people admitted to an orthopaedic trauma ward following a fall resulting in fractured neck of femur. In keeping with previous research into perspectives of health and illness, the authors discovered that individualized accounts of falls were neither neutral nor objective, but fashioned to achieve particular ends. The therapists' accounts were formulated through a risk discourse, in which their expertise as

healthcare professionals was privileged. Within this discourse, falls were considered predictable events which healthcare professionals had a duty to try and prevent. Older people were presented as vulnerable, needy, ignorant, and sometimes foolhardy. In contrast, the older people's responses were formulated through a moral discourse, in which their commendable personal qualities and competencies were highlighted. Although the older people were appreciative of all the help they had received whilst in hospital, they refuted negative assessments of their mental state, moral character and ability to take care of themselves. The older people were reluctant to assume responsibility for the events leading to their hospital admission, often attributing their fall to the carelessness of others.

The findings from this study would suggest that older people's accounts of falling have a moral dimension in which personal identities need to be protected. Identity is knowing who you are and what is meaningful to you (Kidd, 2002). In sociological terms, identity is derived through social interaction since it is through interaction in our social groups that we develop our values, personal beliefs and meanings (Walker et al., 2011). Conceptually, Jenkins (2008) suggests that identity may be distinguished on three levels: one socially constructed (collective identity); and two levels of personal identity – outer self (shown to others), and inner self (a unique self-definition). Identity is not fixed but continues to develop over time in response to life experiences. The collective identity of ageing is recognized by all. However, as individuals age, it has been suggested that this collective identity may begin to conflict with personal identity (Walker et al., 2011).

Research involving older people is beginning to question accepted stereotypes. However, Minichiello et al (2000) have demonstrated that negative attitudes are internalized by older people, impelling them to dissociate from old age by struggling to maintain the appearance and self-perception of independence. Evidence from qualitative studies would suggest that traditional approaches to clinical service delivery emphasize the negative social consequences of ageing that many older people fear. The need to attend falls prevention classes, make safety modifications in the home, wear protective clothing or use mobility aids is often seen as announcing the transition to old age, physical decline and functional dependence (Kingston, 2000). Such findings may help to explain the low levels of uptake and adherence documented in the academic literature and witnessed in routine clinical practice.

Understanding an individual's core belief systems can assist healthcare professionals to work in partnership with older people to promote self-management and participatory decision-making (Vermeire et al., 2001; Sabate, 2003). Yardley et al (2007) developed a postal questionnaire based on the theory of planned behaviour to determine whether threat appraisals (perceived risks of consequences of falling) or coping appraisals (perceived benefits and appropriateness of undertaking exercise-based falls prevention programmes) were most closely related to older people's intention to participate in an exercise-based falls programme and, therefore, more likely to promote uptake. Four hundred and fifty one community-dwelling older people were recruited from a diverse range of sources. To ensure that frailer older people who may find it difficult to complete and return a postal survey were included in the study, 107 individuals were recruited from sheltered accommodation

and luncheon clubs and invited to participate in structured interviews. The authors discovered that intention to carry out an exercise-based falls prevention programme was most closely related to coping appraisal than to threat appraisal. Coping appraisal was based on an evaluation of the many potential benefits of exercise, including enjoyment of the activity and improvement in general health status, mood, confidence and the ability to get out and about, as well as reduction in falls-risk. As expected, participants' intention to participate in an exercise-based falls prevention programme was strongly associated with the belief that it was a suitable activity for someone like themselves, and that family, friends and healthcare professionals considered it to be appropriate. Concerns about whether the exercises would be harmful, tiring or painful and whether the respondents would be able to perform them were also related to strength of intention to participate in an exercise-based falls prevention programme.

This study only examined intention to participate in an exercise-based falls prevention programme, not the actual undertaking and maintenance of regular exercise. However, these findings would indicate that older people respond more favourably to health promotion messages about healthy ageing and maintenance of independence than to warnings about falls-risk and injury prevention. Although it may be necessary to try to overcome denial of personal falls-risk in order to persuade older people of the need to undertake specific exercises to improve strength and balance (Whitehead et al., 2006), it would appear that presenting exercise-based falls prevention programmes primarily as a means of maintaining or improving physical functioning would be more compatible with an older person's sense of

positive self-identity. This may provide the key to promoting uptake and long-term adherence with an exercise-based falls prevention programme.

1.7.3. Recommendation 3: Use a variety of forms of social support to engage older people in interventions

Whilst the majority of early falls prevention studies focussed on home-exercise (Campbell et al., 1997; Robertson et al., 2001), evidence from randomized controlled trials has emerged more recently to indicate that once-weekly supervised group exercise, conducted in community settings with at-risk older people, is also effective in reducing falls (Barnett et al., 2003; Skelton et al., 2005). Group programmes have been commended for their interactive nature and fostering of social relationships, which have been shown to improve health by inducing feelings of emotional wellbeing (McAuley et al., 2003). Despite such observations, however, it has been suggested that home-based interventions are easier to tailor to individual need and are associated with fewer barriers to participation, such as difficulties with transport (Newman et al., 2004). A Cochrane review of certain condition-specific exercise programmes identified that home-based initiatives were generally more effective in sustaining long-term adherence (Ashworth et al., 2005).

To identify the extent to which older people are willing to participate in different falls prevention activities and how this may vary in different sectors of the population, Yardley et al (2008) surveyed individuals aged over 54 years of age from 10 cities across the United Kingdom. The survey assessed willingness to attend

classes of strength and balance training, carry out exercise-based falls prevention programmes at home, or accept support to reduce home hazards. Participants were asked their gender, age, education, home tenure, ethnic group, and how often they had fallen in the past year. Based on 5440 responses, it was discovered that over 60% of the sample would consider following an exercise-based falls prevention programme at home, and 36.4% would definitely participate. In contrast, however, only 22% would definitely attend group sessions, and 41.1% would definitely not attend. Over half of respondents were willing to consider making home modifications. As expected, older age and recent falls were associated with undertaking exercise-based falls prevention programmes at home and accepting home modification, suggesting that falls prevention strategies are viewed as most relevant by those considered at highest risk. The authors concluded that health promotion programmes should give prominence to home-based performance of strength and balance training as a method of encouraging the entire older population to engage in falls prevention activities, including those most at risk.

Regardless of whether exercise-based falls prevention programmes are delivered in a home or group environment, the relationship between the patient and healthcare professional is often considered an important determinant of treatment outcome (Hall et al., 2010). To explore the meaning of falling for older people who had participated in a falls prevention programme and to establish the importance of personal identity in falls prevention interventions, Walker et al (2011) conducted semi-structured interviews in a convenience sample of 11 older people who had recently completed a weekly exercise-based falls prevention programme. The

authors discovered that participants attended the falls prevention programme because a healthcare professional they respected had referred them, not because they believed they would receive any personal benefits from attending. In keeping with the findings of Ballinger and Payne (2000), the older people interviewed described the importance of good manners and respect when participating in exercise-based falls prevention programmes – a learned behaviour the authors referred to as polite compliance.

It has been suggested that until older people can be open with healthcare professionals about their experiences and ideas, they cannot fully engage in participatory decision-making (Paterson, 2001). However, such findings would indicate that current approaches to clinical service delivery have allowed the relationship between healthcare professionals and older people at risk of falling to remain grounded in the traditional power differential of active doctor and passive patient (Boote et al., 2002). These observations conflict with the philosophical principles underpinning self-management for long-term conditions and may be contributing to the low levels of uptake and adherence with an exercise-based falls prevention programme documented in the research literature and witnessed in routine clinical practice.

It has been estimated that 80-90% of care for individuals with long-term conditions is undertaken by older people or their relatives (de Silva, 2011). Despite such observations, however, healthcare professionals often assume that family members hold similar views about goals and treatment planning without asking them to

validate this assumption (Paterson, 2001). Within falls prevention, little is known about the consequences of falling for informal care-givers who are predominantly the family members of frailer older people with some degree of cognitive impairment. To explore the impact of falling for frail community-dwelling older people with and without cognitive impairment and their family members, Faes et al (2010) conducted grounded theory interviews with 10 older people (three cognitively unimpaired; four with mild cognitive impairment; and three with dementia) and their primary care-givers. All of the participants described fear of falling and social withdrawal. Most were unable to name a cause for their fall, and rejected the idea that falls were preventable or that fear of falling could be reduced by carrying out specific exercises to improve strength and balance. The primary care-givers all reported a fear of their family member falling. However, they indicated that their relative's cognitive impairment was more burdensome than their falls and believed that a falls prevention programme would not be useful because of their family member's cognitive impairment, physical health problems, age and personality.

To complement these findings, Horton and Arber (2004) conducted separate in-depth interviews with 35 older people who had experienced recurrent falls and their primary care-givers. The actions taken by relatives to prevent future falls were classified as: protective; coercive; negotiating; engaging; and reflective of mutual respect. The authors discovered that negotiation between older people and their family members varied according to gender. Sons caring for mothers undertook only protective and coercive actions, resulting in their older relative developing a passive

and submissive role. In contrast, daughters caring for their fathers most often undertook engaging and negotiating actions, which empowered their older relative in the decision-making process. Daughters were found to have a peer-like relationship with their mothers, and undertook primarily negotiating as well as engaging actions. The two sons who cared for their fathers took no specific actions but maintained mutual respect for each other.

These findings would suggest that falling has major physical and psychological consequences for older people and their relatives, and that primary care-givers need more advice and support from healthcare professionals to manage falls in the community. An enhanced understanding of the ways in which the gender of dyad members influences the nature of negotiation between older people at risk of falling and their primary care-givers may enable healthcare professionals to develop more appropriate strategies to support older people and their relatives to develop a long-term active commitment to exercise-based falls prevention programmes.

1.7.4. Recommendation 4: Ensure that the intervention is designed to meet the needs, preferences and capabilities of the individual

Personalized assessment and education for falls prevention is very resource intensive and, it has been argued, is only reliably cost effective for those considered at increased risk of falling due to advanced age or the presence of established medical risk factors (Chang et al., 2004; Gillespie, 2004; Kannus et al., 2005). Whilst there is marked heterogeneity in the characteristics of individuals who fall (Davison &

Marrinan, 2007), established approaches to clinical service delivery commonly involve the identification of high-risk sub-groups of the population deemed most at risk of falling, such as those with cognitive impairment (Shaw, 2002), hospital inpatients (Oliver et al., 2007), or care home residents (Rubenstein et al., 1996). In practice, however, up to half of injurious falls occur in those who are not very old, frail or unwell, but amongst older people who continue to be active despite some decline in their balance capabilities (Stel et al., 2003; Wijnhuizen et al., 2008).

Clinical specialities and dedicated services aim to concentrate skills and experience, making assessments more effective and targeted interventions easier to deliver than more generalist or broad-based approaches. However, the process of delivering specialist care relies on the assumption that there are categories of patient that can be readily differentiated (Reed et al., 2006). The National Service Framework for Older People (Department of Health, 2001b) suggests that there is a tendency for clinical services to take a collective approach to the care of older people which does not acknowledge their individual needs or perceptions of risk and ill-health. Whilst the Yardley et al (2008) study introduced in Section 1.7.3 identified that advanced age and recent falls were associated with an increased likelihood to undertake exercise-based falls prevention programmes, the authors discovered that individuals who had recently retired or not yet reached retirement age would also consider undertaking specific exercises to improve strength and balance. The acceptability of exercise-based falls prevention programmes to this age group means that it may be possible to engage individuals in activities to reduce their risk of falling in later years at a time when undertaking such interventions may pose fewer concerns or difficulties.

It has been suggested that health promotion specialists and clinical services work together to produce the at-risk individual and that this is achieved through the willing participation of older people, who view it as a duty and moral obligation to participate in the maintenance of their own health (Ballinger & Payne, 2002). When asked about falling, the older people and relatives participating in the Walker et al (2011) study introduced in Section 1.7.3 demonstrated a shared construct of individuals they considered to be fallers and non-fallers. In keeping with the findings of Zecevic et al (2006), these were not defined in the same way as in the research literature. It was suggested that individuals at risk of falling would be over the age of 80 and have ill health or poor mobility. Only two of the nine participants who had fallen before recognized themselves as fallers. The authors identified that the participants' personal values and beliefs about falls enabled them to place themselves in one of two groups: the self-assessed faller and the self-assessed non-faller. Participants' self-assessments were found to be based upon individual perceptions of their health and role in society rather than the number of falls experienced. One participant who described herself as a non-faller had experienced five falls over an 18 month period.

Placing individuals into groups or categories for the purposes of identifying risk of falling has stereotyped older people (Reed et al., 2006). Such findings provide further evidence to support the importance of personal identity in falls prevention and question the cost-effectiveness of a collective approach to clinical service delivery. In keeping with the philosophical principles underpinning self-management for long-term conditions it would appear that a holistic, person-centred

approach to falls prevention that acknowledges the personal identity of the individual and not the social construct of an older person at risk of falling is vital to the promotion of uptake and adherence with an exercise-based falls prevention programme.

1.7.5. Recommendation 5: Encourage confidence in self-management rather than dependence on professionals, by giving older people an active role

Over the past decade, fear of falling has emerged as an important and common syndrome affecting as many as one in four community-dwelling older people (Martin et al., 2005). The concept of fear of falling was originally introduced by Murphy and Isaacs (1982) who described it as post-fall syndrome. However, studies have shown that up to 50% of older people presenting with fear of falling have never actually experienced a fall (Murphy et al., 2002). Whilst fear of falling may be a reasonable response to certain life events or situations, self-imposed activity restriction caused by fear of falling often exceeds safety requirements (Cheal & Clemson, 2001). Moreover, evidence from prospective community-based studies would suggest that self-mediated gait changes and deconditioning secondary to fear of falling and activity restriction may actually cause older people to fall (Friedman et al., 2002).

Enhancing self-efficacy is one strategy that has been found to be effective as a means to enhance activity participation after a fall. Self-efficacy is a central

construct of social cognitive theory from which many of the current programmes aimed at promoting self-management for individuals with long-term conditions are derived. Bandura (1997) suggests that the following components should be included in a programme aimed at changing health behaviour:

- Skills development and practice
- Mastery experiences
- Exposure to positive role models
- Information provision
- Self-affirming verbal persuasion (assurance of ability to carry out behavioural change)
- Development of social supports

In a small qualitative study, Cheal and Clemson (2001) used in-depth interviews and a Modified Falls Efficacy Scale (Tinetti et al., 1994) to evaluate a 6 session falls prevention and self-efficacy training programme. Based on Bandura's recommendations, a major emphasis of the programme was providing mastery experiences and skills development in community mobility activities. Interviews were conducted 2 weeks prior to commencing the programme and 4 weeks after completion. Ten referrals were received, and 8 individuals (5 men and 3 women)

agreed to participate in the study. Before the programme, 6 individuals reported having fallen at least once and the remaining two had experienced loss of balance. Prior to attending the programme, all participants described reduced activity levels due to fear of falling. Four participants no longer did their own shopping and only one participant continued to use public transport.

Prior to commencing the programme, the older people suggested that falls and physical decline were an inevitable part of the ageing process. Few were able to make suggestions for avoiding future falls; one participant claiming she was too old to learn anything new. Upon completion of the programme, however, the older people demonstrated enhanced levels of self-efficacy and were able to identify appropriate strategies for reducing falls-risk and promoting independence. Six out of seven participants demonstrated an increase in their Modified Falls Efficacy Scale scores as a result of participating in the programme. Improvements in Modified Falls Efficacy Scale scores were associated with increased activity participation, such as walking outdoors, using public transport and the completion of housekeeping tasks.

A central theme of the British Government's modernization agenda for health and social services in England and Wales is the promotion of independence for all client and patient groups. This is linked, on the one hand, to a general requirement for services to be more focussed on the needs of the individuals using them and, on the other hand, to the aim of reducing dependence on resource-intensive services through prevention and rehabilitation (Finset, 2008). Despite such observations, however, the concept of independence is rarely defined in these publications. In

search of an appropriate operational definition, Secker et al (2003) reviewed the published literature on independence in old age. The most common conceptualization in the academic literature equated independence with the absence of reliance on others. However, for older people, independence was found to be broader concept that encompassed not only self-reliance but also self-esteem, self-determination, purpose in life, personal growth and continuity of the self.

Empowering older people to make informed choices about their care and treatment, through discussion and time for reflection, is fundamental to the promotion of independence (Tanner, 2001). However, it has been suggested that viewing the assessment of falls-risk as a professional and technical task which is the preserve of experts has contributed to a conservative approach to clinical service delivery in which patient-initiated activity is seen as challenging and potentially dangerous (Ballinger & Payne, 2002). Learned helplessness is the state in which individuals believe they have no opportunity or ability to change their lives. In contrast, however, learned resourcefulness exists when individuals take charge of their lives (Walker et al., 2003). By recognizing that independence is a subjectively self-lived experience, Secker et al (2003) suggest that it may be possible to combine high levels of dependence with high levels of experienced or felt independence; a particularly pertinent combination for healthcare professionals working with older people at risk of falling.

Roe et al (2008) conducted semi-structured interviews with a convenience sample of 27 older people (mean age 84 years; range 65-98) who had experienced a recent fall

(within the last 10 days). Eighteen of these individuals agreed to participate in follow-up interviews (3 - 4 months later). They discovered that people who reflected on their falls and sought to understand why and how they had occurred developed strategies to prevent future falls, faced their fear, maintained control and choice, and continued with activities of daily living. Those who did not reflect on their fall and did not know why it occurred restricted their activities and environments and remained in fear of falling.

Whilst the added value of cognitive behavioural strategies over traditional approaches remains uncertain, it would appear that Bandura's recommendations are easily translated into routine clinical practice and readily applicable to the issue of falls prevention in older people. Assisting individuals to reflect on their falls and to understand why and how they occurred could help prevent future falls, allay fear, enhance self-efficacy, and aid the promotion of independence relating to activities of daily living.

1.7.6. Recommendation 6: Draw on validated methods for promoting and assessing the processes that maintain adherence, especially for the longer term

Sustainability is viewed as an important dimension in the quality and success of health promotion programmes (Scheirer, 2005). It is widely accepted that for communities and individuals to derive continued benefits, programmes and programme involvement must be maintained in the long-term (Alexander et al.,

2003). Preventing falls amongst community-dwelling older people is an ongoing process that cannot be dealt with effectively through the adoption of a short-term strategy. At a community level, individuals are continually entering old age and emerging as potential candidates for health promotion and injury prevention programmes. At an individual level, there is increasing recognition that older people should be encouraged to maintain their health and abilities over time (Hanson et al., 2009). Whilst long-term adherence has been shown to be poor across a range of health promotion interventions, Carter et al (2003) suggest that it may be particularly likely to occur if the programme requires prolonged or unsupervised self-management, involves lifestyle modification, or does not provide immediate relief from symptoms. Exercise-based falls prevention programmes have the potential to possess all of these characteristics and it is perhaps not surprising, therefore, that as many as 60-80% of individuals admit to partial or complete non-adherence with a home-exercise programme (Engstrom & Oberg, 2005).

It is easy to assume that such common-sense views as the value of health promotion initiatives, such as exercise-based falls prevention programmes, are universally held. However, in doing so healthcare professionals may be minimizing the social dimension of such activities (Ballinger & Payne, 2000). Whilst the prevention of falls and associated injuries is a public health priority in many developed countries, there is increasing recognition in the academic literature that older people may not attach the same significance to this goal in routine clinical practice. Ballinger and Clemson (2006) conducted semi-structured interviews with 11 individuals (9 women, 2 men) who had recently completed a 6 session multi-faceted falls

prevention and self-efficacy training programme. When discussing the consequences or outcomes of participation, a decrease in the likelihood of future falls was rarely mentioned. Despite such findings, however, several of the participants did speak about improvements in performance, skills or attributes associated with risk of falling, such as lower limb muscle strength and fear of falling. These observations led the authors to suggest that the issue of falling might be better addressed within health promotion initiatives for older people by situating it amongst more general aims, such as the enhancement of lifestyle and the promotion of wellbeing.

Little research has been carried out to evaluate the best context for the delivery of exercise-based falls prevention programmes. However, the National Institute for Health and Clinical Excellence (2007) have suggested that significant events or transition points in people's lives, such as being diagnosed with a long-term condition, may provide a valuable opportunity for behaviour change because it is then that individuals often re-evaluate their own behaviour and have the necessary contact with healthcare professionals to be supported through the incremental stages of behaviour change.

The increased use of screening liver biochemistry profiles means that individuals with asymptomatic disease now constitute 20-60% of all first time diagnoses in primary biliary cirrhosis (Talwalkar & Lindor, 2003). The changing clinical spectrum of this long-term condition results partly from earlier diagnosis and partly from the recognition of anti-mitochondrial antibodies as a marker for the disease (Newton et al., 2000). As many individuals now present with non-classic features, a

key question arises as to the natural history of primary biliary cirrhoses. Although the risk of progression remains, the disease course can be extremely prolonged, with a significant proportion of individuals remaining in early-stage disease throughout the normal lifespan (Metcalf et al., 1997). In this respect, the prognosis associated with non-classic forms of the disease can be extremely good. Despite such observations, however, two concerns are emerging in the academic literature. Firstly, even in those with little or no disease progression, health-related quality of life can remain significantly impaired over many years. Secondly, emerging data from longitudinal studies would suggest that, although liver-related mortality remains relatively low in individuals with non-classic forms of the disease, overall mortality is elevated significantly, with an excess of non-liver related deaths (Jones & Newton, 2005).

Delivering health promotion interventions, such as exercise-based falls prevention programmes, within the fully-engaged scenario of specialist services for older people with long-term conditions may provide the key to promoting long-term active participation; reducing mortality and morbidity and improving health-related quality of life.

1.8. Future directions from the literature

An emphasis on supporting self-management for individuals with long-term conditions has led to increased recognition in the academic literature that active ongoing participation with an exercise-based falls prevention programme should be

considered a form of behaviour change. However, if older people are to feel empowered to take greater responsibility for their care, they need to feel they have the ability to change their behaviour and that it is in their best interests to do so (Hughes, 2004). The use of theory in self-management needs to become more explicit if we are to establish which social cognition models and their constructs are most valuable in supporting self-management and adherence with clinical interventions, such as exercise-based falls prevention programmes.

Despite the existence of policy directives in the United Kingdom advocating self-management for individuals with long-term condition, the critical review of the academic literature presented in this chapter continues to expose conflicting trends in contemporary healthcare. On the one hand, there is a growing insistence on patient participation, empowerment, shared decision-making and effective clinical communication; on the other, an increased emphasis on economic constraints, efficiency, fragmentation of services and hi-technology healthcare (Finset, 2008). The danger of the latter is that older people at risk of falling may be looked upon as objects, rather than as individuals with complex healthcare requirements. Modern healthcare delivery is currently influenced by two paradigms: patient-centred practice and evidence-based practice (Hughes, 2004). Over the last decade both approaches have rapidly gained in popularity and are supposed to affect the daily decision-making of healthcare professionals during routine clinical practice (Hasnain-Wynia, 2006). Whilst both are highly relevant, however, a closer inspection of the academic literature would suggest that evidence-based practice and

patient-centred practice are traditionally considered as belonging to entirely separate paradigms (Ford et al, 2002).

Patient-centred practice is a humanistic bio-psychosocial concept, combining ethical values on the ideal clinician with psychotherapeutic theories on facilitating individuals' disclosure of real worries and negotiation theories on clinical decision-making (Bensing, 2000). In contrast, evidence-based practice is a positivistic biomedical concept which focuses on offering healthcare professionals the best available evidence about the most effective treatment for their patients (Hasnain-Wynia, 2006). Although at first glance the concept of evidence-based practice may appear patient-centred, it is not (Bensing, 2000). By treating modern healthcare delivery as a rational-cognitive enterprise, it has been suggested that the uniqueness of individuals accessing healthcare services, their needs, preferences and emotional status may be easily overlooked as relevant factors in the clinical decision-making process (Ford et al., 2002).

First described in the 1970s in response to a general sense of dissatisfaction with traditional biomedical models of healthcare delivery, patient-centred practice has evolved over the years to embody a complex set of professional, sociological and political ideas about the patient-practitioner relationship (Mead & Bowers, 2000; van Dulman, 2003). Whilst it has been argued that patient-centred practice is justifiable on humanistic grounds alone (Hughes, 2004), there is still not enough evidence available to support the statement that patient-centred practice leads to better health outcomes (Hughes et al., 2008). These observations have inevitably

raised the question: how patient-centred is evidence-based practice; and how evidence-based is patient-centred practice (Bensing, 2000; Hasnain-Wynia, 2006)? The challenge in actualizing the concept of self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition may lie in attempting to bring these separate worlds together.

Most professions have their own histories which have shaped and thus determined the culture of science within that discipline (Bergman, 2011). From its grass roots in remedial massage in the late 19th century, physiotherapy gained recognition as a professional discipline by adopting the traditional biomedical model of clinical service delivery (Wiles & Barnard, 2001). Treatments were anticipated to provoke repeatable responses from human bodies which were expected to respond in predictable ways (Roberts, 1994). Physiotherapists accepted that diseases and disorders could be explained in terms of changes or failures in body systems and did not consider that both response to and origins of illness could be accounted for in psychological and sociological terms (Pratt, 1989). Physiotherapy intervention was applied to counter disease or disability, with the aim of curing the individual or restoring normal function (Roberts, 1994). The treatment of physical problems by physical means formed the core of physiotherapy and physiotherapists' use of their hands in treatment became the key element that distinguished them from other disciplines (Williams, 1986).

By aligning themselves with established biomedical models of healthcare delivery, the evidence-base underpinning physiotherapy developed very much in accordance

with the logical positivist paradigm of science, which focuses on describing, explaining, predicting and controlling from a reductionist perspective (Wilson-Thomas, 1995). Evidence-based practice and best-practice guidelines often rely on randomized controlled trials, or rather on meta-analyses of only the best randomized controlled trials, as the gold standard for informing clinical decision-making (Hasnain-Wynia, 2006). Whilst not wanting to undermine the enormous relevance that randomized controlled trials have had, and will have, for the scientific development of modern healthcare delivery, it is important to emphasize that randomized controlled trials are disease-orientated *not* patient-orientated (Bensing, 2000). Randomized controlled trials are performed on homogenous patient groups that are artificially constructed by the strictly defined diagnostic criteria of the disease under investigation (Ford et al., 2002). In contrast, however, routine clinical practice is filled with individuals who demonstrate a wide diversity in related symptom patterns and an even wider diversity in the way they evaluate and cope with these symptoms (Gzil et al., 2007). It is exactly this diversity, the author of this thesis would argue, that makes routine clinical practice so rewarding. To work in an ontological framework based on empowerment and shared decision-making, healthcare professionals and researchers working with older people at risk of falling must begin to ask different questions, negotiate different actions and assess outcomes in a different way to traditional research methods and approaches to clinical service delivery.

1.9. Summary

Whilst there is good research evidence to support the efficacy of exercise-based falls prevention programmes, typically half those invited to take part accept and subsequent adherence is often only partial. A critical review of the academic literature would suggest that supporting self-management and behaviour change may provide the key to promoting uptake and adherence with an exercise-based falls prevention programme. The increased prevalence of long-term conditions associated with an ageing population has placed patient-centred practice, empowerment and shared decision-making at the heart of United Kingdom healthcare policy. However, to actualize the concept of self-management for individuals with long-term conditions, healthcare professionals and researchers must be prepared to change the way they deliver and evaluate clinical interventions, such as exercise-based falls prevention programmes. This chapter has provided the context to and justification for the current study. Chapters 2 and 3 will outline the methodological and philosophical principles underpinning the study and describe the associated research methods employed to develop a framework for physiotherapy practice to promote self-management and adherence with an exercise-based fall prevention programme for older people with a long-term condition.

CHAPTER 2. METHODOLOGY

2.1. Overview of chapter

This chapter will set out the research aim, objectives and theoretical propositions underpinning the current study, examine the philosophical paradigm and methodological assumptions, and introduce the methods employed. (Chapter 3 will provide a more detailed account of the associated research methods). It will discuss the ontological and epistemological complexities associated with mixed methods research and provide a critical realist rationale for combining qualitative and quantitative approaches. A methodological critique of the Medical Research Council guidelines for the development, evaluation and implementation of complex interventions to improve health will be provided and consideration given to the suitability of this framework to inform the design of critical realist studies. Recognizing the emancipatory potential of critical realism, the chapter will conclude by emphasizing the importance of involving local stakeholder groups in health research that attempts to change or enhance existing clinical practices.

2.2. Research aim

To develop a framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.

2.3. Research objectives

1. To identify the factors influencing uptake and adherence with an exercise-based falls prevention programme from the perspectives of older people at risk of falling, relatives and local physiotherapy practitioners.
2. To develop and test acceptable strategies to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition identified as being at increased risk of falling.

2.4. Theoretical propositions

1. Established models of clinical service delivery that focus on the short-term reduction of physical falls-risk are not compatible with older people's sense of positive self-identity, leading to low levels of uptake and adherence.
2. Practical self-management strategies, based on the central constructs of social cognition models, have the potential to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition identified as being at increased risk of falling.

2.5. Clarification of terminology

The definitions provided in this section represent key terms that will be used throughout this chapter. The philosophical stance adopted by the researcher provides a basic set of beliefs that guide their actions (Creswell, 2007 p. 248). The overarching research philosophy is considered a ‘net that contains the researcher’s epistemological, ontological, and methodological premises’ (Denzin & Lincoln, 2007 p. 13). Ontology refers to the nature of being or existence (Bergin et al., 2008), and epistemology to ‘the study of the nature of knowledge and justification’ (Schwandt, 2001 p.71). Methodologies are the research approaches that structure and rationalize epistemic concepts for investigative purposes (Lipscomb, 2008), and methods the technical means by which data are identified, collected and analysed (Rolfe, 2006). Table 2.1 sets out the methodological strategy of the current study to be explicated in this and the following chapter.

Table 2.1. Methodological strategy of current study

Research process	Methodological strategy	Thesis section
Philosophical paradigm	Critical realism	2.6
Research approach	Qualitatively-driven mixed methods	2.7
Research framework	Informed by Medical Research Council guidelines for complex interventions	2.8
Methods	Focus groups and experimental case-series	3.2 and 3.6
Data	Qualitative (focus groups) and Quantitative-Qualitative (case-series)	3.4 and 3.9
Analyses	Framework analysis (focus groups) Graphical, visual and framework analysis (case-series)	3.5 and 3.11

2.6. Research philosophy

To enhance rigour, it is important to carefully consider not only the research methodology but also the philosophical intent of the study (Wilson & McCormack, 2006). This section will introduce critical realism as the philosophical paradigm underpinning the current study. Critical realism is an umbrella term used to categorize the work of a range of philosophers who have taken ontological questions about the nature of the natural and social world as a starting point for their analysis (McEvoy & Richards, 2003). Contemporary critical realism most commonly refers to a philosophical approach associated with the British philosopher Roy Bhaskar,

which combines a general philosophy of science (transcendental realism) with a philosophy of social science (critical naturalism) to describe the interface between the natural and social worlds (Modell, 2009). Since Bhaskar made the first steps in popularising the theory of critical realism in the 1970s, it has become one of the major strands of social scientific method (McEvoy & Richards, 2006).

Critical realists distinguish between three different ontological domains of reality: the empirical; the actual; and the real (Harrits, 2011). The empirical domain is founded on (observable) experience. However, critical realists acknowledge that not all events are experienced. As a result of this, the actual domain consists of both experiences (the empirical) and events. Critical realists believe that reality exists independent of our knowledge of it (Kazi, 2003). Although reality cannot be apprehended directly as it is not open to observation, it can be inferred through a combination of empirical observation and theory generation (McEvoy & Richards, 2006). This leads to the third domain, the real, in which experience (empirical), events (actual) and mechanisms all occur (Bergin et al., 2008). The three ontological domains within the critical realist paradigm are illustrated in Table 2.2.

Table 2.2. The three ontological domains within the critical realist paradigm
(Adapted from Bhaskar, 2008)

	Experiences	Events	Mechanisms
Empirical	•		
Actual	•	•	
Real	•	•	•

Within the context of the current study:

- The real is comprised of the factors influencing self-management and adherence with an exercise-based falls prevention programme.
- The actual relates to the implementation of an exercise-based falls prevention programme in practice and the ensuing events that may or may not be observed.
- The empirical refers to what happens as a result of the implementation of an exercise-based falls prevention programme and the experiences of physiotherapy practitioners and older people at risk of falling as a result of prescribing and participating in these programmes.

Critical realism argues that science is a social product, and makes a fundamental distinction between two dimensions of knowledge: the transitive and the intransitive (Bergin et al., 2008). Critical realists believe that progress is possible because the

intransitive nature of reality (enduring structures and processes) provides a point of reference against which theories can be tested (Patomaki & Wight, 2000). However, it not possible to fully apprehend this reality as our perceptions are shaped by our theoretical resources and investigative interests (Kazi, 2003). The distinction between the three ontological domains of reality (empirical, actual and real) implies notions of relativity: the same event might be perceived differently; influenced by different mechanisms; or that the same underlying mechanism may lead to different events in varying contexts (Vassilev et al., 2011).

Causal concepts are ubiquitous in every branch of theoretical science, in the practical disciplines and in everyday life (Howick et al., 2009). In the medical sciences, in particular, claims about causal relationships are often based on the application of statistical methods of data analysis. However, the source and type of data often place important constraints on the choice of statistical method as well as on the warrant attributed to the causal claims based on the use of such methods (Ward, 2009). Statistical methods cannot establish proof of a causal relationship through association. The causal significance of an association is a matter of judgement which goes beyond any statement of statistical probability (Howick et al., 2009). Even in those cases in which there are good reason to believe that an association between a purported cause and effect is not an artefact of selection or measurement bias, an ever present danger is that the association is the result of confounding and not a genuine cause-and-effect relationship (Ward, 2009).

The most influential and widely applied work on identifying causality in the health sciences is that of the British epidemiologist and statistician, Austin Bradford Hill. Hill (1965) described nine features that may be used to evaluate whether an association is causal. These are: (1) strength: how strong is the association between cause and effect; (2) consistency: the relationship is present in multiple places, and the results are replicable; (3) specificity: whether the cause leads to an effect or group of effects (for example, smoking causing illness versus smoking causing lung cancer); (4) temporality: the cause precedes the effect; (5) biological gradient: does the level of the effect or risk of it occurring increase with an increase in the level of the cause (for example, a dose-response curve); (6) plausibility: is there some event that could potentially connect cause and effect, given current biological knowledge; (7) coherence: the relationships should not conflict with what we know of the disease; (8) experiment: the condition can be altered (prevented or ameliorated) by an appropriate experimental regimen; and (9) analogy: after finding the relationship between, for example, human papillomavirus and cervical cancer we may more readily accept that a virus could cause another type of cancer.

Whilst originally developed as a research tool in the medical sciences, it has been suggested that Hill's criteria are equally applicable to research conducted in the social sciences which attempts to establish the existence of causal relationships between social phenomena (Ward, 2009). Despite such observations, however, not everybody is sanguine about their use. Rothman and Sander (2005) suggest that, whilst epidemiologists frequently make use of Hill's criteria, their use has, at best, dubious value. The problem, they claim, is that there are ambiguities, fallacies and

vagaries associated with each criterion. In a similar vein, Goodman and Philips (2004) note that there is no clear way to quantify the degree to which each criterion is met (which makes comparative assessments of different statistical associations very difficult at best), or how to aggregate such results into a judgement about causation. These kinds of criticisms have led to a large body of literature debating the meaning, application and use of specific criteria, as well as proposals for extending and modifying Hill's original criteria (Ward, 2009).

It has been suggested that high-quality randomized controlled trials often provide sufficient evidence that a particular treatment caused an outcome. However, sufficiently well-conducted randomized controlled trials are rare. Trials can be unsuccessfully blinded, and may suffer from undetected biases (Howick et al., 2008). In addition, much of the research conducted in the health and social sciences is based upon non-experimental or observational data. One of the most important issues in contemporary health and social sciences, therefore, concerns making warranted causal claims from non-experimental or observation data (Ward et al., 2009). Causality, from a critical realist perspective, refers to the process of identifying generative mechanisms and how they work, discovering if they have been activated and under what circumstances they have been activated (Sayer, 2000). Critical realists recognize that world is a complex and messy place and, with few exceptions (and those are almost exclusively in controlled laboratory conditions), a characteristic feature of social phenomena is that they are usually the result of multiple causal influences (Modell, 2009). According to critical realism, therefore, different generative mechanisms are not necessarily equally comparable as

they operate on different levels of abstraction. For this reason, a variety of concepts are necessary to deal with relationships and mechanisms operating on different levels. The latter means that the complex relationship between the empirical, actual and real can only be grasped through the development of multiple perspectives, whilst the ultimate test for conceptual and theoretical development should be their practical adequacy for understanding the events or processes under investigation (Vassilev et al., 2011)

In critical realist studies, understanding the mechanisms at work and the contexts in which they operate provides a theoretical understanding of a given phenomena which can then be used to optimize the effects of an intervention by countering blocking mechanisms, or by changing the intervention so that it is more in keeping with the contexts in which a positive outcome has already been achieved (Robson, 2002). The philosophical and methodological principles underpinning the current study meant that it was possible to utilise the findings from the focus group and experimental case-series to build upon the theoretical propositions developed in response to clinical observations in the workplace and a comprehensive review of the contemporary academic literature. The outcome of this process was the development of the framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition presented in the final chapter of this thesis.

At a fundamental level, all forms of research and inquiry develop from a human desire to understand and make sense of the world around us (Bryman, 2007).

Despite such observations, however, many methodology textbooks continue to differentiate between qualitative and quantitative approaches, which have traditionally been regarded as separate paradigms (Bergman, 2011). It has been suggested that critical realism offers an attractive alternative to the established research paradigms of positivism and interpretivism (McEvoy & Richards, 2006; Modell, 2009). To provide a contextualized account of critical realism in relation to the current study, it is necessary to briefly consider the philosophical paradigms of positivism and interpretivism and their associated methodological underpinnings.

Quantitative approaches that incorporate standardized measures and statistical techniques are usually affiliated with the positivist paradigm. Often associated with the natural sciences, positivism is based on the philosophy that an individual's preconceptions must be set aside in order to identify objective facts based on empirical observations (Robson, 2002). With regard to definitional characteristics, researchers engaged in quantitative research tend to employ large and random samples, reduce complex phenomena to a few simple variables, test hypotheses, work deductively, and generalize their findings to a wider population (Bergman, 2011). Quantitative approaches associated with the positivist paradigm include closed-response interviews and questionnaires, randomized controlled trials and systematic reviews with meta-analyses (McEvoy & Richards, 2006).

In contrast, qualitative approaches, based on non-numeric narratives, are commonly associated with the interpretivist paradigm. Researchers conducting qualitative research typically employ small samples, are non-reductionist about their subject

matter, concern themselves with subjective experience, work inductively, and study phenomena in their natural setting (Bergman, 2011). Participants are selected on the basis of how useful they are likely to be for the pursuit of the inquiry, and the views of participants who are not representative of the general sample are actively sought out (Kitzinger 2006). Qualitative approaches associated with the interpretivist paradigm include focus groups, unstructured interviews, textual analysis and ethnographic case-studies (McEvoy & Richards, 2006).

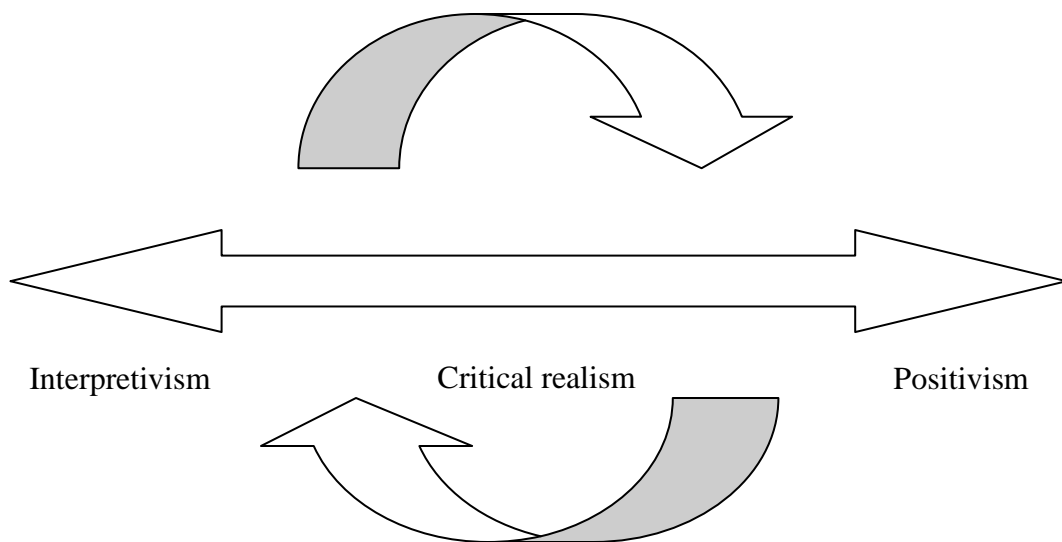
From a critical realist perspective there are two main problems with positivist methodologies. Firstly, they focus exclusively on observable events and fail to take into account the extent to which these observations are influenced by *a priori* theoretical frameworks (Modell, 2009). Secondly, positivist approaches deal with relationships between the various elements of a social system as though they were cut off from external influences in a closed system, and fail to take account of the interactions between mechanisms and the contexts in which they occur (McEvoy & Richards, 2006). Whilst critical realists acknowledge the value of interpretivist methodologies that focus upon human discourse, perceptions and motivations, they are critical of interpretivist researchers who fail to relate these factors to the underlying social structures which may enable or constrain the actions of individuals or to the social structures in which these individuals are embedded (Williams, 2003).

The logic that underpins critical realism is called retrodution. This involves moving from the level of observation and lived experience to postulate about the underlying structures and mechanisms which may account for the phenomena involved

(Mingers, 2003). Retroduction has been defined as: ‘a mode of analysis in which events are studied with respect to what may have, must have, or could have caused them’ (Kazi, 2003 p. 806). In short, it means asking why events happened in the way they did. For critical realists the ultimate goal of research is not to identify generalisable laws (positivism), or to investigate the lived experience or belief of social actors (interpretivism), but to develop deeper levels of explanation and understanding (McEvoy & Richards, 2006).

Adopting a critical realist stance within the current study meant that it was possible to navigate and reconcile the polarized paradigms of interpretivism and positivism. The epistemological journey undertaken during the course of the current study is illustrated in Figure 2.1.

Figure 2.1. Representation of philosophical underpinnings of current study



In Figure 2.1, critical realism occupies a central position on a philosophical continuum anchored at either end by the polarized paradigms of interpretivism and positivism. To identify the factors influencing uptake and adherence with an exercise-based falls prevention programme at a local level, a series of focus groups were conducted with older people attending a regional falls and syncope service, relatives and physiotherapy practitioners. In this way, it can be seen that the study began towards the interpretivist end of the philosophical continuum.

Whilst acknowledging the value of interpretivist methodologies, however, critical realists allow for the possibility that the accounts of research participants may be incomplete or even misguided (Appleton & King, 2002). Recognizing the limitations of a purely qualitative paradigm (Mason, 2006), the focus group findings were used to develop practical strategies to promote self-management and adherence with an exercise-based falls prevention programme. These were tested and refined in an experimental case-series with a small sample of older people with primary biliary cirrhosis. Experimental approaches attempt to eliminate plausible rival hypotheses which might explain a series of observations and enable the researcher to make valid inferences about the available data (Robson, 2002), and this could be seen to represent a move towards the positivist end of the philosophical continuum. However, whilst group-based methods often obscure and wash out fluctuations in behaviour by pooling the data, single-case experiments offer a way of investigating fluctuations in behaviour over time and enable the effects of an intervention to be judged against these fluctuations (Morley, 1994).

In critical realist research, Clare (2003) suggests that quantitative data should always be complemented by an interpretivist approach. On completion of the experimental case-series, the quantitative data were presented graphically and a series of semi-structured interviews conducted with participants to help explain the trends and patterns observed in the data. In this way, it can be seen that the study ended by returning towards the interpretivist end of the philosophical continuum.

2.7. Methodology

Although employing a mixed methods methodology, Figure 2.1 illustrates that the current study began and ended towards the interpretivist end of the philosophical continuum. Adopting a qualitative approach to mixed methods research (Mason, 2006) offers enormous potential for generating new ways of understanding the complexities and contexts of social experience. Over the last 10 years, mixed methods have become widely advocated in healthcare research (Pawson & Tilley, 2001; Johnstone, 2004; Bryman, 2006, Lipscomb, 2008) due to increased recognition that social experience and lived realities are multi-dimensional, and that our understandings of these phenomena may be impoverished or inadequate when viewed through a single methodological lens (Mason, 2006).

Whilst the qualitative-quantitative dispute has dismissively been described as 'sterile' (Rycroft-Malone et al., 2004 p. 88), Lipscomb (2008) warns that the advantages of a mixed methods approach may be squandered if researchers do not adequately explore the theoretical and philosophical (ontological and

epistemological) arguments underpinning these methodological arguments. In this section, methodological pragmatism will be contrasted with a critical realist stance to mixed methods research to illustrate how the latter involves a more ‘principled approach’ (McEvoy & Richards 2006 p. 68) to the combining qualitative and quantitative approaches.

Methodological pragmatists, such as Johnson and Onwuegbuzie (2004); Morgan (2007); Scott and Briggs (2009); and Felizer (2010), argue that researchers should use whatever methods are necessary to obtain optimum results, even if this involves switching between alternative paradigms. The logic of the pragmatist position is that neither quantitative nor qualitative methods alone are sufficient to develop a complete analysis. For this reason, both approaches may be used in combination to complement each other (Creswell et al., 2004). Being explicit about the methodological underpinnings of mixed methods studies may appear needlessly abstract to healthcare researchers who are grappling with complex real world issues (Foss & Ellefsen, 2002). However, if the qualitative part of a mixed methods study is grounded in interpretivism, whilst the quantitative part is steeped in positivism, the two components cannot be logically combined within one single, coherent and consistent research design (Bergman, 2011), and researchers will encounter difficulties when attempting to make sense of dissonant data obtained using methods based on conflicting epistemological assumptions (Perlesz & Lindsay, 2003; Johnstone, 2004).

Critical realists argue that the choice of research methods should be dictated by the nature of the research problem, and in many cases it is suggested that the most effective approach will be to use a combination of quantitative and qualitative approaches. What is important from a critical realist perspective, however, is *how* these methods are used (Modell, 2009). Critical realists argue that it is only appropriate to combine qualitative and quantitative approaches if a common ontological and epistemological position can be sustained (Liscomb, 2008). Adopting an anti-conflationist position, critical realists have pointed out that, although there are general differences between quantitative and qualitative methods, these differences cannot be described as an all-embracing dichotomy. They argue that there are many approaches which cross the traditional quantitative-qualitative divide and that the differences between these methods are not always as extreme as they are made out to be (Bergman, 2011). Critical realists who undertake mixed methods research to explore the intransitive nature of reality explicitly distance themselves from the underpinning ontic and epistemic idealist philosophies that might be associated with forms of qualitative methodologies as well as empiricist philosophy and its quantitative underpinnings. ‘And, with the ontological base secured, healthcare researchers are free to – indeed they must – use existing epistemological frameworks and their methodological embodiments in new or different ways’ (Liscomb, 2008 p. 42).

Moran-Ellis et al (2006) distinguish between mixed methods approaches that seek to *combine* quantitative and qualitative methods and those which aim to *integrate* them. Within the current study, the focus group discussions helped to identify clear and

consistent issues with local clinical service delivery that were confirmed and elaborated on by the experimental case-series. The findings from both approaches stimulated the retroductive reasoning that led the development of a framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.

It has been suggested that integrating qualitative and quantitative data strengthens the evidential support for theory generation (McEvoy & Richards, 2006). To provide further justification for the 'blending' (Risjord et al 2002 p. 269) or 'meshing' (Mason, 2006 p. 9) of qualitative and quantitative approaches in critical realist studies, consideration will be given to the concept of triangulation within the context of the current study.

2.8. Methodological triangulation

The notion of triangulation in the social sciences is generally used in a less literal sense than in its original application in the fields of navigation and land surveying (McEvoy & Richards, 2006). The conventional logic of methodological triangulation implies that different methods are combined to provide complementary insights into the same empirical phenomenon, with the aim of enhancing the validity of the research findings (Robson, 2002). Triangulation is a defensible validation procedure when research is confined to the positivist paradigm, with its underlying view of reality as an objective, unified and readily observable entity. However, it has been argued that triangulation may not be appropriate when research contains more

subjectivist elements, as is the case in mixed methods studies that attempt to straddle positivist and interpretivist paradigms (Modell, 2009). Risjord et al (2002) suggest that methodological triangulation is usually applied for three reasons: completeness, confirmation and abductive inspiration. In this section, a critical realist approach to methodological triangulation will be compared with the usual positivist and interpretivist standpoints to illustrate how the triangulation of qualitative and quantitative approaches in critical realist studies can be used to confirm or refine a theory more effectively than either method alone.

2.8.1. Completeness

Risjord et al (2002) suggest that qualitative and quantitative data may be triangulated for the purpose of completeness in order to obtain complementary perspectives, and a greater level of detail than could be gained from either data source alone. In the current study, the focus groups and experimental case-series both provided valuable insights into the factors influencing uptake and adherence with an exercise-based falls prevention programme at a local level. From a positivist standpoint, the goal of completeness is to reveal different aspects of a phenomenon, whereas from an interpretivist perspective the aim is to provide a wider range of perspectives. Both of these goals are compatible with a critical realist approach. Within the philosophy of critical realism, quantitative and qualitative methods can be employed to reveal different facets of the same reality and also to examine reality from different perspectives (McEvoy & Richards, 2006).

2.8.2. Confirmation

The use of triangulation for the purposes of confirmation probably comes closest to the original use of the term which describes a set of techniques that are used to locate a fixed position (McEvoy & Richards, 2006). In social and evaluation research, data is triangulated for the purpose of confirmation in order to enhance the reliability and validity of the findings. By using a combination of methods, researchers attempt to counteract the biases that are associated with single method studies. In this way quantitative and qualitative findings are used to corroborate each other and support a more robust conclusion than either data source alone (Robson 2002). In the current study, the focus group findings helped to identify clear and consistent issues with local service delivery that were confirmed and elaborated on by the experimental case-series. This approach to triangulation makes sense from both a positivist and critical realist perspective since it is based on the assumption that there is a tangible social reality. However, the goal of confirmation is less compatible from an interpretivist standpoint. Interpretivists are agnostic over whether or not there is a tangible social reality, preferring instead to stress the importance of alternative subjective positions and different ways of making sense of the social world (McEvoy & Richards, 2006).

2.8.3. Abductive inspiration

Abduction is the logical process by which a researcher arrives at a new explanation for a phenomenon. Abductive inspiration, therefore, is very similar in meaning to the

critical realist concept of retrodution and refers to the use of one method to generate ideas that are tested and refined by another method (Risjord et al., 2002). In the current study, the focus group findings were used to develop acceptable strategies to promote self-management and adherence with an exercise-based falls prevention programme which were tested and refined in the experimental case-series. Triangulation for the purposes of abductive inspiration may play a valuable role in a research study that is underpinned by the philosophy of critical realism. This is because detailed observations can provide a platform for making retroductive inferences about the mechanisms that are active in a given situation (Harrits, 2011). Retrodution makes little sense from either a positivist or interpretivist perspective, but for different reasons. Positivism maintains that researchers should confine themselves to making observations about empirical events, as they search for regularities from which to make generalizations. They are wary of speculative theory and argue that claims cannot be made about social mechanisms and structures that cannot be observed. Retrodution is also problematic from an interpretivist standpoint because their ontological perspective is restricted to the understanding of subjective meaning. The material aspects of reality are intangible from an interpretivist perspective and there is no firm basis to support retroductive inferences about social structures or mechanisms (McEvoy & Richards, 2006).

For critical realists, deductive methods (based on testing specific hypotheses) and inductive methods (based on the formation of general inferences) are necessary but insufficient for theory development without retrodution or abductive inspiration (Patomaki & Wight, 2000). In the context of scientific research, abductive

inspiration is a creative form of reasoning that takes place retrospectively as mechanisms are postulated to account for observed phenomena via analogy, metaphor and model building (McEvoy & Richards, 2003). In the current study, the findings from the focus groups and experimental case-series were used to develop the theoretical propositions set out in Section 2.4 and stimulated the retroductive reasoning that led to the development of a framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition. When retroduction is combined with deduction and induction in this way, competing explanations can be compared on the basis of their explanatory power and methodological triangulation is used to develop a more complete understanding of a phenomenon by mapping its different aspects, rather than to confirm the accuracy of diverse sets of data (Risjord et al., 2002).

2.9. Research framework

Like many healthcare activities, exercise-based falls prevention programmes should be considered a complex intervention built up from a number of components, which may act both independently and interdependently (Medical Research Council, 2000). These components commonly include behaviours, parameters of behaviour (such as frequency, timing), and methods of organizing and delivering those behaviours (such as type of practitioner, setting and location) (Medical Research Council, 2008).

It is widely acknowledged that evaluating complex interventions provides a considerable challenge and requires a significant investment of time. Traditional research methods commonly fail to illuminate processes and mechanisms and are, therefore, often of limited use to the practising clinician. If the findings are negative, it can be difficult to establish whether the intervention under evaluation is inherently ineffective, inadequately applied, delivered in an inappropriate context, or whether the research team used a suitable design, comparison group and outcomes. If there is a positive effect, it may be difficult to judge how the findings might be applied in a different clinical setting or population group (Campbell et al., 2007).

In an attempt to address some of the issues highlighted above, The Medical Research Council (2000) published guidelines which proposed a stepwise approach to the development, evaluation and implementation of complex interventions to improve health:

- Phase 0 – Pre-clinical or theoretical (why should this intervention work?)

- Phase 1 – Modelling (how does it work?)

- Phase 2 – Exploratory or pilot trial (optimising trial measures)

- Phase 3 – Definitive randomized controlled trial

- Phase 4 – Implementation

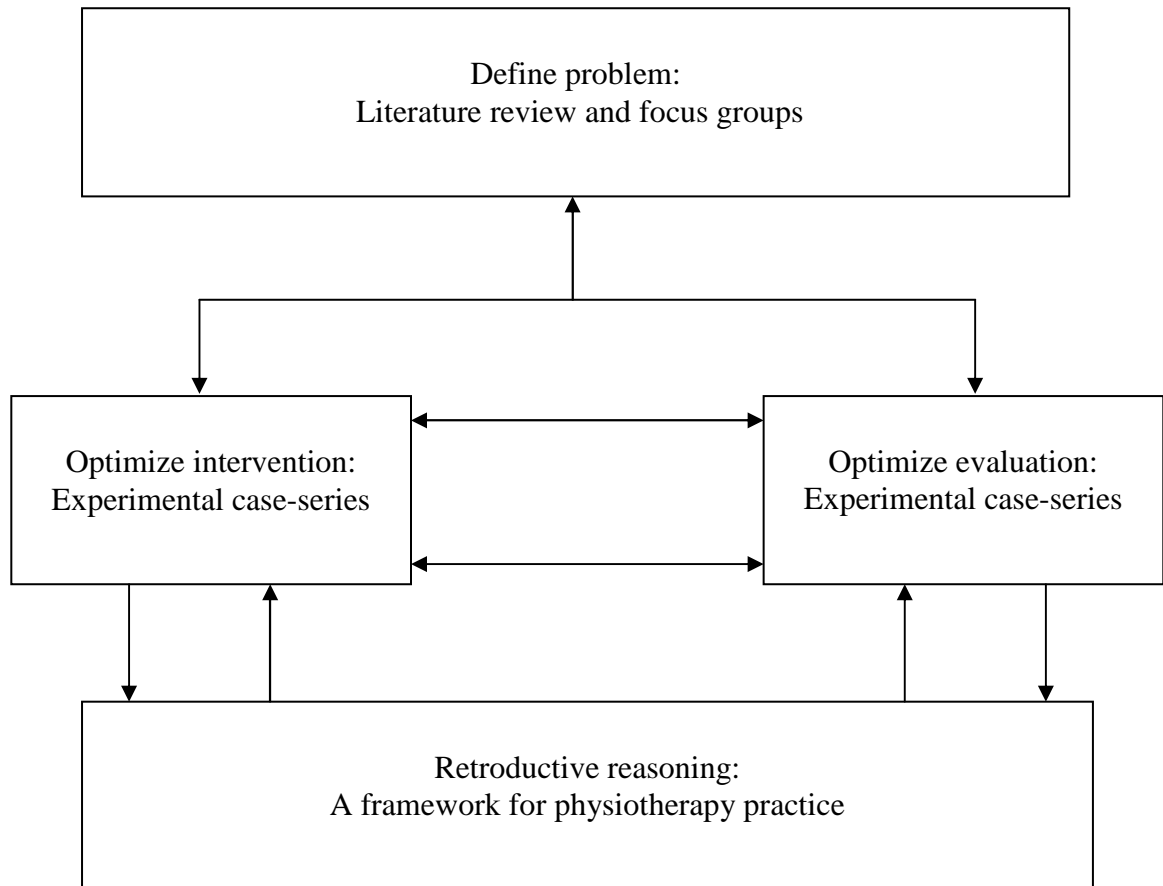
The original framework was criticized by some authors for being narrow and misconceived in its original definition of the complexity of interventions and for suggesting phases for developing and evaluating complex interventions that were considered unhelpfully similar to those of a commercial drug trial (Anderson, 2008). Despite such limitations, however, the document stimulated and promoted discussion about alternative research methodologies and assisted healthcare practitioners to contextualize their research findings (Campbell, 2000). Updated in 2008, the guidelines now recommend greater attention to early phase piloting and development work, a less linear model of evaluation, integration of process / outcome appraisal and an increased recognition that complex interventions work best if they are tailored to local contexts rather than being completely standardized (Craig et al., 2008).

Critical realist investigations set out to understand why an intervention works, for whom it works and under what circumstances it works (Wilson & McCormack, 2006). A key question in evaluating complex interventions is whether they are effective in everyday practice. In keeping with critical realist philosophy, the Medical Research Council guidelines acknowledge that it is important to understand the whole range of effects and how they might vary amongst recipients or between sites. A second key question when evaluating complex interventions is how the intervention works - what are the active ingredients and how do they exert their effect (Craig et al., 2008)? Critical realists seek to understand social events (at the level of the actual domain) by exploring the underlying structures and mechanisms (at the level of the real domain) (Harrits, 2011). When adopting a critical realist

approach to the development, evaluation and implementation of complex interventions to improve health it is important to employ research methods that are sensitive enough to identify the mechanisms through which the interventions under evaluation produce particular outcomes within the contexts in which they are delivered (McEvoy & Richards, 2003).

The current study was informed by a model which considers phases 0, 1 and 2 of the Medical Research Council guidelines for the development, evaluation and implementation of complex interventions to improve health as one larger iterative activity (Campbell et al., 2007). However, rather than focussing on the exploratory work preceding a definitive randomized controlled trial, the findings from the current study were used to develop the theoretical propositions set out in Section 2.4 and informed the retroductive reasoning that led to the development of a framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition. The design of the current study is illustrated in Figure 2.2.

Figure 2.2. Research design of current study (Adapted from Campbell et al., 2007)



Each of the components illustrated in Figure 2.2 will be discussed within the context of the current study.

2.9.1. Define problem

The rationale for evaluating a complex intervention, the changes that are expected, and how these changes might be achieved is often not clear from the outset. An early key task, therefore, is to develop a theoretical understanding of the likely process of

change by drawing on existing evidence, supplemented by new primary research as necessary (Craig et al., 2008). Campbell et al (2007) suggest that qualitative research may be valuable at this stage for exploring opportunities for, and barriers to, change.

Focus group data are embedded within a group discussion that is context specific. However, as Yardley (2000) emphasizes, theoretical worth rather than statistical generalizability is of primary importance in qualitative research. Some analyses are important, she claims, not because they provide an accurate and complete explanation of a particular body of empirical data but because they draw on empirical data to present a novel and challenging perspective. This may open up new ways of understanding a topic. Conducting a series of focus groups with older people attending a regional falls and syncope service, relatives and physiotherapy practitioners provided an enhanced understanding of the factors influencing uptake and adherence with an exercise-based falls prevention programme at a local level. Whilst not automatically transferable to other population groups, it was possible to successfully combine this primary qualitative data with a comprehensive review of the contemporary academic literature to develop a novel approach to the delivery of exercise-based falls prevention programmes that could be tested and refined in the experimental case-series.

2.9.2. Modelling processes and outcomes

Modelling a complex intervention can provide important information about the design of both the intervention and the evaluation (Craig et al., 2008). Critical

realists believe that researchers need to have a very substantial knowledge of the phenomenon they are interested in before it is worth their while setting up a formal experiment. Through theory and observation, and as a result of previous experiments, critical realists develop knowledge and understanding about the mechanism through which an action causes an outcome, and about the contexts which provide the ideal conditions to trigger the mechanism (Harrits, 2011). As a result of this, Robson (2002) acknowledges that a series of studies may be required to progressively refine the research processes and outcomes under evaluation.

Older people with primary biliary cirrhosis suffer from a range of co-morbidities in addition to the liver-related disease processes that characterize their condition (Frith et al., 2010). These could make the implementation of a complex intervention, such as an exercise-based falls prevention programme, particularly challenging in this patient group. This, together with a dearth of published research evidence on suitable methods for evaluating the impact of physiotherapeutic interventions in this population group, meant it was necessary to employ an experimental design that treated each participant as a single unit. This approach meant that it was possible to test and refine the strategies developed in response to the focus group findings and identify the mechanisms responsible for promoting self-management and adherence with exercise-based falls prevention programme in a novel population of older people with a long-term condition identified as being at increased risk of falling.

2.9.3. Retroductive reasoning

Given the politics of research funding procurement, the scientific establishment may favour approaches with which they are familiar, such as randomized controlled trials and systematic reviews, which are firmly established at the top of the hierarchy of evidence (Lipsey & Wilson, 2001). However, when the findings of a randomized controlled trial are published, the theoretical rationale that underpins an intervention tends to receive comparatively little attention in contrast to the efficacy of the intervention (McEvoy & Richards, 2003). This can lead to problems when complex interventions, such as exercise-based falls prevention programmes, are implemented in routine clinical practice as there is usually little or no information to enable healthcare professionals to make decisions about how to best adjust the programme in the light of specific circumstances (Medical Research Council, 2008).

Despite the growing body of research evidence from systematic reviews and meta-analyses to support the efficacy of exercise-based falls prevention programmes, uptake and adherence rates continue to vary greatly. Conducting further randomized controlled trials may, therefore, prove prohibitively expensive and tell us little more than we already know (McEvoy & Richards, 2003). It is argued, therefore, that a theory-driven approach to the development, evaluation and implementation of exercise-based falls prevention programmes may now prove more appropriate for identifying the mechanisms that make these clinical interventions effective (and less effective) in particular contexts.

2.10. Practitioner-researcher role

The role of practitioner-researcher was adopted throughout the current study. A practitioner-researcher is 'someone who holds down a job in some particular area and is, at the same time, involved in carrying out a systematic enquiry which is of relevance to that job' (Robson, 2002 p. 534). The practitioner-researcher is becoming increasingly common in health research as it is widely recognized that investigation, enquiry, evaluation and innovation are an important part of the professional clinical role (Costley & Gibbs, 2006).

There is a substantial body of literature documenting the need to understand barriers to optimal healthcare delivery, translation of research into practice and diffusion / dissemination of innovation. Despite the existence of such publications, however, a significant gap often exists between research recommendations, scientific evidence and clinical practice guidelines on the one hand, and actual clinical practice on the other (Cochrane et al., 2007). The decisive criterion by which any piece of research must be judged is, arguably, its impact and utility. It is not sufficient to develop a thorough and plausible piece of research if the ideas propounded by the study have no influence on the beliefs or actions of anyone else (Yardley, 2000). It has been suggested that, all too often, healthcare professionals who theorize and those who practice are out of touch with each other. In other words 'the thinkers are separated from the doers' (Wilson-Thomas, 1995 p. 572). Adopting the role of practitioner-researcher ensured that the research aim, objectives and theoretical propositions underpinning the current study were informed by clinical observations in the

workplace. The unique and privileged position of practitioner-researcher provided a valuable opportunity to work closely with older people at risk of falling, relatives and physiotherapy colleagues to gain a better understanding of the factors influencing uptake and adherence with an exercise-based falls prevention programme at a local level. Utilizing these findings to develop and test an alternative approach to clinical service delivery that focussed on self-management and adherence during the experimental case-series meant that the views of the focus group participants had a direct impact on local clinical service delivery.

Despite such observations, however, it should be pointed out at this stage that conducting clinical research with patients and colleagues raises different ethical and methodological issues from those where the relationship between researcher and participants is more transitional, informal and definable. The latter allows the researcher to distance themselves from the research setting and detach themselves emotionally from the research context. Costley & Gibbs (2006) suggest that practitioner-researchers are unable to do this since they work with patients and colleagues who are temporarily transformed into research participants and then return to patients and colleagues again, in much the same way that the practitioner-researcher adopts the role of academic researcher before returning to that of clinician.

The advantages and disadvantages of the practitioner-researcher role within the context of the current study are presented in Table 2.3.

Table 2.3. Advantages and disadvantages of practitioner-researcher role (Based on Reed & Proctor, 1995)

	Advantages	Disadvantages
<p>1. Aims</p> <p>The primary aim of practitioner-research is often to solve a critical problem, thereby contributing to the body of professional knowledge.</p>	<p>By participating in the focus group research, local stakeholder groups were able to contribute to the development of practical strategies to promote self-management and adherence with an exercise-based falls prevention programme that had a direct impact on local clinical service delivery. The evolving theoretical understanding of self-management and adherence developed during the course of the current study resulted in changes in the thesis author's clinical practice that extended beyond the confines of the experimental case-series.</p>	<p>The practitioner-researcher may not have the authority to influence local service delivery beyond the confines of their own clinical practice. Towards the end of the focus group research, the physiotherapists began to re-evaluate their original assumptions regarding self-management and adherence with an exercise-based falls prevention programme. However, it is not possible to determine the extent to which these alternative insights corresponded with actual changes in their routine clinical practice.</p>
<p>2. Access</p> <p>The choice of research setting is limited but the contact is deep</p>	<p>The research setting is often the practitioner-researcher's place of work and is, therefore, more compatible with qualitative-driven approaches that typically employ small samples and study phenomena in their natural setting. The focus groups and experimental case-series were ideally suited to exploring the complexity surrounding self-management and adherence with an exercise-based falls prevention programme <i>within the lived experience</i> of older people at risk of falling, relatives and local physiotherapy practitioners.</p>	<p>Practitioner-research tends to deal with messy contextually-dependent issues. Whilst the framework for physiotherapy practice presented in the final chapter of this thesis provides an enhanced theoretical understanding of the factors influencing self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition, further exploration of these findings in other patient groups and practice settings would be necessary to establish transferability of principles.</p>

Table 2.3. Continued

	Advantages	Disadvantages
<p>3. Negotiation of role</p> <p>The practitioner-researcher is a member of the world being researched. They may have multiple roles, some of which are permanent.</p>	<p>It has been suggested that, by viewing the practitioner-researcher as a practitioner first and a researcher second, participants may not always exercise appropriate restrictions on self-disclosure. However, the therapeutic and professional relationships that the thesis author had developed with local stakeholder groups provided a relatively safe environment in which to express their frustrations with local clinical service delivery. In doing so, they were able to contribute to an enhanced understanding of the factors influencing self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.</p>	<p>Data collected whilst assuming the role of practitioner may not be considered legitimate, and the individual making the remark may not be happy to have it included in the research. During the delivery of the enhanced intervention, the relatives of the experimental case-series participants provided valuable insights into the factors influencing self-management and adherence with an exercise-based falls prevention programme. However, failure to obtain formal ethical approval to involve these relatives in the follow up interviews meant that their views and experiences were not incorporated into the final data analysis.</p>
<p>4. Design and planning</p> <p>Informed by insider knowledge and frequently governed by therapeutic imperatives.</p>	<p>The aim and objectives underpinning the current study were influenced by clinical observations in the thesis author's workplace. These informed a critical review of the academic literature which contributed to a novel theoretical understanding of the factors influencing self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.</p>	<p>Many practitioner-researchers are undertaking research on limited budgets with tightly-defined deadlines. Failure to include a stakeholder perspective in the early developmental stages of the focus group and experimental case-series research may have limited the current study's ability to impact on local clinical service delivery.</p>

Table 2.3. Continued

	Advantages	Disadvantages
<p>5. Analysis</p> <p>Shares taken-for-granted assumptions, the significance of which may not be recognised.</p>	<p>Practitioner-research aims to explicate the tacit knowledge embedded in routine clinical practice. During the data analysis process, particular attention was paid to contradictions and disconfirming excerpts in the data. These were used to interrogate the academic literature, leading to an enhanced understanding of the factors influencing self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.</p>	<p>Practitioner-researchers often conduct research about a particular topic which is close to their professional or academic interest. This lack of distance or objectivity may be regarded as undermining the validity of the research findings. However, involving local stakeholder groups in the interpretation of the focus group and experimental case-series findings encouraged the thesis author to adopt a more critically-reflexive stance to the data obtained.</p>
<p>6. Dissemination and commitment</p> <p>To colleagues, professional and academic communities. Concerned about the way in which the research is used both locally and professionally.</p>	<p>To promote transparency, local dissemination sessions were arranged at regular intervals throughout the course of the current study. Individuals were provided with the opportunity to ask questions / provide comments and these were used to shape the ongoing data collection and analysis process. Such strategies may be considered to democratize the research process, as well as contributing to the development of more ecologically-valid data.</p>	<p>Local dissemination sessions provided an opportunity for clinical colleagues to rationalize their behaviour as the data collection and analysis process progressed, and to give or withhold consent from an informed perspective. Despite such observations, however, the findings of the current study might still be perceived as politically damaging, highlighting areas of poor practice which some clinicians and service managers may prefer not to be made public.</p>

2.11. Stakeholder involvement

Critical realism is ‘critical’ in the sense that it provides the philosophical foundation for a critical social science; that is, one that criticizes the social practices it studies (Wilson & McCormack, 2006). It has been suggested that identifying false understandings and the actions based on them may provide the impetus for change (Manias & Street, 2000). In this way critical realism can help to fulfil the emancipatory potential of health research (Robson, 2002). This section will introduce critical social theory as the critical social science underpinning the current study and provide a methodological rationale for involving local stakeholder groups in health research that attempts to change or enhance existing clinical practice.

The emergence of critical theory within the philosophy of social sciences has added another dimension to the study of human behaviour. Critical theory refers to a style of neo-Marxist philosophy associated with the Frankfurt School which originated in Europe in the 1920s. The influence of the Frankfurt School underwent a revival in the 1950s. The leading proponent of this second generation of critical theorists is commonly considered to be Jurgen Habermas (Clare, 2003). Most contemporary writers would agree that critical theories combine a form of action theory with a form of structuralist theory, but do not view these as dealing with an ontologically distinct area of social reality (Owen-Mills, 1995). Within this paradigm, social structures are theorized as having their origins in human action, not as static role structures as in positivist science, but as dynamic systems built up of the actions and interactions of individuals. Critical social theory acknowledges that people both

shape and are shaped by socio-political and cultural arrangements (Manias & Street, 2000). Social structures may come to dominate those who produce them, they may fragment social relationships, and oppress those who live and work within them (Wilson-Thomas, 1995). However, critical social theory also recognizes that people are capable of transforming their socio-political environment and, through individual and collective action, change oppressive conditions (Clare 2003). The central aim of critical social science is social theorizing (Cresswell, 2007), which has been defined as ‘the desire to comprehend, and in some cases, transform (through praxis) the underlying orders of social life – those social and systematic relations that constitute society’ (Morrow & Brown, 1994 p. 211).

Enlightenment, empowerment and emancipation are the processes that create the practical intent of critical social theory (Manias & Street, 2000). Enlightenment, or raising the consciousness of the oppressed, is used by critical social theorists to explain why people are dissatisfied with their lives. Using this process, critical theorists work collaboratively with individuals to develop alternative ways of understanding themselves and their social context (Clare, 2003). However, enlightenment itself is not enough for individuals to become liberated from a social order. Critical social theory must provide a motivating resource for individuals, therefore empowering them. Empowerment encourages people to undertake activities by which they work to improve their situation (Wilson-Thomas, 1995). Finally, emancipation is the goal of empowerment through which new arrangements replace oppressive ones, permitting individuals to relate and act in more satisfying ways (Manias & Street, 2000). Contemporary critical scholars have rejected the

grandiose claims of enlightenment empowerment and emancipation, whilst retaining a concern to identify and redress injustices of race, class, ethnicity, gender, sexual preferences, age and ability (Clare, 2003).

Critical social theory abrogates traditional positivist methods. It seeks to explore phenomena by judging the contextual effects of power, knowledge and values rather than by adopting rigorous tests deemed verifiable and replicable (Manias & Street, 2000). Critical social theory has emancipatory potential. Through a critical praxis, action can be initiated to examine the existing realities of healthcare (Wilson-Thomas, 1995). To achieve this, local stakeholder groups are viewed as central to the process of doing research. By working together through the different stages of the research process, researchers and local stakeholder groups are able to work together to challenge existing structures and facilitate a change in clinical practice (Manias & Street, 2000). Stakeholder involvement challenges the positivist position that knowledge can be developed at a distance from research participants, who have traditionally been treated as the passive suppliers of data (Barber et al., 2007).

The rise in popularity of inclusive research methodologies is important, epistemologically, because it implies a shift away from positivism towards a more phenomenological, experiential focus, grounded in the social realities of those being researched (Williamson & Prosser, 2002). Despite strong political and philosophical underpinnings (Barber et al., 2007), however, very little guidance currently exists regarding the most effective way to involve stakeholder groups in clinical research or how to demonstrate the impact of stakeholder involvement on research processes

and outcomes (Staley, 2009). The involvement of local stakeholder groups in the design and execution of the current study will be considered in Chapter 4 of this thesis.

2.12. Summary

Adopting a critical realist stance, the current study employed a ‘qualitatively-driven’ mixed methods approach informed by the Medical Research Council framework for the development, evaluation and implementation of complex interventions to improve health. Critical realists recognize the existence of logical connections between the ontological, epistemological and methodological premises that underpin their work and suggest that studies which overtly acknowledge these logical and conceptual linkages are more likely to demonstrate argumentative coherence and validity than studies which ignore and / or break such linkages. This chapter has presented a critical realist rationale for mixed methods research that will assist the reader to judge the merits of the chosen methodology and its influence on the research processes and outcomes presented in this thesis. Chapter 3 will provide a detailed account of the associated research methods.

CHAPTER 3. METHODS

3.1. Overview of chapter

This chapter will provide a detailed account of the research methods employed in the current study. It will set out the rationale for selecting the focus groups and experimental case-series and discuss the sampling and recruitment, data collection and data analysis strategies underpinning these two approaches. Emphasizing the reciprocity between methodology and ethics, the chapter will conclude with a critical examination of the ethical issues encountered during the design and execution of the focus group and experimental case-series research.

3.2. Focus groups

Despite the advantages of reason and empiricism, the best-planned clinical interventions often fail to deliver as intended and healthcare researchers now recognize the importance of learning from those who deliver and receive clinical services about the nuances and subtleties which might dramatically affect the eventual outcome (Thorne, 2010). To identify the factors influencing uptake and adherence with an exercise-based falls prevention programme at a local level, a series of focus groups were conducted with older people attending a regional falls and syncope service (3 groups, total 12 participants), relatives (1 group, total 4 participants) and physiotherapy practitioners working with older people at risk of falling in a variety of clinical settings (4 groups, total 18 participants).

Focus group research has been defined as a ‘carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment’ (Krueger & Casey, 2009 p. 2). Although often used as a quick and convenient method of collecting data from several individuals spontaneously, focus groups were explicitly designed to capitalize on group interaction and provide a distinctive type of data (Kitzinger, 2006). Bloor et al (2001) suggest that focus groups should be the method of choice when the purpose of the research is to study group norms, group meanings and group processes. Focus groups aim to understand and explain the beliefs and cultures that influence the attitudes and beliefs of participants as well as illuminating the differences in perspective that might exist between groups of individuals (Rabiee, 2004).

Stakeholder involvement and empowerment were important considerations in the design and execution of the current study and focus groups were ideally suited to exploring the complexity surrounding uptake and adherence with an exercise-based falls prevention programme *within the lived experience* of older people at risk of falling, relatives and local physiotherapy practitioners. Focus groups ‘encourage research participants to explore issues of importance to them, in their own vocabulary, generating their own questions and pursuing their own priorities’ (Kitzinger, 2006 p. 22). When group dynamics work well, participants can act as co-researchers, taking the research in new and often unexpected directions (Barbour, 2008).

Critical social theory recognizes that the intentions and desires of individuals may be socially constrained or refined by external agencies (Clare, 2003), and focus groups have been successfully employed in health services research to access the process through which collaborative meaning is negotiated and group identities elaborated. Focus groups can be invaluable in assisting individuals to ‘problemize’ (Barbour, 2008 p. 134) taken for granted assumptions, encouraging participants to collectively address topics to which, as individuals, they may have previously devoted little attention. In this way, focus group research can help to achieve the critical realist goal of liberating individuals from the conscious and unconscious constraints of existing socio-political and cultural arrangements, such as established approaches to clinical service delivery (Wilson-Thomas, 1995). The focus groups encouraged local stakeholder groups to engage positively with the research process. By participating in the focus group discussions, older people attending a regional falls and syncope service, relatives and physiotherapy colleagues were able to contribute to the development of practical strategies to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition that would have a direct impact on local clinical practice.

3.3. Sampling and recruitment

Barbour (2007) suggests that recruiting focus group participants involves making a number of pragmatic and ethical decisions. Rather than aspiring to recruit a representative sample, qualitative researchers employ purposive sampling where participants are selected ‘by virtue of characteristics thought by the researcher to be

likely to have some bearing on their perceptions and experiences' (Barbour, 2008 p. 52). Older people, relatives and physiotherapy practitioners were identified as three important local stakeholder groups, and triangulation of these data sources was undertaken to achieve a more rounded, multi-layered understanding of the factors influencing uptake and adherence with an exercise-based falls prevention programme.

Homogeneity means that participants have something in common that is of interest to the researcher; in the current study, experience of prescribing or participating in an exercise-based falls prevention programme. Homogenous groups provide a relatively safe environment for individuals to share their views and experiences, and are said to dilute the balance of power between the researcher and participants by taking advantage of naturally occurring peer groups (Barbour, 2005). However, to promote lively debate and discussion, Krueger and Casey (2009) suggest that focus groups should be homogenous in terms of background rather than attitude. The aim of sampling in the focus group research, therefore, was to aim for homogeneity but with sufficient variation amongst participants to allow for contrasting opinions.

It is important to be aware of how hierarchy within groups can affect the data obtained. As a result of this, Sim (1995) suggests that it might not be advisable to mix patients and healthcare professionals in a single focus group session. In the current study, older people attending a regional falls and syncope service, relatives and local physiotherapy practitioners were invited to attend separate focus groups. Details pertaining to the sampling and recruitment of these three groups are

presented separately below. However, it should be pointed out that, in practice, the focus group sessions were conducted over the same time period.

3.3.1. Older people

Over a three month recruitment period consecutive older people attending a regional falls and syncope service were screened to identify those with the following common characteristics:

- 65 years of age and over
- Experience of participating in an exercise-based falls prevention programme
- Living in own home
- Resident in Newcastle upon Tyne
- Medically stable
- Independently mobile (with or without walking aid)
- Mini Mental State Examination $\geq 24/30$
- Able to provide informed written consent

To avoid the risk of perceived coercion, these individuals were issued with a participant information sheet (Appendix I) and invited to return an expression of interest form at their convenience in a pre-paid envelope if they wanted to participate in the focus group discussions. Individuals were reassured that participation was entirely voluntary, and that a decision not to take part in the focus group research would not affect their relationship with any member of the healthcare team or the standard of care they received whilst attending the regional falls and syncope service.

As a result of their capacity to explore ‘Why not....?’ type questions, focus groups are often used to investigate poor take-up or non-adherence of health service activities (Barbour, 2007). However, as can be seen in the opening chapter of this thesis, the potential barriers to undertaking exercise-based falls prevention programmes are widely documented in the falls prevention literature. The purposive sampling of older people who were actively participating in an exercise-based falls prevention programme meant that their views and experiences could be used to develop an alternative approach to clinical service delivery that could be tested and refined in the experimental case-series.

3.3.2. Relatives

Over the 3 month recruitment period, the relatives of older people attending the regional falls and syncope service were provided with a copy of the same participant information sheet (Appendix I) and invited to return an expression of interest form at

their convenience in a pre-paid envelope if they wanted to participate in the focus group discussions. Again, individuals were reassured that participation was entirely voluntary and that a decision not to take part in the focus group research would not affect their relationship with any member of the healthcare team or the standard of care received by their relative whilst attending the regional falls and syncope service.

3.3.3. Physiotherapy practitioners

To reduce the risk of pre-existing patterns of leadership, Murphy et al (1992) suggest it is preferable if focus group participants do not know each other. However, as Kitzinger (2006) acknowledges, naturally occurring groups, such as individuals who work together, may provide a valuable insight into peer group dynamics. An additional advantage, she claims, is that friends or colleagues can relate each other's comments to instances in their shared daily lives, challenging each other on the contradictions between what they profess to believe and how they actually behave. At the beginning of the 3 month recruitment period, physiotherapy practitioners from the local primary care trust, working with older people at risk of falling in a variety of clinical environments, were issued with a participant information sheet (Appendix II) and invited to return an expression of interest form at their convenience in a pre-paid envelope if they wanted to participate in the focus group discussions. This similar method of recruitment was chosen to avoid the risk of perceived coercion as the thesis author was known to the physiotherapy practitioners in a professional capacity.

3.4. Data collection

Each focus group was composed of 4-6 participants and lasted approximately 1 hour. Whilst the qualitative research textbooks recommend the ideal size of a focus group to be anywhere between 4 and 12 participants, Krueger and Casey (2009) suggest that smaller groups are often easier to host and that there is less likelihood of domination by opinionated individuals. In the current study, focus groups of 4-6 participants proved large enough to reveal variations in perspectives and attitudes, whilst still permitting individuals to share in-depth insights into their experiences of prescribing and participating in an exercise-based falls prevention programme.

The focus groups were audio-taped, with participants' consent, and transcribed verbatim by a professional typist with experience of undertaking focus group transcription. The transcription of focus group data can be a costly and time-consuming process, which some authors claim is often unnecessary. However, one of the particular strengths of focus group data is the richness and complexity of the responses generated by group interaction. Frankland and Bloor (1999) suggest that much of this richness would be lost without accurate transcription. Furthermore, they claim, there is the danger of selective recall of, and attention to, certain data and the neglect of other contrasting or qualifying material if the researcher relies purely on indexed recordings and field notes. Verbatim transcripts also open up the possibility of returning to the data at a later date to undertake further analysis in the light of new insights gained from subsequent studies or further reading (Barbour 2007). Although the focus group findings were used to develop practical strategies

to promote self-management and adherence with an exercise-based falls prevention programme that could be tested and refined in the experimental case-series, analysis of the focus group and experimental case-series data occurred in an iterative manner. The experimental case-series findings helped to shape the interpretation of the focus group data and both approaches were used to inform the retroductive reasoning that led to the development of the framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition presented in the final chapter of this thesis.

In keeping with the role of practitioner-researcher, the thesis author moderated all of the focus group discussions. This proved a challenging experience on a number of occasions since the practitioner-researcher must be able to generate interest in and discussion about a particular topic, which is close to their professional or academic interest, without at the same time leading the group to reinforce existing expectations or confirm a prior hypothesis (Richards & Emslie, 2000). Reflexivity involves acknowledging the multiple ways in which the researcher actively contributes to the data that he or she is generating (Barbour 2007). Throughout this thesis, the process of qualitative data analysis will be described as one that involves producing findings rather than results. As Barbour (2008) acknowledges, this formulation emphasizes the agency of the researcher and avoids the reification of data as a separate identity. Focus groups are particularly useful for examining how knowledge and ideas develop, operate and are expressed in a given cultural setting and it is important to acknowledge that the social context of the relationship between researcher and participants will influence the data obtained (Yardley, 2000).

As far as possible, the moderator should attempt to ensure that dialogue occurs amongst focus group members rather than between participant and moderator. The moderator should take a backseat initially, allowing for a type of ‘structured eavesdropping’ (Kitzinger, 2006 p.26). Later in the session, however, he / she may wish to adopt a more interventionalist style, urging debate to continue beyond the stage at which it might otherwise have ended and encouraging individuals to discuss any inconsistencies, both between participants and within their own thinking. In the current study, open-ended questions were used in an attempt to elicit the genuine beliefs and attitudes of participants. However, to be able to compare and contrast the views of older people at risk of falling, relatives and local physiotherapy practitioners, a topic guide (Appendix III) was prepared in advance of the focus group research and provided some structure to the discussions. Phrases such as ‘Any other thoughts?’, ‘Is there anyone we haven’t heard from yet?’, and ‘Is there anything else you think we haven’t already covered?’ were used to maintain the flow of discussion without unduly prompting participants.

A physiotherapy colleague was invited to attend the focus group discussions and adopted the role of assistant or ‘silent moderator’ (Barbour, 2007 p. 38). She was able to sit back from the interaction and provide feedback on the moderator’s performance at the end of each session. Krueger and Casey (2009) recommend that written notes should be taken during focus group discussions in addition to audio-taping. Not only does this guard against machine failure but, more importantly, it provides a means whereby observations of the non-verbal interaction taking place within groups can be linked to the verbal accounts provided by participants. Since

note taking can be distracting and inhibit the flow of the discussion, written notes were taken by the assistant moderator throughout the focus group research and provided a richer dialogue for analysis.

A feature of qualitative research is that the analytical process commonly begins during the data collection phase. Undertaking 'sequential' or 'interim' analysis (Pope et al., 2006 p. 65) enabled the views and experiences of local stakeholder groups to shape the ongoing data collection process. Focus group research provides unrivalled potential to engage in what she refers to as 'second-stage' or 'wildcard' sampling (Barbour, 2007 p. 65), and that this can be used to enhance analytical sophistication. Many of the physiotherapists working in the local primary care trust had over 10 years experience working with older people at risk of falling in a variety of clinical environments. In response to the similarity of views obtained from local physiotherapy practitioners, an additional focus group of recent physiotherapy graduates was arranged approximately half way through the data collection process. Undertaking theoretical sampling in this way meant that it was possible to establish whether the views and experiences of newly qualified physiotherapists differed greatly from those of more experienced practitioners.

Yardley (2000) suggests that rigour in qualitative research relates to the completeness of data collection and analysis. This, she argues, is dependent on the adequacy of the sample, not in terms of size but in relation to its ability to supply all the data needed to undertake a comprehensive analysis. Whilst agreement on the factors influencing uptake and adherence with an exercise-based falls prevention

programme was not achieved across the three stakeholder groups, adopting an iterative approach to data collection and analysis meant that it was possible to establish the point at which data saturation (when the information occurs so repeatedly that the researcher can anticipate it and whereby the collection of more data appears to have no additional interpretative worth), and theoretical saturation (when the researcher can assume that his / her emergent theory is adequately developed to fit any future data collected) had been achieved (Onwuegbuzie et al., 2009). At this point, Sim (1998) suggests that further focus groups need not be conducted, and the findings could be used to identify the factors influencing uptake and adherence with an exercise-based falls prevention programme at a local level (data saturation) and to develop alternative approaches to clinical service delivery that could be tested and refined in the experimental case-series (theoretical saturation).

3.5. Data analysis

Focus group discussions generate large amounts of complex raw data. Qualitative data analysis has been described as ‘an interplay between the researcher and the data’ (Higgs & McAllister, 2001 p. 38), acknowledging that a degree of subjectivity exists in the selection and interpretation of the data obtained. Regardless of the type of analysis undertaken, however, Barbour (2005) emphasizes that the main challenge of qualitative data analysis lies in being systematic and thorough when attempting to provide an explanation for the patterns identified in the data. Kruger and Casey (2009) suggest that analysis should be systematic, sequential, verifiable and

continuous. Following this recommendation provides a trail of evidence as well as increasing the degree of dependency, consistency and conformity; important factors in ensuring the quality of qualitative data analysis.

Framework analysis, as described by Rabiee (2004), was used to analyse the focus group findings. This approach provided a clear set of distinct though highly interconnected stages which assisted the thesis author to manage and interact with the qualitative data obtained. To promote transparency, these stages (familiarization; identifying a thematic framework; indexing; charting; mapping and interpretation) are described sequentially below. However it is important to emphasize that data analysis did not occur in a linear fashion and that, in reality, the five stages overlapped each other.

3.5.1. Familiarization

After each focus group, the audio-tape was listened to in its entirety to ensure the quality of the recording before sending it to the professional typist for transcription. During this time, a series of reflexive field notes were made to supplement those of the assistant moderator. Undertaking sequential or interim analysis enabled the thesis author to consider her performance as a moderator whilst listening to the audio-tapes and use these reflections to shape the ongoing data collection process. When moderating the focus group discussions there appeared to be several uncomfortable silences, particularly during the physiotherapy practitioner sessions. However, when listening to the audio-tapes, these silences did not appear to be as

long or uncomfortable as originally perceived. Not only are occasional pauses necessary for focus group participants to consider and articulate their views, but as Barbour acknowledges, 'what is *not* said can often be as important as what *is* said during focus group discussions' (Barbour, 2007 p. 141). The realization that silences can sometimes be as revealing as comments relating to a particular topic enabled the moderator to take a less active role in the focus group discussions as data collection progressed and provided an additional layer to the analysis of the focus group findings.

On receipt of each focus group transcript, the audio-tape was listened to again whilst reading through the text to establish its accuracy. The thesis author's knowledge of the focus group participants enabled her to recognize individual voices and attribute each section of dialogue to a particular individual. Listening to the audio-tapes in their entirety before and after reading the written transcripts meant that it was possible to become immersed in the details of each focus group discussion as a whole, gaining an understanding of the group dynamics at work before breaking the sessions down into their component parts (Rabiee, 2004).

3.5.2. Identifying a thematic framework

Whilst listening to the audio-tapes, memos were written in the margins of each transcript in the form of short phrases, ideas or concepts arising from the text and provisional categories were identified for further analysis. Pope et al (2006) suggest that this process should be carried out by drawing on *a priori* issues and questions

derived from the research aim and objectives of the study as well as issues raised by the focus group participants themselves and the views or experiences that reoccur in the data. The end product of this stage was the development of the thematic headings presented in Section 5.2 of this thesis.

3.5.3. Indexing

The focus group transcripts were sifted, quotes were highlighted and comparisons made both within and between focus groups. At this stage, the data were labelled using the thematic headings for subsequent retrieval and exploration.

3.5.4. Charting

Here, selected quotes were lifted from their original context and re-arranged under the newly developed thematic headings. Charting proved a valuable stage in helping to manage the data, making sense of what was going on by getting rid of extra and irrelevant data. Indexing and charting are viewed as key stages in the management of qualitative data (Rabiee, 2004). Specialist computer software packages, such as N-Vivo and ATLAS-ti, have been developed to assist with the process of qualitative data analysis. However, Barbour (2008) warns that computer-assisted analysis is not necessarily any more rigorous than manual analysis and recommends learning the principles of qualitative data analysis before exploring any of the assistive software available. Some of the most commonly-reported problems encountered by novice qualitative researchers arise, she claims, because they are simultaneously learning

how to undertake qualitative data analysis and how to use a specific computer package. In the current study, the focus group data were analysed manually using the 'long table approach' (Krueger & Casey 2009 p. 119). This process involved cutting, pasting, sorting, arranging and rearranging the data by hand to compare and contrast the views of older people at risk of falling, relatives and local physiotherapy practitioners.

3.5.5. Mapping and interpretation

The aim of this stage is not only to make sense of original quotes but to be imaginative and analytical enough to see the relationship between quotes and the links between the data as a whole (Rabiee, 2004). Nicholson and Anderson (2003) are critical of mixed method studies which use focus group findings towards an endpoint in which the data is narrowed down to become valid, reliable and measurable. The findings from the focus group research were used to identify clear and consistent issues with local clinical service delivery that were confirmed and elaborated on by the experimental case-series. However, the philosophical paradigm underpinning the current study ensured that the findings from both approaches were used to stimulate the retroductive reasoning that led to the development of the framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition presented in the final chapter of this thesis.

3.6. Experimental case-series

Upon completion of the focus group research, an experimental case-series was conducted with 10 older people with the falls-associated chronic liver disease primary biliary cirrhosis. The purpose of this experimental case-series was to test and refine the strategies developed to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition. An experimental approach was selected to identify the mechanisms responsible for promoting self-management and adherence with an exercise-based falls prevention programme in this novel population of older people with a long-term condition identified as being at increased risk of falling.

Experimental case-series involve studying a single individual or system (small group) by taking repeated measurement of one or two dependent variables (outcome measures) and systematically applying, and sometimes withdrawing, the independent variable (intervention). If the application, withdrawal or manipulation of the intervention (independent variable) is associated with a consistent change in the outcome measures (dependent variables), an inference can be made that it was the intervention that produced this change (Ottenbacher, 1997). Long-commended for their applicability to clinical practice (Riddoch & Sunderland, 1991) and well-established in health psychology (Morley, 1994), experimental case-series are gaining popularity within the field of physiotherapy (Goodwin & Sunderland, 2003; Zetterberg et al., 2008), and have been described as the only option if the research

interest is the evaluation of a radically individualized custom-made therapy (Onghena & Edgington, 2005).

Whilst a randomized controlled trial poses the question ‘Is this treatment effective in individuals of this type?’ a properly designed experimental case-series concerns itself with the question ‘Do these individuals show improvement with treatment?’ Experimental case-series have been described as practice-based and practitioner-orientated, and provide an attractive alternative to traditional experimental approaches requiring the random assignment of large numbers of participants to treatment and no treatment (control) groups (Ottenbacher, 1997). Experimental case-series are data driven; that is, the design of the experiment may be constructed in response to the data as they are collected and analysed. This process enables the researcher to use measures which are of particular relevance to participants (Morley, 1994).

3.7. Sampling and recruitment

An experimental case-series is usually composed of several single-case experiments since evidence gathered from multiple cases is considered more compelling and the overall design regarded as more robust (Onghena & Edgington, 2005). Upon uncovering a significant finding from a single-case experiment, the immediate research goal would be to replicate this finding by conducting further experiments. Some of these experiments attempt to replicate the exact conditions of the original

experiment; whilst others aim to alter the experiment slightly to identify whether the findings are still duplicated (Robson, 2002).

Given the lengthy nature of data collection within the current study, the single-case experiments ran concurrently. However, the flexibility provided by the experimental case-series design enabled the interventions under evaluation to be altered in response to the data as they were collected and analysed. Robson (2002) suggests that critical realism provides a sound basis for the use of replication in the development and refinement of theories, and it was anticipated that 10 single-case experiments (or replications) would be sufficient to identify the mechanisms associated with self-management and adherence with an exercise-based falls prevention programme in the patient group under investigation. Together with the focus group findings, these replications were used to inform the development of the framework for physiotherapy practice to promote self-management and adherence with exercise-based falls programme for older people with a long-term condition presented in the final chapter of this thesis.

Upon receipt of ethical approval, consecutive patients attending a weekly autoimmune liver clinic at the local hospital were screened to identify those with the following common characteristics:

- 60 years of age and over
- Living in own homes

- Diagnosis of primary biliary cirrhosis (with or without liver transplantation)
- Medically stable
- Independently mobile (with or without walking aid)
- History of falls / unsteadiness within last 12 months
- Mini Mental State Examination $\geq 24/30$
- Able to provide informed written consent

To avoid the risk of perceived coercion, these individuals were provided with a participant information sheet (Appendix IV) and invited to return an expression of interest form at their convenience in a pre-paid envelope if they wanted to participate in the experimental case-series. As with the older people attending the regional falls and syncope service, reassurance was provided that participation was entirely voluntary and that a decision not to take part in the experimental case-series would not affect the standard of care they received or their relationship with any member of the healthcare team.

3.8. Intervention

Morley (1994) suggests that any experimental investigation of why a treatment or clinical intervention works (a process question), must involve the comparison of two or more independent variables. However, in order to identify the mechanisms influencing uptake and adherence with an exercise-based falls prevention and to test and refine the self-management strategies developed in response to the focus group findings, it was necessary to study *both* existing local clinical practice for older people at risk of falling (Treatment A) and what, despite the emerging body of research evidence, is still considered a ‘novel’ or ‘enhanced’ intervention (Treatment B). As the enhanced intervention took longer to complete, the first 5 experimental case-series participants recruited from the auto-immune liver clinic received Treatment B, the other 5 participants received Treatment A.

Table 3.1 outlines the key features of Treatments A and B. Although the key characteristics were the same for all participants, it should be pointed out that the research strategy employed in the current study enabled the components of each intervention to be altered slightly on the basis of individual need (Zetterberg et al., 2008).

Table 3.1. Key features of Treatments A and B

Treatment A	Treatment B
Considered 'usual' local clinical practice for older people identified to be at increased risk of falling	Considered 'enhanced' clinical practice for older people identified to be at increased risk of falling
Informed by focus group findings of physiotherapy practitioners and local clinical practice	Informed by focus group findings of older people and review of contemporary self-management literature
6 weeks duration	6 months duration
Composed of 6 x once-weekly appointments	Composed of 6 x four-weekly appointments
Individualized home-based exercise programme	Individualized home-based exercise programme
Delivered by research nurse at local hospital	Delivered by physiotherapist (thesis author) at local hospital
Outcome measures collected by an independent assessor	Outcome measures collected by an independent assessor
n = 5	n = 5

3.8.1. Treatment A

In their systematic review and meta-analysis of effective exercise interventions for the prevention of falls, Sherrington et al (2008) suggest that the criterion for a minimally effective exercise dose equates to a twice weekly exercise-based falls prevention programme running over 25 weeks. In reality, however, many clinical departments are providing services to patients with limited resources and it is often

not possible to provide regular contact from a healthcare professional over such a prolonged time period. In an attempt to incorporate research evidence into routine clinical practice, the majority of older people at risk of falling in the local region are offered an exercise-based falls prevention programme averaging only 6 weeks in duration with once-weekly review by a physiotherapist or healthcare assistant. Older people are then instructed to continue with this programme on discharge from the service. As will be seen in Chapters 4 and 5, this approach to clinical service delivery had not been successful in promoting long-term active participation with an exercise-based falls prevention programme and was proving dissatisfying and limiting for physiotherapy practitioners' creativity and sense of professional autonomy.

Informed by usual local clinical practice for older people at risk of falling and the physiotherapy practitioner focus group findings, 5 case-series participants received a 6 week exercise-based falls prevention programme composed of 6 x once-weekly visits to a research nurse at the local hospital. On their first visit, each participant received an individualized exercise programme from a resource file of evidence-based falls prevention exercises. After ensuring that participants were able to perform these exercises safely and competently, the older people with primary biliary cirrhosis were instructed to complete this programme at home on a daily basis. Participants were reviewed at the local hospital each week and the exercise programme was adjusted or progressed as appropriate. On completion of the 6 week programme, participants were encouraged to continue with their current exercise-regime over the 6 month follow up quantitative data collection period.

3.8.2. Treatment B

Self-monitoring is an important tool in helping individuals understand the process of change during therapy (de Silva, 2011). Freeston and Thwaites (2004) suggest that the use of such measures increases an individual's stake in the treatment programme, leading to greater decision-making about their care. By focussing on self-management support, it was theorized that less-frequent contact with a healthcare professional would be required, allowing clinicians to manage a much larger caseload over a longer time period as well as encouraging older people at risk of falling to develop a long-term active commitment to an exercise-based falls prevention programme. As will be discussed in Sections 3.10.9 and 3.10.10, exercise diaries and visual analogue scales were used by all participants to record adherence rates and track clinically-relevant information over the course of the experimental case-series. However, the exercise diaries and visual analogue scales were also used as self-monitoring tools by those receiving Treatment B to identify and monitor the enabling and disabling mechanisms associated with self-management and adherence. As a result of this, the exercise diaries and visual analogue scales represented an integral part of the enhanced intervention.

Informed by the older people's focus group findings and a review of the self-management literature, 5 case-series participants received a 6 month exercise-based falls prevention programme composed of 6 x four-weekly visits to a physiotherapist (thesis author) at the local hospital. On their first visit, participants were issued with an individualized exercise programme from the same resource file of evidence-based

falls prevention exercises. After ensuring that participants were able to perform these exercises safely and competently, the older people with primary biliary cirrhosis were instructed to complete this programme at home on a daily basis. Participants were reviewed at the local hospital every four weeks, at which time the visual analogue scales and exercise diaries were used to encourage individuals to reflect upon their performances over the last four weeks and to progress or adjust the exercise programme accordingly. On completion of the 6 month programme, the experimental case-series participants receiving the enhanced intervention were encouraged to utilize the self-monitoring skills they had developed to set their own goals and targets to promote continued active participation with an exercise-based falls prevention programme over the 6 month follow up quantitative data collection period.

3.9. Data collection

Experimental case-series involve the repeated assessment of individuals through a pre-determined sequence of baseline and intervention phases (Goodwin & Sunderland, 2003). The current study adopted an A-B-A design (i.e. baseline, no intervention; intervention; follow up, no intervention) with continuous assessment throughout the baseline, intervention and follow up phases (Zetterberg et al., 2008). In a simple pre-test / post-test design it can be difficult for the researcher to infer that any changes observed in the post-test measures are truly the result of the intervention under evaluation (Morley, 1994). In an experimental case-series, the effectiveness of an intervention is judged by the extent to which the post-test

measures shift when the intervention is introduced and by whether this change is sustained throughout the duration of the intervention and follow up phases. If the measures are relatively stable during the baseline phase, Ottenbacher (1997) suggests that it is not unreasonable to infer that any changes observed at the point of introducing the intervention occurred as a direct result of that intervention. In this way, each participant acts as his / her own 'control' during the baseline data collection phase (Zetterberg et al., 2008).

3.10. Evaluation tools

The choice of outcome measures in an experimental case-series should be influenced by the aim and objectives of the study, the psychometric and scaling characteristics of available measures and the practical constraints of implementing these measures (Morley, 1994). Informed by the comprehensive review of the self-management and falls prevention literature and the focus group findings of local stakeholder groups, the range of measures selected reflects the exploratory nature of the experimental case-series and the novel patient group under investigation.

The aim of the current study was not to compare the effectiveness or efficacy of Treatments A and B, but to develop an enhanced theoretical understanding of the factors influencing self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition. For this reason, it was not necessary for the research team or experimental case-series participants to be blinded to the clinical interventions under evaluation. However, to promote

objectivity and to avoid the risk of observer bias (Robson, 2002) all measures were collected by an independent assessor (a physiotherapy colleague) at four-weekly intervals throughout the baseline, treatment and follow quantitative data collection up phases. During the 6 week standard intervention, the measures were completed at weeks 1 and 6. Table 3.2 provides an overview of the evaluation tools used during the experimental case-series.

Table 3.2. Overview of evaluation tools used in experimental case-series

	Purpose of evaluation tool					Timing of administration		
	Monitor and predict falls risk	Monitor disease specific symptoms and quality of life	Monitor central constructs of social cognition models	Monitor adherence	Promote self -management (Treatment B only)	Baseline	Treatment	Follow up
PBC-40		●				●	●	●
Self-Efficacy for Exercise Scale			●			●	●	●
Outcome Expectation for Exercise Scale			●			●	●	●
Falls Efficacy Scale – International	●					●	●	●
5 x Sit-to-Stand	●					●	●	●
Performance Orientated Assessment of Mobility	●					●	●	●
Dynamic Gait Index	●					●	●	●
Exercise Diaries				●	●		●	●
Visual Analogue Scales			●		●		●	●

3.10.1. PBC-40

There is an increasing appreciation that quality of life is frequently impaired in individuals with long-term conditions. The PBC-40 (Jacoby et al., 2005) is a health-

related quality of life questionnaire specific to primary biliary cirrhosis. Developed, validated and evaluated in the local region, patient satisfaction (measured in terms of the extent to which the questionnaire addresses the issues that individuals with primary biliary cirrhosis commonly experience) was found to be significantly higher for the PBC-40 than more generic health-related quality of life measures. The PBC-40 is composed of six domains: fatigue; emotional; social; cognitive functioning; general symptoms; and itch. Individuals are asked to consider a number of statements relating to their condition over the last four weeks and select a response from the following list of options: never; rarely; sometimes; most of the time; always; did not apply. The scale is scored using an established protocol to obtain an overall numeric rating for each domain (Appendix V).

3.10.2. Self-Efficacy for Exercise Scale

Self-efficacy refers to an individual's perceptions of their capabilities relating to specific situations and activities (Bandura 1997). An individual's judgement of their self-efficacy influences activity choice and coping behaviour. A person with low self-efficacy will, for example, avoid engaging in activities they believe exceed their coping abilities, whereas a person with high self-efficacy will confidently engage in a given activity, making a greater effort to master the challenges involved (Cheal & Clemson, 2001). For this reason, interventions that enhance self-efficacy are also said to promote adherence (Bandura, 1997). The Self-Efficacy for Exercise Scale (Resnick & Jenkins, 2000) is a self-assessment questionnaire validated for use in the older population. Individuals are asked to rate perceived levels of confidence in their

ability to exercise three times per week for 20 minutes in the face of 9 potential barriers (the weather was bothering you; you were bored by the programme or activity; you felt pain whilst exercising; you had to exercise alone; you did not enjoy it; you were busy with other activities; you felt tired; you felt stressed; you felt depressed) on a 10 point scale (1 = not confident; 10 = confident). The scale is scored by summing the numerical ratings for each response and dividing by the number of responses to obtain an overall mean score (Appendix VI).

3.10.3. Outcome Expectation for Exercise Scale

Outcome expectations are beliefs that certain consequences will be produced by specific personal actions (Bandura, 1997). Knowing that an individual has the ability to engage in a particular activity is not necessarily enough to sustain behaviour change, they must also believe that the effort involved will produce beneficial results and that they have some degree of control over these results (Bandura, 1997). The Outcome Expectation for Exercise Scale (Resnick et al., 2001) is a self-assessment questionnaire focussing on the perceived consequences of exercise for older people. Individuals are asked to consider 9 statements about the possible outcomes / benefits of exercise (makes me feel better physically; makes my mood better in general; helps me feel less tired; makes my muscles stronger; is an activity I enjoy doing; gives me a personal sense of accomplishment; makes me more alert mentally; improves my endurance in performing my daily activities; helps me to strengthen my bones) and to rate their reactions to these statements using the following scale: 1 (strongly agree); 2 (agree); 3 (neither agree nor disagree); 4 (disagree); 5 (strongly

disagree). The scale is scored by summing the numerical ratings for each response and dividing by the total number of responses to obtain an overall mean score (Appendix VII).

3.10.4. Falls Efficacy Scale – International

As discussed in Section 1.6.5, fear of falling is common in community-dwelling older people and has been associated with distress and reduced quality of life, decline in physical functioning, increased risk of falling, and admission to long-term nursing or residential care (Bruce et al., 2004). Based on the original Falls Efficacy Scale (Tinetti et al., 1994), the Falls Efficacy Scale – International (Yardley et al., 2005) is a self-assessment questionnaire validated for use in the older population. Individuals are asked to consider how concerned they would be about falling whilst undertaking 16 functional activities (cleaning the house; getting dressed / undressed; preparing simple meals; taking a bath or shower; going to the shop; getting in and out of a chair; going up or down stairs; walking around outside; reaching up or bending down; answering the telephone; walking on a slippery surface; visiting a friend / relative; going to a place with crowds; walking on an uneven surface; walking up or down a slope; going out to a social event), and to rate these concerns on a four point ordinal scale: 1 (not at all concerned); 2 (somewhat concerned); 3 (fairly concerned); 4 (very concerned). The scale is scored by summing individual scores for each activity to obtain a total overall score between 16 and 64 (Appendix VIII). According to Delbaere et al (2010), low concern of falling is defined as 16-19; moderate concern 20-27; and high concern 28-64.

3.10.5. 5 x Sit-to-Stand

Muscle weakness is an independent risk factor for falls remediable through targeted intervention (National Institute for Health and Clinical Excellence, 2004). Sit-to-Stand is widely recognized as a clinical measure of lower limb muscle function in community-dwelling older people (Whitney et al., 2005; Bohannon, 2011). The 5 x Sit-to-Stand measures how long (in seconds) it takes an individual to stand five times from a standard height chair without using their arms (Appendix IX). Sit-to-Stand is widely used to assess falls-risk in older people (Barnett et al., 2003), with individuals taking longer than 15 seconds to complete 5 sit-to-stands identified as being at high risk of falling (Buatois et al., 2008).

3.10.6. Performance Orientated Assessment of Mobility

Impaired balance and abnormal gait are also independent risk factors for falls remediable through targeted intervention (National Institute for Health and Clinical Excellence, 2004). The Performance Orientated Assessment of Mobility (Tinetti 1986) is a measure of balance and gait widely used in local clinical practice (Appendix X). For the balance component of this measure, individuals are asked to perform 13 functional activities (sitting balance; arising from chair; immediate standing balance; standing balance; balance with eyes closed; turning balance; nudge on sternum; neck turning; one leg standing balance; back extension; reaching up; bending down; sitting down). The assessor rates their performance on each activity using a three point ordinal scale: 2 (normal); 1 (adaptive); 0 (abnormal). A final

score between 0 and 26 is obtained by summing individual scores. For the gait component of this measure, the assessor rates 9 components of an individual's gait (initiation of gait; step height; step length; step symmetry; step continuity; path deviation; trunk stability; walk stance; turning) as either 1 (normal) or 0 (abnormal). A final score between 0 and 9 is obtained by summing individual scores.

3.10.7. Dynamic Gait Index

The use of dual-task paradigms to examine the effects of age-related changes in attentional requirements of balance control and age-related reductions in stability when performing a secondary task has shown that these are important contributors to instability in both healthy and balance-impaired older people (Shumway-Cook & Woollacot, 2002). The Dynamic Gait Index (Shumway-Cook, 1995) is an 8-item test which evaluates and documents an individual's ability to modify gait in response to changing task demand (gait level surface; change in gait speed; gait with horizontal head turns; gait with vertical head turns; gait and pivot turn; step over obstacle; step around obstacle; stairs) Individuals are rated as exhibiting no (3); minimal (2); moderate (1); or severe (0) levels of gait impairment whilst performing each of these 8 activities. A total score between 0 and 24 is obtained by summing individual scores (Appendix XI). Scores of 19 or less are associated with increased risk of falling in community-dwelling older people (Shumway-Cook et al., 1997).

3.10.8. Exercise Diaries

The most common way to measure adherence with clinical interventions is through the use of self-reported measures, such as participant-held diaries (Robson, 2002 p. 258). Whilst acknowledging the inherent threats to reliability and validity caused by response biases (such as social desirability and acquiescence) participant-held diaries provide a fast, flexible and inexpensive method of monitoring adherence patterns over time, and are said to possess high levels of face validity (Vitolins et al., 2000). To monitor adherence with the exercise-based falls prevention programmes under evaluation, a weekly exercise diary (1 week = 1 page) was developed which combined both structured (quantitative) and unstructured (qualitative) methods of data collection. In addition to indicating how many times the prescribed exercise programme had been completed, participants were given the opportunity to record any additional comments / activities they felt might be of relevance (Appendix XII).

3.10.9. Visual Analogue Scales

Visual analogue scales are widely employed in clinical or psychological research to measure subjective states, such as pain or anxiety levels (Tiplady et al., 1998). The simplest form of visual analogue scale is a straight horizontal line of fixed length (usually 10 centimetres). The ends of the line are defined as the extreme limits of the parameter to be measured (Tiplady et al., 1998, Paul-Dauphin et al., 1999). Visual analogue scales are more sensitive to small changes than simple descriptive ordinal scales in which symptoms are rated as mild, moderate, or severe (Paul-Dauphin et

al., 1999). Whilst providing a different perspective to standardized questionnaires, visual analogue scales and standardized questionnaires are often used in tandem (Freeston & Thwaites, 2004). For the purposes of the current study, participants were asked to complete visual analogue scales on a once-weekly basis to indicate their level of agreement / disagreement with a series of statements (I feel confident to do my exercises today; I am finding the exercise programme beneficial; I will continue to follow the exercise programme) based on the central constructs of the social cognition models presented in Section 1.5 (Appendix XIII).

3.11. Pilot measurement study

Although statistical analysis is not a defining aspect of experimental case-series, the validity of a researcher's inferences will depend largely on the reliability and validity of the outcome measures selected (Onghena & Edgington, 2005). The use of repeated measures introduces two potential confounds to the internal validity: testing and instrumentation (Ottenbacher, 1995). Testing may be a threat to the internal validity of a study if the behaviour of an individual is altered simply by monitoring or measuring it (Robson, 2002). Ottenbacher (1997) suggests this may be a particular problem in case-series experiments because of the requirement for repeated measures. Instrumentation becomes a threat to the internal validity of a study when changes in the outcome measures collected occur as a result of alterations in the instrument used to measure the dependent variable rather than to the introduction, withdrawal or manipulation of the independent variable (Robson, 2002). Case-series experiments involve the repeated assessment of individuals. For

this reason, Ottenbacher (1997) stresses it is particularly important to ensure that systematic changes in the way outcome measures are collected do not occur throughout the course of the data collection process.

The reliability and validity of the selected evaluation tools are well-established in community-dwelling older people (Appendix XIV). However, older people with primary biliary cirrhosis had not previously taken part in an exercise-based falls prevention study. Prior to conducting the experimental case-series a physiotherapy student from the local university conducted a pilot measurement study (Jamieson, 2009), under the supervision of the thesis author and the thesis author's principal supervisor. To minimize the potential threats to internal validity caused by testing, the primary aim of the measurement study was to establish the stability of the measures selected for the experimental case-series. To reduce the risk of instrumentation, the pilot measurement study also sought to determine the inter-rater reliability of the chosen measures within the patient group under investigation.

Four older people with primary biliary cirrhosis, meeting the inclusion criteria of the experimental case-series, were identified from the local patient support group and invited to attend the local hospital once-weekly over a four week intervention period. The evaluation tools presented in Section 3.10 were completed by all participants at each visit (with the exception of the PBC-40 which was completed at weeks 1 and 4). To provide an indication of inter-rater reliability, the objective measures of falls-risk were completed twice by all participants at each visit (once with the thesis author and once with the physiotherapy student). Each rater was

blinded to the other's scores by carrying out the assessments in separate rooms. On completion of the 4 week measurement study, participants were invited to take part in a focus group discussion to provide feedback on the acceptability and face validity of the evaluation tools and proposed data collection process.

Intra-rater reliability found to be excellent for all 3 objective measures of balance, gait and lower limb muscle strength (Performance Orientated Assessment of Mobility, Dynamic Gait Index and 5 x Sit-to-Stand) with no significant differences between measurements of the same participant within raters. Bland and Altman plots displayed good reliability between raters for all 3 measures; with the thesis author demonstrating greater reliability on the measures she had previous experience using. Inter-rater reliability was also found to be excellent for all 3 measures with no significant differences for each of the participants between raters. Bland and Altman plots displayed good reliability between raters for all 3 measures. Intraclass correlation coefficients for the 3 measures are provided in Table 3.3.

Table 3.3. Intra-rater and inter-rater reliability of selected measures from pilot measurement study

	Intra-rater reliability (Thesis author)	Intra-rater reliability (MSc student)	Inter-rater reliability
POAM - Balance	ICC 0.99 95% CI 0.97 – 1.0 P < 0.001	ICC 0.96 95% CI 0.81 – 1.0 P < 0.001	ICC 0.99 95% CI 0.96 – 1.0 P < 0.001
POAM - Gait	ICC 0.99 95% CI 0.96 – 1.0 P < 0.001	ICC 0.97 95% CI 0.83 – 1.0 P < 0.001	ICC 0.99 95% CI 0.95 – 1.0 P < 0.001
DGI	ICC 0.98 95% CI 0.92 – 1.0 P < 0.001	ICC 0.99 95% CI 0.97 – 1.0 P < 0.001	ICC 0.99 95% CI 0.98 – 1.0 P < 0.001
5 x STS	ICC 0.96 95% CI 0.81 – 1.0 P < 0.001	ICC 0.98 95% CI 0.87 – 1.0 P < 0.001	ICC 0.98 95% CI 0.93 – 1.0 P < 0.001

The stability of the measures over the 4 week data collection period was determined visually, by averaging the raters' scores for each participant and presenting them graphically for each measure. The Performance Orientated Assessment of Mobility, Dynamic Gait Index, PBC-40, Falls Efficacy Scale – International and Outcome Expectation for Exercise Scale remained stable in the majority of participants over the 4 week measurement study. However, the physiotherapy student concluded that it was not possible to establish the stability of the 5 x Sit-to-Stand or Self-Efficacy for Exercise Scale over the 4 week period.

All 4 participants completed the 4 week pilot measurement study, which was taken to indicate the acceptability of the data collection process. The qualitative data collected during the focus group discussion provided support for the face and content validity of the selected evaluation tools in the patient group under investigation. The findings of the pilot measurement study will be considered further within the context of the experimental case-series data in the final chapter of this thesis.

3.12. Data analysis

In routine clinical practice the basic question for patient and practitioner alike is whether the intervention is producing a beneficial change (Ottenbacher, 1997). However, as will be seen in Chapters 5 and 6, it would appear that older people at risk of falling and healthcare professionals do not always agree on the best way to capture the beneficial effects of an exercise-based falls prevention programme. One of the principal challenges of the current study, therefore, was in deciding how to present the experimental case-series findings in a way that would be informative and meaningful to older people at risk of falling, local physiotherapy practitioners and the wider academic research community (Onghena & Edgington, 2005).

Although at a theoretical and meaning level critical realism is distinct, the data collection methods it uses are based on established approaches (McEvoy & Richards, 2006). Whilst the evaluation of experimental case-series data has been a source of lively debate for a number of years, visual inspection remains the

predominant mode of analysis (Morley, 1994). In keeping with the philosophical assumptions underpinning the current study, the experimental case-series data were displayed graphically for each participant and subjected to visual analysis to identify patterns and trends in the data over time. To establish the acceptability and perceived effectiveness of the exercise-based falls prevention programmes and self-management strategies under evaluation, a series of semi-structured interviews were conducted with the experimental case-series participants on completion of the follow-up data collection phase. Participants were presented with the graphical interpretations of their data and asked to help explain and contextualize the patterns and trends observed in the selected measures. To compare and contrast the views and experiences of the experimental case-series participants, a topic guide (Appendix XV) was prepared in advance of the semi-structured interviews. During the follow up interviews, experimental case-series participants were encouraged to reflect and expand upon the unstructured data provided in the exercise diaries.

3.13. Ethical considerations

Health services research ‘will be more ethically sensitive and methodologically persuasive when founded on a clear appreciation of the relationship between ethics and methodology’ (Shaw, 2003 p. 9). Ethics are often considered to be part and parcel of the paradigm positional held by the researcher. It has been suggested that ‘conventional (positivist) science has failed ethically’ (Lincoln & Guba, 1989 p. 225). However, it is now widely recognized that qualitative researchers do not live in a state of methodological grace and that no research methodology is ethically

privileged (Shaw, 2003). This section will provide a critical examination of the ethical issues encountered during the design and execution of the current study. Although some of the ethical considerations relate specifically to the focus group or experimental case-series research, the majority transcend these two approaches. Whilst much has been written about the ethical implications of conducting clinical research with older people (Ross et al., 2005; Walker, 2007; Fudge et al., 2007), this section will also consider the ethical dilemmas encountered by practitioner-researchers undertaking applied health research with professional colleagues.

3.13.1. Independent review

Prior to conducting both the focus groups and the experimental case-series, ethical approval was obtained from the University Research Ethics Sub-Committee, the Local Research Ethics Committee, the Acute Trust Research and Development Department and the Primary Care Trust Clinical Governance Department. Independent review ensures that individuals unaffiliated with the research project evaluate the proposal to ensure that certain ethical and scientific standards are met (Khanlou & Peter, 2005). However, Shaw (2003) warns against placing undue emphasis on the initial ethical review process since it implies that ethical issues can be addressed and neatly tidied away for the duration of the study. Some of the ethical considerations presented in this section were anticipated during the developmental stage of the study whilst others emerged as the research progressed. The subsequent discussion should, therefore, be seen to represent an ongoing

reflection on, and response to, the ethical considerations encountered throughout the design and execution of the focus group and experimental case-series research.

3.13.2. Informed consent

All participants were asked to provide informed written consent (Appendices XVI and XVII) prior to taking part in the focus groups and experimental case-series. Blackmer (2003) suggests that 3 conditions must be met for an individual to provide informed consent to participate in a research study: capacity (the ability to understand the nature of the research, including the risks and benefits involved); voluntariness (freedom from undue coercion, be it deliberate or non-intentional); and disclosure (provision of all the information necessary to assist in the clinical decision making process). This section will discuss each of these factors within the context of the current study.

A fairly large proportion of older people receiving clinical services suffer from some degree of cognitive impairment, be it significant and overt or minor and more subtle (Blackmer, 2003). Older people with primary biliary cirrhosis, in particular, are known to suffer from impairments of memory and concentration (Newton & Jones, 2007) which could impact on their decision-making capacity. As an experienced healthcare professional, the thesis author was able to use her clinical judgement skills to establish decision-making capacity. However, to assist in this process, a Mini Mental State Examination (Folstein et al., 1975) was performed on all older people attending the regional falls and syncope service (focus groups) and auto-

immune liver clinic (experimental case-series) during the screening and recruitment process. Whilst it is acknowledged that the Mini Mental State Examination is not a measure of capacity, only those scoring $\geq 24/30$ were included in the sampling pool of potential participants, since the cut-off point most commonly used to indicate cognitive impairment requiring further investigation is 23/24 (McDowell 2006). Working within a supportive multi-disciplinary environment, any concerns regarding informed consent or decision-making capacity would have been referred to the thesis author's work-place research supervisor (a consultant physician and geriatrician) for further assessment.

Shaw (2003) suggests that voluntary participation can be more difficult to ensure when adopting the role of practitioner-researcher. Individuals may be motivated to take part in a research study out of a desire to please the researcher or because they perceive their participation as being one way in which they can repay the care and attention provided by the healthcare team (Blackmer, 2003). To reduce the risk of perceived coercion in the current study, potential participants were provided with a participant information sheet and asked to return an expression of interest form at their convenience in a pre-paid envelope if they wanted to participate in the focus group discussions or experimental case-series. Individuals were reassured that participation was entirely voluntary and that a decision not to take part in the study would not affect the quality of care they received whilst attending the regional falls and syncope service or auto-immune liver clinic. Potential participants were also advised that they could withdraw from the study at any time, without giving a reason, and that this would not affect their relationship with any member of the

healthcare team. A similar method of recruitment was employed for the physiotherapy practitioners since it was acknowledged that the thesis author's pre-existing relationship with professional colleagues might predispose them to higher levels of perceived coercion.

The participant information sheets were developed in accordance with National Research Ethics Service Guidelines and disclosed information relating to all aspects of the study, including the purpose of the investigation, the risks and benefits of participation and the eventual dissemination strategies. Individuals were encouraged to retain a copy of the participation information sheet and signed consent form for their records and had regular contact with members of the healthcare team throughout the duration of the study to ask questions / request additional information. The participant information sheets provided an outline of the Hospital Complaints Procedure and contact details for the Patient Advice and Liaison Service, should participants wish to discuss any concerns relating to the current study with a nominated individual unaffiliated with the research process.

It has been suggested that informed consent in qualitative research is particularly hazardous because it implies that the researcher knows in advance of undertaking the study what the outcome will be and its possible consequences (Shaw, 2003). However, it is argued that the same could be said for any empirical investigation. In the majority of practitioner-researcher projects, the researcher is likely to be conducting a piece of research which aims to change or enhance existing clinical practice (Costley & Gibbs, 2006). This is an intensely political activity which may

be perceived by some as a threat to the status quo (Wilson-Thomas, 1995). The practitioner-researcher role could be regarded as subversive by professional colleagues, as it involves questioning organizational and individual practitioner norms and belief systems (Williams & Posser, 2002). To promote transparency, local dissemination sessions were arranged at regular intervals throughout the course of the current study to update physiotherapy managers and colleagues on the evolving research design and outcomes. Individuals were provided with the opportunity to ask questions / make comments throughout the study and these were used to shape the ongoing data collection and analysis process.

3.13.3. Anonymity and confidentiality

All written information collected during the course of the current study was stored in a locked filing cabinet and managed in accordance with the Hospital Research and Development Department Guidelines. All data were coded and anonymised on a secure password-protected National Health Service computer prior to undertaking analysis. Whilst every attempt was made to maintain participant anonymity and confidentiality on the part of the research team, it should be pointed out that anonymity and confidentiality between research participants cannot be fully guaranteed, particularly when undertaking focus group research (Krueger & Casey, 2009). To overcome this, participants were specifically asked to maintain confidentiality for each other at the start of each focus group session.

Barbour (2007) claims that using pre-existing groups raises important ethical issues with regard to ensuring anonymity and confidentiality. Researchers need to be mindful that these groups have a life that continues after they have elicited their data and should seek to minimize possible negative ramifications. Whilst not deliberately seeking to recruit individuals from established networks for the older people's focus group discussions, participants in three of the groups knew each other from unrelated activities in the local community and this could be seen as compromising their anonymity and confidentiality as patients of the regional falls and syncope service.

Although the data collection and analysis process can be made anonymous, completely disguising personal identities in finished reports and academic theses may prove problematic. Williams & Posser (2002) suggest that it can be difficult to ensure anonymity and confidentiality in research studies when individuals from an organization know who participated. In the current study, the focus groups and experimental case-series both included working with small samples from pre-existing social networks (physiotherapists working for the local primary care trust and members of the primary biliary cirrhosis support group respectively). The similarity of views obtained from the physiotherapy practitioners participating in the focus group discussions helped to protect individual identities during local feedback sessions and a similar approach was adopted when disseminating the experimental case-series findings. Although case-series participants were provided with an overview of their individual performances during the semi-structured interviews, the quantity of data collected during the course of the experimental case-series meant

that it was impractical to present detailed individual cases during local dissemination sessions. The homogeneity of the case-series participants meant that it was possible to use the qualitative exercise diary and interview data to identify a series of clear and consistent themes surrounding self-management and adherence with exercise-based falls prevention programmes for older people with primary biliary cirrhosis. To maintain participant confidentiality, an overview of these themes was presented to the local patient support group, supplemented by anonymised graphical representations of the selected outcome measures.

3.13.4. Issues of consensus, dissent and disclosure

All qualitative researchers need to consider how interviewees perceive them and what effect characteristics such as class, race and sex will have on the data obtained (Barbour, 2006). However, Britten (1995) believes that these issues become more acute if the researcher is someone perceived to be in a position of authority, such as a medical practitioner or healthcare professional. The social desirability effect occurs when participants respond or act in a way that they feel the researcher would like them to (Krueger & Casey, 2009) and, it is argued, may occur in any empirical investigation, regardless of whether or not the researcher and participants are known to each other before the study commences. To obtain the genuine views and experiences of older people and physiotherapy colleagues when undertaking both the focus groups and experimental case-series it was made clear throughout that the underlying aim of the study was to develop a framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention

programme for older people with a long-term condition, and that these findings would be used to develop an alternative approach to local clinical service delivery.

Whilst it has been suggested that group norms may silence individual voices of dissent, Kitzinger (2006) claims that focus group participants can provide mutual support for each other when expressing feelings that are common to their group, but which they consider may deviate from mainstream culture. This was particularly evident during the physiotherapy practitioner focus group sessions. Shaw (2003) suggests that ethical problems can arise if the practitioner-researcher role is not fully-understood by research participants. By viewing the practitioner-researcher as a practitioner first and a researcher second, participants may not always exercise appropriate restrictions on self-disclosure. Within the context of the current study, however, is argued that the thesis author's shared identity as a practising clinician provided the physiotherapy practitioners with a relatively safe environment in which to express their frustrations with current clinical service delivery. In doing so, they were able to contribute to the development of practical strategies to promote self-management and adherence with an exercise-based falls prevention programme that could be tested and refined in the experimental case-series.

3.13.5. Distress and inconvenience to participants

When individuals are members of a diagnostic group with relatively small numbers the potential exists for individuals to be recruited for multiple studies, sharing a disproportionate burden for research participation (Blackmer, 2003). Primary biliary

cirrhosis is a relatively rare condition, affecting only 1 in 700 women over the age of 45 years (Jones & Newton, 2005). The potential for population overuse in high-prevalence geographical areas, such as the local region (Prince et al., 2002), is significant and this was taken into account when screening and recruiting potential participants for the experimental case-series.

Members of the local primary biliary cirrhosis patient support group regularly take part in research projects conducted by the healthcare team which have a direct impact on local clinical service delivery. The purpose of the experimental case-series was to test and refine acceptable strategies to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term health condition. This process involved the collection of multiple measures over a prolonged time period. For this reason, this exploratory experimental investigation was deliberately undertaken with members of a 'research active' patient group. However, to promote inclusivity and to reduce the potential burden of research participation, potential participants were screened and recruited from a weekly auto-immune liver clinic rather than via the patient support group directly. Although several of the older people with primary biliary cirrhosis recruited into this study had previously taking part in local research, none of the participants were involved in additional projects at the time of the experimental case-series.

The local hospital provided a central and accessible location for both the focus groups and experimental case-series. Whilst it was not possible to reimburse participants financially for their time commitment, transport to and from the hospital

was provided by taxi if needed. The data collection sessions were organized at mutually-convenient times throughout the working week and participants were informed of their appointment times as far in advance as possible. If experimental case-series participants experienced difficulties attending particular sessions, flexibility was provided by the research team. On a couple of occasions the experimental case-series data were collected at a neighbouring hospital to coincide with participants' attendances at the auto-immune liver clinic. Recognizing the busy workload of professional colleagues, scheduled staff meetings were used to provide regular and ongoing feedback to physiotherapy managers and practitioners throughout the course of the current study.

3.13.6. Risk-benefit ratio and loss of therapeutic benefits

For many individuals with long-term conditions, such as primary biliary cirrhosis, curative treatment is not available and it is only possible to manage symptoms and maximize functional ability. Blackmer (2003) claims that there is a greater probability of therapeutic misconception in such groups as individuals are more likely to participate in clinical research in the hope that it will provide some degree of benefit for them. Very little information currently exists regarding the impact of chronic liver disease on the ageing population. Multi-disciplinary assessments conducted by our research team (Frith et al., 2010) demonstrated that older people with primary biliary cirrhosis present with a number of recognized risk factors for falling. However, this patient group had not previously had access to a dedicated physiotherapy service in the local region. Regular contact with members of the

healthcare team during the baseline, intervention and follow up quantitative data collection phases of the experimental case-series meant that it was possible to closely monitor participants' responses to the exercise-based falls prevention programme and to address any ongoing issues regarding their general health status. On completion of the follow up quantitative data collection phase, all experimental case-series participants (including the 4 individuals taking part in the pilot measurement study described in Section 3.11) were provided with the opportunity to attend the regional falls and syncope service for ongoing physiotherapy intervention as appropriate.

3.14. Summary

This chapter has provided a detailed account of the research methods employed in the current study and the ethical issues encountered during the design and execution of the focus groups and experimental case-series. Chapter 4 will continue the methodological discussion by reflecting upon the process of conducting clinical research with local stakeholder groups.

CHAPTER 4. STAKEHOLDER INVOLVEMENT

4.1. Overview of chapter

A conceptual model for evaluating and reporting the impact of public involvement in health research was developed during the course of the current study. This chapter will begin by setting out the background to, and rationale for, this model. Building upon the methodological discussion surrounding stakeholder involvement introduced in Section 2.11, the model will be considered within the context of the focus group research and the wider public involvement literature to illustrate how the inclusion of a stakeholder perspective influenced the research processes and outcomes presented in this thesis.

4.2. Background to and rationale for conceptual model

Throughout this chapter the position of the thesis author within the research process will be presented in the first person to provide a contemplative account of how the research and researcher interacted, and to illustrate how my philosophical perspective widened as the study progressed. Stakeholder involvement and empowerment were important considerations in the design and execution of this study. As can be seen in Chapters 2 and 3, the methodological and philosophical principles underpinning the current study and the research methods employed enabled local stakeholder groups (older people identified as being at increased risk of falling; relatives; and local physiotherapy practitioners) to actively participate in

the development and evaluation of strategies to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition. However, as well as being involved in the current study as research participants, I also invited a separate group of older people attending the regional falls and syncope service and their relatives and a separate group of local physiotherapy practitioners with experience of prescribing an exercise-based falls prevention programme to contribute to the design and execution of the focus group research.

The public is a portmanteau phrase used to encapsulate the many types of stakeholder who may be involved in health research, including patients, service users and carers (Hanley et al., 2003). Whilst not included in this traditional definition, the philosophical and methodological principles underpinning the current study also recognize the importance of involving local healthcare practitioners in research that attempts to change or enhance existing clinical practice. For the purposes of the subsequent discussion, therefore, the public should be seen to collectively refer to users, potential users and providers of clinical services.

The conceptual model for evaluating and reporting the impact of public involvement in health research presented in Section 4.3 and illustrated in Figure 4.1 was developed in response to a comprehensive review of the contemporary public involvement literature and represents an attempt to reflect upon and articulate my own experiences of conducting clinical research with older people, relatives and local physiotherapists. To provide the background to, and rationale for, the model it

is necessary to briefly consider the wider methodological debate surrounding public involvement in health research.

Public involvement in health research refers to research conducted with or by the public rather than to, about or for them (Hanley et al., 2003). Proponents of this initiative suggest that the unique perspective provided by people who use, or are eligible to use, health services provides higher quality research of greater clinical relevance (Fudge et al., 2007; Hogg 2007; Boote et al., 2010). Despite strong political and philosophical underpinnings, however, a survey of National Health Service researchers demonstrated that public involvement in health research continues to be making relatively small inroads, is fragmented, and often concentrated in particular groups or geographical areas (Barber et al., 2007).

A recent report (Tarpey, 2011) analysed information on the extent and nature of reported public involvement in health and social care. The study was based on a sample of applications submitted to the National Research Ethics Service in 2010 as part of the ethical review process, and focussed on responses to a two-part question asking how applicants intended to involve members of the public in their research. The report identified that 19% of researchers reported involving, or intending to involve, the public in their research. They ticked one or more of the involvement boxes, and their free-text responses confirmed these plans. In contrast, 38% stated that they had no plans for involvement. Perhaps most interestingly, however, the report highlighted that 43% seemed to have misunderstood what the question on involvement was asking. Whilst they ticked at least one of the involvement boxes,

their free-text responses described plans for engagement rather than public involvement, such as recruiting patients to participate in their research or disseminating their findings to local stakeholder groups.

Formal appraisal of public involvement in health research is rare. Whilst the academic literature may be replete with enthusiastic reports and reflections, there is often little or no detail provided about the process of undertaking clinical research with members of the public or any attempt to evaluate the impact of public involvement on research outcomes (Oliver et al., 2008). INVOLVE, a national advisory group funded by the National Institute for Health Research to promote public engagement, participation and dialogue, commissioned a report exploring the impact of public involvement in health and social care research (Staley, 2009). A structured review of the literature identified only 89 articles suitable for in-depth evaluation. Whilst a number of strong and consistent themes were identified which provided support for the inclusion of a public perspective at all stages of the research process, a number of limitations were also acknowledged; most notably, surrounding the inherent difficulties of assessing and reporting the impact of public involvement on research processes and outcomes.

Public involvement in health research has traditionally been viewed on a continuum, ranging from low to high levels of participation. INVOLVE recognize three 'levels' of public involvement: consultation (where researchers seek the views of the public on key aspects of the research); collaboration (an ongoing partnership between researchers and the public throughout the research process); and user-control (where

the public design and undertake the research and researchers are only invited to participate at the invitation of the public) (Hanley et al., 2003).

These definitions may help researchers to consider the type of public involvement in health research. However, it is important to recognize that public involvement is a complex and multi-faceted activity and that, in reality, public involvement may range from none, to some, to full engagement as the project develops (Ross et al., 2005). As Beresford (2007) acknowledges, members of the public may, for example, have no involvement in designing the research, be consulted over the data collection, and have complete control of the dissemination of the research findings. For this reason, it has been suggested that the INVOLVE definitions lack the degree of flexibility health researchers require and that this may discourage them from including members of the public in investigations that attempt to change or enhance existing clinical practices (Oliver et al., 2008).

4.3. A conceptual model for evaluating and reporting the impact of public involvement in health research

Presenting the process of public involvement diagrammatically has limitations yet serves to promote conceptual clarity. In the model presented in Figure 4.1, public involvement is considered a product of the degree of collaboration (vertical axis) and empowerment (horizontal axis), expressed in terms of a top-down or bottom-up approach. The two axes divide the model into four quadrants: public ignored; public acknowledged; public advised; and public engaged, and permit different levels of

public involvement to occur within the same research project. The impact of public involvement may be evaluated and reported by considering the degree of collaboration and empowerment at key stages of the research process.

Figure 4.1. A conceptual model for evaluating and reporting the impact of public involvement in health research (Robinson et al., 2012)



A paper relating to this model has been accepted for publication in a peer-reviewed journal (Appendix XVIII) and was well-received at a national public involvement conference in November 2010. In this section, each of the four quadrants will be presented within the context of the focus group research and the wider public involvement literature to illustrate how the involvement a stakeholder perspective

influenced the research processes and outcomes underpinning the current study. I will consider the model's potential to contribute to the wider methodological development of public involvement in health research in the final chapter of this thesis.

4.3.1. Public ignored (non-collaborative / top-down – no impact)

The purpose of the current study was to develop a framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition. It was anticipated that a better understanding of the factors influencing uptake and adherence with an exercise-based falls prevention programme, together with an exploration of practical strategies to promote self-management, would have a direct impact on clinical practice and improve local service delivery for older people with a long-term condition. However, it can be seen that the aim, objectives and theoretical propositions underpinning the current study were informed by my clinical observations as a practising clinician and a comprehensive review of the academic literature rather than discussions with members of the public as users, potential users, or providers of clinical services.

Many funding bodies now request that researchers provide evidence of public involvement when submitting their research proposals. However, as Thompson et al (2009) acknowledge, it can often be difficult to involve members of the public in a meaningful way during the initial developmental stages of a clinical research project.

All researchers conducting clinical investigations in the National Health Service require approval from the National Research Ethics Service before commencing data collection. Academic research culture is fundamentally project-driven and researchers are frequently hired on short-term contracts to undertake clinical studies within tightly-defined deadlines (Thompson et al, 2009). For many researchers, therefore, 'the research begins when the project begins' (Mellor, 1998 p. 453). I always intended to involve older people, relatives and local physiotherapists in the design and execution of the focus group research. However, taking a critically reflexive stance, it can now be seen that the drive to obtain ethical approval prior to embarking on the data collection process meant that a stakeholder perspective was absent from the early developmental stages of the focus group research.

Whilst the research design of this study enabled local stakeholder groups to actively participate in the development and evaluation of strategies to promote self-management and adherence, failure to include a public perspective in the early developmental stages of the focus group research meant that the current study began in the public ignored quadrant in the bottom-left-hand-corner of the model. Here, research is designed, undertaken and disseminated by professional researchers with no public involvement. The public have no impact on the research processes and outcomes in a public ignored paradigm, and the balance of power remains solely with the professional researcher in a non-collaborative top-down approach.

4.3.2. Public acknowledged (more-collaborative / top-down – low impact because limited power)

As soon as ethical approval had been obtained for the focus group research, I identified a small group of older people from my current clinical caseload at the regional falls and syncope service (4 older people at risk of falling and 2 relatives) and a small group of professional colleagues (3 physiotherapy practitioners with experience of prescribing an exercise-based falls prevention programme in the local region). The views and opinions of these individuals were sought at strategic points throughout the study on matters relating to the design and execution of the focus group research. It was anticipated that small groups would allow for variations in perspective and attitude without inhibiting decision-making and productivity. Whilst overlaps in role are acknowledged, a deliberate distinction was made between older people at risk of falling and relatives to gain a better appreciation of the different opinions and interests that may exist, and to avoid one group speaking on behalf of, or being seen to represent, the other (Beresford, 2007).

In neglecting to engage with large swathes of the general public, it has been suggested that public involvement may be seen to fall short of its promise to provide a direct, more-than-tokenistic say in the governance of health research (Martin, 2008). In their review of 1108 papers on public involvement for change in health research, Crawford et al (2003) emphasize that statements about representativeness are very common in the literature, but the meaning of the term is rarely considered. Providing a representative sample of a target research population is a concept

traditionally associated with the positivist paradigm. However, such methods do not necessarily guarantee accurate representation (Boote et al, 2010). As Parkinson (2003) acknowledges, there is no fundamental reason why the descriptive representation of shared characteristics, such as ethnicity or social class, promised by randomization should translate into accurate representation at the level of expressed opinion. One of the most successful ways to involve members of the public in health research is through relationships that already exist and are well-established (Trevedi & Wykes, 2002). Rather than advertise for volunteers, I chose to approach individuals whom I felt would possess the relevant skills, life experiences and personal attributes necessary to challenge my thinking and positively influence the research processes and outcomes presented in this thesis.

Prior to identifying potential focus group participants, I visited these older people, relatives and local physiotherapy practitioners in their home or place of work. Their views and opinions were sought on matters relating to the methodological design of the focus group research; such as the suitability of the language used in the participant information sheets, the appropriateness of the data collection methods selected and the proposed sampling and recruitment strategy. The purpose of the focus group research was to provide an enhanced understanding of the factors influencing uptake and adherence with an exercise-based falls prevention programme at a local level. For this reason, it was important that I obtained the genuine views and experiences of focus group participants in an inclusive, non-threatening manner. In keeping with the qualitative research literature presented in Section 3.2, the older people, relatives and local physiotherapy practitioners

suggested that focus groups would prove less intimidating for participants than one-to-one interviews. The older people and relatives, in particular, felt that the focus groups would provide an enjoyable forum for their peers to come together to discuss a topic considered to be of universal interest, and that the input of local stakeholder groups would lead to the development of more acceptable strategies to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.

The subject matter was not considered to be particularly sensitive in nature and, as a result of this, the older people, relatives and local physiotherapy practitioners did not anticipate any problems with me moderating the focus group discussions. It was suggested that the professional and therapeutic relationships I had developed with local stakeholder groups would provide a permissive atmosphere for focus group participants to share their potential frustrations with current approaches to clinical service delivery. During the developmental stages of the focus group research, an eminent qualitative researcher had advised me against conducting research with older people from my current clinical caseload. However, the older people and relatives did not feel it was necessary to wait until individuals had been discharged from the regional falls and syncope service before inviting them to participate in the focus group research. It was suggested that waiting until this time would cause the subject matter to become less interesting and personally relevant to potential participants.

Whilst I deliberately approached older people attending the regional falls and syncope service at different stages of the clinical practice encounter, the older people and relatives indicated that approximately 6 weeks into the treatment programme would provide the ideal window of opportunity for recruiting potential participants into the study. They suggested that this would provide sufficient time for the older person to gain experience of participating in an exercise-based falls prevention programme and enable me to establish whether or not the older person would be able to function in a focus group environment.

The aim of practitioner-led projects is to change or enhance existing working practices, and this can sometimes be regarded with suspicion by professional colleagues (Williams & Posser, 2002). Prior to sending out the participant information sheets, the physiotherapy practitioners advised me to present an overview of my research proposal to professional colleagues as part of the clinical in-service training programme. This would demystify the research process in an informal setting, they suggested, before attempting to recruit potential participants. Presenting the research proposal provided an ideal opportunity to promote discussion about the current study and revealed the importance of obtaining management endorsement prior to approaching professional colleagues. This factor had been overlooked during the developmental stages of the focus group research. However, physiotherapy managers were reassured that the time commitment required from staff would be minimal and volunteered to distribute the participant information sheets themselves to demonstrate their approval. I was later able to minimize the risk of perceived coercion by asking managers to collectively remind

physiotherapy colleagues at staff meetings to return their expression of interest forms if they wanted to participate in the focus group research.

By asking the older people, relatives and local physiotherapy practitioners to comment on the suitability of the data collection methods selected and the proposed sampling and recruitment strategy, the current study moved into the public acknowledged quadrant in the top-left-hand corner of the model. Here, research is designed, undertaken and disseminated with the acknowledgement of a public perspective on ideas that are professionally-led. The inclusion of a stakeholder perspective provided support for the research methods selected. However, reflecting on the experiential learning process, it can now be seen that the advice I sought at this stage was largely procedural and based on an approved project design. Whilst representing a move into a more collaborative paradigm, the impact of a public perspective in the public acknowledged quadrant remains limited by the lack of public empowerment (top-down approach).

4.3.3. Public advised (less collaborative / bottom-up – low impact because limited collaboration)

A common criticism of qualitative research is that the analysis and interpretation of the data can vary considerably depending on who is involved in the process. It has been suggested that involving research participants in the analysis and interpretation of qualitative data increases the cultural and internal validity of the findings, and strengthens the scientific rigour of an investigation (McCauley, 1999). ‘Respondent

validation' or 'member checking' (Mays & Pope, 2006 p. 88) is popular with action researchers and involves comparing the researcher's account of the qualitative data with those of the participants. Whilst some commentators claim this to be the strongest available check on the credibility of qualitative research findings, others have highlighted its limitations (Bloor et al., 2001; Barbour, 2007). Mays and Pope (2000) suggest that since the researcher's account is intended for a wider audience it will, inevitably, be different from those of individual research participants simply because of their different roles in the research process.

Qualitative research produces large amounts of complex raw data. A single focus group discussion may, for example, generate anything between 20 and 40 pages of single spaced text (Pope & Mays, 2000). Respondent validation exercises place considerable demands on research participants' time and, Barbour (2005) argues, raise a number of ethical and practical considerations. Instead of asking participants to read focus group transcripts, she proposes feeding back preliminary research findings in the form of a short report or dissemination session. Approximately half way through the focus group research, I arranged separate feedback sessions for the older people and relatives and the physiotherapy practitioners to provide them with an overview of the emerging themes. By asking them to comment on whether the data resonated with them as the users, potential users or providers of falls prevention services and to propose topics which might not yet have been identified, I was able to ensure that the focus group research had not been overly affected by the social desirability effect (Krueger & Casey, 2009) and to establish how close I was to achieving data / theoretical saturation (Onwuegbuzie et al., 2009).

Interim analysis of the focus group findings revealed opposing views and standpoints on the part of older people at risk of falling and local physiotherapy practitioners. As will be seen in Chapter 5, the older people participating in the focus group research were motivated to take part in an exercise-based falls prevention programme to remain independent in activities of daily living. They valued strategies that promoted self-efficacy and self-management. In contrast, however, the physiotherapy practitioners indicated that the majority of the older people they came into contact with were poorly motivated to participate in an exercise-based falls prevention programme. Whilst acknowledging that older people should be encouraged to play a more active role in the management of long-term conditions, the local physiotherapists demonstrated a conflicting desire to remain 'in control' of the treatment programme.

The older people, relatives and physiotherapy practitioners quickly validated their peers' views and opinions during the preliminary feedback sessions. However, perhaps not unsurprisingly, it was the qualitative data from the physiotherapy focus groups that the older people and relatives found most interesting and chose to discuss in greater detail. It was suggested that failure to appreciate the benefits experienced by older people as a result of participating in an exercise-based falls prevention programme had resulted in a sense of poor job satisfaction and professional apathy amongst local physiotherapists. This, together with a degree of professional arrogance, was likely to have contributed to the data obtained.

The involvement of local stakeholder groups in the interpretation of the focus group findings represents a shift into the public advised quadrant in the bottom right-hand-corner of the model. Here, research is designed, undertaken and disseminated with advice from the public but limited active collaboration. From a public involvement perspective, this activity can be seen to represent a shift from a top-down to a bottom-up approach since the alternative insights provided by the older people and relatives' group enabled me to take a more reflexive stance in the analysis of the focus group findings. However, because I selected the data to be presented, it could be argued that there was limited collaboration and, as a result of this, the overall impact of public involvement in a public advised paradigm remains relatively low.

4.3.4. Public engaged (collaborative / bottom-up – high impact)

It has been suggested that members of the public participating in clinical research should also be involved in the documentation and dissemination of the research findings (Trevedi & Wykes, 2002). In response to the interim focus group data, one of the older people expressed the desire to meet with local physiotherapy practitioners to describe the benefits she had experienced as a result of participating in an exercise-based falls prevention programme. Although their input heavily impacted on the interpretation and presentation the focus group findings, I decided not to involve the older people and their relatives in local feedback sessions due to concerns that my professional colleagues would be dismissive of their views. When discussing potential dissemination strategies, one of the physiotherapy practitioners highlighted that healthcare professionals were often given very little opportunity to

receive formal feedback from their patients. Rather than simply comparing and contrasting the views of local physiotherapists and older people at risk of falling, it was suggested that I provide professional colleagues with an overview of the older people's experiences of exercise-based falls prevention programmes, the aspects they found most beneficial and the ways in which they would like clinical services to be delivered.

To have a direct impact on clinical practice, it was important that the focus group findings were received favourably professional colleagues. Appreciative inquiry is described as 'a simple but radical approach to understanding the social world' (Reed 2007 p.2). As a research framework, it concentrates on exploring ideas that individuals have about what is valuable in what they do and attempts to work on ways that build upon these activities. The radical aspect of appreciative inquiry, Reed (2007) believes, is the way in which it challenges individuals to rethink their ideas regarding how they work, how change happens, and how they can contribute to this process. If individuals are used to thinking about themselves as being unsuccessful, using appreciative inquiry to ask questions about their achievements can be an effective way of challenging those ideas and encouraging individuals to think more critically about what they do and how they do it.

The inclusion of a stakeholder perspective informed a dissemination strategy that was in keeping with the methodological and philosophical principles underpinning the current study. However, with hindsight, my decision not to involve older people and their relatives in local feedback sessions might have represented a missed

opportunity for the focus group findings to impact on clinical service delivery. Involving the older people and their relatives in feeding back the focus group findings would have represented a move into the public engaged quadrant in the top right-hand-corner of the model. Here, research is designed, undertaken and disseminated with the public fully engaged, included and actively influencing the study. In the public engaged paradigm, the impact of public is highest because collaboration is successfully combined with a bottom-up approach.

4.4. Summary

This chapter has presented a conceptual model for evaluating and reporting the impact of public involvement developed during the course of the current study within the context of the focus group research and wider public involvement literature. Chapter 5 will provide a detailed account of the focus group findings.

CHAPTER 5. FOCUS GROUP FINDINGS

5.1. Overview of chapter

This chapter will present the integrated findings of eight focus groups conducted with older people attending a regional falls and syncope service, relatives and local physiotherapy practitioners. To promote transparency and reflexivity, consideration will be given to the data analysis process and the personal characteristics of the focus group participants. This will be followed by a detailed discussion of the focus group findings within the wider context of the academic falls prevention and self-management literature.

5.2. Background to analysis and presentation of focus group findings

The focus groups were conducted over a 12 month period (January to December 2007) and subjected to a version of framework analysis described by Rabiee (2004). Whilst some proponents of thematic analysis suggest that focus group data should be approached without recourse to a preconceived theoretical framework, Barbour (2008) argues that qualitative data analysis must be guided by a study's original research questions and underlying theoretical assumptions. Although it uses a thematic approach, framework analysis allows these themes to develop from both the research questions and the narratives of research participants (Rabiee, 2004) and was, therefore, felt to be compatible with the philosophical and methodological principles underpinning the current study.

Undertaking qualitative research is an iterative process and data analysis, or rather analytical thinking, began whilst conducting the first focus group session. A provisional coding framework was developed and progressively refined throughout the data collection / analysis process. Five themes were identified which relate back to the original research aim, objectives and theoretical propositions underpinning the current study and provided a basis for ongoing analysis:

- Theme 1: Factors influencing uptake and adherence
- Theme 2: Predicting and monitoring uptake and adherence
- Theme 3: Roles and responsibilities
- Theme 4: Stakeholder views and experiences of local clinical service delivery
- Theme 5: Strategies to promote self-management and adherence

Qualitative research thrives analytically on differences and discrepancies (Barbour, 2007). If qualitative researchers identify differences in the data, Morgan (1993) argues that the methodological goal should be to understand the sources of these differences. During the mapping and interpretation phase, particular attention was paid to exceptions, contradictions and disconfirming excerpts in the data. These were used to interrogate the academic literature presented in the opening chapter of

this thesis and contributed to the development of the framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term health condition.

5.3. Sample characteristics

A frequently debated issue in focus group research is the extent to which the researcher should seek to elicit, and attend in analysis, to individual as opposed to group data. However, when attempting to gain an insight into group processes, it is the interchange between participants that is valuable data for the researcher, not the outcome of the group discussions. Although the group is the main unit of analysis, Barbour (2007) emphasizes that it is also worth taking account of individual voices within the group. It would be a pity, she acknowledges, to follow an approach that did not allow the researcher (and reader) to take advantage of the additional insights that such intra-group comparisons may yield. For the purposes of the current study, each focus group participant was allocated a pseudonym during the data analysis process. Providing participants with an alternative name rather than an arbitrary code number ensures anonymity and confidentiality whilst maintaining a human quality to the presentation of the focus group findings, and enables the reader to cross-link concepts and themes with the roles, identities and attributes of individual focus group members (Sim 1998). The personal characteristics of the older people, relatives and physiotherapy practitioners taking part in the focus group sessions are provided in Tables 5.1, 5.2 and 5.3 respectively. The shaded / un-shaded areas represent the composition of each focus group session.

Table 5.1. Characteristics of older people participating in focus group discussions

Pseudonym	Age	Background Information	Additional Medical History	Social Circumstances
Barbara	80	No falls to date, but dizziness, unsteadiness and fear of falling	Atrial fibrillation, Previous mitral valve replacement	Lives alone
Les	76	No falls to date, but blackouts, unsteadiness and fear of falling	Ischaemic heart disease, Treated hypertension, rheumatoid arthritis, type II diabetes, right total hip replacement, vasovagal syncope	Lives with wife
Pauline	80	Multiple injurious falls, unsteadiness and fear of falling	Previous colles fracture, bilateral fractured elbows, osteoporosis, treated hypertension	Lives alone
Ann	76	Previous injurious falls and blackouts, denies unsteadiness and fear of falling	Previous colles fracture, normal bone mineral density on DEXA scanning	Lives alone
Brian	74	No falls to date, but pre-syncope and unsteadiness, denies fear of falling	Coronary artery bypass graft x 4, abdominal aortic aneurysm repair, lumbar stenosis, Depression	Lives with wife
Jim	87	No falls to date, but previous blackouts, unsteadiness and fear of falling	Medication-induced carotid sinus syndrome, angina	Lives alone

Table 5.1. Continued

Joyce	80	No falls to date, but blackouts and unsteadiness, denies fear of falling	vasovagal syncope, transient ischaemic attacks, bronchiectasis, osteoporosis, vitamin B12 deficiency	Lives alone. Sheltered accommodation
Martha	85	Previous injurious falls, unsteadiness and fear of falling	Osteoarthritis, Osteoporosis, Left Total Hip Replacement, Hypertension, Vasovagal Syncope	Lives alone, sheltered accommodation
Norma	88	No falls to date, but unsteadiness and fear of falling	Lower back pain, temporal arthritis, atrial fibrillation, hyperthyroidism	Lives alone, retirement accommodation
Charles	75	No falls to date, but blackouts, dizziness and unsteadiness, denies fear of falling	Vasovagal syncope, previous viral labyrinthitis	Lives with wife (Christine – see below), retirement accommodation
Margaret	75	Previous non-injurious falls, unsteadiness and fear of falling	Right total hip replacement, asthma	Lives with husband
Susan	72	Previous non-injurious falls, unsteadiness, denies fear of falling	Orthostatic hypotension, rheumatoid arthritis, Right total hip replacement 1997, Awaiting left total hip and left total knee replacements	Lives alone

Table 5.2. Characteristics of relatives participating in focus group discussions

Pseudonym	Age	Social Circumstances
Christine	72	Husband (Charles – see above) participated in older people’s focus group sessions.
Hilda	74	Husband has Advanced Parkinson’s Disease and was not eligible to participate in focus group sessions due to cognitive impairment. At the time of the focus group sessions, cared for husband at home with no formal support. However, husband has subsequently moved into 24 hour nursing care.
Mary	78	Husband physically frail due to multiple chronic health conditions (widespread osteoarthritis, glaucoma, cataracts, and chronic obstructive pulmonary disease). Husband participated in older people and relatives’ involvement group and was, therefore, not eligible to take part in the focus group sessions.
Claire	76	Husband suffered traumatic brain injury aged 34. Physically quite able, but did not participate in focus group sessions due to mild cognitive impairment and communication difficulties.

Table 5.3. Characteristics of physiotherapy practitioners participating in focus group discussions

Pseudonym	Grade	Year Qualified	Current Post
Michelle	Clinical Specialist	1995	Domiciliary Physiotherapy
Liz	Senior II	2005	Community Resource Team
Angela	Senior I	1996	Orthopaedic Discharge Team
Tom	Senior I	1995	Domiciliary Physiotherapy
Julie	Senior I	1979	Day Hospital
Kate	Recent Graduate	2007	Seeking Employment

Table 5.3. Continued

Rachel	Recent Graduate	2007	Seeking Employment
James	Junior	2006	Rotational Post
Sally	Junior	2006	Rotational Post
Emma	Recent Graduate	2007	Seeking Employment
Linda	Service Manager	1982	Domiciliary Physiotherapy
Andrea	Senior I	1996	Domiciliary Physiotherapy
Sue	Senior II	1997	Community Resource Team
Adam	Senior I	1996	Orthopaedic Discharge Team
Karen	Clinical Specialist / Service Manager	1991	Day Hospital
Jane	Senior I	1984	Community Resource Team
Sandra	Senior I	1996	Community Resource Team
Simon	Senior I	1994	Orthopaedic Discharge Team

5.4. Theme 1 – Factors influencing uptake and adherence

In keeping with the findings of Yardley et al (2006) and the philosophical principles underpinning self-management for long-term conditions, the older people attending the regional falls and syncope service cited ‘maintenance of independence’ as their main reason for choosing to participate in an exercise-based falls prevention programme rather than reduction in falls-rate or falls-risk. Mirroring the work of Ballinger and Payne (2000), the older people emphasized that they were healthy and

able to manage at home, if not independently then with the help of family members which they indicated was readily available.

'As you get older, you want to be as independent as you can be and that's my motive. I want to be independent; I don't want to be dependent on anybody'
(Margaret – Older Person)

'I've got my independence back. As you can see, I'm at home, I do everything myself' (Jim – Older Person)

In contrast, the physiotherapy practitioners suggested that many of the older people they came into contact with were not motivated to remain independent in activities of daily living. The older people accessing exercise-based falls prevention programmes in the local region were presented as frail, vulnerable and largely responsible for their own functional decline.

'A lot of people have that, I know it's horrible but "roll over and die" attitude' (Kate – Physiotherapist)

Whilst social cognitive factors have been focussed on by health psychologists as the most proximal determinants of behaviour and behaviour change, the relatives and physiotherapy practitioners indicated that adherence was largely influenced by the individual's personality. The relatives, in particular, felt there was a certain 'type' of older person who would be motivated to exercise at home and that there was very little that could be done to encourage those who did not wish to participate in an exercise-based falls prevention programme. Within both stakeholder groups, there

was an acknowledgement that members would be reluctant to participate in an exercise-based falls prevention programme themselves. One relative stated that, unlike her husband, she did not think she would be the ‘sort of person’ to adhere to a prescribed exercise-regime.

‘Honestly, if it were me, if something happened, I think I would find it difficult. (My husband) always manages to do them, but that’s just him’
(Christine – Relative)

The group of recently-qualified physiotherapy graduates admitted that their personal views impacted on their professional role delivering exercise-based falls prevention programmes.

‘I think it’s difficult to get older people on board with home-exercises because they’re boring. I find it difficult to prescribe them for someone because I know I wouldn’t do it’ (Emma – Physiotherapist)

Many of the older people accessing community-based services in the local region suffer from a range of pre-existing physical health problems. In keeping with the biomedical falls literature, the physiotherapists felt that these would negatively impact on uptake and adherence with an exercise-based falls prevention programme.

‘They might just be on the border of getting through the day without a carer’s help or on the border of going into residential care, so getting through the day is hard for them; anything else is exhausting’
(Angela – Physiotherapist)

Tiredness, associated with the older person's co-existing physical health problems, was proposed by the relatives' group as another barrier to successful exercise participation.

'I think in my husband's case its tiredness; he's desperately tired all the time. I suppose, like a lot of people, he has to take a lot of drugs for the original condition which have a very soporific effect and, with old age, he's very tired' (Claire – Relative)

In keeping with the findings of Ballinger and Payne (2000), the physiotherapy practitioners suggested that cognitive assets or abilities also influenced uptake and adherence with an exercise-based falls prevention programme.

'Somebody with vascular dementia wouldn't be appropriate because there not going to retain the information, they're not going to do it and you're wasting their time and yours' (James – Physiotherapist)

The domiciliary physiotherapists identified significant environmental barriers to home-exercise.

'Obviously some houses you go into are very cluttered or have animals lying about the place that you have to try to move to be able to do the exercise programme or, you know, children, grandchildren, that sort of thing. There can be lots of barriers; trying to get some space can often be a problem' (Linda – Physiotherapist)

The physiotherapy practitioners indicated that nursing homes provided a particularly challenging environment in which to support older people to adhere to an exercise-based falls prevention programme.

'Yes, you've got carer's there, but unless you can target someone who's interested and enthusiastic about supporting the older person it's very difficult to get any adherence because, you know, their confidence is maybe low in that environment anyway. They don't want to worry anyone because they know they are busy so they don't ring the bell, even to go to the toilet' (Andrea – Physiotherapist)

Whether or not the exercise programme was prescribed in a hospital or home setting was felt to influence uptake and adherence. However, opinion was divided as to which environment would be most conducive to successful participation.

'If you go out to their home environment where they fall, or a fall is more likely to occur, I think the patient, or person rather, can make the link with what you are trying to achieve rather than in a closed hospital environment with a bit of paper left on a table' (Sue – Physiotherapist)

'As you've said, if you are going somewhere, you're more likely to be motivated. Quite often I see people at home; I mean they're just not interested in the things we've just talked about, the benefits and what might happen if they didn't exercise' (Michelle – Physiotherapist)

The physiotherapy practitioners participating in the focus group discussions believed that low self-efficacy was a major barrier to exercise adherence. However, whilst it was acknowledged that older people could become more confident in their abilities to undertake an exercise-based falls prevention programme, it was generally felt that

fear of falling remained a longstanding issue that was difficult for an older person to overcome.

'I think confidence is a big issue as well, except you can't actually improve your patient's confidence in themselves to, well, not fall over because I don't think they ever lose that fear' (Emma – Physiotherapist)

Despite such findings, however, the older people attending the regional falls and syncope service demonstrated high levels of self-efficacy when describing their experiences of participating in an exercise-based falls prevention programme. Whilst the physiotherapy practitioners perceived that physical conditions, such as pre-existing musculoskeletal pain, reduced adherence with an exercise-based falls prevention programme, the older people participating in the focus group sessions demonstrated an ongoing commitment to home-exercise in the face of these potential barriers.

'Well it's the arthritis in my feet that's bothering me, especially during that exercise you gave me, toe-heel, but I persevere' (Susan – Older Person)

One older person described how she had experienced secondary health benefits as a result of participating in an exercise-based falls prevention programme. These had encouraged her to continue with the home-exercise programme following discharge by the regional falls and syncope service.

'Strangely, over the last few years I've had physio for various things and I've found now that these exercises somehow or other have improved the other things. The exercises for balance have made my neck feel easier as well as making my legs feel stronger' (Margaret – Older Person)

A number of functional benefits were reported by the older people participating in the focus group discussions, and these motivated them to continue with an exercise-based falls prevention programme.

'I do my exercises regularly and the last 4 you gave me were superb, I can feel the difference already' (Pauline – Older Person)

'I think I owe all my independence to the exercises one way or another'
(Jim – Older Person)

Many of the older people participating in the focus group discussions demonstrated a long-term active commitment to an exercise-based falls prevention programme.

'There's no way I'll turn around and say "Well, I've had enough of that I'm not doing that anymore." I've started and it's an ongoing thing for me now'
(Charles – Older Person)

5.5. Theme 2 – Predicting and monitoring uptake and adherence

Despite the multiple factors considered to be associated with uptake and adherence, the physiotherapy practitioners appeared confident in their abilities as 'experienced healthcare professionals' to predict which older people would be motivated to participate in an exercise-based falls prevention programme.

'I think just with experience you get an idea of who is going to comply and who isn't' (Michelle – Physiotherapist)

'Sometimes it's intuition as well, isn't it?' (Sally – Physiotherapist)

They identified a number of non-verbal cues which helped them to recognize which older people would be motivated to engage with a home-exercise programme.

'Sometimes it's their body language, you know? You get the feeling that they don't want you there' (Linda – Physiotherapist)

'It's often what they don't say as opposed to what they do say!'
(Adam – Physiotherapist)

In the local region, the west of the city is traditionally associated with areas of lower economic and educational status than the north. Whilst opinion was divided as to which socio-demographic variables were associated with uptake and adherence, failure to appreciate the role of social cognitive factors in predicting and monitoring uptake and adherence with exercise-based falls prevention programmes meant that many of the physiotherapy practitioners claimed to be able to identify which older people would be motivated to participate in a home-exercise programme based purely on their postcode.

'The west side of the city tend to be very, very grateful for what you do for them and they tend to be more compliant whereas the north of the city, they aren't so compliant' (Liz – Physiotherapist)

'We've found in the west that people don't necessarily expect to get better. They are, as you say, grateful for what's happening but in my experience of working in the north, people expect to get better and ask questions as to why they're not' (Michelle – Physiotherapist)

Whilst it was acknowledged that it could take more than one therapy session to establish adherence, several of the physiotherapists participating in the focus group discussions indicated that they would be able to identify whether an older person would be motivated to participate in an exercise-based falls prevention programme during the initial clinical practice encounter.

'You know right from the beginning, when you do your initial assessment really, you get an idea of whether you are going to be able to prescribe an exercise programme which they are probably going to follow'
(Linda – Physiotherapist)

Despite suggestions in the academic literature that healthcare professionals have an important role to play in supporting individuals with long-term conditions to move through the incremental stages of behaviour change (Burbank et al., 2000), local physiotherapy practitioners participating in the focus group discussions often made a simple dichotomous distinction about whether or not an older person would be motivated to participate in an exercise-based falls prevention programme.

'You can kind of talk to them 'til you're blue in the face and explain why but if they don't want to be there and they're not really interested then there's not really a lot you can do' (Emma – Physiotherapist)

Although it was acknowledged that healthcare professionals should provide older people with the opportunity to participate in an exercise-based falls prevention programme, the physiotherapy practitioners appeared reluctant to actively encourage their patients to adhere to a home-based exercise programme.

'But there's a difficult balance because obviously there's consent issues there as well. If they don't really want to do it you can't really persuade them to do it' (Sue – Physiotherapist)

Despite such observations, however, only one physiotherapist acknowledged that, within a fully-engaged scenario, it was important to actively relinquish control if an older person made an informed choice not to participate an exercise-based falls prevention programme.

'The other big thing we need to bear in mind is that although we all know the benefits of exercise and as physios we all want people to be included in falls rehab, that might not actually be what the patient wants and I think we have to accept that as well, even if it means they might have another fall' (Michelle – Physiotherapist)

Whilst several of the physiotherapists claimed that it was easy to tell whether or not an older person had been following a home-exercise programme, others admitted that they found it difficult to establish and monitor adherence. One physiotherapist had experience of using exercise diaries. However, the majority relied on much less formal methods of measuring adherence.

'If you get the piece of paper with the exercises on and it looks like it's not been touched at all, there's no folds in the paper and it looks pristine, just the way you left it, then they probably haven't been doing their exercises' (Sue – Physiotherapist)

It has been suggested that until patients can be open with healthcare professionals about their experiences and ideas, they cannot fully engage in participatory decision-making (Paterson, 2001). Despite such observations, however, there was an overriding perception that older people would not reveal to the physiotherapist whether or not they had been following a prescribed home-exercise-regime.

'It's hard to know whether older people are actually doing their exercises. If someone says to you "Oh, I get up, do my exercises, have breakfast, go out, come back home and do my exercises again" and then demonstrate them perfectly it doesn't actually mean they are actually doing their exercises, does it?' (Rachel – Physiotherapist)

One physiotherapist indicated that she preferred to rely on the testimonies of family members when attempting to formally monitor uptake and adherence with an exercise-based falls prevention programme.

'I had a lady in this week and said "Have you been doing your exercises?" and the lady said "Yes" but her niece was standing behind her shaking her head!' (Emma – Physiotherapist)

5.6. Theme 3 – Roles and responsibilities

The older people participating in the focus group sessions presented themselves as capable and competent, refuting negative assessments of their mental state, moral

character and ability to take care of themselves. One group described how they had previously challenged health professionals' stereotypical views of older people.

'That's what I was told at (the hospital) a few months ago. The Doctor said "You are 76" so I said "Well, you know there are plenty of 76 year olds who are fit and well that I know of." I wasn't meaning to be cheeky; I was just pointing it out' (Les – Older Person)

The majority of older people participating in the focus group sessions expressed the desire to actively participate in an exercise-based falls prevention programme.

'I'm fortunate, I can help to put this right myself' (Pauline – Older Person)

'It's no good just sitting back and expecting it all to happen. Somebody doesn't just wave a magic wand' (Barbara – Older Person)

Whilst the older people acknowledged that loyalty to the prescribing physiotherapist promoted adherence, they strongly believed that the decision to participate in an exercise-based falls prevention programme had been their own. In keeping with the findings of Yardley et al (2007), the older people attending the falls and syncope service indicated that the provision of information regarding the benefits of undertaking specific exercises to improve strength and balance had enabled them to make an informed decision regarding participation.

'I think you put it across well, because you don't say "You'd better do this." You tell us why and explain the benefits, and I think that's a good thing'
(Les – Older Person)

In traditional approaches to clinical service delivery, patient-initiated activity is often perceived as challenging and potentially dangerous (Ballinger & Payne, 2002). The physiotherapy practitioners participating in the focus group discussions reproduced accepted and well-respected views in the biomedical literature of older people as the passive recipients of exercise-based falls prevention programmes.

‘Well, a lot of people who want physio want you to do something to them that will miraculously stop them from falling. But you have to have that commitment from them to actually go home and do the exercises everyday. A lot of people don’t want that kind of physio’ (Tom – Physiotherapist)

Whilst many of the physiotherapy practitioners indicated that older people should be encouraged to take greater responsibility for the maintenance of their own health, there appeared to be a conflicting desire to remain in control of the treatment programme.

‘I think the key thing is if we are prescribing the exercises, we are responsible for them as well, aren’t we?’ (Jane – Physiotherapist)

In keeping with traditional biomedical models of clinical service delivery, local physiotherapists positioned themselves as experts in assessing and managing risk factors for falling. The physiotherapy practitioners indicated that an older person’s confidence in the knowledge and skills of the healthcare professional was central to promoting uptake and adherence with an exercise-based falls prevention programme.

'I was thinking of this chap I had recently who was absolutely blindingly full of trust and did everything I asked. He exercised religiously'
(Sandra – Physiotherapist)

There was a perception that older people would participate in an exercise-based falls prevention programme purely out of a desire to please the prescribing physiotherapist.

'I think that sometimes they think they've disappointed you in a way, haven't they, if they can't do the exercise. They're worried that you will be disappointed about it in some way' (Julie – Physiotherapist)

The majority of physiotherapy practitioners responded to older people's decisions to reject falls prevention advice as a challenge to their professional ability and authority, rather than an alternative perspective about risk and safety (Ballinger & Payne, 2002). This was particularly apparent in the recent graduates' focus group session.

'You feel like you've failed, and maybe you have, I don't know'
(Rachel – Physiotherapist)

In keeping with the findings of Yardley et al (2006), the older people taking part in the focus group discussions agreed that the endorsement of family, friends or influential healthcare professionals provided valuable encouragement and promoted self-efficacy.

'My family and friends have all remarked on the fact that I'm getting around much better which is a big help with confidence, so I've got them involved as well' (Les – Older Person)

However, whilst several of the physiotherapists felt that involving an enthusiastic or supportive relative or primary care-giver would promote uptake and adherence, it was suggested that family members were often sceptical about the benefits of exercise-based falls prevention programmes.

'I've been to a house recently and was actually busy with a lady when her daughter came in and spoke to her dad and he said "Oh, the physio is here doing her exercises" and her comment was "Well, what's she coming now for, it's a bit late isn't it, she's 86" which doesn't help if you're trying to get people to do things independently' (Andrea – Physiotherapist)

Many of the physiotherapists appeared reluctant to include family members in an exercise-based falls prevention programme. It was suggested that involving a physiotherapy assistant or generic support worker was often considered to be more appropriate.

'I've had experiences where some patients don't want family members to know, because it puts pressure on them and family members can see that they can probably do a lot more for themselves than they let on – there's still quite a few of them in the community' (Liz – Physiotherapist)

'You've got to pick your patients because some relatives don't want that extra responsibility. They may already care for somebody and then you say "Look, can you get them to do these exercises 3 times a day?" It might just be too much. Also family / patient dynamics aren't always as rosy as perhaps we think and it could just lead to more tension' (Michelle – Physiotherapist)

One of the relatives participating in the focus group discussions had adopted a primary care-giving role and felt responsible for ensuring that her husband completed his daily exercise-regime. However, the other three relatives did not feel it was their role to supervise or monitor a home-exercise programme prescribed by a healthcare professional.

'I think my responsibility seems to end with asking if he's done them and if he says he has then I would tend to believe him. I don't think he would want me standing over him particularly' (Claire – Relative)

'I consider he's an adult and has to make his own decisions, and if he doesn't want to do them, or can't be bothered, or forgets, I think that's up to him' (Mary – Relative)

The relative who had adopted a primary care-giving role supported physiotherapy practitioners' claims that active participation in the delivery of exercise programme had the potential to cause conflict between family members.

'You know the one where he's standing on one leg whilst holding onto the bench and the other one goes out to the side? Well, it doesn't come out very far. I mentioned this to him last week and was told in no uncertain terms that's as far as he can do it!' (Hilda – Relative)

The personal anxieties associated with supporting a family member to remain independent in activities of daily living provided a valuable insight into the additional daily stresses encountered by the relatives of older people with multiple co-morbidities identified as being at increased risk of falling.

'I think my anxiety comes into it for me sometimes. I think "Have I got the nerve, as it were, to let him go?" I'm double checking mobiles etcetera because his memory's not so good. It's not Alzheimer's or anything but part of the brain damage he has, his concentration and memory are a bit dodgy. Too many times, I've had the police coming to the door and things like that, it's horrible' (Claire – Relative)

Although only one relative had formally adopted a primary care-giving role, the other three acknowledged their husbands' deteriorating physical health status and shared their occasional frustrations at the altered dynamics of their relationship.

'If the shoe were on the other foot, I would try harder. I don't want to criticize him you understand, but I have arthritis and it doesn't stop me doing anything. If the roles were reversed, he would do his best but he wouldn't be able to cope, I'd still end up doing most things' (Mary – Relative)

'I'm more than happy to do whatever I can, but just occasionally, once in a blue moon, it would be nice to be looked after instead of being the one doing the looking after' (Hilda – Relative)

Despite such observations, however, the relatives participating in the focus group discussions were quick to reassert their loyalties to their family member by reinforcing their husbands' sense of positive self-identity.

'Well, I don't know how you feel, but I'm so thankful to have him, and he's very important to our family, hugely important. I mean, obviously, he's ageing and can't do the things he used to do, but he's a very important figure in the lives of our children and grandchildren. I've got to say, I'm very grateful that he's here, even if he is a bit shaky and needs to be reminded about things' (Claire – Relative)

5.7. Theme 4 – Stakeholder views and experiences of local clinical services delivery

In keeping with the academic literature surrounding uptake and adherence with an exercise-based falls prevention programme (Minichello et al 2000; Yardley et al 2003), several of the physiotherapy practitioners suggested that older people were reluctant to label themselves as fallers or, as Zecevic et al (2006) identified, conceptualized falls in a different way to healthcare professionals.

‘Some people are actually quite proud as well. They don’t want to admit that they’ve fallen or they don’t really agree that, say, something that they consider isn’t a fall actually is a fall’ (Sally – Physiotherapist)

Others felt that many of the older people they came into contact with had an ‘ageist’ attitude to exercise. They described how falling was considered an inevitable part of the ageing process. This was felt to have a negative impact on uptake and adherence with an exercise-based falls prevention programme.

‘I wonder sometimes how important it is to them, you know. They’ve had a couple of falls, but in their minds it might be “Well, I’m 82, that’s something I have to expect. This girl wants me to exercise, but I’m 82” and they just aren’t interested’ (Sandra – Physiotherapist)

Despite such observations, however, the older people’s accounts of unsteadiness, falls and blackouts provided a valuable insight into their devastating impact on self-confidence, autonomy and quality of life.

'Well, you know the state of me when I arrived. The only way I can describe to these people what I was like when I first came to be on your books was when it's icy weather, real icy like we used to get but don't get anymore, and your feet get about an inch off the floor and you're frightened to lift them too far in case you topple over. Well, that was me, and it was summertime!'
(Jim – Older Person)

'As far as I'm concerned with falls, it's just out of the blue with me. I don't feel off colour, I just go down, in the house, in the street even. I just go down. I just wait until I hit the ground. Half the time I'm not sure whether I've had a blackout because when I hit the ground I feel no pain and just lie there for a few minutes until someone gets me up, and then the pain starts. I'm never sure whether I've tripped or what you see, especially with the diabetes'
(Les – Older Person)

All three stakeholder groups suggested that early referral to a falls prevention service was desirable, but indicated this rarely happened in the local region. In keeping with the observations of Yardley and Todd (2005), referral to the regional falls and syncope service seemed to occur on a largely ad hoc basis, usually after the older person had experienced an injurious fall or considerable functional impairment.

'I think (my husband) might have gone to see his doctor about his increasing imbalance, but they more or less take your blood pressure and that's it. I'm not complaining, I'm just trying to think back in the sequence of things. I think he did go and see one of our nice doctors and said he was losing his balance but I can't remember anything being done about it – until he fell badly' (Claire – Relative)

Whilst it has been suggested that older people may reject falls prevention advice because it emphasizes the negative social consequences of falling that many older people fear (Kingston, 2000), several of the older people participating in the focus

group discussions described how attending the regional falls and syncope service had led to feelings of enhanced self-efficacy.

'I came to the falls clinic and really it has done me a lot of good because I've had all the tests and it's really given me a lot of confidence. I'm not, you know, unhappy that something nasty is going to happen to me'
(Ann – Older Person)

One older person even described how she had played an active role in initiating a referral to the regional falls and syncope service.

'Since 1985 I've had lots of falls and fractures, then I had another accident in 2005 and I read an article about the falls clinic and went to see my GP. He thought I was already coming to see you, but obviously the various fracture clinics hadn't referred me' (Pauline – Older Person)

It is now widely recognized that up to half of injurious falls occur in those who are not very old and unwell, but amongst older people who continue to be active despite some decline in their balance capabilities (Stel et al., 2003; Wijnhuizen et al., 2008). Despite such observations, however, clinical services in the local region tend to target frailer older people with significant co-morbidities and high levels of functional impairment in domiciliary or day hospital environments. The physiotherapy practitioners indicated that, within existing models of clinical service delivery, it was often difficult for themselves and their patients to appreciate the benefits of participating in an exercise-based falls prevention programme.

'It can be hard with some patients who've been through the process 3 or 4 times, it's harder to get them to appreciate the benefits. It's hard to appreciate them yourself because you know they are going to remain in the same situation and they are not going to take on board the advice that's provided' (Andrea – Physiotherapist)

Whilst it has been suggested that older people may reject falls prevention advice because they are falsely optimistic about their capabilities (Whitehead et al., 2006), the majority of older people participating in the focus group sessions indicated that they had been receptive to falls prevention advice / education and felt that the information received was relevant and of personal interest to them.

'I hope that, through all this constant exercise, once I get older I can anticipate a fall, or when I start swinging and swaying on an icy patch, I will remember "Oh, such and such said..." Yes, everything is helping because once you reach the old age mark you hear from someone "Such and such had a fall' and the next minute "Well, what do you think of such and such – he passed away". All because of losing control of walking and that' (Susan – Older Person)

One participant, who had originally been referred to the regional falls and syncope service with light-headedness, expressed his initial surprise at being referred to a physiotherapist. However he indicated that, on reflection, he had been pleased to accept the advice and intervention offered and considered it to be a positive and worthwhile experience.

'Well, when I first came, the idea of walking up and down and the two of you watching, I thought "What's this got to do with the way I am?" but, after that, things started to fall into place and I thought "Thinking years ahead, what have I learnt from this conversation?" If it means walking a lot better, well I think it's worth finding out about' (Brian – Older Person)

5.8. Theme 5 - Strategies for promoting self-management and adherence

The physiotherapy practitioners identified a number of strategies to promote self-management and adherence with an exercise-based falls prevention programme. In keeping with the philosophical principles underpinning patient-centred practice, it was suggested that an ‘individualized approach’ was vital to the success of any clinical intervention. However, the physiotherapists appeared confident in their abilities as ‘experienced healthcare professionals’ to determine the approach that would be most appropriate for their patients. Again, this was most noticeable in the recent graduates’ focus group session.

‘So, again, it goes back to making it individualize. Making sure you’re good enough to know what’s going to be most appropriate for that person to achieve the best outcome’ (Sally – Physiotherapist)

‘You need to decide from the subjective assessment what sort of approach that person will respond to best’ (Rachel – Physiotherapist)

Many of the physiotherapists taking part in the focus group sessions offered practical solutions to overcoming poor adherence, such as providing written details of the exercise programme.

‘I have been known to laminate things and stick them in people’s kitchens to act as visual reminders. I like my laminated sheets because it guilts them into doing their exercises whilst they are in the kitchen’
(Sandra – Physiotherapist)

One physiotherapist described how she had used exercise diaries with good effect. However, in keeping with traditional approaches to clinical service delivery, these had been used to monitor and track adherence levels rather than to support the older person to play an active role in managing their own treatment programme.

'I sometimes use like a diary system, where they have to write down how many times they've done things. I think sometimes that can be quite useful because they know that you are going to be coming back and looking at it'
(Linda – Physiotherapist)

Presenting the older people they came into contact with as frail and vulnerable, the physiotherapy practitioners participating in the focus group discussions indicated that adopting a 'little and often' approach ensured that the exercises were 'convenient' and 'manageable' for the older person. This would ensure that they did not feel 'overwhelmed' by the exercise-based falls prevention programme.

'I think physiotherapists prescribe too many exercises for older people but I only give them two or three because I don't want to overload them'
(Liz – Physiotherapist)

Only one physiotherapist suggested that the exercise programme should be challenging enough to provide the older person with a sense of personal accomplishment.

'I think it needs to be quite hard, you know, it must be a challenge for them. If you give them a bunch of exercises that are really easy, aren't challenging, and are really boring, then it doesn't do anything for their self-confidence. But if you challenge them, and it's quite a physically-demanding exercise programme, they are more likely to enjoy it and it also gives them confidence. And once you've increased their confidence, they're actually more motivated to continue rather than just giving up'
(Emma – Physiotherapist)

Incorporating the exercises into their daily routine proved a popular strategy amongst the older people participating in the focus group discussions. However, in contrast to the views of local physiotherapists, it would appear that this approach provided older people with the flexibility required to take ownership of the exercise programme.

'You must discipline yourself into a routine. The advantage I have is that, on instruction, it can be done, not straightaway, but over the period of a day. But now I find, after all this time that I've done it, that if I can get them done in the morning, I'm free for the rest of the day' (Jim – Older Person)

'As far as I'm concerned I do mine twice a day, unless I go for a walk in the mornings, then I do them once a day' (Les – Older Person)

The physiotherapy practitioners suggested that exercising in a group or gym environment would be preferable to exercising at home, and that this would promote uptake and adherence. However, whilst the older people acknowledged the potential benefits of group exercise, the majority indicated that they preferred to exercise at home. Presenting themselves as virtuous and independent, the older people participating in the focus group sessions suggested that successful participation with a home-exercise programme was largely dependent on self-discipline.

'You've got to discipline yourself completely if you want to do it at home or give up altogether, there's no half way' (Joyce – Older Person)

'I literally do what any housewife would do under normal circumstances, so I literally run the house myself from the minute I get up to the minute I go to sleep. If I had to take a break in the middle of all that to come here and do the exercises, then my whole routine would be gone' (Jim – Older Person)

The physiotherapists suggested that the use of objective outcome measures and other visual aids, such as goniometry, had a role to play in promoting adherence. However, in keeping with traditional approaches to clinical service delivery, these measures were often used to promote an older person's confidence in the skills and abilities of the physiotherapist.

'Being able to measure something so you can say "Actually, you are less at risk of falling now". An outcome measure makes it more real for them and they are more likely to feel confident in what you are asking them to do' (James – Physiotherapist)

Although the older people participating in the focus group discussions demonstrated an awareness of their performance on standardized assessment tools, it would appear that such measures enhanced self-efficacy in their own abilities, encouraging them to play a more active role in the prescribed exercise-regime.

'That thing you did, you said 26 was the best and I got 13, so I'm halfway there. The next time I come, I'm sure I'll have gone up, you'll see' (Norma – Older Person)

The physiotherapy practitioners acknowledged that they found it difficult, within existing approaches to clinical service delivery, to encourage older people to adhere to an exercise-based falls prevention programme over a prolonged time period.

'I think it's quite difficult, for falls especially, to give people an exercise programme to do because they, kind of, have to do it forever. It's not like a knee replacement, where you have a short course of exercise and do it because they have to, because they've committed themselves to having surgery and, if they don't do them they won't get the best from their new knee. With falls, it's an ongoing exercise programme, all the time, and I don't think people want to do it everyday for the rest of their lives, so they don't do it' (Simon – Physiotherapist)

Despite acknowledging that falls represented an ongoing issue for older people, however, only one group discussed the possibility of viewing long-term active participation with an exercise-based fall prevention programme as a form of behavioural change.

'I do think that exercising and partaking in an exercise programme is part of a lifestyle change and it's the same for any lifestyle change, such as stopping smoking or reducing your cholesterol, you know, you have to tap into a time when the patients have decide that the benefits outweigh, you know, doing nothing' (Karen – Physiotherapist)

'It's funny, talking about this makes me think of cardiac and pulmonary rehabilitation – it's the same, it's exactly the same. It's all about education and mind-setting, understanding that change is for life'
(Jane – Physiotherapist)

It is widely recognized that physiotherapists acting in an educational / advisory role can be more efficient, but just as effective, as their colleagues working within a more

traditional framework (Hall et al., 2010). Towards the end of the focus group discussions, the physiotherapy practitioners acknowledged that healthcare professionals should take a less-active role in the assessment and treatment process.

'We should listen more to our patients because physios are generally so chatty and will happily talk away, but we should bite our lip, you know, sometimes and be a pair of ears. If a treatment isn't working for a patient then just sitting down and listening might help us to find out why'
(Rachel – Physiotherapist)

One group suggested that providing a graded level of self-management support would encourage older people to become more confident in their abilities to carry out an exercise-based falls prevention programme over a prolonged time period.

'We could give them the appropriate amount of 1-1 sessions early on so they've got the confidence to do more themselves later on'
(Adam – Physiotherapist)

Although confident in their abilities to develop a long-term active commitment to an exercise-based falls prevention programme, the older people participating in the focus group discussions also expressed the desire to remain in contact with clinical services over a prolonged time period. They indicated that ongoing input from a healthcare professional in an educational or advisory capacity would promote feelings of self-efficacy and promote ongoing adherence.

'I think perhaps some kind of ongoing check up would be useful'
(Margaret – Older Person)

'When my wife had her hip done, the second one, they introduced a service where you go back every 12 months for an x-ray, and the reassurance that you get from that, you know....' (Charles – Older Person)

Whilst the relatives demonstrated a limited awareness of strategies to promote self-management and adherence with an exercise-based falls prevention programme. However, they agreed that long-term follow up by a healthcare professional would be beneficial and felt that this would be favourably received by their husbands.

'I think my husband might quite like someone behind him as he's ageing and watching to see if there's anything going wrong or anything that can be improved' (Claire – Relative)

5.9. Summary

This chapter has presented the integrated findings of eight focus groups conducted with older people attending a regional falls and syncope service, relatives and local physiotherapy practitioners within the wider context of the academic falls prevention and self-management literature. Chapter 6 will consider these findings further in relation to the experimental case-series data.

CHAPTER 6. EXPERIMENTAL CASE-SERIES

FINDINGS

6.1. Overview of chapter

This chapter will present the integrated findings of eight older people with primary biliary cirrhosis who completed the experimental case-series. In keeping with the focus group findings set out in Chapter 5, consideration will be given to the data analysis process and the personal characteristics of the experimental case-series participants. This will be followed by a detailed discussion of the qualitative and quantitative experimental case-series data within the wider context of the focus group findings and academic falls prevention and self-management literature.

6.2. Background to analysis and presentation of experimental case-series findings

The experimental case-series was conducted between September 2009 and November 2010 (Enhanced Intervention), and November 2009 and September 2010 (Standard Intervention). On completion of the quantitative data collection phases, the data were displayed graphically using PASW Statistics 18 and subjected to visual inspection to identify patterns and trends in the data over time. Semi-structured interviews were conducted with eight of the experimental case-series participants throughout January 2011 to explore the acceptability and perceived

impact of the exercise-based falls prevention programmes and self-management strategies under evaluation. During these follow up interviews, the older people with primary biliary cirrhosis were shown the graphical representations of their measures to help facilitate the discussion and to obtain, from them, their own interpretations and explanations of the patterns and trends observed in the selected measures over time.

Multiple cases enable comparisons that clarify whether an emergent finding is simply idiosyncratic to a single case or consistently replicated by several cases (Onghena & Edgington, 2005). Despite such observations, however, presenting a relatively complete and unbroken narrative of each participant is unfeasible in experimental case-series research, particularly as the number of cases increases (Eisenhardt & Graebner, 2007). To provide an enhanced understanding of the factors influencing self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition, the follow up interview data were subjected to framework analysis and considered under the same five thematic headings as the focus group findings:

- Theme 1: Factors influencing uptake and adherence

- Theme 2: Predicting and monitoring uptake and adherence

- Theme 3: Roles and responsibilities

- Theme 4: Stakeholder views and experiences
- Theme 5: Strategies to promote self-management and adherence

During the familiarization phase, a data summary table was produced for each experimental case-series participant (Appendix XIX) to systematically track the context, content, enabling mechanisms, disabling mechanisms, and outcomes of the exercise-based falls prevention programmes and self-management strategies under evaluation. This process provided an enhanced understanding of what worked, for whom, in what context (Wilson & McCormack, 2006), before breaking the interview transcripts down into their component parts. Throughout the indexing and charting phases, the views and experiences of the older people with primary biliary cirrhosis receiving both the standard and enhanced intervention were considered in parallel to gain a better understanding of the factors influencing uptake and adherence with an exercise-based falls prevention programme and to establish the added value of the self-management strategies under evaluation. During the mapping and interpretation phase, particular attention was paid to exceptions, contradictions and disconfirming extracts in the data. These were used to interrogate the focus group findings and provided an insight into the additional impact of long-term conditions on self-management and adherence with an exercise-based falls prevention programme.

In keeping with the qualitatively-driven mixed methods approach underpinning the current study, the experiential narratives of the older people with primary biliary cirrhosis will be supplemented by graphical representations of the selected outcome

measures to illustrate how the experimental case-series participants interacted with the quantitative data during the follow up interviews and to help explain and contextualize the patterns and trends observed in the measures over time.

6.3. Sample characteristics

The experimental case-series participants were allocated pseudonyms during the data analysis process. As discussed in section 5.3, providing participants with an alternative name rather than an arbitrary code number ensures anonymity and confidentiality whilst maintaining a human quality to the presentation of the experimental case-series data, and enables the reader to cross-link concepts and themes with the roles, identities and attributes of individual experimental case-series members (Sim, 1998). The personal characteristics of the older people with primary biliary cirrhosis taking part in the experimental case-series are provided in Table 6.1. The shaded / un-shaded areas represent the participants receiving the enhanced and standard interventions respectively.

Table 6.1. Characteristics of older people participating in experimental case-series

Pseudonym	Age	Background Information	Additional Medical History	Social Circumstances
Shirley	66	No falls to date but progressive unsteadiness	Primary biliary cirrhosis diagnosed in 2005 following problems with immune system. Ischaemic heart disease, hypertension, type II diabetes and myopathy secondary to mitochondrial disease	Lives with husband who is in good physical health
Helena	70	No falls to date but progressive unsteadiness	Primary biliary cirrhosis diagnosed in 1992 by routine blood tests taken following spinal surgery. Liver transplant 1992. Insulin dependent diabetic	Lives alone
Jane	78	Several mechanical falls to date and progressive unsteadiness.	Primary biliary cirrhosis diagnosed in 1994 following routine blood tests taken for steroidal therapy. Chronic lower back pain, fibromyalgia, stroke disease and hypothyroidism	Lives alone

Table 6.1 Continued

Denise	64	Two mechanical falls to date and progressive unsteadiness	Primary biliary cirrhosis diagnosed in 2003 after complaining of symptoms for 2 years. Widespread osteoarthritis and hypertension	Lives with husband who is in good physical health
Patricia	68	Previous mechanical fall and progressive unsteadiness	Primary biliary cirrhosis diagnosed in 1996 by routine blood tests taken following removal of gall bladder. Hypothyroidism and osteopenia	Lives with husband who is in good physical health
Dorothy	78	Several mechanical falls to date and progressive unsteadiness	Primary biliary cirrhosis diagnosed in 2007 following routine bloods taken on admission to hospital with suspected transient ischaemic attack. Widespread osteoarthritis – awaiting total knee replacement	Lives with husband who has long-standing physical health problems
Eleanor	63	No falls to date but progressive unsteadiness	Primary biliary cirrhosis diagnosed by GP in 2006 from routine blood tests taken for suspected tendonitis of feet and ankles. Hiatus hernia and hypothyroidism	Lives alone

Table 6.1 Continued

Jenny	80	Previous mechanical fall and progressive unsteadiness	Primary biliary cirrhosis diagnosed in 1981 when developed jaundice following fractured left femur. Liver transplant 1995. Widespread osteoarthritis and osteoporosis	Lives alone
Louise*	67	Several mechanical falls to date and progressive unsteadiness	Primary biliary cirrhosis diagnosed in 1992. Referred to auto-immune liver clinic by GP as complaining of intractable itch. Hypothyroidism and hypertension	Lives with husband who is in good physical health
Elsie**	80	Two mechanical falls to date and progressive unsteadiness	Primary biliary cirrhosis diagnosed in 1996 by routine blood tests taken following period of unexplained weight loss. Osteoporosis and pernicious anaemia.	Lives with husband who has long-standing physical health problems

* Louise withdrew from the experimental case-series prior to commencing the baseline data collection phase following an accidental fall on the ice which resulted in a dislocated right shoulder.

** Elsie completed the follow up data collection phase but did not participate in the semi-structured interviews as her husband developed a chest infection resulting in prolonged a hospital admission.

6.4. Theme 1 - Factors influencing uptake and adherence

In keeping with the focus group data presented in Chapter 5 and the findings of Yardley et al (2006), the older people with primary biliary cirrhosis cited ‘maintenance of independence’ as their main reason for choosing to participate in an exercise-based falls prevention programme rather than reduction in falls-rate or falls-risk.

‘I’ve always had problems getting up and down the stairs and it got to the point where when I was out walking the dogs and we came to a path with a stile I couldn’t get over it, so I wanted something to strengthen my leg muscles’ (Eileen – Standard Intervention)

‘The house sees too much of me!’ (Helena – Enhanced Intervention)

Despite such observations, however, the experimental case-series participants suffered from a range of co-existing physical health problems. In contrast to the older people attending the regional falls and syncope service, these were found to impact on their ability to adhere with an exercise-based falls prevention programme.

‘To be honest I did them, but there were days when I didn’t because my spine was so bad and my leg, so I couldn’t’ (Jane – Enhanced Intervention)

'I couldn't do them all when my foot was really bad'
(Jenny – Standard Intervention)

The older people with primary biliary cirrhosis participating in the experimental case-series completed the PBC-40 at four-weekly intervals throughout the baseline, intervention and follow up quantitative data collection phases. Whilst this measure provided a valuable insight into participants' self-perceived health-status and quality of life, the experimental case-series participants suggested that they often found it difficult to separate their primary biliary cirrhosis symptoms from their co-existing physical health problems.

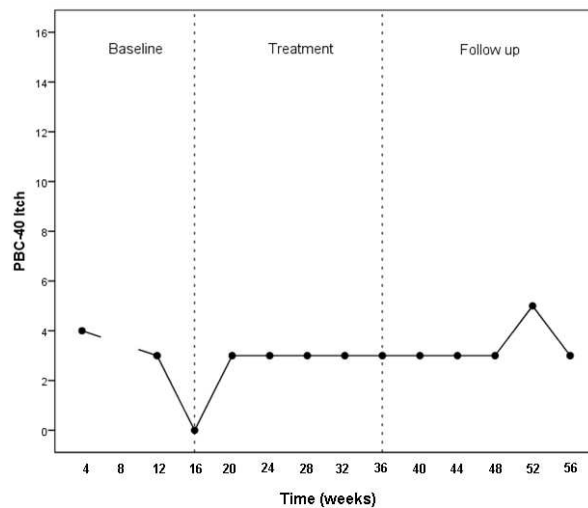
'I mean I understand that you could be stressed and just get on and cope with things. But, on reflection, that makes me wonder if some weeks I might just have responded to the questions in a different way'
(Dorothy – Standard Intervention)

'I mean I suffer from extreme fatigue, but you've got to remember that there are other factors. I've got an underactive thyroid for which I need to take medication. In an older person, you see, there could be other factors at work. See where this goes down? It might be because I was on amlodipine at the time and that causes itchy feet, and then my amlodipine was discontinued'
(Jane – Enhanced Intervention)

The itch domain of Jane's PBC-40 questionnaire is presented graphically in Figure 6.1. Her amlodipine medication was discontinued at the start of the treatment phase and this can be seen to correspond with a decrease in the perceived severity of her symptoms. Despite such observations, however, Jane's self-rated itch score returned to its previous level four weeks later and remained relatively stable throughout the

treatment and follow up quantitative data collection phases despite no longer taking the amlodipine medication.

Figure 6.1. Graphical representation of PBC-40 Itch Domain



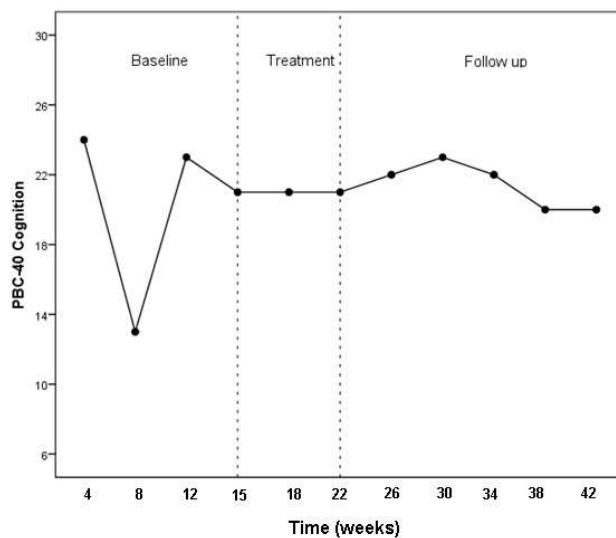
In keeping with the views and experiences of local physiotherapy practitioners, cognitive assets or abilities were also considered to influence ongoing participation with an exercise-based falls prevention programme.

'My memory's not very good you know' (Eleanor – Standard Intervention)

'I've got to the point where I can't remember words. It's something that comes with age, you know. Poirot's little grey cells are not working!'
(Jane – Enhanced Intervention)

Despite scoring 29/30 on the Mini Mental State Examination prior to commencing the experimental case-series, the cognition domain of Eleanor's PBC-40 questionnaire illustrated in Figure 6.2 demonstrates the self-perceived difficulties with memory and concentration experienced by many older people with primary biliary cirrhosis (Newton & Jones, 2007). The fluctuations in self-perceived cognitive impairment observed during the baseline data collection phase could not be explained, and highlight the potential for measurement error in experimental designs involving repeated measures (Ottenbacher, 1995).

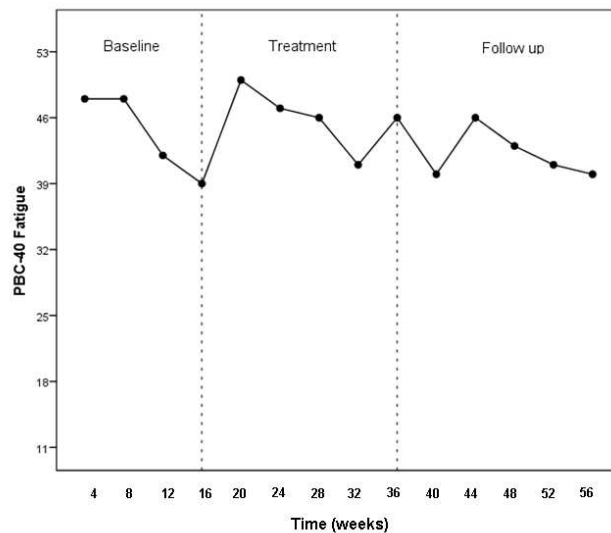
Figure 6.2. Graphical representation of PBC-40 Cognition Domain



During the focus group discussions, tiredness associated with the older person's pre-existing physical health problems was proposed by the relatives' group as a barrier to successful exercise participation. Fatigue is well established as a significant

clinical problem in primary biliary cirrhosis, affecting 65 – 85% of individuals, and has been shown to dramatically reduce health-related quality of life (Jones & Newton, 2005). The fatigue domain of Denise’s PBC-40 questionnaire presented in Figure 6.3 illustrates the high levels of tiredness and fatigue experienced by many older people with primary biliary cirrhosis.

Figure 6.3. Graphical representation of PBC-40 Fatigue Domain



Despite such observations, however, fatigue was not considered to be as significant a barrier to ongoing exercise adherence as originally anticipated.

'I don't let it get me down, I just get on with things really'
(Jenny – Standard Intervention)

'It is a bit more difficult with the fatigue, but you just have to accept that some days you are going to have more energy and other days everything is going to be a bit more of an effort' (Denise – Enhanced Intervention)

One of the experimental case-series participants suggested that the skills she had developed in relation to planning and pacing her activities actually made it easier to schedule regular sessions in which to complete the prescribed exercise-regime.

'I mean, I didn't really find it difficult to make time for the exercises because I'm quite used to planning my day, because of the fatigue you see'
(Patricia – Enhanced Intervention)

Whilst the physiotherapy practitioners participating in the focus group discussions acknowledged that older people could become more confident in their abilities to undertake an exercise-based falls prevention programme, it was generally felt that fear of falling remained a longstanding issue that was difficult for an older person to overcome. Only one experimental case-series participant discussed their fatigue symptoms within the context of exercise adherence. However, there was an overriding perception amongst the older people with primary biliary cirrhosis that fatigue impacted on fear of falling.

'It's difficult with words to choose the right one. It's not so much confidence but more the fact that I feel really washed out some days and I suppose you could call that confidence if you interpret the term broadly. I wouldn't say I'm not confident in the sense that I'm worried that I might fall. In my case, it's feeling well enough to do things' (Jane – Enhanced Intervention)

'I would say that I gained more confidence because I realized I was fitter, I could move better, and instead of shuffling I could walk better, so that made me feel more confident to do things. The reason why I don't think confidence is going up on the scale is that for a long time I haven't allowed myself to do things, and I think it's because of the fatigue – I'm fearful that I will get into a situation like going out for a walk, get tired, and not be able to get back again' (Denise – Enhanced Intervention)

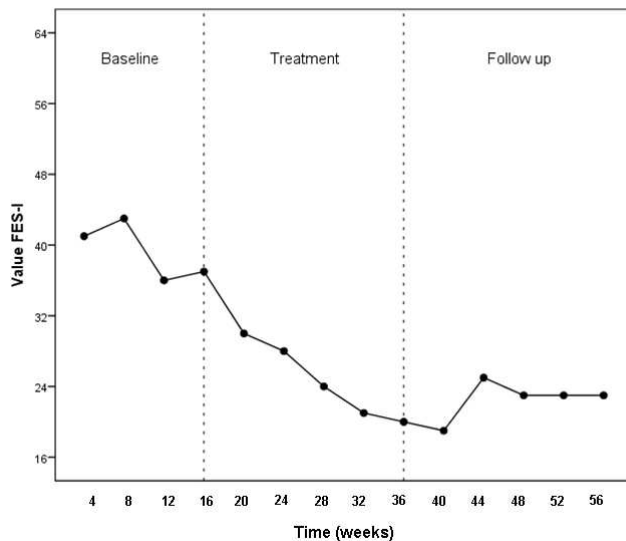
Despite such observations, however, the experimental case-series participants receiving the enhanced intervention indicated that ongoing active participation with an exercise-based falls prevention programme had reduced their fear of falling.

'I think my fear of falling has definitely improved. I wouldn't say completely, but particularly weather-wise and in certain situations, like coming down the stairs. I think overall there has definitely been an improvement'
(Patricia – Enhanced Intervention)

'I think I do feel more confident now. I don't like mud and I don't like ice but I would say I'm confident to do most things'
(Helena – Enhanced Intervention)

The graphical representation of Denise's Falls Efficacy Scale – International scores illustrated in Figure 6.4 demonstrates the reduction in fear of falling (lower score = more confident) reported by many of the older people with primary biliary cirrhosis as a result of participating in the enhanced intervention.

Figure 6.4. Graphical representation of Falls Efficacy Scale – International



Although the experimental case-series participants receiving the enhanced intervention described a number of challenges associated with living with a long-term condition, it was suggested that participating in a home-exercise regime could produce wider health benefits. These had the potential to positively impact on their primary biliary cirrhosis symptoms and encouraged them to develop a long-term active commitment to an exercise-based falls prevention programme.

'The heart specialist said to me "Well, you know, your heart is your biggest muscle and if it's not being fed, then it's not going to work properly, just like the muscles in your arms and legs." And, I mean, I have problems with the mitochondria in my muscles so it's even more important that I keep them working' (Shirley – Enhanced Intervention)

'I personally think that exercise is good for you. I think that it helps with your confidence and, mentally, it's good to have something to focus on. You have to push yourself with fatigue instead of just thinking "Oh, I just can't be bothered" you just need to get up and get it done, and I do think that sometimes exercise can help with fatigue' (Patricia – Enhanced Intervention)

6.5. Theme 2 - Predicting and monitoring uptake and adherence

In an attempt to ensure that the exercise-based falls prevention programmes would be meaningful and relevant to the target population, consecutive patients attending a weekly auto-immune liver clinic at the local hospital were screened to identify those with a history of falls / unsteadiness in the 12 months preceding the experimental case-series. Despite such attempts, however, many of the older people with primary biliary cirrhosis indicated that they had signed up for the programme primarily because it was a research study.

'Well, obviously, I'm always interested in doing research and helping with research' (Patricia – Enhanced Intervention)

'It was the fact that I've taken part in a few other research things. I mean, I don't go out to work anymore so I'm available all the time'
(Jenny – Standard Intervention)

The experimental case-series participants highlighted the opportunistic nature of their recruitment into the study. Even when their decision to take part in the experimental case-series had been influenced by the desire to participate in an exercise-based falls prevention programme, there was the suggestion that the thesis

author and / or older person with primary biliary cirrhosis had simply been in ‘the right place at the right time’.

‘I was asked! I thought I might be excluded because I’d had a liver transplant, even though I’ve still got PBC and it was proven in a liver biopsy’ (Helena – Enhanced Intervention)

‘You caught me on the day I’d been to see about the weakness in my legs’
(Eleanor – Standard Intervention)

This meant that the majority of the experimental case-series participants did not have any personal goals or aspirations regarding the clinical interventions under evaluation prior to commencing the programme.

‘Well, I knew it was research so I didn’t expect to benefit from it personally’
(Jane – Enhanced Intervention)

‘It was just a case of signing up’ (Jenny – Standard Intervention)

For many, the fact that they had committed to the research was the primary reason that they initially adhered to the exercise-based falls prevention programme.

‘I did them because I was committed to doing the research’
(Jane – Enhanced Intervention)

‘Because I had signed up for the study and made a commitment, I felt that I had to see it through’ (Jenny – Standard Intervention)

Despite suggestions in the academic literature that healthcare professionals have an important role to play in supporting individuals with long-term conditions to move through the incremental stages of behaviour change (Burbank et al., 2000), the physiotherapists participating in the focus group discussions often made a simple dichotomous distinction about whether or not an older person would be motivated to participate in an exercise-based falls prevention programme. The older people with primary biliary cirrhosis receiving the enhanced intervention admitted to initial uncertainties regarding the benefits to be gained from participating in an exercise-based falls prevention programme. However, continued participation with the prescribed exercise-regime enabled them to re-evaluate these initial assumptions and to recognize the personal relevance of the home-exercise programmes under evaluation.

'Well, the first meeting I had with you, as I say, I didn't really know what to expect. But when I was first shown the exercises and started off with just those few, you know, those few repetitions, I actually came home and thought "Well, I can't see how these are going to benefit me" because there didn't seem to be the quantity of exercises there to make an impact. It was only after a few weeks that I realized that this was good preventative exercise for everyday use' (Denise – Enhanced Intervention)

'I initially thought some good might come out of it, if not to help me then to help other people, although I did also hope that something might just click for me personally – and it did' (Shirley – Enhanced Intervention)

6.6. Theme 3 - Roles and responsibilities

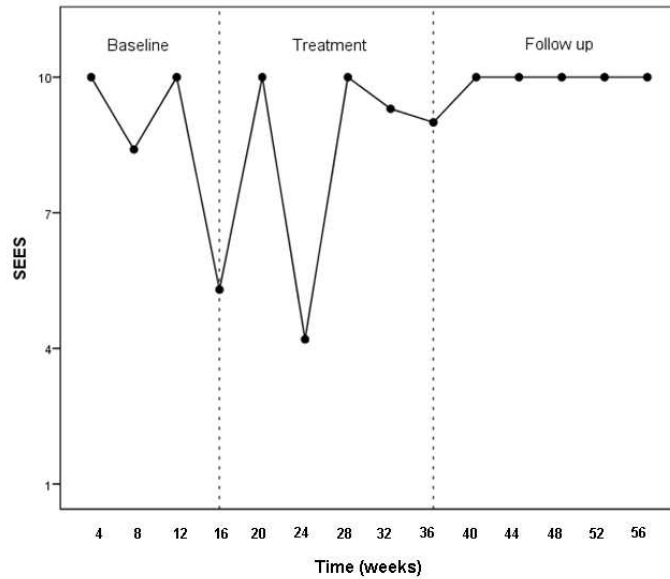
Consistent with the focus group findings, the older people with primary biliary cirrhosis presented themselves as capable and competent. Participants receiving both the standard and enhanced intervention expressed the desire to actively participate in an exercise-based falls prevention programme.

'Once you say you are going to do something, you really ought to do it'
(Dorothy – Standard Intervention)

'I'm a person that if I say I'm going to do something I will do it regardless'
(Helena – Enhanced Intervention)

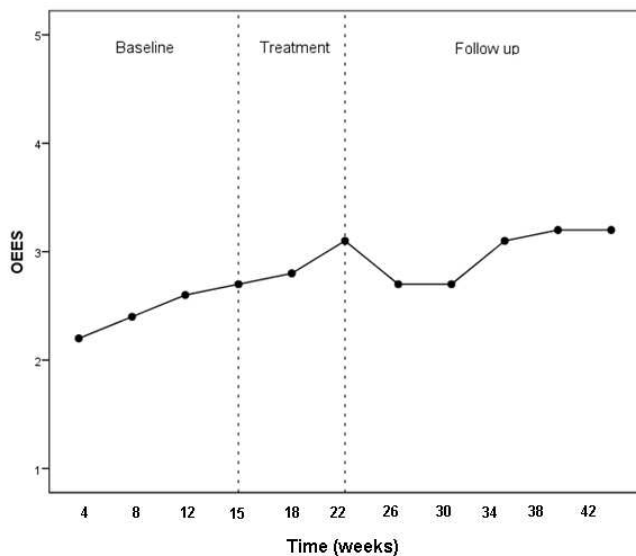
Despite such observations, however, the majority of the experimental case-series participants demonstrated huge fluctuations in their Self-Efficacy for Exercise Scale scores throughout the course of the experimental case-series. In Figure 6.5, Helena's previous and ongoing experience of recreational exercise is reflected in the high levels of self-efficacy demonstrated on commencing and completing of the study. However, her physical health status fluctuated greatly throughout the course of the baseline and treatment quantitative data collection phases, and this was associated with corresponding fluctuations in her Self-Efficacy for Exercise Scale scores.

Figure 6.5. Graphical representation of Self-Efficacy for Exercise Scale



In contrast, however, the experimental case-series participants' Outcome Expectation for Exercise Scale scores tended to remain relatively stable throughout the baseline, treatment and follow up quantitative data collection phases. The graphical representation of Eleanor's Outcome Expectation for Exercise Scale scores illustrated in Figure 6.6 would indicate that she experienced relatively low levels of outcome expectation for exercise throughout the duration of the experimental case-series (higher score = lower outcome expectation for exercise).

Figure 6.6. Graphical Representation of Outcome Expectation for Exercise Scale



Regardless of whether or not their scores fluctuated throughout the baseline, treatment and follow up quantitative data collection phases of the experimental case-series, the older people with primary biliary cirrhosis demonstrating high levels of self-efficacy and outcome expectation for exercise on commencing the study suggested that they found it relatively easy to adhere to the home-exercise programmes under evaluation.

'Exercise, honestly, I would put my life on it, exercise is so important. Even on days when I am feeling really weak or stiff or whatever, I will do a few exercises because if you don't do exercises, your muscles will just get weaker and weaker' (Shirley – Enhanced Intervention)

'I do them in some unusual places. I do the leg ones in church in the pew during the hymns, and things like that! It was no problem for me to do them at home. I was quite happy' (Helena – Enhanced Intervention)

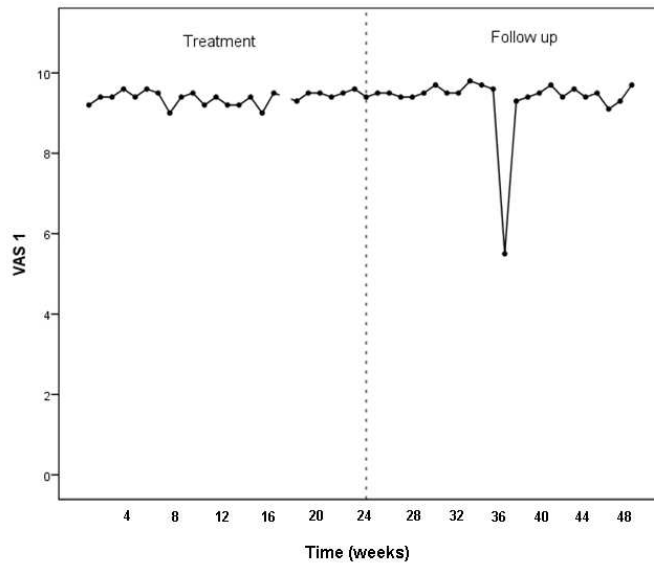
In contrast, however, the experimental case-series participants who demonstrated lower levels of self-efficacy and outcome expectation for exercise on commencing the study found it more difficult to adhere to the prescribed exercise-regime.

'Well, I'm hopeless at self-motivation; I really need to be part of a group. I was more motivated to do the ones I asked for to try and strengthen my legs, but I found doing the exercises on my own very difficult'
(Eleanor – Standard Intervention)

'I had no desire to do the exercises! I found it really difficult to motivate myself to do them at home. I would often do them in the mornings just to get them out of the way, so that I could get on with something else'
(Jane – Enhanced Intervention)

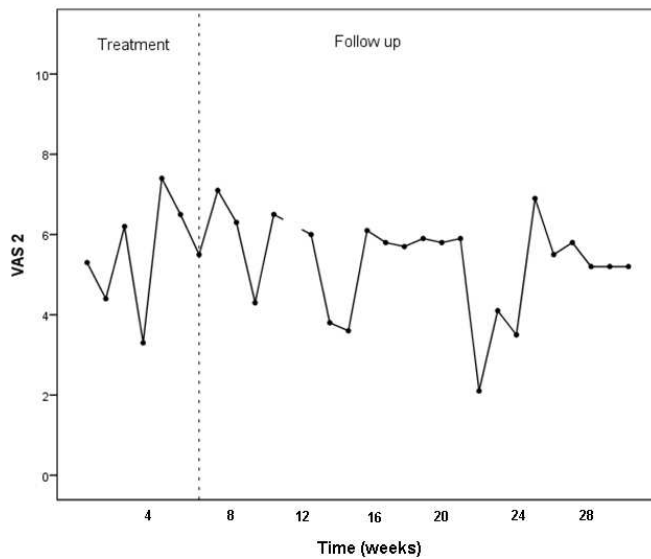
For the purposes of the current study, participants were asked to complete visual analogue scales on a once-weekly basis to indicate their level of agreement with a series of statements based on the central constructs of the social cognition models presented in Section 1.5. Whilst Helena's Self-Efficacy for Exercise Scale scores fluctuated greatly throughout the course of the experimental case-series, the graphical representation of her visual analogue scale based on the central construct of self-efficacy (I feel confident to do my exercises today), illustrated in Figure 6.7 would indicate that she experienced relatively high levels of self-efficacy for the prescribed exercise-regime.

Figure 6.7. Graphical representation of Visual Analogue Scale 1 (I feel confident to do my exercises today)



In contrast, however, the graphical representation of Eleanor’s visual analogue scale based on the central construct of outcome expectation (I am finding the exercise programme beneficial) illustrated in Figure 6.8 would suggest that her belief in the benefits to be gained from completing the prescribed exercise-regime fluctuated greatly throughout the course of the experimental case-series.

Figure 6.8. Graphical representation of Visual Analogue Scale 2 (I am finding the exercise programme beneficial)



In keeping with the focus group findings, the experimental case-series participants suggested that the endorsement of family, friends or influential healthcare professionals impacted on their decision to participate in an exercise-based falls prevention programme.

‘Well, you know, (Eleanor) said she would be willing to do it, and that was good because it meant we could travel in together’
 (Dorothy – Standard Intervention)

‘You came to the clinic and (consultant) said “Are you going to sign up for the exercises with Lisa?” and I said “Yes, I’ve already seen Lisa” so it was good to know that she thought it was a good idea’
 (Patricia – Enhanced Intervention)

One participant indicated that the therapeutic relationship she had developed with the treating clinician provided a valuable source of encouragement and that this promoted ongoing adherence.

'I really enjoyed coming through to the (local hospital) and telling you how I'd been getting on' (Denise – Enhanced Intervention)

Although none of the experimental case-series participants indicated that input from a family member had directly impacted upon their ability to adhere with the prescribed exercise-regime, it was suggested that relatives had an important role to play in supporting older people with long-term conditions to manage their physical activity levels and maintain a sense of positive self-identity.

'Usually we will pop out. We will go to the garden centre or something like that. But when (my husband) was going up to my son's new house everyday to help with the decorating, I didn't have the courage to just put my coat on and go out for a walk' (Denise – Enhanced Intervention)

'If I didn't have (my husband) it would be quite different because he does a lot of the heavy things, but I still do quite a lot – ironing and things like that' (Patricia – Enhanced Intervention)

6.7. Theme 4 - Stakeholder views of local clinical service delivery

During the semi-structured interviews, the experimental case-series participants reflected upon their experiences of being diagnosed with primary biliary cirrhosis.

For many this had occurred at their local district general hospital and was not considered to have been a very informative or empowering experience.

'She said to me "You have a thing called primary biliary cirrhosis, it's nothing to worry about, it just baffles us all!" I think she might have put it in a letter to me now I come to think about it' (Dorothy – Standard Intervention)

'All he could say was "Well, you could walk out of this door and you might die crossing the road!" I mean, what do you think about that?'
(Helena – Enhanced Intervention)

In an attempt to find out more about their condition and to actively manage their symptoms, several of the experimental case-series participants had joined the local patient support group. They described how their experiences of participating in clinical research had encouraged them to transfer to the auto-immune liver clinic for their routine clinical care.

'I wasn't very happy with what was happening (at the local hospital). The Doctor that I was seeing wasn't the sort of person who would give me information, so I spoke to (co-ordinator of local patient support group) and after that I transferred to the (auto-immune liver clinic)'
(Helena – Enhanced Intervention)

'Now as a result of that (Eleanor) said to me "If you have PBC you should go and see a proper liver specialist." So I asked my GP if I could go to the (auto-immune liver clinic) to see (consultant) as I already had a friend going there and he reluctantly said "Yes, I will do a referral". So that was that really' (Dorothy – Standard Intervention)

Whilst delivering exercise-based falls prevention programmes within the fully engaged scenario of specialist services for individuals with long-term conditions may provide the key to promoting long-term active participation, the experimental case-series highlighted the importance of supporting the older people with long-term conditions to overcome denial of personal falls-risk in order to persuade them of the need to undertake specific exercises to improve strength and balance (Whitehead et al., 2006).

'I'm not really one for falling down. Well, I have had a fall in the back garden, but I wouldn't have fallen if I hadn't been so stupid. I put my leg up on a little wall to reach over for something and as I came back I forgot – well I didn't really forget – I didn't lift my foot up high enough and I just kept going, like a train. But I wasn't really falling regularly or feeling unsteady' (Dorothy – Standard Intervention)

'I mean, quite frankly, if I lost my balance and fell down I would think "That's just me, that's just me getting older." I wouldn't think to go and seek advice about it because it's just part of the ageing process. I would never go and ask for treatment because I've been losing my balance and falling down, I just wouldn't you see' (Jane – Enhanced Intervention)

Despite such observations, however, the older people with primary biliary cirrhosis receiving both the standard and enhanced interventions indicated that participating in an exercise-based falls prevention programme had promoted their personal awareness of falls and falls prevention strategies. In keeping with the older people attending the regional falls and syncope service, the experimental case-series participants indicated that they had been pleased to accept the falls prevention advice

and intervention offered and considered it to be a positive and worthwhile experience.

'I thought all these things I was doing – the tripping, weakness in my legs going up stairs – I actually thought they were due to the tiredness of PBC. I mean, I still get tired, I get exhausted. But even when I'm exhausted, I can still use my leg muscles' (Eleanor – Standard Intervention)

'You know, you hear about people falling, but I hadn't really thought about it. I used to say "No, I don't fall" but then I thought about how I was always tripping and (my husband) was always catching me, and when I was in the bath or shower I used to turn around and go "Oops" but, you know, I didn't really associate it with anything until I started filling out the questionnaires, then I would think "Well, yes, I am a bit timid when I have to walk on uneven ground" and things like that' (Denise – Enhanced Intervention)

6.8. Theme 5 - Strategies to promote self-management and adherence

Experimental case-series participants receiving both the standard and enhanced intervention indicated that the exercise-based falls prevention programme could be easily incorporated into their daily routine and, in keeping with the focus group findings, this was felt to play an important role in promoting adherence.

'None of it troubled me, I didn't think "Oh heck, I've got to spend time on this" because it could be done whilst you were doing other jobs'
(Dorothy – Standard Intervention)

'The exercises I found were perfect because I could do them in the bathroom if I was running a bath, or just before stepping into the shower'
(Patricia – Enhanced Intervention)

Opinion was divided amongst the physiotherapy practitioners participating in the focus group discussions regarding how difficult the prescribed exercise-regime should be. Despite such observations, however, only one physiotherapist suggested that the programme should be challenging enough to provide the older person with a sense of personal accomplishment. Whilst the experimental case-series participants receiving the enhanced intervention found the exercise-based falls prevention programme varied and challenging, those participating in the standard intervention indicated that the prescribed exercise-regime had been too easy for them. This was felt to have a negative impact on adherence.

'I think a bit of a challenge is good because you can get a bit complacent, no matter what type of exercise you are doing, and think "Oh well, I know I can do them, so I'll just not bother today" but I thought they were challenging enough, and the variety of exercises was good'
(Shirley – Enhanced Intervention)

'I think at the time they weren't really making much of a difference because they weren't really difficult enough' (Jenny – Standard Intervention)

The physiotherapy practitioners participating in the focus group research suggested that 'an individualized approach' was vital to the success of any clinical intervention. However, whilst the experimental case-series participants receiving the enhanced intervention indicated that the exercise-based falls prevention programme had been tailored to their own specific needs, those receiving the standard intervention suggested that the prescribed exercise-regime had been too generic. This was associated with lower levels of active ongoing participation.

'I wanted something to strengthen my ankles and I understood that that's what they were doing' (Patricia – Enhanced Intervention)

'It wasn't tailored for me, it wasn't tailored for me specifically'
(Eleanor – Enhanced Intervention)

The older people with primary biliary cirrhosis participating in the enhanced intervention recognized that the prescribed exercise-regime had been progressed throughout the course of the treatment phase. Although one of the experimental case-series participants had specifically requested that the nurse delivering the standard intervention issue a more challenging set of exercises, the others followed the same programme throughout the treatment and follow up phases and did not recall being provided with any strategies to progress the home-exercise programme. Again, this was felt to negatively impact on adherence.

'I found that over the weeks and months I could increase, say from 6 to 10, and so I kept going until I had actually doubled the number of repetitions'
(Denise – Enhanced Intervention)

'I didn't think the ones she gave me really gave me any progression, they were too repetitive' (Eleanor – Standard Intervention)

In keeping with the older people attending the regional falls and syncope service, the experimental case-series participants felt that the use of objective outcome measures played an important role in promoting self-management and adherence with an exercise-based falls prevention programme.

'I liked the measures and seeing an improvement. I mean, you know yourself that you are improving, but it just confirms things'
(Dorothy – Standard Intervention)

'I think it's important because if you don't see any improvement, you won't do it. I know myself that I have to have something concrete, I have to see something of benefit' (Helena – Enhanced Intervention)

However, whilst the experimental case-series participants all acknowledged that they experienced difficulties with lower limb muscle weakness, balance and walking, the selected outcome measures were considered too generic and lacked personal relevance for older people with primary biliary cirrhosis.

'Well, that's what I'm saying; I felt that they didn't represent real life enough' (Shirley – Enhanced Intervention)

'But with them being so general I didn't get the feedback I hoped for and that's what I came into the programme for'
(Eleanor – Standard Intervention)

The clinical measures of balance and gait, in particular, were not felt to be challenging enough for older people with primary biliary cirrhosis identified as being at increased risk of falling.

'On reflection they might have been too easy, I mean I didn't find the things you asked me to do particularly challenging' (Jane – Enhanced Intervention)

‘Well, if you asked me to walk across this room and back, whilst I might be a bit wobbly at times, I could do it. But ask me to do it 10, 15 times and there would be a big difference’ (Shirley – Enhanced Intervention)

Graphical representations of the balance and gait components of Jane’s Performance Orientated Assessment of Mobility illustrated in Figures 6.9 and 6.10 demonstrate the ceiling effect experienced by many of the experimental case-series participants. The reduction in her gait score observed during the follow up phase was related to an exacerbation of chronic low back pain.

Figure 6.9. Graphical representation of Performance Orientated Assessment of Mobility (Balance)

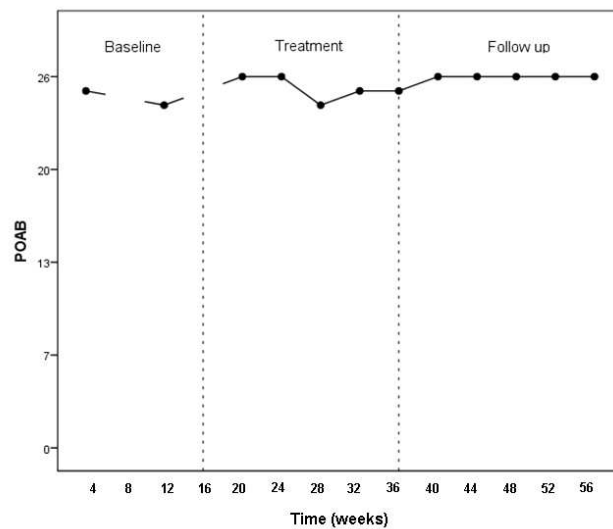
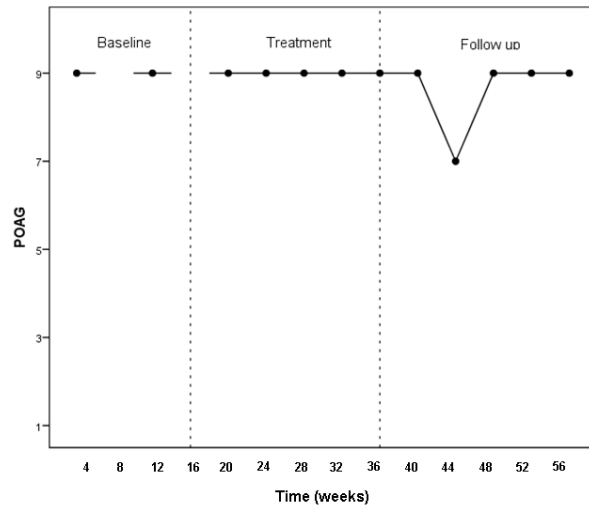
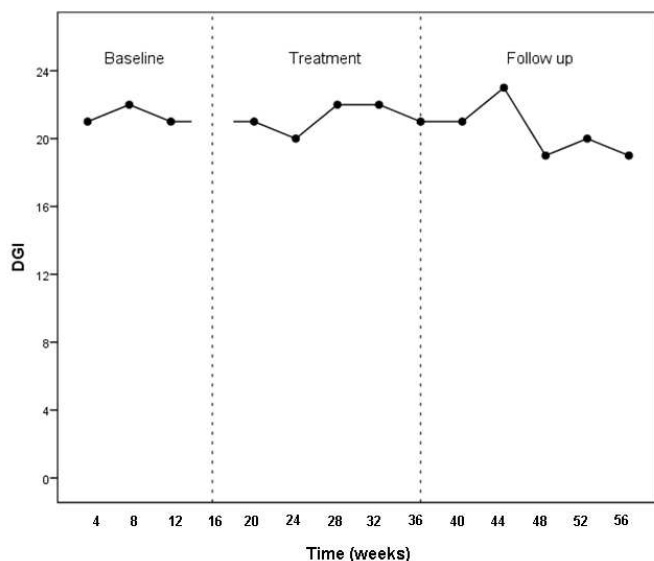


Figure 6.10. Graphical representation of Performance Orientated Assessment of Mobility (Gait)



Although Shirley's Dynamic Gait Index scores fluctuated slightly throughout the course of the experimental case-series, her performance on this measure, illustrated in Figure 6.11, was not felt to adequately reflect the problems she was experiencing with balance and walking.

Figure 6.11. Graphical representation of Dynamic Gait Index



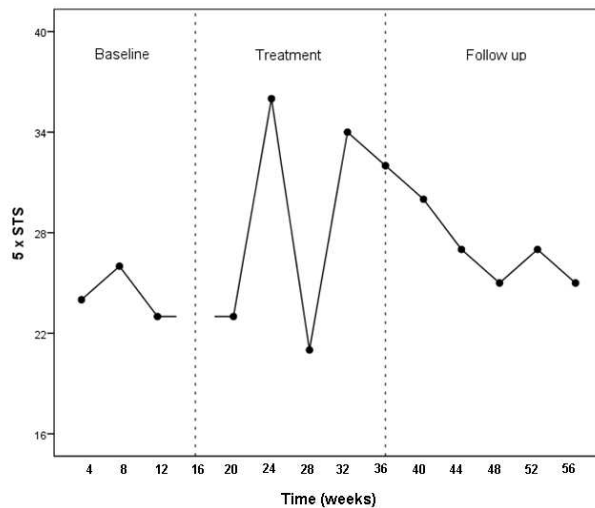
Opinion was divided as to the value of the 5 x Sit-to-Stand measure. One participant was unable to complete 5 sit-to-stands on commencing the study. However, many of the experimental case-series participants felt that more repetitions would be required to adequately capture the problems with abnormal muscle function and fatigue that many people with primary biliary cirrhosis experience.

'Yes, they were definitely challenging enough. I found that when I was doing those stand up and sit down things, that 5 or 6 was definitely as many as I could manage' (Dorothy – Standard Intervention)

'I thought the time that you tested muscle strength for was a bit short. In the real world, I'm lucky if I can walk to the end of the street and back, but get me to walk a short distance and I'm not too bad. And it's the same with the muscles, you know, doing things for a short amount of time is fine, but the longer it goes on....' (Patricia – Enhanced Intervention)

The graphical representation of Patricia's 5 x Sit-to-Stand scores illustrated in Figure 6.12 demonstrates the fluctuations in performance experienced by many of the older people with primary biliary cirrhosis participating in the experimental case-series.

Figure 6.12. Graphical representation of 5 x Sit-to-Stand



To promote objectivity and to reduce the risk of observer bias (Robson, 2002), all measures were collected by an independent assessor at specified data collection points throughout the baseline, intervention and follow up quantitative data collection phases. Although the use of objective outcome measures was felt to play an important role in promoting self-management and adherence, one of the experimental case-series participants commented that the assessment and treatment elements of the clinical intervention did not seem very 'joined up'. It was suggested that not enough time had been devoted to the selected outcome measures, and this was felt to have a negative impact on self-management and adherence.

'I know in my mind which is my weaker side, but in my opinion I felt that there wasn't enough time spent on the measures'
(Shirley – Enhanced Intervention)

Participants receiving both the standard and enhanced interventions suggested that the exercise diaries encouraged them to complete the prescribed exercise-regime. However, in keeping with traditional approaches to clinical service delivery, it would appear that the experimental case-series participants receiving both the standard and enhanced interventions regarded the exercise diaries as a device to monitor and track adherence levels rather than as a strategy to support older people with long-term conditions to play an active role in managing their own treatment programme.

'And because we were given the exercise diaries to fill in, I did the exercises and filled the diaries in' (Jenny – Standard Intervention)

'I was wearying towards the end. I would get the sheets out and put the dates on them in advance of coming to see you' (Jane – Enhanced Intervention)

Opinion was divided as to the value of the visual analogue scales as self-monitoring tools amongst the experimental case-series participants receiving the enhanced intervention.

'I think they helped to focus your mind. You thought about what you were doing more and why you were doing them. I wanted something that was a challenge and I knew I was improving because I could see I was moving further along the line' (Helena – Enhanced Intervention)

'That was the one part I thought was a complete waste of time!'
(Shirley – Enhanced Intervention)

One participant suggested that she preferred a more traditional approach to clinical service delivery, in which the healthcare professional took the lead in establishing what progress had been made with the exercise-based falls prevention programme.

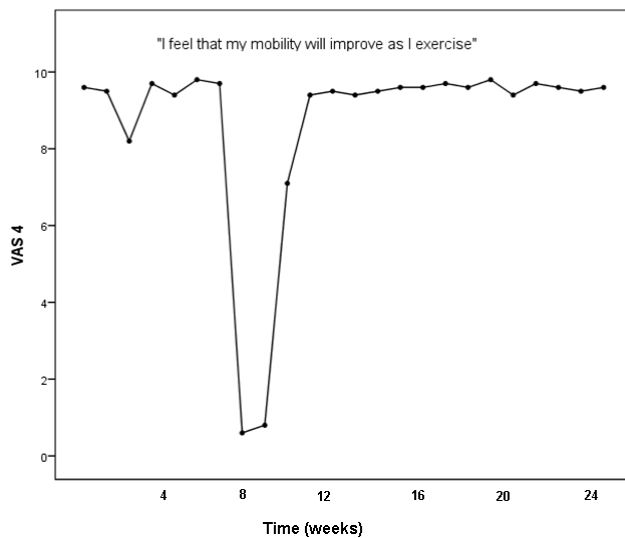
'I would rather somebody just said "How did you get on over the last couple of weeks?" and I could say "Well, I had quite a lot of pain so I didn't do them as often as I should have done." You know a general overview rather than detailed day to day' (Jane – Enhanced Intervention)

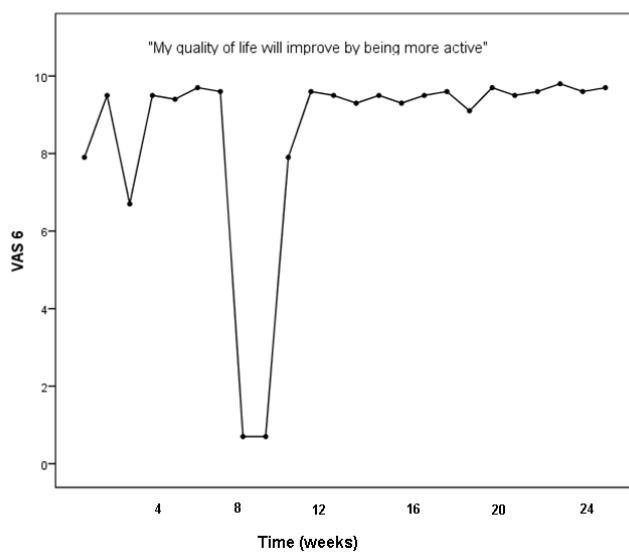
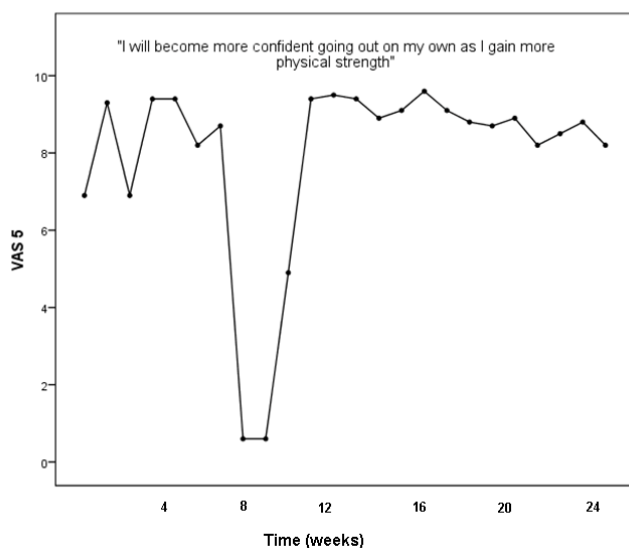
The experimental case-series participants receiving the enhanced intervention were encouraged to use visual analogue scales to set their own goals and targets to promote continued active participation with the exercise-based falls prevention programme during the 6 month follow up quantitative data collection period. However, the older people with primary biliary cirrhosis indicated that they lacked the necessary skills to formally monitor their progress with an exercise-based falls prevention programme on completion of the 6 month treatment programme.

'Actually, I found those the hardest thing to do. One of mine was about going out for walks on my own, and I used to think "Will I ever reach the end of this scale?" I wanted to, but whether it was due to PBC, or tiredness, or mental attitude, every time I came to put that line down I thought I had failed, because I couldn't get to the end of the line. All my life it has always been "I want to achieve this or that" and every time I came to fill that one in I'd think "Why did I choose that one specifically?" I felt committed to it – I couldn't change it but I knew I'd never achieve it'
(Denise – Enhanced Intervention)

As can be seen in Figure 6.13, Denise's visual analogue scales completed throughout the 6 month follow up quantitative data collection phase did not adequately capture the difficulties she experienced setting realistic and achievable personal goals. Denise experienced an upper respiratory tract infection approximately half way through the follow up quantitative data collection phase, and this can be seen to correspond with a decrease in her self-rated scores.

Figure 6.13. Graphical representation of follow up Visual Analogue Scales (Enhanced Intervention)





Although the formal self-management strategies under evaluation had low perceived levels of acceptability, the older people with primary biliary cirrhosis indicated that the duration of the enhanced intervention had enabled them to develop an appreciation of the personal benefits to be gained from participating in an exercise-

based falls prevention programme. These were associated with ongoing active participation.

'I think if you do something quickly you don't absorb things so well, and I think over a longer period it gives you, and it gives the physiotherapist, the chance to iron out any problems' (Denise – Enhanced Intervention)

'I don't think you could have done it in 6 weeks. I don't think you would really have seen any benefit, or very little. You would have learned the exercises but whether it would have given you the impetus to carry on yourself, and to progress, and to see the benefit, I don't know. I think you needed that time' (Patricia – Enhanced Intervention)

The four weeks between appointment times encouraged the experimental case-series participants receiving the enhanced intervention to progress the prescribed exercise-regime and take ownership of the treatment programme.

'I think if I'd come back to see you in a week I honestly don't think that I would have seen any difference in what I was doing because it was something new and it was something I don't normally do. But when I saw you four weeks later I could say "I feel much better and I know my muscles are stronger because I was able to increase the number of repetitions" so that was the most useful part for me' (Denise – Enhanced Intervention)

For those participating in the enhanced intervention, the individualized, challenging and progressive nature of the exercise-based falls prevention programme enabled them to experience a number of functional health benefits over the course of the 6 month treatment programme and, in keeping, with the focus group findings, these were associated with ongoing adherence.

'My mother used to shuffle her feet and I used to say "Pick your feet up" and I noticed that (my husband) was starting to say the same to me! The stairs, I always used to use the handrail, I used to get half way up and think "How am I going to get up there?" and I would haul myself up using my upper body rather than my legs. And if the phone rang, I would really struggle to get up out of the chair to answer it. But after starting the programme, I realized that I was getting up the stairs without the aid of the banister rail, and if the phone rang, I didn't have to haul myself up out of the chair to answer it – it was amazing!' (Denise – Enhanced Intervention)

'Well, I've always had problems with going over on my ankles and it used to be a huge problem, obviously, when I was walking on uneven ground. But since I started the exercises, I still go over on my ankles occasionally, but definitely not as much as before. And I know that my balance has improved, because at my exercise club they told me I could go on the little trampoline. At one point I never would have considered going on that, but now I do!' (Patricia – Enhanced Intervention)

Consistent with the older people attending the regional falls and syncope service, the experimental case-series participants receiving the enhanced intervention demonstrated a long-term active commitment to an exercise-based falls prevention programme on completion of the six month follow up phase.

'I'm the kind of person that if I'm given a job to do I'll stick to it rigidly, so at the start of the 6 month programme you gave me a number of exercises to do and I did them rigidly because I knew I'd be seeing you and that you would expect that I had done them. But I have to tell you that around Christmas I wasn't feeling so hot, so for 2 weeks I didn't do the exercises, and at the end of those 2 weeks I noticed that when I was going up the stairs I was starting to use the rail again. And it just hit me "Yes, this is what happens if you neglect something that is important for the sake of 10 or 15 minutes a day, you will lose all the benefits." So after that I started up again – but it took those 2 weeks of not doing them to realize that I can't not do them, they're part of my life now' (Denise – Enhanced Intervention)

'I would say I do mine at least twice a week – I don't want to lose the muscles I've got!' (Helena – Enhanced Intervention)

6.9. Summary

This chapter has presented the integrated findings of the eight older people with primary biliary cirrhosis who completed the experimental case-series within the wider context of the focus group data and the academic falls prevention and self-management literature. The final chapter of this thesis will consider the focus group and experimental case-series findings further in relation to the framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.

CHAPTER 7. DISCUSSION AND CONCLUSION

7.1. Overview of chapter

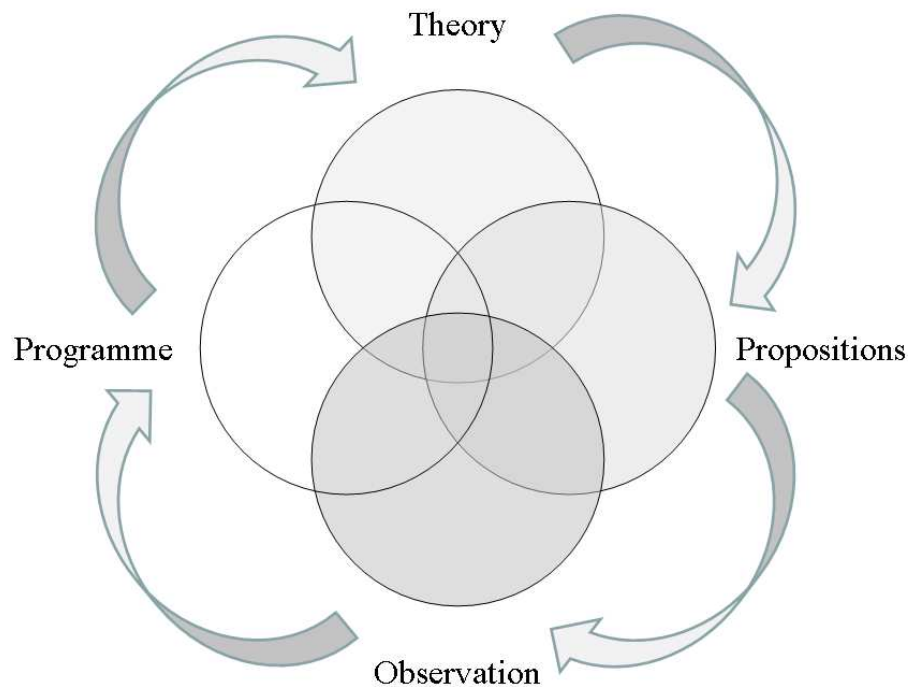
The aim of the current study was to develop a framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition. The final chapter of this thesis will re-examine four key areas necessary for the development and evaluation of complex interventions to improve health (theory, propositions, observation, and programme) in relation to this original research aim to illustrate what the current study has been able to contribute to the knowledge base in each area. The specific implications for research and clinical practice will be discussed and conclusions regarding the overall impact of the work presented. The limitations of the current study will be considered within the context of the methodological and philosophical assumptions underpinning the focus group and experimental case-series research. The chapter will conclude by considering future directions for physiotherapy research and practice.

7.2. A framework for physiotherapy practice

Physiotherapy interventions take place at the interface of the individual and social, where multiple factors and influences are continuously at work (Modell, 2009). In the critical realist worldview, the outcomes of physiotherapy interventions cannot be interpreted in isolation; rather, they can only be explained in the sense of a

mechanism that is introduced to effect change within a constellation of other mechanisms and structures that are embedded within pre-existing historical, economic, cultural and social contexts (Kazi, 2003). Based on a realist effectiveness cycle (Pawson & Tilley, 1997), the framework for physiotherapy practice illustrated in Figure 7.1 promotes a dialectical relationship between research and the realities of routine clinical practice, and permits the practitioner-researcher to not only systematically track outcomes, but also the mechanisms that produce these outcomes, the contexts in which the mechanisms are triggered, and the content of the intervention (or generative mechanisms introduced by the programme).

Figure 7.1. A framework for physiotherapy practice (Adapted from Pawson & Tilley, 1997 p. 85)



Bergman (2011) suggests that the findings of any empirical investigation, whether concerned with structures, processes, or a combination thereof, are influenced by the researcher's theoretical assumptions as well as the research methods employed. The first area of the framework, therefore, is theory which includes propositions of how the mechanisms introduced by a programme into pre-existing contexts can generate particular outcomes. In keeping with the philosophy of critical realism, this process entails a theoretical analysis of the contexts, mechanisms and expected outcomes underpinning the clinical intervention under investigation, using a logic of analogy and metaphor building (McEvoy & Richards, 2003). When developing their theoretical propositions, the framework for physiotherapy practice encourages practitioner-researchers to draw upon prior knowledge of the mechanisms which accounted for the effectiveness, or otherwise, of established interventions in pre-existing clinical contexts (Kazi, 2003; Thorne, 2010). In the current study, clinical experience and a comprehensive review of the academic falls prevention and self-management literature provided a theoretical understanding of the factors influencing uptake and adherence with an exercise-based falls prevention programme that could be refined and elaborated on by the focus group and experimental case-series research.

The second area of the framework is propositions. Based on realist abstraction, these propositions should typically address the following questions:

- What changes will be brought about?

- What social, cultural and other mechanisms in the pre-existing environment would enable these changes?
- What contexts might impinge on these?

To provide an enhanced understanding of why an intervention works, for whom it works, and under what circumstances it works (Wilson & McCormack, 2006), the framework for physiotherapy practice acknowledges that it is often necessary to adopt a theory-building as well as a theory-testing approach (Eisenhardt & Graebner, 2007). In the current study, the theoretical framework of self-management for long-term conditions and a comprehensive review of the academic falls prevention literature led to the development of the theoretical propositions presented in Section 2.4. However, as will be seen in Section 7.2.2, the complexity of the subject matter under evaluation and the iterative nature of the study design meant that it was necessary to revisit and develop these propositions after the focus group and experimental case-series data had been collected and analysed.

The next area of the framework involves the selection of appropriate methods of data collection. Here, the framework for physiotherapy practice encourages practitioner-researchers to select data collection methods that can address the questions raised by the theory, and provide data on the propositions, identified mechanisms, and identified outcomes of the programme. In keeping with realist philosophy, a mixed methods approach is advocated since it is recognized that quantitative and qualitative methods often complement each other (McEvoy &

Richards, 2006). In the current study, quantitative methods of data collection and analysis were employed during the experimental case-series to identify patterns and correlations in the data over time and qualitative approaches to trace the mechanisms responsible for these observations.

The final area of the framework is the actual programme of clinical intervention. This programme may be directed at a single patient, a group, a community, or an entire population (Kazi, 2003). However, unlike disease-based approaches to clinical service delivery, the framework for physiotherapy practice enables the practitioner-researcher to identify the active ingredients of an intervention and to tailor these mechanisms to the needs, preferences and personal circumstances of each individual patient. For the purposes of the current study, the opposing views and standpoints of local stakeholder groups were combined with an experimental exploration of alternative approaches to clinical service delivery. These were used to develop an enhanced understanding of the mechanisms impacting upon self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.

A cyclical approach is advocated to emphasize that, unlike in the natural sciences, knowledge acquisition in applied health research is never static and understood to be temporary and situational (Thorne, 2010). The findings in a critical realist investigation are composed of outcome patterns which reflect the practitioner-researcher's current understanding of the mechanisms and contexts shaping the phenomenon under investigation (Appleton & King, 2002). From a critical realist

perspective, there can be no *a priori* assumption that a scientific endeavour could ever come to an end (Kazi, 2003). As one phenomenon is explained by a deeper level of understanding, that deeper layer itself becomes a new phenomenon requiring explanation. Equally, as deeper layers are also resolved and understood, the knowledge gained necessitates practitioner-researchers to continually revise their understanding of the original phenomenon. In this way, science is seen to proceed through a constant cycle of discovery, understanding, further discovery, revision, and, hopefully, more adequate levels of understanding (Patomaki & Wight, 2000).

Upon completion of the clinical intervention, the framework for physiotherapy practice encourages practitioner-researchers to continue the cycle – extending the theoretical propositions based on the explanatory evidence gathered thus far, developing the data collection methods and applying them more appropriately. This enables the clinical intervention to be delivered more effectively. The practitioner-researcher is then directed to re-examine their evolving theoretical understanding of the phenomenon under investigation, thus continuing the cycle. It is this iterative between conceptualizing and testing that characterizes knowledge processes within the routine clinical practice of the healthcare professional (Thorne, 2010).

Whilst highly inter-related, each of the four areas illustrated in Figure 7.1 will be considered separately within the context of the current study and the wider academic literature to illustrate how the focus group and experimental case-series findings stimulated the retroductive reasoning that led to the development of the framework for physiotherapy practice, and to demonstrate the framework's ability to empower

older people at risk of falling and physiotherapy practitioners to work in collaboration to challenge established approaches to clinical service delivery.

7.2.1. Theory

The National Institute for Health and Clinical Excellence (2007) recommend that all behavioural change interventions should be developed and evaluated using an established model, such as the Medical Research Council framework for the development, evaluation and implementation of complex interventions to improve health. This ensures that they are based on the best available evidence of feasibility, acceptability, safety, effectiveness and efficiency. The design of this study was informed by a version of the Medical Research Centre guidelines which advocates a less linear approach to clinical service evaluation (Campbell et al., 2007). However, rather than focussing on the exploratory work preceding a definitive randomized controlled trial, the findings from the current study were used to develop the theoretical propositions set out in Section 2.4 and stimulated the retroductive reasoning that led to the framework for physiotherapy practice illustrated in Figure 7.1. This novel interpretation and application of the Medical Research Council guidelines provided a robust framework within which to develop an enhanced theoretical understanding of the complexities surrounding self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.

Critical realists believe that progress is possible because the intransitive nature of reality (enduring structures and processes) provides a point of reference against which theories can be tested (Patomaki & Wight, 2000). However, it is not possible to fully comprehend this reality as our perceptions are shaped by our theoretical resources and investigative interests (Kazi, 2003). Examining the concept of self-management from a political, psychosocial and biomedical perspective in the early stages of this study led to the identification of a number of historical, economic, cultural and social paradoxes inherent in modern healthcare delivery. These inconsistencies provided a theoretical lens through which to critically review the academic falls prevention literature, and resulted in a completely new interpretation of the existing data that could be refined and elaborated on by the focus group and experimental case-series findings.

Much of the discussion surrounding self-management in contemporary healthcare is based on a model of empowerment, in which older people with long-term conditions are considered equal partners in the clinical decision-making process (Holmstrom & Roing, 2010). However, within falls prevention, healthcare professionals have traditionally adopted an actuarial approach to clinical service delivery (Rubenstein, 2006; Swift, 2006). Despite the publication of clinical guidelines to promote the engagement of older people in activities to prevent falls (Yardley et al., 2007), there is little indication that researchers and healthcare professionals are currently supporting older people at risk of falling and their family members to play a major role in determining what types of interventions are relevant and what kinds of outcomes are desirable (Gzil et al., 2007).

Participatory research aims to empower participants to instigate changes at a local level (Appleton & King, 2002). However, it has been suggested that traditional interpretivist approaches often fail to address the centrality of power, both within physiotherapy itself and between physiotherapy contexts and the wider social and political domains that influence and constrain the discipline (Clare, 2003). Provisional analysis of the focus group findings revealed opposing views and standpoints on the part of older people at risk of falling and local physiotherapists. The older people attending the regional falls and syncope service were motivated to participate in an exercise-based falls prevention programme to remain independent in activities of daily living. They valued strategies that promoted self-management and self-efficacy. In contrast, however, the physiotherapy practitioners suggested that many of the older people they came into contact with were poorly motivated to participate in an exercise-based falls prevention programme. Whilst it was acknowledged that older people should be encouraged to play a more active role in the management of long-term conditions, local physiotherapists demonstrated a conflicting desire to remain in control of the treatment programme.

Clinical encounters between older people with long-term conditions and healthcare professionals provide a critical juncture for the exchange of information to promote patient empowerment and participatory decision-making (Finset, 2008). However, it has been suggested that, all too often, healthcare professionals assume the language of empowerment, including statements that patient participation in treatment decisions is welcome, whilst at the same time behaving in a manner that implies professional dominance (Mead & Bower, 2000). On initial viewing, the focus group

findings would appear to support these observations. However, the alternative insights provided by the older people and relatives contributing to the design and execution of the focus group research enabled the thesis author to adopt a more critically reflexive stance to the data obtained. It is suggested that failure to appreciate the benefits experienced by older people with a long-term condition as a result of participating in clinical interventions, such as exercise-based falls prevention programmes, has led to a sense of poor job satisfaction and professional apathy amongst healthcare practitioners. This, together with a degree of professional arrogance, may be contributing to the paradoxes observed in the academic literature.

Practitioner-researchers employed in applied health research need to be conscious of the constraints acting upon individuals within organizations, such as the National Health Service, since an enhanced understanding of the challenges healthcare professionals face can empower them to respond, where appropriate, with practice changes (Wilson-Thomas, 1995). Towards the end of the focus group discussions, the physiotherapy practitioners began to re-evaluate their original assumptions regarding self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition. Although they demonstrated a limited awareness of the role of social cognitive factors in predicting and monitoring uptake and adherence, it was suggested that ongoing active participation with an exercise-based falls prevention programme should be viewed as a form of behaviour change.

Applied health researchers study a phenomenon because they are bound by a moral code requiring them to try and solve them. If a tentative idea proposed within a qualitative research conclusion rings true as a plausible explanation for a clinical problem that has been difficult to grasp conceptually, Thorne (2010) argues that it should be taken up immediately and tested for its utility. Whilst not automatically transferable to other patient groups, the methodological and philosophical assumptions underpinning the current study meant that it was possible to successfully combine the primary qualitative data obtained from the focus group research with a comprehensive review of the academic falls prevention and self-management literature to develop a novel approach to the delivery of exercise-based falls prevention programmes that could be tested and refined in the experimental case-series.

In the context of an ageing population, increasing numbers of older people with long-term conditions are presenting to secondary healthcare facilities having experienced a fall or fall-related injury (Newton et al., 2000). Despite such observations, however, falls and long-term conditions have traditionally been considered as entirely separate entities. It has been suggested that significant events or transition points in people's lives, such as being diagnosed with a long-term condition, may provide an opportunity for behaviour change because it is then that individuals often re-evaluate their own behaviour and have the necessary contact with healthcare professionals to be supported through the incremental stages of behaviour change (National Institute of Health and Clinical Excellence, 2007). Although identified as being at increased risk of falling, older people with primary

biliary cirrhosis had not previously had access to an exercise-based falls prevention programme in the local region. It was with this novel population of older people with a long-term condition that the thesis author chose to test and refine acceptable strategies to promote self-management and adherence. In this way, the views and experiences of the older people, relatives and physiotherapy practitioners participating in the focus group research had a direct impact on local clinical service delivery.

Sackett et al (1996) have suggested that it is when asking questions about complex interventions, such as exercise-based falls prevention programmes, that we should try to avoid traditional experimental approaches, since they often lead to false-positive conclusions about treatment efficacy. Critical realists recognize that it is not only the clinical intervention that works, but the individuals prescribing and participating in these interventions choosing to make them work (Robson, 2002). Despite the growing body of research evidence from systematic reviews and meta-analyses to support the efficacy of exercise-based falls prevention programmes, uptake and adherence rates continue to vary greatly. Conducting further randomized controlled trials may, therefore, prove prohibitively expensive and tell us little more than we already know (McEvoy & Richards, 2003).

The logic that underpins critical realism is called retroduction. This process involves moving from the level of lived experience to postulate about the underlying structures and mechanisms which may account for the phenomena involved (Mingers, 2003). For critical realists, deductive methods (based on testing specific

hypotheses) and inductive methods (based on the formulation of general inferences) are necessary but insufficient for theory generation without retroductive reasoning (Patomaki & Wight, 2000). As will be seen in subsequent sections, undertaking the process of retroductive reasoning meant that it was possible to consider the focus group and experimental case-series findings in parallel within the wider context of the academic falls prevention and self-management literature to develop an enhanced understanding of the mechanisms that make exercise-based falls prevention programmes effective (and less effective) in particular contexts.

7.2.2. Propositions

Most clinical investigations are one-off affairs, which neither look back and build on previous findings nor look forward to future evaluations (Pawson & Tilley 1997). However, for practitioner-researchers the truly exciting questions are always complex and inherently messy (Thorne, 2010). Theory is used in different ways in applied health research: to help scaffold our inquiries within the knowledge traditions that have attempted various understandings of the entity we are studying; and to help deconstruct our initial assumptions about why we make the data-based observations we do, and the alternative ways in which these might be interpreted (Morse, 2004). For this reason, Robson (2002) acknowledges that a series of studies may be required to progressively refine and develop the research processes and outcomes under evaluation. This section will revisit the theoretical propositions presented in Section 2.4 within the context of the focus group and experimental case-series findings to demonstrate how the primary research presented in this thesis

has contributed to the knowledge base surrounding self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition in order to provide future directions for physiotherapy research and practice.

7.2.2.1. From polite compliance to personal relevance

Theoretical proposition 1: Established models of clinical service delivery that focus on the short-term reduction of physical falls-risk are not compatible with older people's sense of positive self-identity, leading to low levels of uptake and adherence.

In their systematic review and meta-analyses of effective exercise interventions for the prevention of falls, Sherrington et al (2008) suggest that the criterion for a minimally effective dose equates to a twice weekly exercise-based falls prevention programme running over 25 weeks. In reality, however, many clinical departments are providing services to patients with limited resources and it is often not possible to provide regular contact from a healthcare professional over such a prolonged time period. In an attempt to incorporate research evidence into routine clinical practice, the majority of older people in the local region are currently offered an exercise-based falls prevention programme averaging only 6 weeks in duration with once-weekly review by a physiotherapist or healthcare assistant. Older people are then instructed to continue with this programme on discharge from the service. During the focus group research, local physiotherapists acknowledged that they often found

it difficult to support older people at risk of falling to develop an ongoing active commitment to an exercise-based falls prevention programme. Despite such observations, however, these practitioners had not previously questioned or challenged existing approaches to local clinical service delivery.

The standard intervention delivered within the context of the experimental case-series was based on usual clinical practice, and was composed of 6 x once-weekly visits to a research nurse at the local hospital. The older people with primary biliary cirrhosis receiving the standard intervention completed the exercise-based falls prevention programme as instructed throughout the treatment and follow up quantitative data collection phases. However, none of these individuals continued to follow the prescribed exercise-regime on completion of the study. During the follow up interviews, the older people receiving the standard intervention indicated that they had signed up for the experimental case-series primarily because it was a research study or because a medical practitioner they respected had recommended it, not because they expected to achieve any personal benefit as a result of their participation. These observations are in keeping with the learned behaviour of 'polite compliance' (Walker et al., 2011 p. 24) described in the opening chapter of this thesis.

Whilst observed within the context of the experimental case-series, parallels can be drawn with routine clinical practice. It has been suggested that viewing the assessment of falls-risk as a professional and technical task which is the preserve of experts has contributed to a conservative approach to clinical service delivery in

which patient-initiated activity is seen as challenging and potentially dangerous (Ballinger & Payne, 2002). The physiotherapy practitioners participating in the focus group research acknowledged that, within existing models of clinical service delivery, it was often difficult for themselves and their patients to appreciate the benefits of participating in an exercise-based falls prevention programme. These findings may help to explain the physiotherapy practitioners' sense of poor job satisfaction and professional apathy, and the low levels of uptake and adherence with an exercise-based falls prevention programme reported in the academic literature and witnessed in routine clinical practice.

When encouraged to reflect upon their experiences of participating in the experimental case-series, the older people receiving the standard intervention suggested that the home-exercise programme had not been sufficiently tailored to address the difficulties they were experiencing with lower limb muscle weakness, balance or walking. This meant that the exercise-based falls prevention programme lacked personal relevance for the older people receiving the standard intervention. Although one participant had requested that the research nurse issue a more challenging set of exercises, the others had followed the same programme throughout the course of the treatment and follow up quantitative data collection phases and did not recall being provided with any strategies to progress the prescribed exercise-regime. For this reason, the older people with primary biliary cirrhosis receiving the standard intervention did not perceive that they had any ownership of the treatment programme.

The transtheoretical or stages of change model (Prochaska & DiClement, 1983) is based on the premise that an individual will move through a series of five stages (pre-contemplation; contemplation; preparation; action; and maintenance) when attempting to change their behaviour. Movement through these stages may occur in a linear fashion. However, more commonly, individuals are observed to move through these stages repeatedly, in a cyclical manner, entering and leaving the continuum at varying points before maintenance is finally achieved (Burbank et al., 2000). Despite suggestions in the academic literature that healthcare professionals have an important role to play in supporting older people to move through the incremental stages of behaviour change, the physiotherapy practitioners participating in the focus group research often made a simple dichotomous distinction about whether or not an older person would be motivated to participate in an exercise-based falls prevention programme. Their lack of appreciation of social cognitive factors in predicting and monitoring uptake and adherence meant that the majority of local physiotherapists claimed to be able to identify which older people would be motivated to participate in a home-exercise programme during the initial clinical practice encounter.

The enhanced intervention delivered within the context of the experimental case-series was based on the thesis author's current clinical practice at the regional falls and syncope service, and was composed of 6 x four-weekly visits to a physiotherapist at the local hospital. The older people with primary biliary cirrhosis receiving the enhanced intervention also completed the exercise-based falls prevention programme as instructed throughout the treatment and follow up

quantitative data collection phases. However, four of these individuals continued to carry out the prescribed exercise-regime at least 3 - 4 x weekly on completion of the study. Whilst the older people participating in the enhanced intervention admitted to initial uncertainties regarding the personal benefits to be gained from participating in an exercise-based falls prevention programme, the longer duration of the enhanced intervention enabled them to re-evaluate these initial assumptions and to recognize the personal relevance of the exercise-based falls prevention programmes under evaluation. The four weeks between appointment times encouraged the older people with primary biliary cirrhosis to progress their prescribed exercise-regime and take ownership of the treatment programme. The progressive, targeted and challenging nature of the home-exercise programme enabled the experimental case-series participants receiving the enhanced intervention to experience a number of secondary health benefits, and these were associated with ongoing active participation.

Prochaska et al (1992) have demonstrated that the amount of progress people make with a programme is directly related to the stage they were at prior to commencing the initiative. In keeping with the observations of Rollnick et al (1993), it would appear that the majority of older people accessing exercise-based falls prevention programmes in the local region are in the contemplation stage, where ambivalence is a central problem. The current study has demonstrated that longer periods of clinical intervention are necessary to encourage older people with long-term conditions to move from polite compliance to personal relevance as they are supported through the incremental stages of behaviour change.

7.2.2.2. From self-efficacy to self-realization

Theoretical proposition 2: Practical self-management strategies, based on the central constructs of social cognition models, have the potential to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.

It is now widely recognized that effective self-management support needs to address an individual's confidence (self-efficacy) in their ability to manage specific activities rather than simply convincing them of the value of these activities (Lau-Walker & Thompson, 2009). Self-efficacy and outcome expectation are central constructs of social cognition theory upon which many of the current programmes aimed at promoting self-management for individuals with long-term conditions are derived, and these variables played an integral role in developing an enhanced understanding of the factors influencing self-management and adherence with an exercise-based falls prevention programme within the context of the current study.

Enhancing self-efficacy is one strategy that has been found to be effective as a means of increasing activity participation following a fall (Cheal & Clemson, 2001). Despite such observations, however, the physiotherapy practitioners participating in the focus group research indicated that low self-efficacy was a major barrier to ongoing exercise adherence. Whilst it was acknowledged that an older person could become more confident in their abilities to undertake an exercise-based falls prevention programme, local physiotherapists suggested that fear of falling was a

longstanding issue that was often difficult for an older person to overcome. In contrast, however, the older people participating in the focus group research demonstrated high levels of self-efficacy when describing their experiences of participating in an exercise-based falls prevention programme. Whilst the local physiotherapy practitioners perceived that physical conditions (such as pre-existing musculoskeletal pain) reduced adherence, the older people attending the regional falls and syncope service demonstrated an ongoing commitment to home-exercise in the face of these potential barriers.

Self-efficacy is important to understand within the context of contemporary healthcare delivery because it has proved amenable to clinical intervention (Gallagher et al., 2008). Self-efficacy beliefs determine the initial decision to perform a given behaviour, the effort to be expended, and persistence in the face of adversity (Bandura, 1997). Whilst it has been suggested that older people may reject falls prevention advice because it emphasizes the negative social consequences of falling that many older people fear (Kingston, 2000), the older people participating in the focus group research indicated that attending the regional falls and syncope service had led to feelings of enhanced self-efficacy.

The older people with primary biliary cirrhosis participating in the standard and enhanced interventions demonstrated large fluctuations in their Self Efficacy for Exercise Scale scores throughout the course of the experimental case-series. However, the exercise diary and follow up interview data would indicate that the experimental case-series participants who demonstrated higher levels of self-efficacy

and outcome expectation on commencing the study found it easier to adhere to the prescribed exercise-regime than those with lower self-efficacy and outcome expectation scores. These findings would suggest that self-efficacy and outcome expectation have an important role to play in predicting and monitoring initial uptake and adherence with an exercise-based falls prevention programme. Despite such observations, however, higher levels of self-efficacy and outcome expectation were not associated with continued exercise adherence on completion of the study.

Although the evidence evaluating the use of social cognition models was found to be inconsistent, the National Institute for Health and Clinical Excellence (2007) recommended that a number of concepts drawn from the psychological literature may be helpful when planning work on behaviour change at an individual level. In addition to self-efficacy and outcome expectation, these include: personal relevance; positive attitude; intention formulation and concrete plans; behavioural contracts; and relapse prevention. The experimental case-series participants developed a range of strategies and behaviours throughout the course the enhanced intervention which enabled them to develop an appreciation of the personal benefits to be gained from participating in an exercise-based falls prevention programme. Whilst their Self-Efficacy for Exercise Scale scores fluctuated greatly throughout the course of the experimental case-series, these strategies encouraged the older people with primary biliary cirrhosis receiving the enhanced intervention to develop an ongoing active commitment to an exercise-based falls prevention programme on completion of the study.

During the follow up interviews, one of the older people with primary biliary cirrhosis receiving the enhanced intervention described how she had initially attributed difficulties with lower limb muscle weakness, balance and walking to the fatigue associated with primary biliary cirrhosis. Although she admitted to initial uncertainties regarding the benefits to be gained from undertaking an exercise-based falls prevention programme, ongoing participation enabled her to experience a number of functional health benefits. Whilst demonstrating relatively low levels of self-efficacy for exercise throughout the course of the experimental case-series, these benefits encouraged her to continue to participate in the home-exercise programme on completion of the study. Despite such observations, however, it was only when she experienced a period of ill health and was unable to complete the prescribed exercise-regime that she truly appreciated that problems with lower limb muscle weakness, balance and walking were remediable through targeted exercise. This self-realization encouraged her to take greater responsibility for ensuring that she maintained the functional health benefits achieved during the experimental case-series.

Self-management is more than simple adherence with treatment guidelines. In addition it incorporates the psychological and sociological implications of living with a long-term condition (Newman et al., 2004). Whilst it would appear that self-efficacy and outcome expectation play an important role in encouraging older people with long-term conditions to adhere to a prescribed exercise-regime, the current study has demonstrated that self-management support should focus on developing a wider range of strategies and behaviours based on the central constructs of social

cognition models to encourage older people with long-term conditions to appreciate the importance of continued exercise participation.

7.2.3. Observation

Increasingly, applied health researchers are required to strategically focus their efforts on targeting the serious gaps left by experimental approaches which focus on quantitative measures, such as reduction in falls-rate and falls-risk, by attempting to integrate inductively-derived insights with those that can be captured numerically (Thorne, 2010). It has been suggested that physiotherapists are tolerant of combining research traditions, largely because of the perceived congruence with the recording of subjective and objective information during the clinical practice encounter (Wiles & Barnard, 2001). However, to apply mixed methods research effectively within a diverse culture such as the National Health Service, it is essential for practitioner-researchers to also possess a sound understanding of the ontological, epistemological and methodological foundations underpinning these different philosophical positions.

Perceptions of independence in the academic literature tend to focus on the ability to function unaided (Secker et al., 2003), and this is reflected in the measures used by physiotherapists to assess and monitor older people at risk of falling. The older people with primary biliary cirrhosis participating in the experimental case-series all experienced difficulties with lower limb muscle weakness, balance and walking. However, this was not evident in the measures selected, many of which

demonstrated a ceiling effect and lacked personal relevance for the patient group under investigation. Despite such observations, however, the methodological and philosophical principles underpinning the current study enabled the graphical representations of the selected measures to be considered within the context of the experiential narratives of the experimental case-series participants to develop an enhanced understanding of the factors influencing self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.

The older people with primary biliary cirrhosis participating in the experimental cases-series completed the PBC-40 at four-weekly intervals throughout the baseline, treatment and follow up quantitative data collection phases. Whilst this measure provided a valuable insight into participants' self-perceived health status and quality of life, the experimental case-series participants suggested that they often found it difficult to separate their primary biliary cirrhosis symptoms from their co-existing physical health problems. In contrast to the older people attending the regional falls and syncope service, these were considered to have an impact on the experimental case-series participants' ability to adhere to an exercise-based falls prevention programme. Despite such observations, however, the older people with primary biliary cirrhosis receiving the enhanced intervention indicated that participating in a home-exercise programme could produce wider health benefits. These had the potential to positively impact on their primary biliary cirrhosis symptoms and encouraged them to develop an ongoing active commitment to an exercise-based falls prevention programme.

Although fatigue was not found to be as significant a barrier to exercise adherence as originally anticipated, the experimental case-series participants indicated that their fatigue symptoms impacted on fear of falling. This was evident in their performances on the Falls Efficacy Scale – International throughout the course of the baseline, treatment and follow up quantitative data collection phases. The follow up interviews highlighted the importance of supporting older people with primary biliary cirrhosis to overcome denial of physical falls-risk in order to persuade them of the need to undertake specific exercises to improve strength and balance. Despite such observations, however, the experimental case-series participants receiving the standard and enhanced interventions indicated that participating in an exercise-based falls prevention programme had increased their personal awareness of falls and falls-prevention strategies. Although the experimental case-series participants' perceived reduction in their fear of falling was not always reflected in their Falls Efficacy Scale – International scores, it was suggested that this measure had promoted awareness of the functional difficulties experienced by older people with primary biliary cirrhosis identified as being at increased risk of falling. These findings would suggest that, when used within the context of personal goal setting, such measures may have a role to play in promoting self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition.

For many older people living with long-term conditions, variations in the patterns of disease progression and treatment with questionable outcomes create uncertainties about prognosis. The key to effective management is to understand the patterns in

the disease process and the pace of these trends. The goal is not cure, but maintenance of quality of life and independent living (Holman & Lorig, 2000). Although the selected outcome measures had low levels of personal relevance and perceived acceptability for older people with primary biliary cirrhosis, presenting the experimental case-series participants with the graphical representations of their selected outcome measures during the follow up interviews provided a valuable opportunity for guided self-reflection (Roe et al., 2008).

One of the resources identified as necessary for participatory-decision making is time (Paterson, 2001). The process of guided self-reflection provided the experimental case-series participants with an opportunity to articulate and evaluate their experiences of participating in an exercise-based falls prevention programme. Whilst readily available as part of the clinical practice encounter, such insights are characteristically lost within health services research because there is no commitment or mechanism to capture these narratives within the dominant positivist methodologies. Although self-monitoring support may have an important role to play in promoting self-management and adherence, the current study has also highlighted the importance of clinically-relevant outcome measures and ongoing professional support in encouraging older people with long-term conditions to develop an ongoing active commitment to an exercise-based falls prevention programme.

7.2.4. Programme

The older people participating in the focus group and experimental case-series research cited ‘maintenance of independence’ as their main reason for choosing to participate in an exercise-based falls prevention programme. These findings would support observations in the academic literature that older people may respond more favourably to health promotion messages about healthy ageing than to warnings about falls-risk and injury prevention (Yardley et al., 2007), and undoubtedly have the potential to inform the development of clinical interventions that are more in keeping with an older person’s sense of positive self-identity (Ballinger & Payne, 2002). However, if healthcare professionals are to support older people with long-term conditions to develop an ongoing active commitment to exercise-based falls prevention programmes, it is important to also identify the mechanisms and contexts most likely to actualize the ‘subjectively self-assessed lived experience’ (Secker et al., 2003 p. 375) of independence, and the potential barriers which may prevent their activation.

Although it is now widely recognized that up to half of injurious falls occur in those who are not very old or unwell, but amongst older people who remain active despite some decline in their balance capabilities (Stel et al., 2003; Wijlhuizen et al., 2008), clinical services in the local region continue to target frailer older people with significant co-morbidities and high levels of functional impairment. It has been suggested that health promotion specialists and clinical services work together to produce the at-risk individual and that this is achieved through the willing

participation of older people, who view it as their moral obligation to participate in the maintenance of their own health (Ballinger & Payne, 2002). By focussing on the short-term reduction of physical falls-risk in domiciliary and day hospital facilities, local clinical services have contributed to the stereotypical view of an older person at risk of falling as someone over the age of 80 with ill health or poor mobility (Walker et al., 2011) commonly portrayed in the academic literature. It is perhaps not surprising, therefore, that the physiotherapists participating in the focus group research described a number of physical, psychological and environmental barriers to successful exercise participation.

Despite such observations, however, local physiotherapy practitioners positioned themselves as experts in assessing and managing risk factors for falling. It has been suggested that, within the dominant models of clinical service delivery, healthcare professionals diagnose and treat the problem whilst the individual is considered the source of the problem and deemed responsible if the clinical intervention is unsuccessful (Sabate, 2003). During the focus group discussions, there was a perception that older people would participate in an exercise-based falls prevention programme purely out of a desire to please the prescribing physiotherapist. Many of the physiotherapists responded to older people's decision to reject falls prevention advice as a challenge to their professional ability and authority rather than an alternative perspective about risk and safety (Ballinger & Payne, 2002). This was most evident amongst the recent physiotherapy graduates who were, perhaps, still developing confidence in their professional clinical role.

Open and immediate online access to health information has reshaped the boundaries between healthcare professionals and older people with long-term conditions (Thompson et al., 2009). The older people attending the regional falls and syncope service and auto-immune liver clinic represented a novel population of fitter, more-able older people. Whilst identified as being at increased risk of falling, these individuals do not meet the referral criteria of established clinical services and would previously have found it difficult to gain access to an exercise-based falls prevention programme in the local region. Rehabilitation has been defined as ‘the whole process of enabling and facilitating the restoration of the disabled person to regain optimal functioning (physically, socially and psychologically) to the level she / he is able, or motivated, to achieve’ (Waters & Luker, 1996 p. 107). Some patients may not choose to take responsibility for their health and professionals need to value their right to choose (Hughes, 2004). Although one of the experimental case-series participants receiving the enhanced intervention suggested that she preferred a more traditional approach to clinical service delivery in which the healthcare professional took the lead in establishing what progress had been made with a prescribed exercise-regime, the majority of older people attending the falls and syncope service and auto-immune liver clinic expressed the desire to actively participate in an exercise-based falls prevention programme.

In western culture, self-reliance is highly valued whereas dependency is seen as a sign of weakness, a lack of character, or even illness (Secker et al., 2003). The older people with primary biliary cirrhosis participating in the experimental case-series research demonstrated a number of potential barriers to successful exercise

participation. However, the experimental case-series participants receiving the enhanced intervention developed a range of strategies and behaviours to promote ongoing active participation with an exercise-based falls prevention programme throughout the course of the treatment and follow up quantitative data collection phases. Despite such observations, the older people with primary biliary cirrhosis indicated that they lacked the necessary skills to formally monitor their progress with an exercise-based falls prevention programme on completion of the study. It has been suggested that the issue of falling might be better addressed within health promotion initiatives for older people by situating it amongst more general aims, such as the enhancement of lifestyle and the promotion of wellbeing (Ballinger & Clemson, 2006). The current study would suggest that future research must focus on developing approaches to clinical service delivery that emphasize opportunity and valued social identity to support older people with long-term conditions to maintain an ongoing sustainable commitment to exercise-based falls prevention programmes.

The physiotherapy practitioners participating in the focus group research suggested that exercising in a group or gym environment was often preferable to exercising at home and that this would promote uptake and adherence with an exercise-based falls prevention programme. In contrast, however, the older people attending the regional falls and syncope service indicated that they preferred the flexibility of being able to exercise at home. Three of the older people with primary biliary cirrhosis receiving the enhanced intervention had previous and ongoing experience of recreational exercise in the community, and this was associated with continued active

participation with an exercise-based falls prevention programme on completion of the experimental case-series.

During the follow up interviews, the experimental case-series participants receiving the enhanced intervention indicated that the home-exercise programmes complemented their recreational activities. It was suggested that the prescribed exercise-regime provided a positive focus during exacerbations of illness which prevented them from participating in their chosen recreational activities. These findings would provide support for a continuum of exercise provision for older people identified as being at risk of falling in which targeted community exercise groups in leisure-based facilities are available in addition to one-to-one physiotherapy. Recently available in the local region, this approach to clinical service delivery may enable healthcare professionals to better support older people with long-term conditions to develop an ongoing active commitment to exercise-based falls prevention programmes.

It has been estimated that 80-90% of care for individuals with long-term conditions is undertaken by older people or their relatives (de Silva, 2011). Despite such observations, however, healthcare professionals often assume that family members hold similar views about goals and treatment planning without asking them to validate this assumption (Paterson, 2001). The older people participating in the focus group research suggested that the endorsement of family members provided a valuable source of encouragement and promoted self-efficacy. However, the physiotherapy practitioners indicated that the relatives of older people at risk of

falling were often sceptical about the benefits to be gained from participating in an exercise-based falls prevention programme. One of the relatives participating in the focus group research had adopted a primary care-giving role and felt responsible for ensuring that her husband completed his daily exercise-regime. In contrast, however, the other three relatives did not feel it was their responsibility to supervise or monitor a home-exercise programme prescribed by a healthcare professional. The relative who had adopted a primary care-giving role supported local physiotherapists' claims that actively participating in the delivery of an exercise-based falls prevention programme had the potential to cause conflict between family members.

The relatives of the older people attending the regional falls and syncope service acknowledged their husbands' deteriorating physical health status and shared with each other their occasional frustrations at the altered dynamics of their relationship. The personal anxieties associated with supporting a family member to remain independent in activities of daily living provided a valuable insight into the additional daily stresses encountered by the relatives of older people identified as being at increased risk of falling. Although none of the older people with primary biliary cirrhosis participating in the experimental case-series believed that the involvement of a family member had directly impacted on their ability to adhere to exercise-based falls prevention programme, it was acknowledged that relatives often had an important role to play in supporting older people with long-term conditions to manage their physical activity levels and maintain a sense of positive self-identity.

Rather than debating whether or not to involve family members in supervising or monitoring a home-exercise programme prescribed by a healthcare professional, the current study would suggest that physiotherapists must acknowledge the challenging and necessary role that the relatives play in enabling older people with long-term conditions to maintain an ongoing active commitment to an exercise-based falls prevention programme. It would appear that involving the relatives of older people with long-term conditions in the clinical practice encounter would promote self-management and adherence through the development of more realistic and achievable patient-centred goals.

It has been suggested that self-management support often involves reinforcing the value and salience of individual's pre-existing self-care activities, rather than initiating alternative behavioural changes (Rogers et al., 2006). The older people with primary biliary cirrhosis participating in the experimental case-series had been living with their long-term condition for many years and, over time, had developed resilient self-management strategies, including ways to manage potential set-backs such as illness exacerbations. During the follow up interviews, one of the experimental case-series participants suggested that the skills she had developed in relation to pacing and planning her activities had actually made it easier for her to schedule regular sessions in which to complete the prescribed exercise-regime. The four older people receiving the enhanced intervention who continued to follow their home-exercise programme at least 3 – 4 x weekly on completion of the study were all active members of the local patient support group, and this was felt to have an

impact on their ability to develop an ongoing commitment to an exercise-based falls prevention programme.

During the follow up interviews, the experimental case-series participants reflected on their experiences of being diagnosed with primary biliary cirrhosis. For many, this had occurred at their local district general hospital and was not considered to have been a very informative or empowering experience. In an attempt to find out more about their condition and to actively manage their symptoms, several of the experimental case-series participants had joined the local support group. They described how their experiences of participating in clinical research had encouraged them to transfer to the auto-immune liver clinic for their routine clinic care. Changing practitioners on a regular basis or being referred to healthcare professionals who see patients with their condition only occasionally constrains the opportunity for participatory decision-making (Paterson, 2001). Whilst not without its challenges, the current study would support initial suggestions that delivering health promotion initiatives, such as exercise-based falls prevention programmes, within the fully-engaged scenario of specialist services for older people with long-term conditions may provide the key to promoting ongoing active participation.

Towards the end of the focus group research, the physiotherapy practitioners suggested that healthcare professionals should take a less-active role in the assessment and treatment process. Effective listening is not passive hearing (Hughes, 2004). It involves close, directed attention, taking notice of what is and what is not being said, and interpreting what is heard. The key to promoting sustainable exercise

behaviour for older people with long-term conditions may, therefore, be to combine high levels of perceived or felt independence with appropriate levels of professional support and guidance.

7.3. Limitations of study

Many older people accessing hospital-based services are widowed and do not have family members living in the local region. For this reason, it was only possible to conduct one focus group session with the relatives of older people attending the regional falls and syncope service. Despite such limitations, however, the views and experiences of these four relatives provided a valuable and alternative insight into the factors influencing self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition. It would appear that the relatives of older people who remain active despite some decline in their balance capabilities have an important and challenging role to play in supporting these individuals to maintain a sense of positive self-identity. Including the relatives of the experimental case-series participants in the follow up interviews would have enabled further exploration of this dynamic. However, these findings would indicate that involving the family members of older people with long-term conditions in the goal setting process is necessary to promote self-management and ongoing active participation with an exercise-based falls prevention programme.

The choice of outcome measures in an experimental case-series is influenced by the aims and objectives of the study, the psychometric and scaling properties of the

available measures, and the practical constraints of implementing these measures (Morley, 1994). Although attempts were made to establish the stability of the selected measures in older people with primary biliary cirrhosis during the pilot measurement study, visual analysis of the experimental case-series data revealed unstable baselines and fluctuations throughout the treatment and follow up phases in keeping with variations in disease-specific quality of life measures. These findings would suggest that long-term conditions interact with measures that predict and monitor falls-risk and self-efficacy.

The aim of the current study was not to determine the efficacy or effectiveness of exercise-based falls prevention programmes for older people with primary biliary cirrhosis but to test and refine acceptable strategies to promote self-management and adherence. Despite such observations, however, these findings raise important considerations regarding the use of the experimental case-series design in clinical evaluations involving older people with long-term conditions. Whilst most of the measures remained relatively stable in the majority of older people with primary biliary cirrhosis when administered once-weekly over the four week pilot measurement study, the data from the experimental case-series would suggest that recognized measures of falls-risk and self-efficacy may be inappropriate for repeated administration over a prolonged time period.

Although statistical analysis is not a defining aspect of experimental case-series research, Onghena and Edgington (2005) suggest that the credibility of a researcher's inferences will depend largely on the validity and reliability of the

selected outcome measures. The pilot measurement study attempted to eliminate potential threats to internal validity caused by instrumentation and testing. However, to promote objectivity and to reduce the risk of observer bias (Robson, 2002), all measures were collected by an independent assessor at specified points throughout the baseline, treatment and follow up quantitative data collection phases of the experimental case-series. In a clinical setting, it is usual practice for a healthcare professional prescribing a programme of treatment to formally monitor the patient's progress with that intervention. However, the use of an independent assessor distanced the experimental case-series participants from the treating clinician and created a sense of artificiality (Robson, 2002). The older people participating in the focus group and experimental case-series research indicated that the use of objective outcome measures played an important role in promoting self-management and adherence with an exercise-based falls prevention programme. Whilst the selected measures were considered too generic and lacked personal relevance for the older people with primary biliary cirrhosis, it was suggested that the assessment and treatment elements of the experimental case-series were not adequately 'joined up'. For this reason, it could be argued that attempts to promote reliability and objectivity during the data collection process resulted in a corresponding reduction in the ecological validity of the experimental case-series.

The purpose of the 6 month follow up quantitative data collection phase was to establish whether the older people with primary biliary cirrhosis continued to participate in an exercise-based falls prevention programme on completion of the standard or enhanced intervention and to determine whether any trends observed in

the selected measures were maintained or enhanced over a prolonged time period. However, by continuing to attend the local hospital every four weeks during this 6 month period, the experimental case-series participants knew they were being observed and that certain things were expected of them (Robson, 2002). The older people with primary biliary cirrhosis participating in the standard and enhanced interventions completed the home-exercise programme as instructed throughout the treatment and follow up quantitative data collection phases. However, during the follow up interviews, it was identified that none of the experimental case-series participants receiving the standard intervention had continued to follow their prescribed exercise-regime on completion of the study. In contrast, however, four of the older people with primary biliary cirrhosis receiving the enhanced intervention continued to participate in an exercise-based falls prevention programme at least 3 - 4 x weekly. These findings represent a more accurate reflection of ongoing active participation and highlight the difference between the two interventions.

Despite such limitations, however, the 6 month follow up quantitative data collection phase provided a valuable insight into the factors influencing self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition. Many of the older people with primary biliary cirrhosis suggested that they adhered to the home-exercise programme because they had made a commitment to participate in the study. For the experimental case-series participants receiving the standard intervention, the 6 month follow up quantitative data collection phase was considered an integral part of the research process and this was associated with ongoing adherence. However, the

fact that none of these individuals continued to follow the prescribed exercise-regime on completion of the study would indicate that it is not only the length of the clinical intervention, but the focus on self-management support and personal goal setting that influenced continued active participation.

7.4. Summing up and future recommendations for physiotherapy research and practice

Almost four decades of research into falls prevention with older people have produced valuable evidence regarding the efficacy of exercise-based falls prevention programmes (Sherrington et al., 2008; Gillespie et al., 2009), and guidelines have been produced to inform the practice of healthcare professionals working with older people at risk of falling in a variety of clinical environments (Department of Health, 2001; National Institute for Health and Clinical Excellence 2004; American Geriatrics Society et al., 2010). Despite the existence of such publications, however, data collected by the National Patient Safety Agency (2007) would suggest that the process of reducing falls is slow with approximately 200,000 fall-related hospital admissions each year, many of them older people. When acute disease was the primary cause of illness, older people were generally considered to be the inexperienced and passive recipients of healthcare interventions. Now that long-term conditions have become the primary focus, however, services need to adapt and older people must be supported to become active partners in the clinical decision-making process (Sandman & Munthe, 2010). By examining its underlying components within the context of exercise-based falls prevention programmes, this

study has brought the debate surrounding self-management for long-term conditions into a much sharper focus.

The current study has demonstrated that self-management support may provide the key to promoting active ongoing participation with clinical interventions, such as exercise-based falls prevention programmes, for older people with long-term conditions. Despite such observations, however, reflexive analysis of the focus group and experimental case-series findings would indicate that actualizing the concept of self-management is complex and that success will require a greater revolution in the attitudes and behaviours of older people and healthcare professionals than previously anticipated. The recommendations provided in this section are intended to promote productive consideration of, and engagement with, some of the key issues facing the future of physiotherapy research and practice for older people with long-term conditions identified as being at increased risk of falling.

An emphasis on supporting self-management for long-term conditions has led to increased recognition that active ongoing participation with an exercise-based falls prevention programme should be considered a form of behaviour change. However, if older people are to feel empowered to take greater responsibility for their care, they need to feel that they have the ability to change their behaviour and that it is in their best interests to do so. Longer periods of clinical intervention are necessary for older people with long-term conditions to move from polite compliance to personal relevance as they are supported through the incremental stages of behaviour change.

Whilst it would appear that self-efficacy and outcome expectation play an important role in encouraging older people with a long-term condition to develop an active commitment to an exercise-based falls prevention programme, ongoing professional support to enable realistic goal setting in personal context is imperative. A more precise understanding of the practical application of social cognition models and their constructs would enable practitioner-researchers to be more specific in the development and evaluation of acceptable strategies to support self-management for older people with long-term conditions, and more able to differentiate the separate elements of these complex behaviours within the context of exercise-based falls prevention programmes.

Recommendation 1: Further exploration of the activation of social cognition model constructs within the context of exercise-based falls prevention programmes for older people with long-term conditions is required to develop acceptable strategies for self-management support.

The current study has demonstrated that improvements in timed or rated clinical tests of balance, gait and lower limb muscle strength performed in a hospital environment do not necessarily translate into improvements in an older person's experience of living with a long-term condition. The exercise-based falls prevention programme delivered within the context of the enhanced intervention had perceived benefit for older people with primary biliary cirrhosis. However, this was not evident

in the clinical outcome measures selected, many of which lacked personal relevance and demonstrated a ceiling effect in the patient group under investigation. The impact of exercise-based falls prevention programmes for older people with long-term conditions needs to be evaluated from the perspective of patient-centred rather than professionally-driven outcomes. The development of feasible, acceptable, valid, reliable, sensitive and communicable patient-centred outcome measures is necessary. These may only be accessible by inquiring about each patient's individual needs, expectations and preferred level of participation in shared decision-making prior to commencing an exercise-based falls prevention programme, and evaluating its subsequent impact in relation to these *a priori* assumptions.

Recommendation 2: Development of and consensus on patient-centred outcomes with sound psychometric properties is necessary to measure the impact of self-management support within the context of exercise-based falls prevention programmes for older people with long-term conditions.

It has been suggested that long-term active participation with an exercise-based falls prevention programme has the potential to reduce demands on the healthcare delivery system by encouraging older people with long-term conditions to play an active role in improving their mobility and physical functioning as well as reducing future falls. An economic evaluation was beyond the scope of the current study. However, laudable claims will remain just that if not accompanied by persuasive

fiscal arguments. The enhanced intervention delivered within the context of the experimental case-series involved the same amount of face-to-face contact with a healthcare professional as the standard intervention. However, this longer period of clinical intervention (which focussed on self-management support and personal goal setting) was associated with greater ongoing active participation. These findings would suggest that assuming self-management support will reduce health resource utilization is, perhaps, overly simplistic. The aim of supporting self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition may be to alter the pattern of service use rather than to reduce it altogether. Future evaluation should focus on whether different types of healthcare delivery are being employed; such as primary versus secondary care facilities, or on-line versus in-person resources.

Recommendation 3: Economic evaluation of the impact of self-management support within the context of exercise-based falls prevention programmes for older people with long-term conditions must be undertaken and should include a focus on whether different types of healthcare delivery are being employed.

Most professions have their own histories which have shaped and thus determined the culture of science in that discipline. In the 1970s, physiotherapy shrugged off professional dominance to achieve a long fought for clinical autonomy. Despite such observations, however, physiotherapy emerged from physicians' control as a

technique-centred rather than a patient-centred service, still ideologically dominated by medicine. The focus group findings presented in this thesis would suggest that the reductionist influence dominating established models of clinical service delivery has allowed the relationship between local physiotherapists and older people at risk of falling to remain grounded in the traditional power differential of active doctor and passive patient. These findings are at odds with the philosophies underpinning self-management and rehabilitation, and are proving limiting and dissatisfying for physiotherapists' creativity and sense of professional autonomy. The framework for physiotherapy practice developed during the course of the current study enables practitioner-researchers employed in applied health research to penetrate the realities of routine clinical practice deeper than traditionalist approaches to evidence-based practice. By combining evidence-based and patient-centred practice, information that is of value to the patient and the healthcare professional is considered in parallel as part of the clinical decision-making process.

Recommendation 4: The framework for physiotherapy practice should be applied to other patient groups with long-term conditions associated with increased risk of falling to establish transferability of principles.

Academic research culture encourages researchers to report the results of clinical studies rather than to describe the lessons learnt as part of the process. However, greater transparency is needed if practitioner-researchers are to move beyond the

rhetoric of public involvement in health research. It has been suggested that older people are less consumer-orientated than younger people, do not wish to be involved in health research or lack the necessary skills to make a worthwhile contribution. Despite such observations, however, it can be seen that the older people and relatives participating in the focus group research demonstrated high levels of commitment throughout the 14 month qualitative investigation, and that the impact of their involvement was only limited by professional anxieties on the part of the thesis author. Their willingness to take on additional responsibilities as the study progressed supports the notion that public involvement in health research empowers individuals through a realization that they can shape clinical service delivery and bring about change. If more evidence can be provided of its impact, applied health researchers may be less inclined to treat public involvement as something they have to do in order to satisfy funding bodies and regulatory agencies and more as an integral component to be implemented and reported on at every stage of the research process. Whilst it is acknowledged that the impact of public involvement is highly context specific, the conceptual model illustrated in Figure 4.1 proposes terminology and key concepts that promote consistency in the reporting of public involvement in health research.

Recommendation 5: The conceptual model should be used to promote increased awareness and understanding of public involvement in health research through consistency in the evaluation and reporting of its impact.

It is important to understand the skills that clinicians need to help older people to change their behaviour and the barriers that may prevent them from offering such support. Health and wellbeing arise from our genetic inheritance, the circumstances of lives and the manner of our living as well as the interventions provided by healthcare professionals. Physiotherapists cannot be all things to all people. The treatment of physical problems through physical means should remain at the heart of physiotherapy practice and define its distinctiveness as a profession. However, the qualitative data collected during the course of the current study would indicate that older people at risk of falling and their families value the social and emotional support provided by healthcare professionals as much as the physical intervention and practical advice offered. The lesson for physiotherapy practitioners may be that their distinctive physical approach needs to be flexible and tailored to each individual patient within the context of their own sociological and psychological needs and explanations. Formal training in skills such as problem solving, goal setting, motivational interviewing and cognitive behavioural therapy would assist physiotherapy practitioners working with older people to promote ongoing active participation with clinical interventions, such as exercise-based falls prevention programmes.

Recommendation 6: Pre and post-registration education and training should include greater emphasis on providing physiotherapists with the necessary skills to facilitate self-management support and shared decision-making in clinical practice.

7.5. Conclusion

There is growing confidence amongst the recipients of healthcare interventions regarding the expertise to be gained from personal experience. This reflects, in part, a wider scepticism about the role of professional expertise, and provides an important context for the delivery and evaluation of clinical interventions now and in the future. This thesis has charted the research processes and outcomes that led to the development of a framework for physiotherapy practice to promote self-management and adherence with an exercise-based falls prevention programme for older people with a long-term condition. These findings are original in that there are no published studies exploring self-management and adherence with exercise-based falls prevention programmes for older people with long-term conditions.

Practice development occurs in a profession when attempts to find solutions to clinical problems generate and develop theories which challenge epistemological thinking within that professional discipline. There is increasing recognition in academic literature that patient control and ownership are central to the successful

implementation of an exercise-based falls prevention programme. Despite such observations, however, the focus group and experimental case-series findings presented in this thesis would suggest that healthcare professionals and older people at risk of falling remain reluctant to work in ways that acknowledge or support such practices. A culture change is at the heart of a fully-engaged health community. The framework for physiotherapy practice developed during the course of the current study has the potential to empower patients and healthcare professionals to work in collaboration to challenge existing approaches to clinical service delivery. Future work must focus on the use of participatory approaches to further develop and evaluate strategies for embedding self-management support into routine clinical practice for older people with long-term conditions identified as being at increased risk of falling.

APPENDICES

Appendix I. Participant information sheet for focus group research (older people and relatives)

**What Factors Influence Motivation and Adherence with a Home-Based Exercise Programme for Older People at Risk of Falls?
(Part 1)**



PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

- Part 1 tells you the purpose of the study and what will happen to you if you take part
- Part 2 gives you more information about the conduct of the study

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?

A home-based programme of strength and balance exercises has been shown to reduce the risk of falls in older people. However, the factors which influence whether or not a person carries out such a programme are less well understood. The purpose of this study is to explore the views and experiences of older people and their relatives of participating in a home-based exercise programme prescribed by a physiotherapist.

The Principal Investigator [REDACTED] will utilize the findings from this study to form the basis of a Master of Philosophy degree at [REDACTED]

Why have I been chosen?

We are asking a selection of older people and their relatives receiving physiotherapy the [REDACTED] to take part. We hope to recruit approximately 50 individuals.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I decide to take part?

If you decide to take part, you will be contacted by the Principal Investigator [REDACTED] [REDACTED] and invited to attend a small group (4-6 people) discussion at the [REDACTED] [REDACTED]. The session will last approximately 1 hour during which time you will be asked about your views and experiences of carrying out a home-based exercise programme. With your permission, the discussion will be tape recorded and the recording kept in a secure place.

Expenses and payments

Transport to and from the hospital will be provided by taxi if necessary.

What do I have to do?

If you would like to take part in the study, please complete the reply slip at the end of this information sheet and return it in the pre-paid envelope provided. Your care at the [REDACTED] will continue unchanged, regardless of whether you decide to take part in this study or not.

What are the possible benefits of taking part?

The [REDACTED] are always very interested in your opinions. We hope that by listening to your views and experiences, we will gain a better understanding of the factors that influence whether or not a person carries out an exercise programme at home. The findings will be used to improve the physiotherapy service provided to patients attending the [REDACTED] in the future.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in part 2.

Will my taking part in this study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in part 2.

Contact details

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

This completes part 1 of the Information Sheet. If the information in part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

Complaints:

If you have any concern about any aspect of this study, you should ask to speak to the research team who will do their best to answer your questions (please see below). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Harm:

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for compensation against [REDACTED] but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you (see above).

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information that leaves the hospital will have your name and address removed so that you cannot be recognized from it. With your consent, your GP will be informed of your participation in this research project.

What will happen to the results of the research study?

The findings from this study will form the basis of a Master of Philosophy degree at [REDACTED] and be published in scientific journals, however, you will not be identified in any of the reports/publications. A summary of the findings will be available at the end of the project. We can send you a copy if you are interested.

Who is organizing and funding the research?

The research has been organized by [REDACTED]
[REDACTED]

[REDACTED] The Principal Investigator [REDACTED] will not receive any payment for including you in this study.

Who has reviewed this study?

This study was given a favourable ethical opinion for conduct in the NHS by [REDACTED]
[REDACTED]

Thank you for your interest in this study

If you have read the information above and would like to be involved in the study, please return the slip over the page in the envelope provided.

Expression of interest form

I would like to take part in the research study and am happy to be contacted by telephone.

Name:

Telephone number:

Best time to call:

**Appendix II. Participant information sheet for focus group research
(physiotherapy practitioners)**

**What factors Influence Motivation and Adherence with a Home-
Based Exercise Programme for Older People at Risk of Falls?
(Part 1)**



PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

- Part 1 tells you the purpose of the study and what will happen to you if you take part
- Part 2 gives you more information about the conduct of the study

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

There is good evidence that an individualized, home-based exercise programme prescribed and progressed by a suitably trained professional is effective in reducing the risk of falls in community-dwelling older people.

However, despite the proven benefits of exercise interventions in research trials, their impact in a clinical setting is often limited by poor compliance or adherence of

participants, particularly in the long term. A recent report commissioned by Help the Aged claims that uptake rates for simple exercise interventions in the community may be as low as 10 per cent. This would suggest that there is reluctance on the part of older people to take part in such programmes.

Whilst exercise programmes do appear to reduce falls in those who take part, they can only prove effective at a population level if participation rates are high. This issue has received little attention in the falls literature to date. The factors which influence compliance with a falls prevention programme do not appear to be widely understood or documented.

The Researcher [REDACTED] is currently undertaking a part-time Master of Philosophy degree at [REDACTED] exploring the factors influencing motivation and adherence with a home-based exercise programme for older people at risk of falls.

The aims of the study are:

1. To review existing literature around motivation and adherence with exercise interventions amongst older people.
2. To determine the views of older people and their relatives on factors influencing motivation and acceptable strategies to promote adherence with a home-based exercise programme.
3. To determine physiotherapy practitioners' views on patient adherence with a home-based exercise programme to reduce the risk of falls and injuries.
4. To propose treatment strategies that will promote motivation and adherence with a home-based exercise programme to reduce the risk of falls and injuries in community-dwelling older people.

Why have I been chosen?

We are asking all physiotherapists working in [REDACTED] with experience of prescribing a home-based exercise programme for older people at risk of falls to take part. We hope to recruit approximately 20 staff members.

Do I have to take part?

Participation is, of course, entirely optional. If you agree to participate in this study you will be given this information sheet to keep and asked to sign a consent form. However, you are free to withdraw from the study at any time without giving a reason.

What will happen to me if I decide to take part?

You will be contacted by the researcher [REDACTED] and invited to discuss your experiences in a small peer group setting. The focus group will last approximately 1 hour. With your permission, your views will be tape-recorded and the recordings stored in a secure location.

Expenses and payments

Transport to the focus group will be provided by taxi if necessary.

What do I have to do?

If you are interested in taking part in the study, please complete the reply slip at the end of this information sheet and return it to [REDACTED] at the [REDACTED]
[REDACTED]

What are the benefits of taking part?

It is anticipated that the findings of the focus groups will be utilized to propose treatment strategies to promote compliance with a home-based exercise programme for older people at risk of falls. Your opinions and experiences of prescribing such programmes will help to shape local service delivery and improve the efficacy of physiotherapy interventions provided for older people.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in part 2.

Will my taking part in this study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in part 2.

Contact details

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

This completes part 1 of the Information Sheet. If the information in part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

Complaints:

If you have any concern about any aspect of this study, you should ask to speak to the research team who will do their best to answer your questions (please see below). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

[REDACTED]

[REDACTED]

Harm:

In the event that something does go wrong and you are harmed during the research study, there are no special compensation arrangements. If you are harmed and this is due to someone else's negligence then you may have grounds for compensation against the [REDACTED] but you may

have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you (see above).

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information that leaves the hospital will have your name and address removed so that you cannot be recognized from it. With your consent, your manager will be informed of your participation in this research project.

What will happen to the results of the research study?

Locally the findings will be presented at the [REDACTED] and [REDACTED]. Abstracts and papers will be submitted to peer-reviewed journals for publication throughout the course of the research study. You will not be identified in any report or publication.

Who is organizing and funding the research?

The research has been organized by [REDACTED] and the [REDACTED] [REDACTED] and funded by the [REDACTED] [REDACTED]. The Principal Investigator [REDACTED] will not receive any payment for including you in this study.

Who has reviewed this study?

This study was given a favourable ethical opinion for conduct in the NHS by [REDACTED]

Thank you for your interest in this study

If you have read the information above and would like to be involved in the study please return the attached slip in the envelope provided.

Expression of interest form

I would like to take part in the research study and am happy to be contacted by telephone.

Name:

Telephone number:

Best time to call:

Appendix III. Topic guide for focus group research

Older people / relatives

1. Please tell me about your / your relative's experiences of participating in a home-exercise programme to reduce your risk of falling
2. What factors do you think make it easy for you / your relative to participate in a home-exercise programme?
3. What factors do you think make it difficult for you / your relative to participate in a home-exercise programme?
4. What strategies have you / your relative used to promote motivation and adherence with a home-exercise programme?

Physiotherapy Practitioners

1. Please tell me about your experiences of prescribing a home-exercise programme for older people at risk of falls
2. What factors do you think make it easy for an older person to participate in a home-exercise programme?
3. What factors do you think make it difficult for an older person to participate in a home-exercise programme?
4. What strategies have you used or considered using to promote motivation and adherence with a home-exercise programme for older people at risk of falls?

Appendix IV. Participant information sheet for experimental case-series

What factors influence motivation and adherence with a home-based exercise programme for older people at risk of falls? (Part 2)



PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

- Part 1 tells you the purpose of the study and what will happen to you if you take part
- Part 2 gives you more information about the conduct of the study

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?

Multi-disciplinary falls assessments conducted by the [REDACTED] [REDACTED] have identified that older people with chronic liver disease possess a number of recognized risk factors for falling. However, exercise interventions known to reduce falls in older adults have never been tested in this client group.

In addition, the factors which influence whether or not an individual chooses to take part in a home-based exercise programme are also poorly understood. The Principal Investigator [REDACTED] has undertaken a series of focus groups with older people attending the [REDACTED], relatives and local physiotherapists in an attempt to determine the factors which influence motivation and adherence with home exercise and acceptable strategies to promote long term participation.

She would now like to conduct a series of case studies to establish whether strength and balance training reduces the risk of falls in older people with chronic liver disease and to determine whether strategies proposed by the focus group participants promote long term participation.

The Principal Investigator will utilize the findings from this study to form the basis of a Doctor of Philosophy (PhD) degree at [REDACTED]

Why have I been chosen?

We are asking a selection of older people with chronic liver disease attending the [REDACTED] to take part. The Principal Investigator has identified from your medical records today that you would be eligible to participate in this study. The Research Team hope to recruit 10 individuals in total.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. If you do withdraw from the study for any reason, data already collected with consent will be retained and used in the study. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I decide to take part?

If you decide to take part, you will be given this information sheet to keep and asked to sign a consent form. The study will be composed of 3 phases:

Phase 1

During the initial 8 week baseline phase, you will be contacted by a member of the [REDACTED] and asked to attend the [REDACTED] on 3 occasions (during weeks 1, 4 and 8) to undergo a series of clinical measures and self-assessment questionnaires. These assessments will take approximately 1 hour to complete.

Phase 2 – Treatment A

The first 5 participants recruited for this study will receive Treatment A. This will involve attending the [REDACTED] 1 x weekly over a 6 week intervention period. On your first visit to [REDACTED], you will see a research nurse who will provide you with a sheet of exercises. You will be asked to complete these exercises at home on a daily basis. Each week, the Research Nurse will review your progress in clinic and you will be given the opportunity to move on to the next level of exercises. At the end of the 6 week programme, you will be instructed to continue with your current exercise-regime.

Throughout the intervention phase, you will be asked to record your progress with the home exercise programme in a daily exercise diary and record how strongly you agree or disagree with a series of statements relating to the home exercise programme on a visual analogue scale. An independent assessor will repeat the clinical measures and self-assessment questionnaires completed during the baseline phase when you attend the Clinic during weeks 3 and 6 to monitor your progress with the home exercise programme.

Phase 2 – Treatment B

The second 5 participants recruited for this study will receive Treatment B. This will involve attending the [REDACTED] every 4 weeks over a 6 month intervention period. On your first visit to [REDACTED], you will see the Principal Investigator (a qualified physiotherapist) who will provide you with a sheet of exercises. You will be asked to complete these exercises at home on a daily basis. Every 4 weeks, the Principal Investigator will review your progress in the Clinic and you will be given the opportunity to move on to the next level of exercises. At the end of the 6 month programme, you will be instructed to continue with your current exercise-regime.

Throughout the intervention phase, you will be asked to record your progress with the home exercise programme in a daily exercise diary and record how strongly you agree or disagree with a series of statements relating to the home exercise programme on a visual analogue scale. The Principal Investigator will look at this information with you at each clinic visit to help identify any potential barriers to the home exercise programme that you may be experiencing and work collaboratively with you to suggest strategies to overcome these. An independent assessor will repeat the clinical measures and self assessment questionnaires completed during the baseline phase at each clinic visit to monitor your progress.

Phase 3

All participants will be asked to continue with their home exercise programme over a 6 month follow up period and record their progress in a daily exercise diary. An independent assessor will contact you every 4 weeks during this period and invite you to attend [REDACTED] to repeat the clinical measures and self assessment questionnaires completed throughout the baseline and intervention phases.

At the end of the intervention and follow up phases, an independent assessor will contact you and invite you to attend a focus group session at the [REDACTED] to discuss your views of the home exercise programme. With your permission, these focus group sessions will be audio taped and the recordings stored in a secure location. Anonymised quotations from these focus group sessions will be used in reports and publications resulting from this study.

All of the data collected as a result of your participation in this study will be stored in a locked filing cabinet in [REDACTED] office at the [REDACTED] and entered onto an NHS password protected computer by the Principal Investigator. No information that could lead to the identification of participants will be disclosed in any reports resulting from the study or to any other party. No identifiable personal data will be published or shared with any other organization.

Expenses and payments

Transport to and from the hospital will be provided by taxi if necessary.

What do I have to do?

If you would like to take part in the study, please complete the reply slip at the end of this information sheet and return it in the pre-paid envelope provided. Your care at the [REDACTED] will continue unchanged, regardless of whether you decide to take part in this study or not.

What are the possible benefits of taking part?

This study is being conducted as part of the [REDACTED] [REDACTED] Service Development Initiative. By taking part in this study, you will have the opportunity to inform the development of local services for older people with chronic liver disease based at the [REDACTED].

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in part 2.

Will my taking part in this study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in part 2.

Research Team contact details

[Redacted text block containing contact details for the research team, consisting of multiple lines of blacked-out text.]

This completes part 1 of the Information Sheet. If the information in part 1 has interested you and you are considering participating, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

Complaints:

If you have any concern about any aspect of this study, you should ask to speak to a member of the Research Team who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Alternatively, you may wish to contact:

[Redacted contact information]

Harm:

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for compensation against the [REDACTED] but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you (see above).

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information that leaves the hospital will have your name and address removed so that you cannot be recognized from it. With your consent, your GP will be informed of your participation in this research project.

What will happen to the results of the research study?

The findings from this study will form the basis of a Doctor of Philosophy (PhD) degree at [REDACTED] and be published in scientific journals; however, you will not be identified in any of the reports/publications. A summary of the findings will be available at the end of the project. We can send you a copy if you are interested.

Who is funding the research?

The research has been organized by [REDACTED] and the [REDACTED] [REDACTED] and funded by the [REDACTED] [REDACTED]. The Principal Investigator [REDACTED] will not receive any payment for including you in this study.

Who has reviewed this study?

This study was given a favourable ethical opinion for conduct in the NHS by [REDACTED]

Thank you for your interest in this study

If you have read the information above and would like to be involved in the study, please return the slip over the page in the envelope provided.

Expression of interest form

I would like to take part in the research study and am happy to be contacted by telephone.

Name:

Telephone number:

Best time to call:

Appendix V. PBC-40

For each statement, please circle the response that comes closest to how you feel. If any of the statements do not apply, circle “N/A”

Can you say how often the following statements about digestion and diet applied to you in the last four weeks?						
1. I was able to eat what I liked	Never	Rarely	Sometimes	Most of the time	Always	
2. I ate or drank only a small amount and still felt bloated	Never	Rarely	Sometimes	Most of the time	Always	
3. I felt unwell when I drank alcohol	Never	Rarely	Sometimes	Most of the time	Always	N/A

And in the last four weeks, how often did you experience any of the following?						
4. I had discomfort in my right side	Never	Rarely	Sometimes	Most of the time	Always	
5. I had dry eyes	Never	Rarely	Sometimes	Most of the time	Always	
6. My mouth was very dry	Never	Rarely	Sometimes	Most of the time	Always	
7. I had aches in the long bones of my arms and legs	Never	Rarely	Sometimes	Most of the time	Always	

Some people with PBC experience itching. How often did you experience itching in the last four weeks? If you did not itch, please circle “N/A”						
8. Itching disturbed my sleep	Never	Rarely	Sometimes	Most of the time	Always	N/A
9. I scratched so much I made my skin raw	Never	Rarely	Sometimes	Most of the time	Always	N/A
10. I felt embarrassed because of the itching	Never	Rarely	Sometimes	Most of the time	Always	N/A

Fatigue can be a problem for many people with PBC. How often did the following statements apply to you in the last four weeks?						
11. I had to force myself to get out of bed	Never	Rarely	Sometimes	Most of the time	Always	
12. I had to have a sleep during the day	Never	Rarely	Sometimes	Most of the time	Always	
13. Fatigue interfered with my daily routine	Never	Rarely	Sometimes	Most of the time	Always	
14. I felt worn out	Never	Rarely	Sometimes	Most of the time	Always	
15. I felt so tired, I had to force myself to do the things I needed to do	Never	Rarely	Sometimes	Most of the time	Always	
16. I felt so tired I had to go to bed early	Never	Rarely	Sometimes	Most of the time	Always	
17. Fatigue just suddenly hit me	Never	Rarely	Sometimes	Most of the time	Always	
18. PBC drained every ounce of energy out of me	Never	Rarely	Sometimes	Most of the time	Always	

The next section is about the effort and planning that can be involved in living with PBC. Thinking about the last four weeks, how often did the following statements apply to you?						
19. Some days it took me a long time to do anything	Never	Rarely	Sometimes	Most of the time	Always	
20. If I was busy one day I needed at least another day to recover	Never	Rarely	Sometimes	Most of the time	Always	
21. I had to pace myself for day-to-day things	Never	Rarely	Sometimes	Most of the time	Always	

The following statements are about the effects that PBC may have on things like memory and concentration. Thinking about the last four weeks, how often did the following statements apply to you?						
22. Because of PBC I had to make a lot of effort to remember things	Never	Rarely	Sometimes	Most of the time	Always	
23. Because of PBC I had difficulty with remembering things from one day to the next	Never	Rarely	Sometimes	Most of the time	Always	
24. My concentration span was short because of PBC	Never	Rarely	Sometimes	Most of the time	Always	
25. Because of PBC I had difficulty keeping up with conversations	Never	Rarely	Sometimes	Most of the time	Always	
26. Because of PBC I found it difficult to concentrate on anything	Never	Rarely	Sometimes	Most of the time	Always	
27. Because of my PBC I found it difficult to remember what I wanted to do	Never	Rarely	Sometimes	Most of the time	Always	

Now some more general statements about how PBC may be affecting you as a person. How much do the following statements apply to you?						
28. Because of my PBC I get more stressed about things than I used to do	Not at all	A little	Somewhat	Quite a bit	Very much	
29. My sex life has been affected because of PBC	Not at all	A little	Somewhat	Quite a bit	Very much	N/A
30. Having PBC gets me down	Not at all	A little	Somewhat	Quite a bit	Very much	
31. I feel I neglect my family because of having PBC	Not at all	A little	Somewhat	Quite a bit	Very much	N/A
32. I feel guilty that I can't do what I used to do because of having PBC	Not at all	A little	Somewhat	Quite a bit	Very much	
33. I feel worried about how my PBC will be in the future	Not at all	A little	Somewhat	Quite a bit	Very much	

These statements relate to the possible effects of PBC on your social life. Thinking of your own situation, how much do you agree or disagree with them?						
34. I sometimes feel frustrated that I can't go out and enjoy myself	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	
35. I tend to keep the fact that I have PBC to myself	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	
36. I can't plan holidays because of having PBC	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	
37. My social life has almost stopped	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	

The next section is about the impact that PBC may be having on your life overall. How much do you agree or disagree with the following statements?						
38. Everything in my life is affected by PBC	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	
39. PBC has reduced the quality of my life	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	
40. I can still lead a normal life despite having PBC	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	

Appendix VI. Self-Efficacy for Exercise Scale

How confident are you right now that you could exercise 3 times per week for 20 minutes if:

Not confident Very confident

1. The weather was bothering you	1	2	3	4	5	6	7	8	9	10
2. You were bored by the programme or activity	1	2	3	4	5	6	7	8	9	10
3. You felt pain when exercising	1	2	3	4	5	6	7	8	9	10
4. You had to exercise alone	1	2	3	4	5	6	7	8	9	10
5. You did not enjoy it	1	2	3	4	5	6	7	8	9	10
6. You were too busy with other activities	1	2	3	4	5	6	7	8	9	10
7. You felt tired	1	2	3	4	5	6	7	8	9	10
8. You felt stressed	1	2	3	4	5	6	7	8	9	10
9. You felt depressed	1	2	3	4	5	6	7	8	9	10

Appendix VII. Outcome Expectation for Exercise Scale

For each of the statements, please select a number from the scale below:

- (1) Strongly agree
- (2) Agree
- (3) Neither agree nor disagree
- (4) Disagree
- (5) Strongly disagree

Exercise...

- 1. Makes me feel better physically
- 2. Makes my mood better in general
- 3. Helps me feel less tired
- 4. Makes my muscles stronger
- 5. Is an activity I enjoy doing
- 6. Gives me a sense of personal accomplishment
- 7. Makes me more alert mentally
- 8. Improves my endurance in performing my daily activities
- 9. Helps to strengthen my bones

1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

Appendix VIII. Falls Efficacy Scale - International

For each of the following activities, please select a number from the scale below to indicate how concerned you are that you might fall if you did the activity.

1=not at all concerned

2=somewhat concerned

3=fairly concerned

4=very concerned

1. Cleaning the house (e.g. sweep, vacuum or dust)	1	2	3	4
2. Getting dressed or undressed	1	2	3	4
3. Preparing simple meals	1	2	3	4
4. Taking a bath or shower	1	2	3	4
5. Going to the shop	1	2	3	4
6. Getting in or out of a chair	1	2	3	4
7. Going up or down stairs	1	2	3	4
8. Walking around in the neighbourhood	1	2	3	4
9. Reaching for something above your head or on the ground	1	2	3	4
10. Going to answer the telephone before it stops ringing	1	2	3	4
11. Walking on a slippery surface (e.g. wet or ice)	1	2	3	4
12. Visiting a friend or relative	1	2	3	4
13. Walking in a place with crowds	1	2	3	4
14. Walking on an uneven surface(e.g. rocky ground or poorly maintained pavement)	1	2	3	4
15. Walking up and down a slope	1	2	3	4
16. Going out to a social event (e.g. religious event, family gathering or club meeting)	1	2	3	4

Appendix IX. 5 x Sit-to-Stand

- Use a standard padded chair (43.20 cm) without armrests
- The patient will be timed (in seconds) to complete 5 sit to stands
- The procedure should be explained to the patient:
 - cross both arms across chest
 - begin in seated position
 - stand up (knees fully extended)
 - sit down (full weight through chair)
- Instructions to patient: I want you to stand up and sit down 5 times as quickly as you can when I say 'Go'
- Inform the patient to begin and start timer
- Stop timing on return to seated position following 5 sit to stands

	Time taken to complete 5 sit-to-stands (seconds)
Date:	
Date:	
Date:	
Date:	
Date:	
Date:	

Appendix X. Performance Orientated Assessment of Mobility

Manoeuvre	Response			Score
	Normal = 2	Adaptive = 1	Abnormal = 0	
Sitting	Steady	Holds	Leans or slides	
Sit to stand	Able to rise without using arms	Uses arms; shuffles forwards	Multiple attempts; assistance	
Immediate standing	No support	Support	Unsteady	
Prolonged Standing	Feet together	Feet apart	Unsteady regardless of stance	
Standing-eyes closed	Steady	Steady but feet apart	Any sign of unsteadiness or needs support	
360 degree turn	Continuous steps; no need to hold on	Discontinuous	Unsteady; holds on to object	
Nudge on sternum x3 feet together	Steady	Moves feet	Unsteady	
C spine ext & rotation	> ½ ROM; looks at ceiling w/o unsteadiness	Decreased ROM; no staggering or symptoms	Unsteady; symptoms	
Stand 1 leg	5 seconds; no support	Changes from right to left	Unable	
Lumbar extension	Good extension; no support	Decreased ROM; holds on	No attempt; staggers	
Reaching up on toes	No support; steady	Single attempt; needs support	Unsteady	
Bending (pick object off floor)	Single attempt	1 attempt, with support	Multiple attempts; unable	
Standing to sitting	Smooth movements	Uses arms- not smooth	Misjudges, flops	
Total score				

Manoeuvre	Observation		Score
	Normal = 1	Abnormal = 0	
Initiation	No hesitation: first attempt: smooth motion	Hesitates; multiple attempts; not smooth motion	
Step height	1-2" clear	Swing foot not completely raised off floor; foot raised too high (>2")	
Step length	Length of foot	Less than length of foot	
Step symmetry	Equal: alternate L/R	Varies between sides; patient advances with same foot every step	
Step continuity	Heel raises as heel strikes: no breaks: equal steps	Entire foot placed on floor before beginning to raise other foot; step length varies over cycles	
Path deviation	Follows straight line	Deviates from side to side; deviates toward one direction	
Trunk stability	No trunk sway: Knees or back not flexed Arms by side	Trunk sways; Arms abducted to maintain stability	
Walk stance	Feet almost touch	Feet apart with stepping	
Turning	No staggering: continuous turning: continuous steps	Staggers; stops before initiating turn; steps discontinuous	
Total Score			

Appendix XI. Dynamic Gait Index

	Scoring system: 3 = Normal, 2 = Mild impairment, 1 = Moderate impairment, 0 = Severe impairment	Date	Date	Date
1	<p>Gait Level Surface</p> <p>Instructions: Walk at your normal speed from here to next mark (20 ft)</p> <p>Normal: Walks 20ft; no assistive devices; normal speed; no gait deviations</p> <p>Mild impairment: Walks 20ft; uses assistive devices; slower speed; mild gait deviations</p> <p>Moderate impairment: Walks 20ft; slow speed, abnormal gait pattern; evidence of imbalance</p> <p>Severe impairment: Cannot walk 20ft without assistance; severe gait deviations; or imbalance</p>			
2	<p>Change in Gait Speed</p> <p>Instructions: Begin walking at your normal pace (for 5 ft). When I tell you ‘Go’ walk as fast as you can (for 5 ft). When I tell you ‘Slow’ walk as slowly as you can (for 5 ft)</p> <p>Normal: Able to smoothly change walking speed without loss of balance or gait deviation. Shows a significant difference in walking speeds between normal, fast and slow speeds</p> <p>Mild impairment: Is able to change speed but demonstrates mild gait deviations; or has no gait deviations but unable to achieve a significant change in velocity; or uses an assistive device</p> <p>Moderate impairment: Makes only minor adjustments to walking speed; or accomplishes a change in gait speed with significant gait deviations; or changes speed but loses balance, but is able to recover or continue walking</p> <p>Severe impairment: Cannot change gait speeds; or loses balance and has to reach for wall of be caught</p>			
3	<p>Gait with Horizontal Head Turns</p> <p>Instructions: Begin walking at your normal pace. When I say ‘Look right’ keep walking straight, but turn your head to the right. Keep looking to the right until I tell you ‘Look left’ then keep walking straight but turn your head to the left. Keep walking until I tell you to ‘Look straight’ then keep walking straight but return your head to the centre</p> <p>Normal: Performs head turns smoothly with no change in gait speed</p> <p>Mild impairment: Performs head turns smoothly with slight change in gait velocity; or uses walking aid</p> <p>Moderate impairment: performs head turns with moderate change in gait velocity, slows down, staggers but recovers, can continue to walk</p> <p>Severe impairment: Performs task with severe disruptions of gait; loses balance; stops; reaches for wall</p>			

	Scoring system: 3 = Normal, 2 = Mild impairment, 1 = Moderate impairment, 0 = Severe impairment	Date	Date	Date
4	<p>Gait with Vertical Head Turns</p> <p>Instructions: Begin by walking at your normal pace. When I tell you ‘Look up’ keep walking straight but tip your head and look up. Keep looking up until I tell you ‘Look down’. Then keep walking straight and turn your head down. Keep looking down until I tell you to ‘Look straight’ then keep walking straight but return your head to the centre</p> <p>Normal: Performs head turns with no changes in gait</p> <p>Mild impairment: Performs task with slight change in gait velocity; or uses walking aid</p> <p>Moderate impairment: Performs task with moderate changes in gait velocity; slow down; staggers but recovers; can continue to walk</p> <p>Severe impairment: Performs task with severe disruption of gait; loses balance; stops; reaches for wall</p>			
5	<p>Gait with Pivot Turn</p> <p>Instructions: Begin by walking at your normal pace. When I tell you ‘Turn and stop’ turn as quickly as you can to face the opposite direction, and stop</p> <p>Normal: Pivot turns safely within 3 seconds and stops quickly with no loss of balance</p> <p>Mild impairment: Pivot turns safely in > 3 seconds and stops with no loss of balance</p> <p>Moderate impairment: Turns slowly; requires verbal cueing; requires several small steps to catch balance after turn and stop</p> <p>Severe impairment: Cannot turn safely; requires assistance to turn and stop</p>			
6	<p>Step Over Obstacle</p> <p>Instructions: Begin walking at your normal speed. When you come to the shoe box, step over it, not around it, and keep walking</p> <p>Normal: Is able to step over the shoe box without changing gait speed; no evidence of imbalance</p> <p>Mild impairment: Is able to step over box; but must slow down and adjust steps to clear box safely</p> <p>Moderate impairment: Is able to step over box but must stop; then step over. May require verbal cueing</p> <p>Severe impairment: Cannot perform without assistance</p>			

	Scoring system: 3 = Normal, 2 = Mild impairment, 1 = Moderate impairment, 0 = Severe impairment	Date	Date	Date
7	<p>Step Around Obstacles</p> <p>Instructions: Begin walking at your normal speed. When you come to the first cone (about 6ft away), walk around the right side of it. When you come to the second one (6 ft past first cone), walk around it to the left</p> <p>Normal: Is able to walk around cones safely without changing gait speed; no evidence of imbalance</p> <p>Mild impairment: Is able to step around both cones; but must slow down and adjust steps to clear cones</p> <p>Moderate impairment: Is able to clear cones but must significantly slow speed to accomplish task; or requires verbal cueing</p> <p>Severe impairment: Unable to clear cones; walks into one or both cones; or requires physical assistance</p>			
8	<p>Steps</p> <p>Instructions: Walk up these stairs as you would at home (i.e. using the handrail if necessary). At the top turn around and walk down</p> <p>Normal: Alternating feet, no rail</p> <p>Mild impairment: Alternating feet; must use rail</p> <p>Moderate impairment: two feet to stair: must use rail</p> <p>Severe impairment: cannot do safely</p>			

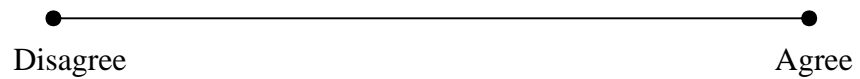
Appendix XII. Exercise Diary

	Home exercises (please tick)	Other activities	Additional comments (please continue on back if necessary)
Monday	<input type="checkbox"/> am / pm <input type="checkbox"/>		
Tuesday	<input type="checkbox"/> am / pm <input type="checkbox"/>		
Wednesday	<input type="checkbox"/> am / pm <input type="checkbox"/>		
Thursday	<input type="checkbox"/> am / pm <input type="checkbox"/>		
Friday	<input type="checkbox"/> am / pm <input type="checkbox"/>		
Saturday	<input type="checkbox"/> am / pm <input type="checkbox"/>		
Sunday	<input type="checkbox"/> am / pm <input type="checkbox"/>		

Appendix XIII. Visual Analogue Scales

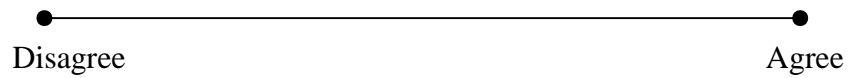
“I feel confident to do my exercises’

Please place a vertical mark on the line below to indicate how strongly you agree / disagree with the above statement **this week**



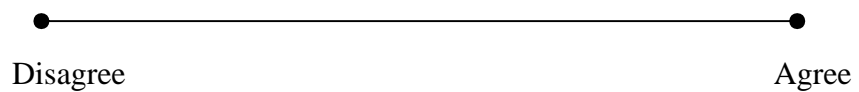
“I am finding the exercise programme beneficial’

Please place a vertical mark on the line below to indicate how strongly you agree / disagree with the above statement **this week**



‘I will continue to follow the exercise programme’

Please place a vertical mark on the line below to indicate how strongly you agree / disagree with the above statement **this week**



Appendix XIV. Selected evaluation tools included in pilot measurement study: summary table of published validity and reliability studies

Selected measure and study authors	Sample and study design	Findings	Conclusions
<p>PBC-40 Jacoby et al., 2005</p>	<ul style="list-style-type: none"> • 1st phase validation – in-depth interviews (n=30) to identify potential questions - systematically reduced, pre-tested and cross-validated in national postal survey (n=900) to produce draft questionnaire • 2nd phase postal validation (n=40) • Draft questionnaire validated against variety of other health-related quality of life questionnaires including: <ul style="list-style-type: none"> - SF-36 - 3 Qs from ESI-55 - 12 general questions relating to perceived 	<ul style="list-style-type: none"> • Developing and pre-testing PBC-40 in postal survey established face and content validity • Reliability – Cronbach’s α ranged from 0.72 to 0.95. 3 out of 6 domains met recommended minimum of 0.9 for individual patient comparisons. ICC scores ranged from 0.83 to 0.96 • Mean satisfaction scores were significantly higher for PBC-40 than for other measures 	<ul style="list-style-type: none"> • PBC-40 is acceptable measure for individuals with primary biliary cirrhosis and has significantly greater relevance than other frequently-used health related quality of life measures • A valuable instrument for use in clinical and research settings

	<p>health status and quality of life</p> <ul style="list-style-type: none"> • Sub-group asked to complete questionnaire 2 wks later to establish reproducibility 		
<p>Self-Efficacy for Exercise Scale Resnick & Jenkins, 2000</p>	<ul style="list-style-type: none"> • Initial validity and reliability testing with sample of older people living in continuing care retirement facility (n=187) • Average age 85 ± 6.2 • Majority were white (98%), female (82%), and unmarried (80%) • Face-to-face interviews were completed and included: <ul style="list-style-type: none"> - SEES - SF-12 - Expected Outcomes and Barriers for Habitual Exercise Scale • Exercise activity based on verbal reporting of participation in aerobic exercise (e.g. walking, swimming, cycling) 	<ul style="list-style-type: none"> • Sufficient evidence to demonstrate internal consistency ($\alpha = 0.92$) • A squared multiple correlation coefficient using structural equation modelling provided further evidence of reliability (R^2 ranged from 0.38 to 0.76) • Evidence of validity based on hypothesis testing: Mental and physical health scores on SF-12 predicted efficacy expectations and efficacy expectations predicted exercise activity • Lambda X estimates (all estimates ≥ 0.81) provided further evidence of validity 	<ul style="list-style-type: none"> • Preliminary testing provided evidence of reliability and validity. • Further testing with young old people and individuals from different socioeconomic and cultural groups is recommended

<p>Outcome Expectation for Exercise Scale Resnick et al., 2001</p>	<ul style="list-style-type: none"> • Questionnaire issued to residents in continuing care retirement facility (n=191) • Average age 85 ± 6.1 • Majority were white (99%), female (76%), and unmarried (76%) • Face-to-face interview were completed and included: <ul style="list-style-type: none"> - OEES - SF-12 - Qs about exercise behaviour - Self-efficacy expectations 	<ul style="list-style-type: none"> • Evidence for reliability based on R² values ranging from 0.42 to 0.77 • Validity was established with path coefficients ranging from 0.69 to 0.87 	<ul style="list-style-type: none"> • The evidence of reliability and validity of this measure has important implications for clinical work and research • The OEES can be used to identify older people who have low outcome expectations for exercise, and interventions can then be implemented to strengthen these expectations to improve exercise behaviour
<p>Falls Efficacy Scale – International Yardley et al., 2005</p>	<ul style="list-style-type: none"> • Cross-sectional survey (n=704) • Average age 74 ± 7.1 • Community-dwelling older people invited to complete postal questionnaire (n=589) • Frailer older people living in sheltered accommodation and attending luncheon clubs invited to participate in face- 	<ul style="list-style-type: none"> • Excellent internal reliability (Cronbach's α = 0.96) • Excellent test-retest reliability for the total score (ICC = 0.96) • All items contributed positively to reliability of scale, inter-item correlations averaged 0.55 (0.29 - 0.79) 	<ul style="list-style-type: none"> • FES-I has at least as good internal and test-retest reliability as any existing measure of fear of falling • Responses to new items on FES-I less skewed towards low concern than responses to original items on FES. • FES-I likely to perform better than FES in detecting

	<p>to-face interviews (n=115)</p> <ul style="list-style-type: none"> • Test-retest reliability established by re-administration of questionnaire one week later to sub-sample of first 16 respondents 		<p>concerns relating to social activities and more demanding outdoor balance-related tasks,</p> <ul style="list-style-type: none"> • Should prove particularly useful for evaluating fear of falling in community-dwelling populations
<p>5 x Sit-to-Stand Lord et al., 2002</p>	<ul style="list-style-type: none"> • 669 community-dwelling men and women aged 75-93 years (mean age 78.9, SD = 4.1) underwent quantitative tests of: <ul style="list-style-type: none"> - strength - vision - peripheral sensation - reaction time - balance - health status - sit-to-stand performance 	<ul style="list-style-type: none"> • Multiple regression analysis revealed that visual contrast sensitivity, lower limb proprioception, peripheral tactile sensitivity, reaction time involving a foot-press response, sway with eyes open on foam rubber mat, body weight, and scores on SF-12 pain, anxiety and vitality scales were significant and independent predictors of S-T-S performance in addition to knee extension, knee flexion and ankle dorsiflexion strength • Of these measures, quadriceps strength had the highest beta weight indicating 	<ul style="list-style-type: none"> • In community-dwelling older people, S-T-S performance is influenced by multiple physiological and psychological processes and represents a particular transfer skill rather than a proxy measure of lower limb strength.

<p>McCarthy et al., 2004</p>	<ul style="list-style-type: none"> • 47 women (mean age 64.5 years) performed 5 x S-t-S and 30 sec S-T-S on same day and bilateral isokinetic hip extension, hip flexor, knee extensor, knee flexor, ankle plantar flexion and ankle dorsiflexion strength testing within 7 days of S-T-S measures. 	<p>it was the most important variable in explaining the variance in S-T-S times.</p> <ul style="list-style-type: none"> • However, the remaining measures accounted for more than half the explained variance in S-T-S times. • The final regression model explained 34.95 of the variance in S-T-s times (multiple R = 0.059) • Regression analyses including all 6 leg strength variables explained 48% ($p = 0.0001$) and 35% ($p = 0.007$) of the variance in 5 x S-T-S and 30 sec S-T-S scores respectively • Ankle plantar flexor, hip flexor, and knee extensor strength were the strongest predictors for both S-T-s tests 	<ul style="list-style-type: none"> • Although ankle plantar flexor, hip flexor and knee extensor strength play essential roles in performing the S-T-S movement, most S-T-S variance was unexplained suggesting that important additional variables are also involved in completing this movement
<p>Whitney et al., 2005</p>	<ul style="list-style-type: none"> • To establish concurrent and discriminate validity of 5 x S-T-S test against: 	<ul style="list-style-type: none"> • Individuals with balance disorders performed 5 x S-T-S more slowly than those without balance disorder. 	<ul style="list-style-type: none"> • The 5 x S-T-s displays discriminative and concurrent validity

	<ul style="list-style-type: none"> - Activities-specific balance confidence scale - DGI <ul style="list-style-type: none"> • Individuals with balance disorder (n=93) and age-matched controls (n=81) completed all 3 measures 	<ul style="list-style-type: none"> • Discriminate analysis demonstrated that the 5 x S-T-S correctly identified 65% of individuals with balance disorder, the ABC identified 80%, and the DGI 78% • Ability of 5 x S-T-S to identify individuals with balance disorder was better for participants younger than 60 years of age (81%) 	<p>properties that make this test potentially useful in clinical decision making, although overall the ABC and DGI were better than the 5 x S-T-S at discriminating between individuals with and individuals without balance disorders.</p>
<p>Performance Orientated Assessment of Mobility Lin et al., 2004</p>	<ul style="list-style-type: none"> • Prospective study to compare the practicality, reliability, validity, and responsiveness of: <ul style="list-style-type: none"> - Timed up and go - One-leg stand - Functional reach - POAM • Community-dwelling older people (n=1,200) in west central Taiwan • In addition to completing 4 balance tests, face-to-face interviews were completed and included: <ul style="list-style-type: none"> - demographic 	<ul style="list-style-type: none"> • Inter-rater reliability within 2 weeks was excellent for all 4 measures (ICC 0.93 to 0.99) • Convergent validity – POAM was strongly or moderately correlated with: <ul style="list-style-type: none"> - TUG (r = - 0.55) - FR (r = 0.48) - ADL (r = 0.60) • POAM had the largest area under the curve in predicting ADL decline and improvement 	<ul style="list-style-type: none"> • The POAM exhibited excellent test-retest reliability • Discriminate, convergent and predictive validity were also confirmed • According to psychometric properties, most suitable performance measure for evaluating balance in community-dwelling older people was the POAM, followed by the TUG

<p>Kegelmeyer et al., 2007</p>	<p>information</p> <ul style="list-style-type: none"> - cognition - falls history - use of walking aid - ADLs <ul style="list-style-type: none"> • Falls ascertained by telephone every 3 mths for a 1 yr follow up • The four balance measures and ADLs were reassessed at end of follow up year • Examined inter-rater and intra-rater reliability of POAM as a falls-risk screening tool in individuals with Parkinson's disease (n=30) + data from retrospective review of 126 patient records • Physiotherapists and physiotherapy students rated live and videotaped performances of the POAB • POAB scores correlated with: <ul style="list-style-type: none"> - UPDRS motor score - comfortable gait speed 	<ul style="list-style-type: none"> • Inter-rater reliability between qualified physiotherapists and students was good to excellent ($r \geq 0.80$, $P < 0.001$). Balance and gait subscales demonstrated similar values ($r = 0.80 - 0.86$, $P < 0.001$) • Intra-rater reliability was moderate to high ($r = 0.69 - 0.88$ $P < 0.001$) • POAM scores correlated with UPDRS motor scores ($r_s = -0.04$) and gait speed ($r_s = 0.53$) • The sensitivity and specificity of the POAM to identify 	<ul style="list-style-type: none"> • POAM is a reliable and valid tool for assessing the mobility status and falls-risk of individuals with Parkinson's disease
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	<ul style="list-style-type: none"> • The ability of the POAB to accurately assess falls-risk was determined 	fallers were 76% and 66% respectively	
<p>Dynamic Gait Index Shumway-Cook et al., 1997</p>	<ul style="list-style-type: none"> • As part of clinical investigation to examine effects of a multi-dimensional exercise programme on balance, mobility, and fall-risk in community-dwelling older people with history of falling, 5 physiotherapists completed DGI in sample of community-dwelling older people (n=5) • 2 of the participants underwent 2 tests, one week apart, to determine test-retest reliability 	<ul style="list-style-type: none"> • Inter-rater reliability ranged from 0.96 to 1.00 	<ul style="list-style-type: none"> • The DGI has excellent inter-rater reliability in community-dwelling older people with a history of falling
McConvey & Bennett, 2005	<ul style="list-style-type: none"> • 11 physiotherapists viewed videos of 10 individuals with multiple sclerosis performing DGI • Videos viewed again 2 wks later and individuals gait rescored 	<ul style="list-style-type: none"> • Inter-rater reliability was 0.98 for the total score and 0.91 to 0.97 for individual tasks (ICC $P < 0.05$) • Intra-rater reliability ranged from 0.76 to 0.98 (Pearson bivariate analysis $P < 0.05$) 	<ul style="list-style-type: none"> • The DGI is a reliable functional tool for assessment of individuals with MS • Concurrent validity established through inverse correlation with timed walk

	<ul style="list-style-type: none"> • To establish concurrent validity DGI scores compared with timed 6.1 meter walk test 	<ul style="list-style-type: none"> • Concurrent validity was demonstrated between DGI and 6.1 m walk test with an inverse relation of -0.80 (Pearson bivariate analysis $P < 0.01$) 	test
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Appendix XV. Topic guide for experimental case-series interviews

1. Can you tell me about your experiences of being diagnosed with primary biliary cirrhosis?
2. What was it that made you decide to participate in this study?
3. Could we look at your measures together?
4. Do you have any other comments / observations that you would like to make about the study?

Appendix XVI. Consent form for focus group research

**What factors influence motivation and adherence with a home-based exercise programme for older people at risk of falls?
(Part 1)**



CONSENT FORM

1. I confirm that I have read and understand the information sheet dated 2.9.06 (Version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is entirely voluntary and that I am free to withdraw at any time, without giving reasons and without my medical care or legal rights being affected.	
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from Newcastle upon Tyne Hospitals NHS Foundation Trust, where it is relevant for my taking part in this research. I give permission for these individuals to have access to my records.	
4. I understand that the Research Team will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law). I give my permission for the Research Team to hold relevant personal data.	

5. I agree to the interviews or focus groups being audio taped	
6. I agree to the use of anonymised quotes from the interviews or focus groups being used in reports or publications resulting from this study.	
7. If I withdraw from this study for any reason, I give my permission for the Research Team to utilize information already collected	
8. I agree to my GP being informed of my participation in the above named study	
9. I agree to take part in the above named study	

Name of Participant

Date

Signature

Name of person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

Appendix XVII. Consent form for experimental case-series

What factors influence motivation and adherence with a home-based exercise programme for older people at risk of falls?



CONSENT FORM

<p>1. I confirm that I have read and understand the information sheet dated 24 February 2009 (Version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</p>	
<p>2. I understand that my participation is entirely voluntary and that I am free to withdraw at any time, without giving reasons and without my medical care or legal rights being affected.</p>	
<p>3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from Newcastle upon Tyne Hospitals NHS Foundation Trust, where it is relevant for my taking part in this research. I give permission for these individuals to have access to my records.</p>	
<p>4. I understand that the Research Team will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law). I give my permission for the Research Team to hold relevant personal data.</p>	

5. I agree to the interviews or focus groups being audio taped	
6. I agree to the use of anonymised quotes from the interviews or focus groups being used in reports or publications resulting from this study	
7. If I withdraw from this study for any reason, I give my permission for the Research Team to utilize information already collected	
8. I agree to my GP being informed of my participation in the above named study	
9. I agree to take part in the above named study	

Name of Participant

Date

Signature

Name of person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

Appendix VIII. Peer Reviewed Publication



Professionals and the public: power or partnership in health research?

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Keywords

conceptual model, evaluation, impact, public involvement, research

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Abstract

Rationale, aims and objectives Involving members of the public in health research is said to produce higher quality research of greater clinical relevance. However, many of the anecdotal accounts of public involvement published in the academic literature to date have focused on the process of recruiting and involving members of the public and the effect of participation on these individuals rather than on how public involvement influenced the research process or outcomes. To strengthen the evidence base, there is clearly a need for more formal methods of capturing and documenting the impact of public involvement in health research.

Methods In the first half of this paper, we discuss the importance of public involvement in health research and critically review the literature to identify current barriers to its successful implementation. In the second half, we present a conceptual model for evaluating and reporting the impact of public involvement in health research. Developed from our examination of the academic literature, we provide empirical support for the model by applying it to our recent experience of conducting a clinically based falls prevention study with members of the public.

Results The conceptual model presented in this paper proposes key concepts and terminology that promote consistency when evaluating and reporting the impact of public involvement in health research. Reflecting on the experiential learning process, we demonstrate how the model promotes conceptual clarity whilst permitting the degree of flexibility required when working in a diverse culture such as the National Health Service.

Conclusion If more evidence can be provided that public involvement enhances research processes and outcomes, researchers may be less inclined to treat this initiative as something they have to do in order to satisfy funding agencies and regulatory bodies and actively embrace this phenomenon, producing accounts of successful public involvement that transcend current barriers to its successful implementation.

Introduction

Public involvement in health research refers to research conducted with or by the public rather than to, about or for them [1]. Over the last 10 years, the Department of Health, National Health Service (NHS) Executive, research charities and funding bodies have emphasized the importance of public involvement in health research [2]. Despite the existence of UK policy directives, however, it would appear that only a small proportion of NHS researchers are currently involving members of the public in health research [3]. Supporters of this initiative suggest the unique perspective provided by individuals who use, or are eligible to use,

health services produces higher quality research of greater clinical relevance [4–7]. However, many of the anecdotal accounts of public involvement published in the academic literature to date have focused on the process of recruiting and involving members of the public and the effect of recruitment upon these individuals rather than on how public involvement influenced the research process or outcomes. Consequently, calls are now being made to strengthen the evidence base underpinning the policy of public involvement in health research [8].

In the first half of this paper, we discuss the importance of public involvement in health research and critically review the literature to identify potential barriers to its successful implementation.

We suggest that the absence of rigorous and robust methods of demonstrating the influence of public involvement in health research is largely responsible for researchers' and clinicians' reluctance to challenge established research paradigms and models of clinical service delivery. In the second half of the paper, we present a conceptual model of public involvement in health research. Developed from an examination of the academic literature, we provide empirical support for the model by applying it to our recent experience of conducting a clinically based falls prevention study with members of the public. It is our intention that this model will assist researchers and clinicians to evaluate and report the impact of public involvement in health research, service delivery and clinical decision making. In this way, we aim to contribute to the development of an evidence base for public involvement in health research.

Clarification of terminology

A lack of agreement remains regarding the language used to specify people who use, or are meant to be served by health care. This debate is fuelled by the fact that it is an argument not just about words, but about ways of seeing and portraying individuals and their relationships with the health care system [9]. Terms such as patient, service user, lay person, client and consumer are used interchangeably in the literature. However, it has been suggested that the choice of terminology applied to health care recipients may actually reflect or be influenced by the agenda of the individual or organization using the term [10]. The public is a portmanteau phrase used to encapsulate the many types of stakeholder who may be involved in health research including patients, service users and carers [1]. While recognizing this term may not be acceptable to everyone due to its lack of precision [3], we have chosen to use 'the public' consistently throughout this paper in an attempt to promote inclusivity.

The case for public involvement in health research

Numerous reasons for involving the public in health research have been cited in the literature. In their review of public involvement in health research, Boote *et al.* suggest these can be broadly categorized into arguments based on theoretical, political and ethical principles [10].

A public perspective is important, theoretically, in any aspect of health care, be it service development, audit or research, because it can complement those of the clinician or researcher. The World Health Organization differentiates between two existing health care paradigms: 'disease, a physiological and clinical abnormality; and illness, the subjective experience of the individual' [11]. The public can act as 'expert witnesses' to an illness, counterbalancing clinical interests in the disease process [12]. Faulkner and Thomas refer to this synergistic relationship as 'a marriage between expertise by experience and expertise by profession' [13].

Various authors have charted the development of UK health policy in relation to public involvement [14,15]. However, put simply, the political argument for involving members of the public in health research is based on the premise that, as citizens and taxpayers, individuals who use health care services have the right to influence research that is funded through public monies [16].

The aim of bringing politics into the health care arena in this way is to change the balance of power by challenging the decision-making monopoly of service providers [4].

The ethics of public involvement have been said to embody 'notions of individual rights, community responsibility, social justice and accountability' [17]. Public involvement in health research challenges the traditional medical model of passive patient and active doctor, placing an ethical obligation on health care providers to achieve a more democratic system of service delivery [10].

Barriers to public involvement in health care research

A recent national survey of NHS researchers demonstrated that, despite strong political and philosophical underpinnings, public involvement in health research continues to be making relatively small inroads, is fragmented and often concentrated within particular groups or geographical areas [18].

Public involvement in health research challenges the positivist position that knowledge can be developed at a distance from research participants, who have traditionally been treated as the passive suppliers of data [19]. Although often criticized as unscientific in the positivist sense, methodological approaches such as participatory and action research have demonstrated the ability to empower members of the public from marginalized groups to challenge health inequalities. The rise in popularity of such methodologies over recent years is important, epistemologically, because it implies a shift away from positivism towards a more phenomenological, experiential focus, grounded in the social realities of those being researched [19].

If public involvement is to be developed into a more inclusive framework for understanding health problems, clinicians and researchers must be prepared to tackle the epistemological and methodological complexities associated with such an initiative. Critical review of the consumerism versus empowerment debate may assist the evolution of public involvement in health research. The levels of public involvement continuum and ensuring representation are potential barriers which we also consider in the following section.

The consumerism versus empowerment debate

The status of the public in health research is one which has been subject to much scrutiny. Public involvement in health research has its roots in the consumerist model of health care deployed alongside the internal market of health and social care in the 1990s. The emphasis on market ideology helped to create a view, in government at least, that recipients of health services deserved the same level of choice, value-for-money and satisfaction as those in more business-focused transactions [20]. Increased interest in the epistemological and methodological issues inherent in public involvement over recent years, however, have led to a sustained attack on consumerist models of participation which are said to be more about customer relations than any enhanced rights which entail true partnership or power sharing [21].

The concept of public involvement in health research has been described by some as being fundamentally related to the issue of rights [17]. Boote *et al.* believe that such rights differ in consum-

erist and empowerment models. They claim that, whereas consumerism is associated with economic outcomes such as satisfaction and value for money, empowerment is very much a political concept related to issues of control and accountability [10].

The argument that remains unresolved in the academic literature relates to the key objective of public involvement in the research process. For example, is involvement in health research fundamentally about increasing the quality of and public satisfaction with the end product (i.e. based on the consumerist model), or does it relate to the empowerment of the public and the democratization of the research process? Martin claims that an analysis of public involvement based solely on these competing ideologies is fundamentally limited [20]. However, such debates may discourage researchers from involving members of the public in health research, particularly if they believe involvement can only be a worthwhile activity within the context of participatory or action research methodologies.

Levels of public involvement continuum

Public involvement has been viewed by some on a continuum, ranging from low to high levels of participation [21]. INVOLVE, an organization funded by the National Institute for Health Research to promote public involvement in health and social care research, has condensed Arnstein's ladder of citizen participation [22] into three levels of public involvement: consultation (where researchers seek the views of the public on key aspects of the research), collaboration (an ongoing partnership between researchers and the public throughout the research process) and user-control (where the public design and undertake the research and researchers are only invited to participate at the invitation of the public) [1].

While Hanley *et al.* acknowledge that different types of involvement will be appropriate for different research projects [1], the levels of involvement continuum has been interpreted by some authors as one of increasing empowerment of the public within the research process [9]. Conceptually, consultation is often aligned with consumerist models of involvement, whereas collaboration and user-control are favoured by exponents of action and participatory methods of health research.

Barber *et al.* warn against assuming that higher levels of public involvement are automatically better, because they do not mirror all the dimensions of involvement that may be significant or take into account the outcomes of public involvement in health research [18]. However, researchers lacking the necessary skills or resources to embrace a model of collaboration or user-control may be dissuaded from including a public perspective in their research as a direct consequence of the perceived weaknesses of consultation commonly portrayed in the academic literature.

While the levels of involvement continuum provides a conceptual framework to articulate public involvement in health research [23], it should be remembered that public involvement is a complex and complicated phenomenon [24]. In reality, public involvement may range from none, to some, or full engagement as a project develops. Members of the public may, for example, have no involvement in designing the research, be consulted over data collection and have complete control over the dissemination of findings [9]. Such models may therefore lack the flexibility

researchers require when conducting a clinical investigation and this may discourage them from involving members of the public in health research.

Ensuring representation

In neglecting to engage with large swathes of the general public, public involvement may be seen by some to fall short of its promise to provide a direct, more-than-tokenistic say in the governance of health research [20]. In their review of 1108 papers on involvement for change in health services, Crawford *et al.* suggest that 'statements about representativeness are very common in the literature, but the meaning of the term is rarely considered' [25].

Providing a statistically representative sample of a target research population is a concept traditionally associated with the positivist paradigm [26]. However, such methods do not necessarily guarantee accurate representation. Parkinson argues 'there is no fundamental reason why the descriptive representation of shared characteristics, such as ethnicity or social class, promised by random selection, should translate into accurate representation on the level of expressed opinion' [27].

It has been suggested that one of the most successful ways to involve the public in health research is through relationships that already exist and are well established [2]. Despite this, such approaches have been criticized in the academic literature for their associations with selectivity and elitism and a reliance on self-selection or the selection of acquiescent or financially better-off individuals which, some authors claim, result in only a few voices being heard, often at the expense of socially marginalized groups [28].

The tensions surrounding representation may have contributed to a delay in the evolution of public involvement in health research. Rather than debating different rationales of representation, however, Beresford believes researchers should concern themselves with the issue of inclusivity [9]. Authors have identified a number of ways in which potentially marginalized social groups can be involved in health research, including: offering time and resources to support their involvement, structuring research meetings to be inclusive, providing advocacy, recognizing the importance of language in ensuring inclusion and developing appropriate language policy and practice [29].

Evaluating the impact of public involvement in health research

Formal appraisal of public involvement in health research is rare. While the literature may be replete with enthusiastic reports and reflections, there is often little or no detail provided about the process of public involvement and a lack of any attempt to evaluate the impact of public involvement on research outcomes [23]. In October 2009, INVOLVE published a report exploring the impact of public involvement in NHS, public health and social care research. A structured review of the literature identified only 89 articles suitable for in-depth evaluation. From these, the author was able to identify a number of strong and consistent themes which provided support for public involvement at all stages of the research process. Despite this a number of limitations were also acknowledged, most notably surrounding the inherent difficulties of assessing and reporting the impact of public involvement on

research processes and outcomes [30]. To strengthen the evidence base, there is clearly a need for consistent and robust methods of conceptualizing public involvement in health research and evaluating its impact in a clinical setting.

The Research Excellence Framework, proposed to replace the Research Assessment Exercise as the new system for assessing and funding research in UK higher education institutions, demonstrates a strong commitment to providing greater accountability for public expenditure on research. As well as collating evidence of quality through research output and environment, higher education institutions will be expected to demonstrate the wider economic and social impact of their research activities. While acknowledging the challenges associated with establishing impact, the Higher Education Funding Council for England suggests this will not be assessed through intellectual influence on scientific knowledge and academia, as for the output and environment elements of the Research Excellence Framework, but by demonstrating that high-quality research has informed practice, well beyond the institution in which that practice was first developed [31].

The INVOLVE report suggests that public involvement may have an impact on the research project (at all stages and levels), the public, clinicians, researchers, participants, consumer groups and the wider community, as well as influencing whether research findings are used to bring about change [30]. In the second half of this paper, we present a conceptual model of public involvement in health research and critically reflect upon our own experience of conducting a clinically based falls prevention study with members of the public to demonstrate how the model may be used to explore and evaluate the impact of public involvement in health research.

Background to falls prevention study

The quality of life of an older person can be dramatically reduced following a fall [32] and we wanted to include individuals identified as being at risk of falling in an exercise-based falls prevention study. Despite the substantial body of research evidence to support the efficacy of strength and balance training as a strategy for reducing falls [33–35], uptake rates average only 50% [36] suggesting that older people may be reluctant to take part in such activities. In order to gain a better understanding of the factors influencing uptake and adherence with strength and balance training, we conducted a series of focus groups with older people attending a regional falls and syncope service (three groups, 12 participants), relatives (one group, four participants) and local physiotherapists (four groups, 18 participants). Participants were asked to propose strategies to promote long-term participation with an exercise-based falls prevention programme and these were used to inform an exploratory case series. Ethical approval for both phases of this investigation was provided by the local research ethics committee.

A conceptual model of public involvement in health research

Public involvement in health research is a dynamic and multifaceted activity. Presenting the process diagrammatically has limitations yet serves to promote conceptual clarity. In our model (Fig. 1), public involvement is considered a product of the degree of collaboration throughout the research process (vertical axis), and empowerment; expressed in terms a top-down or bottom-up approach (horizontal axis). The two axes divide the model into

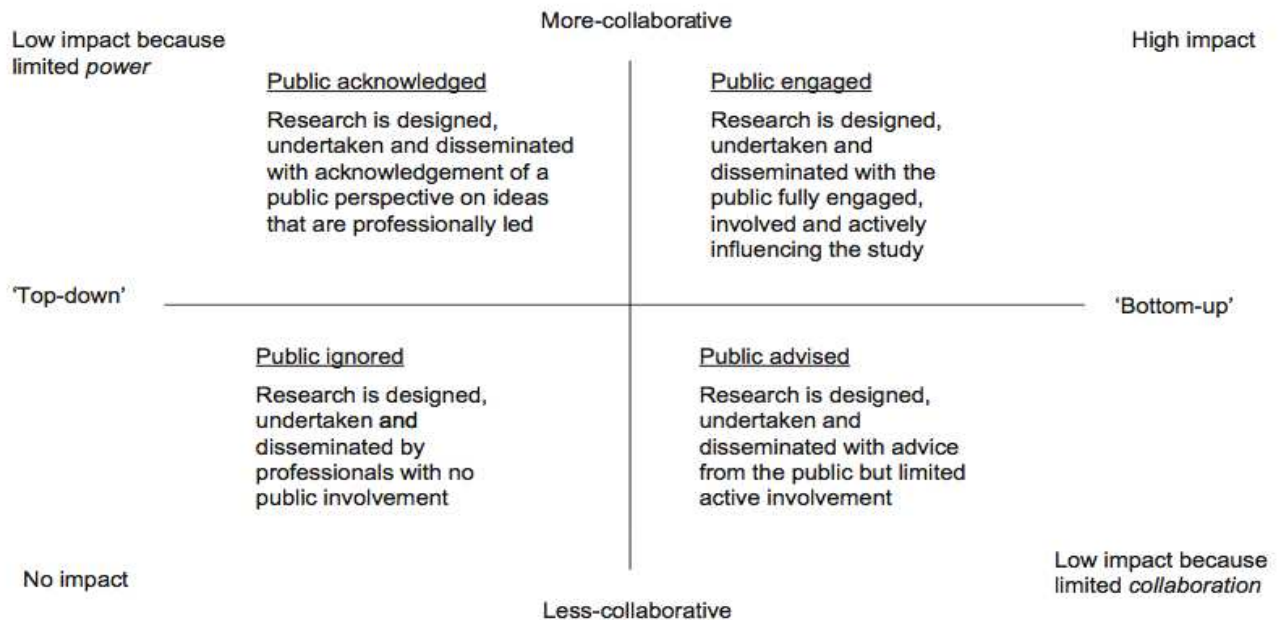


Figure 1 A conceptual model for evaluating and reporting the impact of public involvement in health research.

four quadrants: public ignored, public acknowledged, public advised and public engaged and permit different levels of involvement to occur within the same research project. The impact of public involvement may be evaluated by considering the degree of collaboration and empowerment of the public at key stages throughout the research process.

We now consider each of the four quadrants in relation to our falls prevention study to demonstrate the model's ability to explore and evaluate the impact of public involvement in health research.

Public ignored (non-collaborative/top-down – no impact)

Many funding bodies now request that NHS researchers provide evidence of public involvement when submitting their proposals. However, some authors claim it is still difficult to obtain adequate funding to involve members of the public in a meaningful way during the initial formulation stages of clinical research [3]. All researchers conducting clinical investigations in the NHS require approval from the National Research Ethics Service before commencing their data collection. Academic research culture is fundamentally project-driven and researchers are frequently hired on short-term contracts to undertake projects within tightly defined deadlines [3]. For many NHS researchers therefore the research begins when the project begins [37]. The drive to obtain ethical approval prior to embarking on health research may help to explain why public involvement is often absent from the early developmental stages of many clinically based projects.

The research questions underpinning this falls prevention study were prompted by our experience as NHS practitioners and a review of the academic falls prevention literature rather than discussions with members of the public as users, or potential users, of health care services. It was felt that a better understanding of the factors influencing uptake and adherence with strength and balance training, together with an exploration of potential strategies to promote long-term participation would have a direct impact on clinical practice and improve local service delivery for older people at risk of falling. However, taking a critically reflexive stance, it can now be seen that failure to include a public perspective during the initial developmental stages of this investigation meant that we embarked upon our project within the traditional positivist paradigm described in the first half of this paper.

Our initial approach is represented by the public ignored quadrant in the bottom-left-hand-corner of the model where research is designed, undertaken and disseminated by professionals with no public involvement. Public involvement has no impact on the research process in a public ignored paradigm as members of the public are excluded from the research process and the balance of power remains solely with the researcher in a top-down approach.

Public acknowledged (more-collaborative/top-down – low impact because limited power)

As soon as ethical approval had been obtained for the initial phase of our investigation; however, we identified a small group of older people (four service users and two relatives) from our current clinical caseload. The perspectives of these individuals were sought on matters relating to the design and execution of the study, such as the suitability of language used in the participant informa-

tion sheets and the appropriateness of individual versus focus group methods of data collection. Rather than advertise for volunteers, we approached individuals who we felt possessed the relevant skills, life experiences and personal attributes necessary to influence the development of the investigation. It was felt that a group of six individuals would allow for variations in perspective and attitude without inhibiting decision making and productivity [24]. While overlaps in role are acknowledged, a deliberate distinction was made between service users and relatives to gain a better appreciation of the different interests and perspectives that may exist and to avoid one group speaking on behalf of, or being seen to represent, the other [9].

At this point in the study we shifted into the public acknowledged quadrant in the top-left-hand-corner of our model. Here, research is designed, undertaken and disseminated with acknowledgement of a public perspective on ideas that are professionally led. Much of the advice sought in the early stages of this investigation was procedural, based on an approved project design developed by the research team. While we moved into a more collaborative paradigm, it can be seen that the impact of public involvement is still limited by the lack of public power in a top-down approach.

Public advised (less-collaborative/bottom-up – low impact because limited collaboration)

A common criticism of qualitative research is that the analysis and interpretation of data can vary considerably depending on who is involved in the process [2]. While it is not possible to abolish or fully control for observer bias [38], some authors claim that involving research participants in the analysis and interpretation of qualitative data increases the cultural and internal validity of the findings and, thus, strengthens the scientific rigor of an investigation [39]. In an attempt to overcome observer bias, we met with the service user and relatives' group approximately half way through the focus group sessions and presented them with a summary of emerging themes. By asking them to comment on whether these themes resonated with them as older people, we aimed to ensure the data collected were transparent and meaningful.

Provisional analysis of the focus group data revealed opposing views and standpoints on the part of older people and local physiotherapists. The older people interviewed expressed a long-term commitment to strength and balance training. However, the physiotherapists perceived many of the older people they came into contact with were poorly motivated to participate in exercise-based falls prevention programmes. While the service user and relatives' group quickly validated their peers' views and opinions, perhaps not unsurprisingly, it was the physiotherapy focus group findings they found most interesting and chose to discuss in greater detail. They suggested that failure to appreciate the benefits experienced by older people as a result of undertaking strength and balance training may have resulted in a sense of poor job satisfaction and apathy among the physiotherapists and this, together with a degree of professional arrogance, could account for the views and opinions obtained.

By sharing our early findings with the service user and relatives' group, we moved into the public advised quadrant in the bottom-right-hand-corner of our model in which research is designed, undertaken and disseminated with the advice of the public but limited active collaboration. Such activity can be seen to represent

a shift from a top-down to a bottom-up approach, because the alternative insights they provided encouraged us to take more of a critically reflexive stance in our analysis of the focus group findings. However, because we selected the data presented, it could be argued there was limited public collaboration and the overall impact of public involvement on the research project remained relatively low.

Public engaged (collaborative/bottom-up – high impact)

It is considered good practice for individuals involved in clinical research to know the results of studies in which they have participated before anyone else [7]. However, in practice, when dissemination does occur, it tends to be in peer reviewed journals and through academic conference proceedings which benefit the researcher's professional career and impact on only a small number of 'research-active' clinicians [40]. The Department of Health and funding agencies have come to recognize that a much wider dissemination process is necessary. They argue that public dissemination is vital because, in the new consumer-orientated NHS, it is not only evidence-based randomized controlled trials that determine which interventions are introduced into clinical practice but also public demand [2].

It has been suggested that participants involved in clinical studies should also be included in the documentation and dissemination of the research findings [2]. In response to the focus group findings, one of the service users expressed a desire to meet with local physiotherapists to describe the benefits she had experienced as a result of participating in strength and balance training. Although their views heavily influenced the way in which the focus group findings were disseminated, we chose not to include her in local feedback sessions due to apprehension about physiotherapy colleagues being dismissive of the older people's views. On reflection, the decision not to involve the service user and relatives' group in the dissemination of research findings was a missed opportunity for the study to impact on local service delivery.

Involving the service user and relatives' group in the dissemination of research findings would have represented a move in to the public engaged quadrant in the top-right-hand-corner of our model where research is designed, implemented and disseminated with the public fully engaged, included and actively influencing the study. Within a public engaged paradigm, the impact of involvement is high as collaboration is successfully combined with a bottom-up approach.

Discussion

While we acknowledge that the impact of public involvement in health research is highly context-specific [30], our model proposes terminology and key concepts that promote consistency in the documentation of public involvement in health research. We have demonstrated how this model can assist researchers and clinicians to evaluate and report the impact of public involvement in health research, service delivery and clinical decision making.

Academic research culture encourages researchers to report the results of clinical studies rather than to describe the lessons learnt as part of the process [30]. However, greater transparency is needed if NHS researchers are to move beyond the rhetoric of

public involvement in health research. It is not our intention to provide a perfect example of public involvement in health research for clinicians and researchers to aspire to. By critically reflecting on our experience of conducting a clinical investigation involving members of the public and acknowledging the limitations, we aim to contribute to the methodological development of public involvement in health research and the understanding of its impact on processes and outcomes.

It has been suggested that older adults are less consumer-orientated than younger people, do not wish to be involved in clinical research or lack the necessary skills to make a worthwhile contribution [24]. However, it can be seen that the group demonstrated a high level of commitment throughout the 14-month qualitative study and the impact of their involvement was only limited by professional anxieties on the part of the research team. Their willingness to take on additional responsibilities as the study progressed supports the notion that public involvement in health research empowers individuals through a realization that they can shape public policy and bring about change.

Many of the successful accounts of public involvement in health research published in the academic literature to date have occurred within the context of a participatory or action research design. However, our study demonstrates that public involvement in health research can have an impact beyond the confines of such methodological approaches. While our investigation may have begun in a traditional positive paradigm (public ignored), the flexibility provided by the conceptual model allowed us to move into the public acknowledged and public advised quadrants as the study progressed. Increased collaboration and empowerment of project advisors impacted heavily on the study and this may be seen as an epistemological journey on the part of the research team. The service user and relatives' group wanted to move into the public engaged quadrant in the final stages of the investigation. We had not planned for this, but it became a critical incident in rethinking our approach to public involvement in health research.

Open, immediate and online access to information, previously accessible only to appointed experts, has reshaped the boundaries defining professional and public status [3]. The development and training needs of clinicians and researchers must be addressed if we are to work within a changed context of relationships with members of the public that challenge established NHS traditions [24].

Conclusion

In view of Higher Education Funding Council for England proposals to selectively allocate research funding to higher education institutions based on a quality assessment of output, impact and environment, there is clearly a need for formal methods of capturing and documenting the impact of public involvement in health research. The model presented in this paper seeks to promote conceptual clarity while permitting the degree of flexibility needed when working in a diverse culture such as the NHS. If more evidence can be provided on its impact, researchers may be less inclined to treat public involvement as something they have to do in order to satisfy regulatory bodies and funding agencies and more as an integral component to be implemented and reported on at every stage of the research process.

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Appendix XIX. Experimental case-series data summary tables

Eleanor (Standard Intervention)

Context	Content	Enabling Mechanisms	Disabling Mechanisms	Outcome
<p>Aged 63. Retired school teacher. Lives alone. PBC diagnosed 2006 by GP from blood tests taken for suspected tendonitis of feet and ankles. Referred to local hospital but transferred to auto-immune liver clinic after joining patient support group. Regularly participates in research via patient support group. No falls to date but progressive unsteadiness. Suffers from joint pain and fatigue secondary to PBC. Hiatus hernia and hypothyroidism.</p>	<p>Received 6 week standard intervention. Issued with 4 generic seated / standing exercises which were not progressed throughout intervention phase. No difficulties reported during baseline, intervention and follow up phases.</p>	<p>Aware of lower limb muscle weakness as difficulties climbing over stiles when out walking dog. Also unsteady when turning quickly or side-steeping to left. Keen to participate in exercise-based falls prevention programme to remain independent in activities of daily living and so that she and others could learn more about PBC.</p>	<p>Low self-efficacy and outcome expectation for exercise on commencing study. Did not enjoy exercising at home due to perceived lack of social support. Considered home-exercise programme too easy, not targeted / individualized enough. No noticeable progression of exercises. Did not feel selected measures adequately addressed gait / balance / functional problems she was experiencing.</p>	<p>Completed home-exercises 3-4 x weekly throughout intervention and follow up phases but did not continue on completion of study. Subjective improvements in lower limb muscle strength but remains unsteady on turning and side-stepping to the left. Considered experimental case-series ‘missed opportunity’ to develop long-term commitment to exercise-based falls prevention programme.</p>

Dorothy (Standard Intervention)

Context	Content	Enabling Mechanisms	Disabling Mechanisms	Outcome
<p>Aged 78. Retired social worker. Lives with husband who has longstanding physical health problems. PBC diagnosed in 2007 from routine blood tests taken following admission to hospital with TIA. Initially referred to local hospital but transferred to auto-immune liver clinic on recommendation of friend. Regularly participates in research via patient support group. Several mechanical falls to date. Suffers from fatigue but believes due to advancing age rather than PBC. Widespread arthritis – awaiting total knee replacement.</p>	<p>Received 6 week standard intervention. Issued with 4 generic seated / standing exercises which were not progressed throughout intervention phase. Developed chest infection during intervention phase which limited progress with home-exercise programme, otherwise no difficulties reported.</p>	<p>Found the exercises enjoyable and the programme convenient to complete at home. Persuaded to sign up for experimental case-series by friend (Eleanor) whilst attending auto-immune liver clinic.</p>	<p>Low self-efficacy and outcome expectation for exercise on commencing study. Does not perceive that she experiences any problems with gait or balance so home-exercise programme and selected outcome measures lacked personal relevance. Developed chest infection during intervention phase which limited progress with home-exercise programme.</p>	<p>Completed home-exercises 3-4 x weekly throughout intervention and follow up phases (missed 1 week due to chest infection) but did not continue to follow programme on completion of study. On reflection, reported subjective improvements in lower limb muscle strength as a result of participating in exercise-based falls prevention programme despite awaiting total knee replacement.</p>

Jenny (Standard Intervention)

Context	Content	Enabling Mechanisms	Disabling Mechanisms	Outcome
<p>Aged 80. Lives alone. Retired administrator for family haulage business. PBC diagnosed 1981 when developed jaundice following road traffic accident resulting in fractured left femur, but describes fatigue-type symptoms dating back to birth of son in 1963. Referred to auto-immune liver clinic by GP when moved to local area from Cumbria. Underwent liver transplant in 1995. Regularly participates in research via patient support group. Previous mechanical fall. Ongoing problems with fatigue secondary to PBC.</p>	<p>Received 6 week standard intervention. Issued with 5 generic standing exercises which were not progressed throughout intervention phase. Experienced flare up of osteoarthritis in feet during treatment phase and omitted one of the exercises for 3 weeks, otherwise no difficulties reported.</p>	<p>High self-efficacy and outcome expectation for exercise on commencing study. Previous and ongoing experience of recreational exercise – attends ‘keep-fit’ class once weekly and goes swimming. Keen to participate in experimental case-series so that she and others could learn more about PBC.</p>	<p>Does not consider herself to be at increased risk of falling. Did not enjoy completing home-exercise programme as felt it was boring / too easy. Does not perceive that she is experiencing any gait / balance / functional difficulties so selected measures lacked personal relevance. Experienced flare up of osteoarthritis in feet which limited progress with home-exercise programme.</p>	<p>Completed home-exercises 6 -7 x weekly throughout intervention and follow up phases but did not continue with programme on completion of study. No improvements in lower limb muscle strength / balance etc but did not expect to experience any personal gain as a result of participating in experimental case-series. However, on reflection, felt the experimental case-series represented ‘missed opportunity’ to develop long-term active commitment to exercise-based falls prevention programme.</p>

Shirley (Enhanced Intervention)

Context	Content	Enabling Mechanisms	Disabling Mechanisms	Outcome
<p>Aged 66. Retired shop assistant. Lives with husband who is in good physical health. PBC diagnosed in 2005 as experiencing problems with immune system. Referred to auto-immune liver clinic by GP. Regularly participates in research via patient support group. No falls to date but progressive unsteadiness. Fatigue and joint pain secondary to PBC. Ischaemic heart disease, type II diabetes and myopathy secondary to mitochondrial dysfunction.</p>	<p>Received 6 month enhanced intervention. Initially issued with 5 standing exercises targeting proximal lower limb muscle groups which were progressed at each visit despite fluctuating health status. Encouraged to increase number of sessions / repetitions between appointments as able. Set goal of being able to continue with home-exercise programme despite fluctuating health status on completion of intervention phase.</p>	<p>High self-efficacy and outcome expectation for exercise on commencing study. Previous and ongoing experience of recreational exercise – attends ‘rehab gym’ 5 x weekly. Complemented recreational activities. Aware of lower limb muscle weakness and unsteadiness – unable to carry shopping bags without staggering. Found home-exercise programme varied and enjoyable. Keen to participate in experimental case-series so that she and others could learn more about PBC but also felt subject matter was of personal relevance.</p>	<p>Did not feel selected outcome measures adequately addressed balance / gait / functional difficulties she was experiencing. Perceived that assessment and treatment process was not adequately ‘joined up’ so did not relate home-exercise to goal setting.</p>	<p>Completed home-exercises 7 x weekly throughout intervention and follow up phases despite fluctuating health status. Still following programme 3-4 x weekly on completion of study. Some subjective improvement in lower limb muscle strength and balance reported as a result of participating in the home-exercise programme but felt to be limited by ongoing health problems.</p>

Helena (Enhanced Intervention)

Context	Content	Enabling Mechanisms	Disabling Mechanisms	Outcome
<p>Age 70. Lives alone. Retired nurse. PBC diagnosed 1992 from routine blood tests after spinal surgery. Worked overseas for Missionary Society but returned when physical health deteriorated. Required liver transplant in 1992. Initially attended local hospital but transferred to auto-immune liver clinic after joining patient support group. Regularly participates in research via local patient support group. No falls to date but progressive unsteadiness. Fatigue and abdominal discomfort secondary to PBC. Insulin dependent diabetes</p>	<p>Received 6 month enhanced intervention. Initially prescribed 5 standing exercises targeting proximal lower limb muscle groups which were progressed at each visit despite ongoing physical health problems. Encouraged to increase number of sessions / repetitions between appointments as able. No problems reported during baseline, intervention and follow up phases which impacted on ability to complete home-exercise programme. Set goal to participate in transplant games on completion of intervention phase.</p>	<p>High self-efficacy and outcome expectation for exercise on commencing study. Previous and ongoing experience of recreational exercise – bowling and archery. Aware of lower limb muscle weakness and unsteadiness – difficulties climbing stairs and staggered when walking. Keen to participate in experimental case-series so that she and others could learn more about PBC but also felt subject matter was of personal relevance. Noticed functional benefits which were reflected in selected outcome measures.</p>	<p>Home-exercises became too easy during follow up phase as physical health status improved and recommenced recreational exercise programme.</p>	<p>Completed home-exercises 7 x weekly throughout intervention and follow up phases despite physical health problems. Still following programme 3-4 x weekly on completion of study. Reported subjective improvements in lower limb muscle strength but did not experience any change in dizzy symptoms. Achieved personal goal of participating in transplant games during follow up phase of study.</p>

Jane (Enhanced Intervention)

Context	Content	Enabling Mechanisms	Disabling Mechanisms	Outcome
<p>Aged 78. Lives alone. PBC diagnosed 1994 from routine blood tests as taking steroids for fibromyalgia. Referred to auto-immune liver clinic by GP. Does not attend patient support group and has not previously taken part in local research. Several mechanical falls to date. Suffers from fatigue and memory problems but believes these are due to advancing age and pre-existing co-morbidities rather than PBC. Chronic lower back pain, fibromyalgia, cataracts, hypertension, left bundle branch block, stroke disease and treated hypothyroidism.</p>	<p>Received 6 month enhanced intervention. Initially prescribed 5 standing exercises targeting proximal lower limb muscle groups, feet and ankles. Limited progression due to exacerbation of chronic lower back pain but exercise programme modified or progressed at each visit. Encouraged to increase number of sessions / repetitions etc within limits of back pain. Set goal to increasing general confidence in ADL on completion of intervention phase.</p>	<p>Keen to participate in experimental case-series so that she and others could learn more about PBC. Had never taken part in clinical research before so curious about process.</p>	<p>Low self-efficacy and outcome expectation on commencing study. Musculoskeletal pain exacerbated by home-exercise programme. Previous negative experiences of physiotherapy at local hospital. Did not enjoy exercising at home due to perceived lack of social support. Did not feel selected outcome measures adequately addressed balance / gait / functional difficulties she was experiencing. Did not believe that falls are preventable.</p>	<p>Completed home-exercises 4-5 x weekly throughout intervention and follow up phase as limited by musculoskeletal pain. Did not continue to follow programme on completion of study. Does not feel that she experienced any improvements in lower limb muscle strength / balance as a result of participating in experimental case-series as limited by musculoskeletal pain. Did not believe falls were preventable on completion of study.</p>

Patricia (Enhanced Intervention)

Context	Content	Enabling Mechanisms	Disabling Mechanisms	Outcome
<p>Aged 68. Retired school teacher. Lives with husband who is in good physical health. PBC diagnosed 1996. Longstanding problems with fatigue. Improved following removal of gall bladder but returned several months later. Referred to auto-immune liver clinic by GP. Regularly participates in research via patient support group. Previous mechanical falls. Suffers from fatigue and abdominal discomfort secondary to PBC. Treated hypothyroidism and osteopenia.</p>	<p>Received 6 month enhanced intervention. Initially prescribed 5 standing exercises which targeted feet and ankles which were progressed at each visit. Encouraged to increase number of sessions / repetitions etc between visits. Stressful family situation during treatment phase limited progress with home-exercise programme, otherwise no difficulties reported. Difficult to set achievable goals on completion of intervention phase as no longer felt she was experiencing any difficulties with balance / gait / functional activities</p>	<p>Previous and ongoing experience of recreational exercise – attends ‘keep-fit’ class once weekly. Complemented recreational activities. Aware of unsteadiness on commencing study – went over on ankles when tired or distracted. Keen to participate in experimental case-series so that she and others could learn more about PBC but also felt subject matter was of personal relevance. Felt home-exercise programme was appropriately targeted and convenient to complete at home.</p>	<p>Low self-efficacy and outcome expectation for exercise on commencing study. Did not feel selected measures adequately addressed balance / gait / functional difficulties she was experiencing. Home-exercises became too easy / tedious towards end of follow up phase as no longer felt she was experiencing any problems with balance / gait / functional activities.</p>	<p>Completed home-exercise 5-6 x weekly throughout intervention and follow up phases but did not continue on completion of study as able to do more at ‘keep fit’ class. Reported subjective improvements in ankle stability / balance as a result of participating in exercise-based falls prevention programme – able to use trampet at ‘keep fit’ class during follow up phase.</p>

Denise (Enhanced Intervention)

Context	Content	Enabling Mechanisms	Disabling Mechanisms	Outcome
<p>Aged 64. Lives with husband who is in good physical health. Retired social servant. PBC diagnosed 2003 by GP but had been complaining of fatigue / itch for 2 years prior to diagnosis. Referred to local hospital but transferred to auto-immune liver clinic after joining patient support group. Regularly participates in research via local patient support group. Two mechanical falls to date. Suffers from fatigue secondary to PBC. Widespread osteoarthritis and treated hypertension.</p>	<p>Received 6 month enhanced intervention. Initially prescribed 5 standing exercises primarily targeting proximal lower limb muscle groups which were progressed at each visit. Encouraged to increase number of sets / repetitions between appointments. No difficulties reported during baseline, intervention and follow up phases. Set goals relating to self-efficacy mobilising outdoors on completion of intervention phase.</p>	<p>Found home-exercise programme enjoyable. Keen to participate in experimental case-series so that she and others could learn more about PBC. Selected outcome measures raised awareness of balance / gait and functional difficulties she was experiencing. Length of time between appointments enabled her to progress exercises and ‘take ownership’ of treatment programme.</p>	<p>Low self-efficacy and outcome expectation for exercise on commencing study. Initially found home-exercises programme too easy – thought exercise had to be aerobic to provide health benefits. Difficulties setting achievable and meaningful goals during follow up phase. Ongoing low self-confidence and dependency on husband for activities of daily living.</p>	<p>Completed home exercise programme 7 x weekly throughout intervention and follow up phases. Continued to follow programme 4-5 x weekly on completion of study. Improvements in lower limb muscle strength and function but these did not impact on fatigue symptoms. Whilst self-efficacy and outcome expectation for exercise improved as a result of undertaking experimental case-series did not feel goals pertaining to improving self-efficacy mobilising outdoors were achievable and this had a negative impact on self-confidence.</p>

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