An epidemiological study of self-care restriction and joint pain in community-dwelling older people

Yeliz Prior

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Arthritis Research UK Primary Care Centre
Keele University

Declaration

This study involves secondary analysis of data collected in the North Staffordshire Osteoarthritis Project (NorStOP), which was funded by a Medical Research Council (MRC) programme grant (grant code: G9900220 and G0501798) and is hosted by the Arthritis Research UK Primary Care Centre, Keele University. The proposal for the PhD project was put forward by Dr Ross Wilkie, who obtained the Acorn funding for the studentship.

The NorStOP data were collected prior to the start of my PhD. Dr Ross Wilkie provided me with background information on the NorStOP study with regards to the methods of data collection and content of the surveys. I used the NorStOP data for secondary analysis of previously collected data. I planned and undertook all analyses for this study, with advice from the supervisory team: Dr Ross Wilkie, Dr Roger Beech and Professor George Peat. The supervisory team also advised me on the writing and presentations of the thesis chapters. I received guidance from Dr Rachel Gick on developing the search strategy for the systematic review. Dr Milisa Bucknall provided statistical advice throughout. The interpretation and the discussion of the findings are my own.

Abstract

Self-care restriction is proposed in the World Health Organization's International Classification of Functioning (ICF) as an important functional consequence of health conditions. In contrast to traditional approaches which focus only on an individual's physical capacity, the ICF model also acknowledges the potential role of contextual factors such as environmental factors and personal needs. This thesis aims to understand the occurrence, course, and determinants of self-care restriction, as defined in the ICF, in community-dwelling adults aged 50 years and over, particularly in relation to joint pain and from a novel perspective: person-perceived participation restriction in which individuals judge whether their self-care needs are met "as and when I have wanted".

Data collected at three time points, by postal questionnaire across 6 years in the North Staffordshire Osteoarthritis project, were used in the analysis (n=7725 at baseline). The prevalence of person-perceived restricted self-care was 11.5% (95% CI 10.8, 12.2). A parsimonious model of factors associated with self-care restriction included age, activity limitation, depression, cognitive impairment, perceived inadequacy of income and low educational attainment. Older adults with joint pain were more likely to report self-care restriction, although this association was not independent of other factors. The frequencies of onset and persistence of restricted self-care at three years were 6.6% (95% CI 5.9, 7.5) and 38.9% (95% CI 33.7, 44.3) respectively. The key factors associated with restricted self-care at baseline were also predictive of the onset of self-care restriction at three years, but only depression was predictive of persistence.

Unmet need for help and assistance was associated with restricted self-care in older adults with joint pain. However, those who received help were also more likely to report restriction.

These analyses suggest a range of potential health and social targets for reducing self-care restriction in individuals with joint pain in middle and old age.

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Context of the thesis

I studied for a BSc (Hons) in Occupational Therapy (OT) at the University of Salford. As part of my dissertation, I completed a research project proposal that spurred my interest in evidence based research. During this work, I recognised that there was a paucity of epidemiological research which underpinned the rationale behind the core principals of OT. I decided that I would like to contribute to my profession by getting actively involved in research. In order to do this, I needed to train to be a researcher. Thus, I started to search for funding opportunities to study for a research degree. Following the completion of my degree in 2008, I was successful in obtaining a PhD studentship at the Arthritis Research UK Primary Care Centre, Keele University to study for self-care restrictions and joint pain in older people. Self-care is an important topic in OT, as it is one of the three main occupations (i.e. self-care, productivity and leisure) in which therapists work together with individuals to overcome obstacles and optimise their involvement in activities of daily living.

After completing my PhD studentship at the Arthritis Research UK Primary Care Centre at Keele University, I secured a post as a research assistant to Professor Alison Hammond at the Centre of Health Sciences, University of Salford, where I continue to pursue research into the impact of musculoskeletal conditions further, and to build on the OT research in the assessment of activities of daily living and participation, through projects such as the UK-Evaluation of Daily Activity Questionnaire (UK-EDAQ), Valued Life Activities Scale (VLAS) and Work Rehabilitation in Inflammatory Arthritis (WORK-IA) .

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List of abbreviations

ADL	Activities of Daily Living
AHEAD	Asset and Health Dynamic Survey among the oldest old
AIHW	Australian Institute of Health and Welfare Knowledge
AMED	Allied and Alternative Medicine
ASSIA	Applied Social Sciences Index and Abstracts
AOAT	American Occupational Therapy Association
AUSCAN	Australian/Canadian Osteoarthritis Hand Index
BAOT	British Association of Occupational Therapists
BPS	British Pain Society
CASP	Critical Assessment Skills Programme
CHPR	Centre for Housing Planning and Research
CI	Confidence Interval
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CMOP	Canadian Model of Occupational Performance
COPM	Canadian Occupational Performance Model
COT	College of Occupational Therapists
EARRS	Elderly At Risk Rating Scale
EDAQ	Evaluation of Daily Activity Questionnaire
EMBASE	Excerpta Medica Database
ESCAP	Economic and Social Commission for Asia and the Pacific
FACS	Fair Access to care Services
FIM	Functional Independence Measure
GARS	Groningen Activity Restriction Scale
GMC	General Medical Council
GP	General Practice
HADs	Hospital Anxiety and Depression Scale
HAQ	Health Assessment Questionnaire
HRS	Health Retirement Study
HRQoL	Health Related Quality of Life
IADL	Instrumental Activities of Daily Living
ICD	International Classification of Diseases
ICE	Imputations by Chained Equations
ICF	International Classification of Functioning
ICIDH	The International Classification of Impairments, Disabilities, and Handicaps
ICR	Intelligent Character Recognition
IOM	Institute of Medicine Model
IPA	Impact of Participation and Autonomy
MCR	Medical Components Summary
MEDLINE	Medical Literature Analysis and Retrieval System Online
MESH	Medical Subjects Headings
MI	Multiple Imputation
MOHO	Model of Human Occupation
MOHOST	The Model of Human Occupation Screening Tool
MRC	Medical Research Council

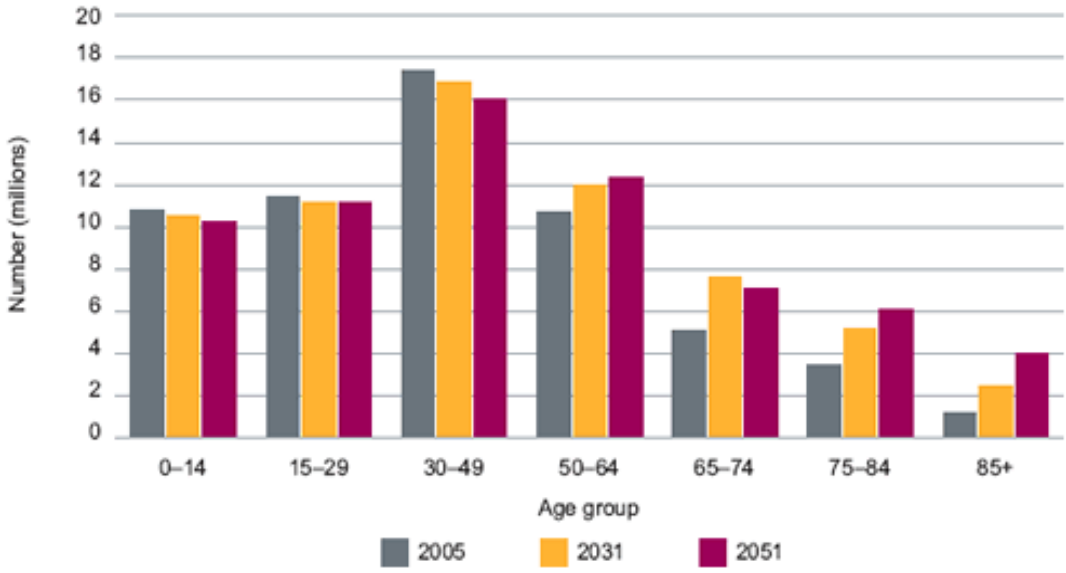
NCMRR	The National Centre for Medical Rehabilitation Research
NIH	National Institute of Health
NHS	National Health Service
NORSTOP	North Staffordshire Osteoarthritis Project
NPSA	National Patient Safety Agency
NRES	National Research Ethics Service
NHSSTS	National Health Service Strategic Tracing Service
OCR	Optic Character Recognition
OMR	Optic Mark Recognition
ONS	Office of National Statistics
OT	Occupational Therapy
PsychINFO	Psychological Information Database
PCS	Physical Components Summary
PF	Physical Functioning
QUIPS	Quality in Prognostic Studies
QUORUM	The Quality of Reporting of Meta-analyses
RCT	Randomised Clinical Trial
REC	Research Ethics Committee
RNL	Reintegration to Normal Living Index
RoC	Receiver Operating Characteristics
SEM	Structural Equation Modelling
SF	Short Form
SIP	Sickness Impact Profile
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
TIMPs	Tissue inhibitors of metalloproteinases
TJR	Tayside Joint Replacement
UK	United Kingdom
VAS	Visual Analogue Scale
VLAS	Valued Life Activities Scale
WHO	World Health Organisation
WOMAC	Western Ontario and McMaster Universities Osteoarthritis Index

Chapter 1
Thesis statement and overview of research studies

1.1 Introduction

Life expectancy is increasing with older adults in the United Kingdom (UK) expected to live until they are 80 years old (Office for National Statistics (ONS), 2010); eight years longer than in the 1970s (Leon, 2007). The number of adults aged 50 years and over has increased over the last two decades, particularly those aged 80 and over, which now represents 4.5 percent of the UK population (ONS, 2010). The proportion and number of adults aged 50 and over is expected to increase even further over the forthcoming years (Figure 1.1). This will have considerable impact on future health and social care provision (Medical Research Council (MRC) 2010) because with increasing life expectancy comes an increased prevalence of chronic health conditions (Denton and Spencer, 2010), disability (Berlov et al., 2012; Martin et al., 2010; MRC 2010; Nusselder et al., 2006) and a reduction in Health Related Quality of Life (HRQoL) (e.g. HRQoL is four times lower in adults aged 75 years and over compared to those aged 30-44 years (Saarni et al., 2007)).

Figure 1.1 Expected population change in the United Kingdom, 2005-2051



Source: ONS, Population estimates 2008

Musculoskeletal conditions (such as osteoarthritis and back pain) are the most frequent morbidity in older adults (World Health Organisation (WHO), 2003). In the UK, pain, the most common symptom of musculoskeletal conditions, affects two thirds of adults aged 50 years and over (Thomas et al., 2004:a) and is often not controlled by medical treatment (British Pain Society, 2004). As a consequence, musculoskeletal pain often becomes chronic (i.e. lasts for more than three months), significantly reduces people's ability to participate in daily activities, and is strongly related to further comorbidities (e.g. anxiety and depression) (Cherubino et al., 2012; Breivik et al., 2006). However the consequences of musculoskeletal conditions are extensive and not completely understood (Woolf and Pfleger, 2003). Many studies have focused on physical function, but greater acknowledgement of the wider impact of musculoskeletal conditions (for example,

the impact on social roles and essential activities of daily life) is required to guide strategies and management to reduce the impact of musculoskeletal conditions in the growing population of older adults. To facilitate this there is a need for epidemiological studies to enhance the understanding of the frequency, incidence, causes and progression of the different forms of impact (Woolf and Pfleger, 2003).

1.2 Self-care

The daily lives of adults are built upon routines and habits that reflect their roles, needs, motivators and responsibilities (Turner et al., 2002). The ability to participate in self-care activities such as bathing and toileting is important to older people, as they are an essential part of daily life. Losing the ability to carry out self-care tasks is directly associated with losing independence (Jagger et al., 2001). The ability to function independently is an important aspect of quality of life (Harwood et al., 2004; Spector et al., 1987). Being dependent on others later in life is one of the biggest fears of older people (Gignac et al., 2000) and is associated with poor health and wellbeing (Covinsky et al., 2008: Dawson et al., 2004: Dunlop et al., 2001: Hosie and Dickson, 2000; Gill and Feinstein, 1994). Limitations in self-care activities predict further morbidity and mortality in older adults (Gill et al., 2004 & 2002; Naik et al., 2004; Jagger et al., 2001; Czaja et al., 1993).

1.2.1 Epidemiology of self-care restriction

Studies reporting the frequency of self-care have tended to measure specific tasks as part of a wider measure of activities of daily living (ADL) or instrumental activities of daily life (IADL). Although ADL limitations are commonly assessed in clinical research, measurement of ADL varies across studies and can include items referring to mobility, transfers (e.g. getting up from a chair) and self-care (e.g. washing, dressing, bathing, toileting). IADL involves more complex tasks such as meal preparation, grocery shopping and using the telephone.

Even though the application of different forms and definitions of self-care restriction in the literature results in varied estimates, there is some consensus that self-care restriction is frequent in older adults. Whilst mobility limitation is the most commonly reported disability amongst the older people, 70% of adults with mobility problems are also restricted in specific self-care tasks (i.e. they were restricted in at least one of the following tasks; dressing, bathing or showering, eating, getting in and out of bed or using the toilet; Melzer et al, 2005). The prevalence of ADL disability in older people ranges from 5-40% depending on how it is defined and measured (Balzi et al., 2010; Gill et al., 2004:a-b and 2002:a; Jagger et al., 2001; Dunlop et al., 1997). The most common ADL disability is bathing disability and is estimated to affect 24% to 34% of older adults (Gill et al., 2006: a; Naik et al., 2004; Jagger et al., 2001). Gill et al. (2002:a) suggested that the occurrence of ADL disability is substantially underestimated because it fluctuates; frequent assessments could provide an improved understanding of the course of disability in community-living older persons (Gill, et al., 2002:a and

2004). In a longitudinal study of 754 community-dwelling older adults aged >70, it was reported that the burden of bathing disability increased with age, was greater in women and in participants who were physically frail (Gill et al, 2006). This study also reported that the onset of bathing disability was associated with a fivefold increase in the likelihood of developing disability in the other essential ADL in the following month (Gill et al, 2006).

Importantly self-care restriction has been found to predict future morbidity and mortality in older adults (Czaja et al., 1993; Spector et al., 1987). Jagger et al. (2001) investigated the patterns of the onset of different types of disability and the association with age and gender. Disability was measured by self-report of performance in mobility around home, getting to and from the toilet, transfer from bed, feeding, dressing and bathing, and defined as being independent but having difficulty, using aids or help, or being unable to perform in any one of these ADL. The overall prevalence of ADL disability was 48% and it occurred in the following order; bathing, mobility, toileting, dressing, transfer from bed or chair and feeding. Women were identified at a higher risk of disability in bathing (relative risk (RR) 1.6; 95% Confidence Interval (CI) 1.3, 1.9; $p<0.001$) and toileting (RR 1.7; 95% CI 1.2, 2.5; $p=0.003$) and for all ADL there was a significant increase for risk of disability with increasing age. However the order of onset of disability for ADL was invariant across age and genders (Jagger et al., 2001). Previously, Dunlop and colleagues (1997) reported a similar order of disability to Jagger (i.e. based on both the ordering of median ages to disability onset and patterns of incident disability, dependency in ADLs were ordered as walking, bathing, transferring,

dressing, toileting, feeding). This study also found gender differences in disability incidence rates, suggesting that although women live longer than men, they spend more time in a disabled state (Dunlop et al., 1997).

Previous research has characterised self-care in terms of an individual's capacity to do specific tasks such as bathing or dressing. However, self-care also involves environmental factors (e.g. bathing entails getting in and out the bath, operating taps and washing oneself; these tasks are influenced by pain, joint stiffness, comorbidities and environmental factors such as access to the bath (i.e. upstairs, downstairs, in a small bathroom difficult to conduct transfers), and the availability of aids and adaptations (i.e. does it have grab rails or is there a bath seat/board/non-slip mat in place; powered bath seats will lower and raise a person into and out of the bath). Investigating self-care restriction only with reference to an individual's capacity prevents a clear understanding of this form of disability, because it fails to consider important factors which determine its occurrence.

1.3 Thesis statement

The International Classification of Functioning, Disability and Health (ICF) is a biopsychosocial model which offers the opportunity to develop an understanding of self-care through the proposal of a definition and a biopsychosocial model. This allows self-care to be viewed as the outcome of the interaction between the individual and their environment (WHO, 2001). This may better identify potential targets to reduce self-care restriction in older adults. This thesis describes an epidemiological study which investigates self-care restriction in line with the

definition and framework proposed in the ICF. In particular it will look at the links with osteoarthritis and focus on potential determinants within older adults who have the condition. Osteoarthritis is the most common musculoskeletal condition in older adults but previous studies have not provided a clear account of the link with self-care restriction (Covinsky et al., 2008; Donald and Foy, 2004; Dunlop et al., 1998; Davis et al., 1991; Yelin and Katz, 1990).

The overall aim of this study was to describe the population prevalence and distribution of self-care restriction, and associated factors, in adults aged 50 years and over with specific reference to joint pain. The impetus of this research was to identify factors that are potentially modifiable and amenable to interventions that can perhaps enhance self-care in older adults with joint pain.

1.4 Overview of research studies

To achieve the overall aim, existing models of disability in the health literature were reviewed and critiqued, and a systematic review was conducted to identify what is already known about self-care restrictions in older people with joint pain to date. Following this, a number of studies with specific objectives were conducted and are described in the subsequent chapters.

1.4.1 Measuring the impact of musculoskeletal conditions in older adults: Models of disability [Chapter 2]

This chapter describes and critiques the current models of disability which were proposed to guide an understanding of the consequences of health conditions,

including musculoskeletal disease, and provides the rationale for selecting the ICF as a framework to guide the analyses in this thesis (i.e. to investigate the wide range of factors associated with self-care disability in older adults with joint pain).

1.4.2 The impact of osteoarthritis on self-care in older adults: A systematic review [Chapter 3]

This chapter describes a systematic review conducted to explore the current literature on restricted self-care in community-dwelling adults aged 50 years and over in the general population and its links with joint pain/osteoarthritis.

The aim of the systematic review was to identify and evaluate literature which has examined links between self-care restriction and joint pain / osteoarthritis. The objectives were:

i. To determine if self-care restriction is associated with joint pain in community-dwelling adults aged 50 years and over in the general population.

ii. Explore the determinants of restricted self-care in community-dwelling adults aged 50 years and over with joint pain / osteoarthritis.

Rationale

Osteoarthritis is the commonest joint condition and a major cause of musculoskeletal pain and disability (Hosie and Dickson, 2000). The impact of osteoarthritis is broad, with many associated outcomes. Despite research suggesting links between joint pain and future self-care disability, the extent and mechanisms are unclear. There is a need to conduct a systematic review of the literature to identify studies which have specifically explored the links between self-

care restriction and joint pain and identified the determinants of this outcome in community-dwelling older adults with joint pain / osteoarthritis.

1.4.3 North Staffordshire Osteoarthritis Project (NorStOP): The survey overview and sample analysis [Chapter 4]

The data used for all analyses described in this thesis were collected in the North Staffordshire Osteoarthritis Project (NorStOP). The aim of this chapter was to critically appraise the potential of NorStOP to fulfil the objectives for this thesis.

To achieve this, the specific objectives were:

i. To review the NorStOP study design, administration and questionnaire content for the capacity to describe the population prevalence and distribution of self-care restriction, and associated factors, in adults aged 50 years and over with specific reference to joint pain.
ii. To evaluate the sample derivation including selection, recruitment, response and attrition over the 6 year period (baseline, 3 years and 6 years follow-up) and identify potential bias on findings.

Rationale

Each research study described in this thesis involved analysis of data from the North Staffordshire Osteoarthritis Project (NorStOP) - a population-based observational cohort of people aged 50 years and over. Notably, the Keele Assessment of Participation (KAP) was developed and applied in NorStOP to measure participation, in line with the conceptual framework of the International

Classification of Functioning (ICF); the conceptual model of this instrument considers self-care to be a form of participation. The suitability and quality of NorStOP data was critically evaluated for the capacity to meet the aims of this thesis. This was evaluated by reviewing the administration of the survey, the quality of data collection (i.e. validity of data) and potential bias related to sample selection and attrition.

1.4.4 Person-perceived self-care restriction in middle and old age: prevalence, distribution and associated factors [Chapter 5]

The aim of this chapter was to describe the extent of restricted self-care and its links with demographic, socio-economic and health factors in a general population of adults aged 50 years and over. In particular this analysis aimed to establish if joint pain was associated with restricted self-care in the general population.

Specific objectives

i. To estimate the prevalence of person-perceived self-care restriction, and its distribution by age and gender.

ii. To determine the direction and strength of association between restricted self-care and selected health conditions, impairments, activity limitation and contextual factors.

iii. To derive and validate a parsimonious model of factors which are independently associated with restricted self-care.

iv. Examine the potential for other factors to ‘explain’ the relationship between joint pain and self-care restriction.

Rationale

Describing the frequency and distribution of health-related states and events in the general population often provides essential information on their extent and may help to generate hypotheses on possible determinants. Thus, quantification of the prevalence and distribution of self-care restriction and its relation to other health, socio-demographic and contextual factors in a general population of older adults is an essential part of understanding the problem and developing hypotheses around factors that may be associated with restricted self-care. The specific focus on the links between self-care restrictions and joint pain is to establish if those with joint pain are more likely to report self-care restriction than those with no joint pain in older people.

1.4.5 Person-perceived self-care restriction in middle and old age: onset and persistence over a 3 year period [Chapter 6]

The aim of this chapter was to describe the longitudinal course of self-care restriction in older people in the general population over a three year period.

Specific objectives

i. To estimate the extent of the onset and persistence of self-care restriction at 3 years.

ii. To describe the relationship between onset and persistence of self-care restriction at 3 years and baseline demographic, socio-economic and health characteristics.

iii. To explore the direction and strength of association between the onset and persistence of self-care restriction at 3 years and the site, number, and pattern of peripheral joint pains at baseline.

Rationale

There are no data on the onset and persistence of participation restriction in self-care. Reported estimates of the onset and persistence of limitations in specific self-care activities measured as part of Activities of Daily Living instruments (ADL) differ between studies, due to a lack of consensus in definitions. It is important to have an estimation of the onset and persistence rates of self-care restriction to understand how the course of self-care restriction develops and persists over time in older people in the general population. Measuring the course of self-care restriction in older people over a 3 years period may help to determine the link between joint pain and future onset or persistence. Examining the demographic, socio-economic and health characteristics of the study cohort provides the estimation of biopsychosocial risk factors associated with the onset and persistence of self-care restrictions in older people in the general population.

1.4.6 Potential predictors of the onset and persistence of restricted self-care in older adults with joint pain [Chapter 7]

Having established a link between self-care restriction and joint pain, the rest of the thesis will focus on older adults with joint pain. In this chapter, the aim was to identify the potential predictors of the onset and persistence of restricted self-care in older adults with joint pain; this focused on investigation of the association

between onset and persistence and (i) joint specific characteristics (e.g. pain severity, stiffness and chronicity) and (ii) the factors that constitute the parsimonious model of factors established in the general population at baseline (this was to determine whether the risk factors for those with joint pain were different to those for the general population).

Specific objectives

i. To examine the association between the onset and persistence of self-care restriction at 3 years and joint specific characteristics at baseline.
ii. To investigate links between the onset and persistence of self-care restriction at 3 years and individual factors that was independently associated with restricted self-care in the cross-sectional analyses at baseline ('the parsimonious model').
iii. To test the extent to which the parsimonious model predicts the onset and persistence of self-care restriction at 3 years and to determine whether joint-specific characteristics make an additional independent contribution to the prediction of future self-care restriction.

Rationale

Previous studies identified joint specific characteristics such as pain severity as an important risk factor that increase poor physical functioning, and predict future disability in ADLs in older people. Psychosocial factors (e.g. depression) may also influence the relationship between impairments and participation restriction. However, the factors associated with the risk of onset or persisting self-care

restriction in those with joint pain is unknown. It is important to determine if (i) factors particular to osteoarthritis (such as frequent or severe pain) and (ii) demographic, comorbid and socio-economic factors are linked to the onset and persistence of self-care restriction to identify potential targets to reduce this burden.

1.4.7 The concordance between activities and participation and the impact of environmental factors on self-care [Chapter 8]

The aim of this chapter was to examine (i) empirical differences between task-specific activity limitation and self-care restriction, and (ii) the link between environmental factors, such as receiving help and assistance and using aids and assistance, and self-care restriction in community-dwelling older people with joint pain.

Specific objectives

i. To compare the frequency and age and gender distribution of task-specific activity limitations, multiple activity limitation, and relative severity of each limitation in relation to the age and gender distribution of person perceived self-care restriction.
ii. To estimate the level of agreement between estimates of person-perceived self-care restriction and task-specific activity limitation.
iii. To determine and compare the risk profiles of person-perceived self-care restriction and task-specific activity limitations.

iv. To determine whether environmental factors moderate the relationship between restricted self-care and task-specific activity limitation.

v. To investigate the associations between task-specific activity limitation and person-perceived participation restriction by the need for, and use of, environmental facilitators.

vi. To examine the socio-demographic, health and joint specific characteristics of the study sample to elucidate the wider factors associated with the need for, and use of, environmental facilitators in older adults with joint pain.

Rationale

In contrast to measuring restriction in self-care as a form of participation and from the perspective of the individual (i.e. measuring whether ones' needs were met as and when they have wanted) limitation in specific self-care tasks was traditionally measured by *difficulty* (none, some, a lot, unable) or *dependence* (requiring help from another person) in executing these tasks (i.e. measuring the individual's capacity (task-specific activity limitation)). Although conceptually different, these two approaches may identify similar populations and there is a need to empirically test if this is true. According to the ICF (WHO, 2001), social and environmental factors impact on all components of functioning and restriction, thus it is important to understand to what extent the relationship between task-specific activity limitation and person-perceived self-care restriction is moderated by environmental factors to identify target populations.

1.4.8 Summary and discussion [Chapter 9]

This chapter summarises the findings from the analyses, critically appraises strengths and weaknesses, and outlines the implication with relation to the research topic, management of self-care restriction in older adults with joint pain, and future research.

Chapter 2
Measuring the impact of musculoskeletal conditions in older adults: Models of disability

2.1 Introduction

Disability models have been proposed to guide an understanding of the consequences of health conditions, including musculoskeletal disease. Disability models offer frameworks that allow information to be organised and guide an understanding of disablement (Bickenbach et al., 1999). For research purposes this allows questions to be framed and different disciplines to discuss how factors interact, which improves the understanding of how disability occurs. However the epidemiology of disability is hindered by different definitions and models (Mont, 2007). This prevents a common approach to research and consensus on the frequency of disability and potential causal mechanisms. There is a need for a standard method for defining and characterising disability to facilitate the development of an epidemiological base.

Despite the lack of consensus, all disability models draw on the medical and social models of disability to a greater or lesser extent. In the medical model disability is defined as "*an observable deviation from biomedical norms of structure or function that directly results from a disease, trauma or other health condition*" (Boorse, 1975: p.19). This places disability as a consequence of a health condition and fails to take account of social, psychological or environmental factors which may help to reduce or enhance the effects of health conditions (Albrecht, 2010; Jette, 2006; WHO, 2001). This affects the potential to reduce disability for those with chronic

health conditions which persist despite medical treatment. In contrast, the social model views disability as a consequence of the environment (e.g. the lack of public transport prevents people with leg pain and problems walking from getting to work or shops) (Albrecht, 2010). Disciplines that focus on the social model often underplay the importance of the signs and symptoms of health conditions and don't link these with the environmental and social factors which lead to disability (Bury, 2000). The complexity of the consequences of health conditions suggests that integrated models, which consider both the medical and social models, may provide the best opportunity to characterise disability and facilitate a greater understanding.

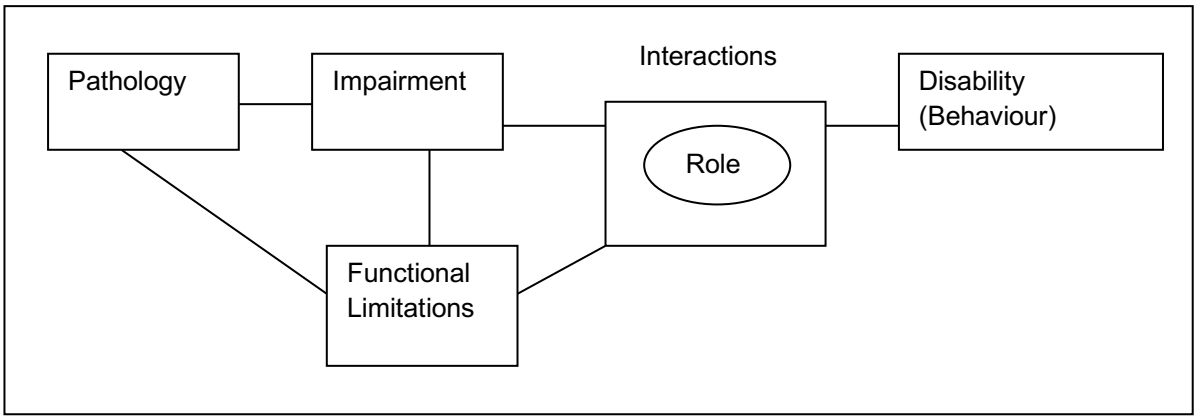
This chapter aims to describe and critique key models which have guided strategies to measure disability in epidemiological studies such as the Nagi model (Nagi, 1965), which has subsequently been revised, two models proposed by the WHO (The International Classification of Impairment, Disability and Handicap and the International Classification of Functioning, Disability and Health) and models of participation developed in Occupational Therapy to provide the rationale behind the chosen framework to guide the research studies undertaken in this thesis.

2.2 An overview of models of disability

2.2.1 The Nagi model of disablement (Nagi, 1965)

The Nagi model of disablement (Nagi, 1965) is a theoretical model of health, functioning and disability and was one of the first attempts to structure the consequences of health problems into different levels. It has been subsequently revised and provides the basis for other models, discussed below. In this model, disablement was explained through four concepts; pathology, impairment, functional limitation, and disability (Nagi, 1965). In this, *active pathology* referred to a state of the body's defences and coping mechanisms caused by infections, trauma, metabolic imbalance, degenerative disease processes, or other pathologies; *impairment* referred to a loss or abnormality at the tissue, organ, and body system level; functional limitation referred to the individual's ability to perform the tasks and obligations of his usual roles and normal daily activities (Pope and Tarlov 1991); and *disability* was defined as an 'expression of a physical or a mental limitation in a social context'. Thus, this model suggested that impairment is associated with functional limitation (i.e. limitation in performing basic physical (i.e. walking, lifting objects, climbing stairs, reading standard-sized print and hearing other people) and mental actions (short-term memory, intelligible speech, alertness, orientation), that are involved in daily activities. However this is not directional and will depend on personal and social factors (i.e. loss of a finger could be severely limiting to a pianist but might not be limiting at all to a teacher) (Nagi 1965, p.102) (Figure 2.1).

Figure 2.1 Nagi Model (Nagi, 1965)



Source: Albrecht et al, 2010

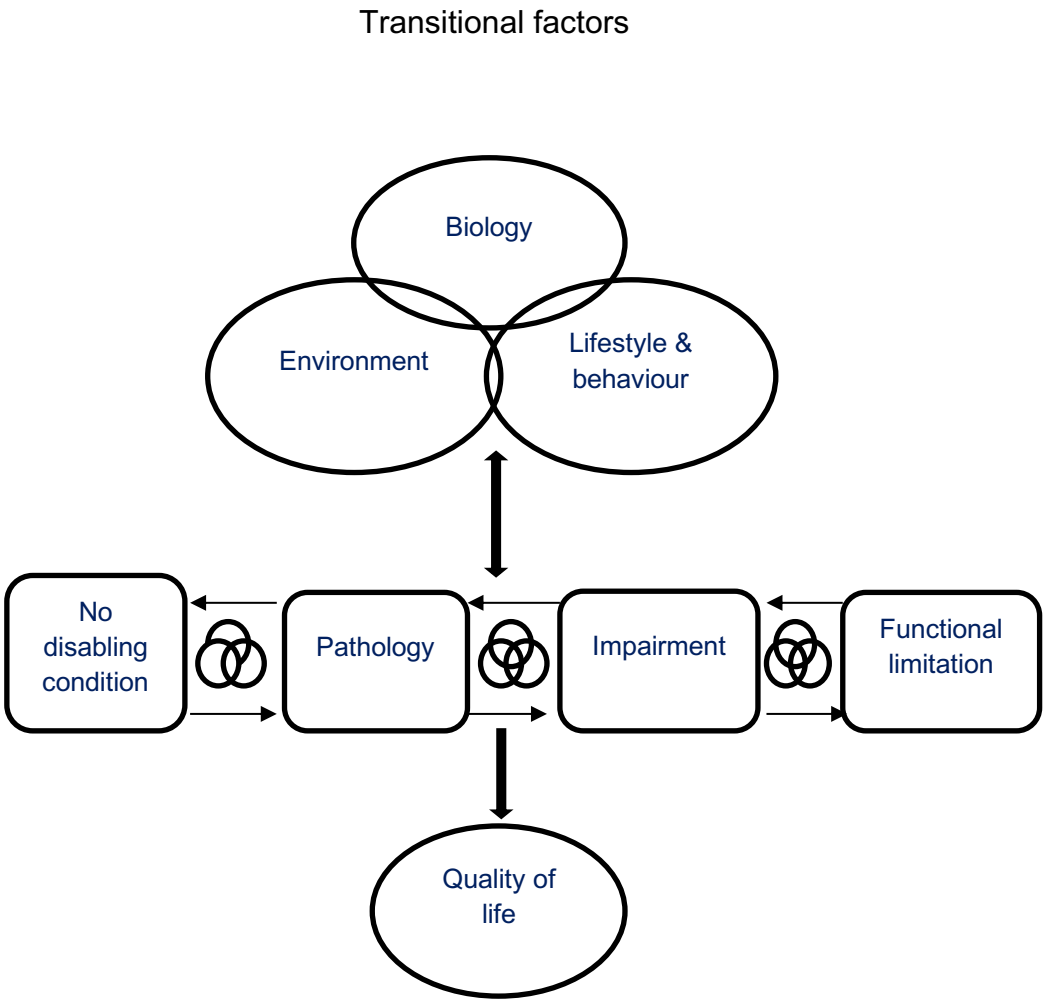
This model was revised in 1991 and the *disability* component was removed due to the view that disability is not inherent within the person. The revised model proposed that the patterns of an individual's impairments are associated with functional limitations and the interaction of the individual and the environment (Nagi, 1991). In this revised model functional limitation may not be a direct result of impairment, but could be also due to personal, social and/or environmental factors, emphasising that disability is the result of the gap in an individual's own capabilities and their social and physical environment (Jette, 2006). However, the revised Nagi model still lacked clarity and necessary detail to study the specific aspects of disability. Thus, following Nagi's own revision, other conceptual models were developed based on the revised model, with the main inclusion being the role of social and physical environment in the disablement process. These models are summarised and discussed below.

Institute of Medicine Model

The development of the Institute of Medicine's (IOM) Model (The enabling-disabling process) (Pope and Tarlov, 1991) involved modifying the Nagi model, to propose a prevention based rehabilitative model (Brandt and Pope, 1997). This model proposed a new conceptual approach by analysing the components of disability, and describing the importance of different risk factors. Nonetheless, over time, the original IOM model (1991) has been criticised for proposing a disablement process that is unidirectional, progressive toward disability without the possibility of its reversal (due to the arrows in the model that pointed toward disability), limited classification of the environment, and its' interaction with the individual (Brandt and Pope, 1997). Even though the significance of the environment is discussed in this model, it was not clearly represented in the model.

The IOM model was revised in 1997 and the new model was designed to provide clarity in describing disability as the interaction of the person with the environment and also to show the possibility of movement in the direction of rehabilitation (Brandt and Pope, 1997). This model defined disability as "a function of the interaction of the person with the environment" and focused on the environmental factors, suggesting that physical and social environmental factors act as risk factors in the disablement process (Masala and Petretto, 2012). This highlighted the role of environmental factors in either leading to or preventing disability. The IOM model also included bidirectional arrows and a state of "no disabling condition" that depicted disability as a reversible state (Figure 2.2).

Figure 2.2 The IOM Enabling-Disabling Process



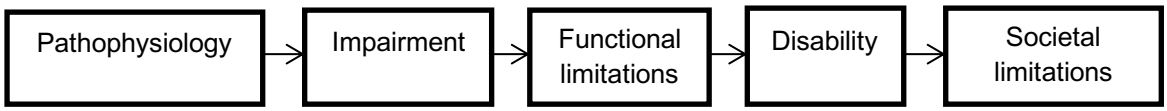
Source: Brandt and Pope, 1997.

The National Centre for Medical Rehabilitation Research Model

The National Centre for Medical Rehabilitation Research (NCMRR) (National Institute of Health (NIH), 1993) model was also developed using Nagi's model, and included consideration of the environment in the dimension called "societal limitation". Societal limitations were defined as barriers to full participation in society that result from attitudes, architectural barriers and social policies. This

model suggested that personal factors may influence an individual's response to a specific situation, thus the interaction among organic, psycho-social, personal and environmental factors would produce the individual's response to impairment (NIH, 1993). The NCMRR model highlighted the fact that the barriers between individuals and the environment could be potentially reduced or eliminated by public policies and services (Figure 2.3).

Figure 2.3 The NCMRR Model



Source: The NCMRR Model, 1993.

The Disablement Process Model

Verbrugge and Jette (1994) extended Nagi's model further and developed "The Disablement Process Model" with the aim of facilitating health research. The term 'disablement' referred to the effect of acute and chronic conditions on the functioning of body systems, and individual's interactions with the environment. The term 'process' considered the impact of changes in functional consequences on individuals over time. This model was based on a "socio-medical" approach (i.e. one that combines the medical and social models of disability) and defined functional limitation and disability as separate behaviours as opposed to different features of measuring the same behaviour. In this model *functional limitations*

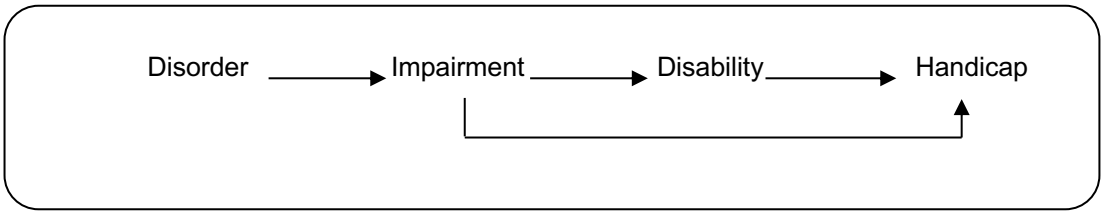
were defined as *restrictions* in performing fundamental physical and mental actions used in daily life by one's age-sex group, and *disability* was defined as 'experienced difficulty in doing activities in any domain of life due to a health or physical problem' (Verbrugge and Jette, 1994).

The disablement process model highlighted the importance of social and environmental factors by emphasising that limitations in activities were not just a result of poor physical functioning because they involved interaction with the environment (e.g. washing oneself would require to undress and get in and out of bath/shower, dry oneself). This model elaborated further on the importance of 'intrinsic' (i.e. capacity: e.g. having difficulty in carrying out a task such as washing without a personal or equipment assistance) and 'actual' (i.e. performance: e.g. having difficulty with carrying out a specific task with personal and equipment assistance) disability, underlining the implications on future health-care policies and design and development of aids and adaptations tools. This division had previously been criticised by researchers, health-care practitioners and civil rights advocates because many people use external sources, such as help and assistance, to enable them to function adequately. Therefore it may be better to measure actual disability rather than intrinsic disability (i.e. it is better measure performance rather than the capacity to perform) (Verbrugge and Jette, 1994).

2.2.2 The International Classification of Impairments, Disabilities, and Handicaps (ICIDH)

The ICIDH, published in 1980, was the first attempt by the WHO to provide a common language to describe the consequences of health and disease, and analyse health related issues. The ICIDH linked with the International Classification of Diseases (ICD), which was established to provide a standard diagnostic tool for epidemiology to monitor the incidence and prevalence of diseases and other health problems by WHO in 1946 with publication of ICD-6. Notably its origin can be traced back into the Bertillon Classification, which was first published in 1893. The ICIDH defined the consequences of health in three sequential levels; body (impairment), individual (disability) and societal (handicap) (Figure 2.4). Impairment was defined as *"any loss or abnormality of psychological, physiological or anatomical structure or function".* Disability was defined as "*any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being*". Handicap was defined as *"disadvantage, resulting from impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual"* (WHO, 1980).

Figure 2.4 The ICIDH Model



Source: WHO, 1980

In the development of the ICIDH, the WHO attempted to integrate the social and medical models of disability by recognising the social consequences of health conditions (i.e. through the inclusion of the handicap concept). Although the ICIDH in general was welcomed in health research, it was criticised for its alignment with the medical model, because its' linear approach (i.e. impairment causes disability which then causes handicap) implied that disability is only a consequence of health conditions (Whiteneck, 2006). Although it acknowledged that health conditions interact with social and environmental factors through the inclusion of handicap, it did not implicitly outline the role of these factors on an individual's function (Imrie, 2004; Bornman, 2004; Simeonsson et al., 2000; Chapireu and Colvez, 1998). The model implied that handicap was an outcome of an individual's impairment, isolated from the societal constraints and choices which were offered to the individual and did not reflect the real experiences of those people living with the health conditions (Simeonsson et al., 2000). The linear approach also failed to show that the body, individual and societal levels were distinctive. It was not possible to assess the degree of severity of disabilities or handicaps using the ICIDH (WHO and Economic and Social Commission for Asia and the Pacific (ESCAP), 2008). Therefore, the ICIDH was seen as inconsistent in general, and its use was not commonly adopted by disability researchers and advocates of the social model of disability (WHO and ESCAP, 2008).

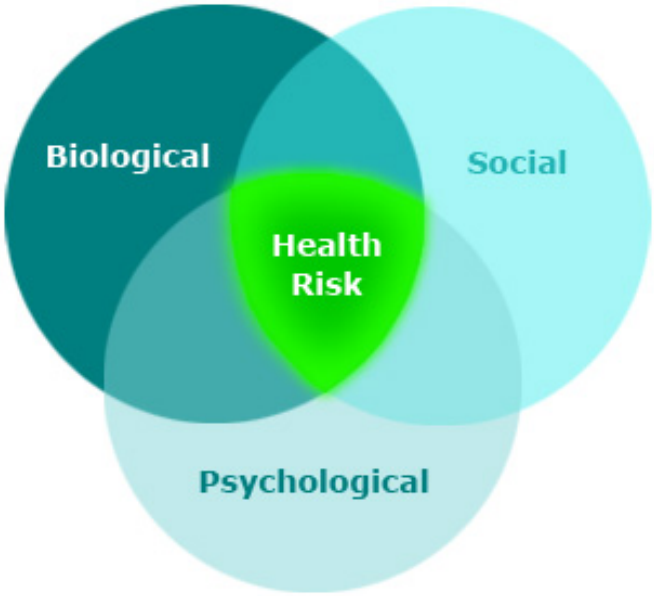
2.2.3 The International Classification of Functioning, Disability and Health (ICF)

As a result of the criticisms of the ICIDH, the WHO collaborated with international researchers to put together a framework which married the medical and social models of disability and incorporated environmental factors. Following seven years of expert partnership, process and validation in over 70 countries, the ICF was officially endorsed by the WHO in 2001.

The ICF was conceptually different to the ICIDH as its rationale was to capture the components of health rather than classify the consequences of disease (Ustun et al., 2003). This is why the ICF was named as it is, with an emphasis on health and functioning, rather than on disability (Jette, 2002). This acknowledges that (i) people can continue to function positively despite having health problems and (ii) that everyone can experience some form of disability, independent of their health status.

The ICF framework was based on a biopsychosocial model of health, which was previously introduced by George Engel (1977; 1980) (Figure 2.5). The biopsychosocial model was a departure from the previous linear, cause–effect based approach to health and included the psychosocial dimensions (personal, emotional, family, community) as well as the biological aspects of diseases.

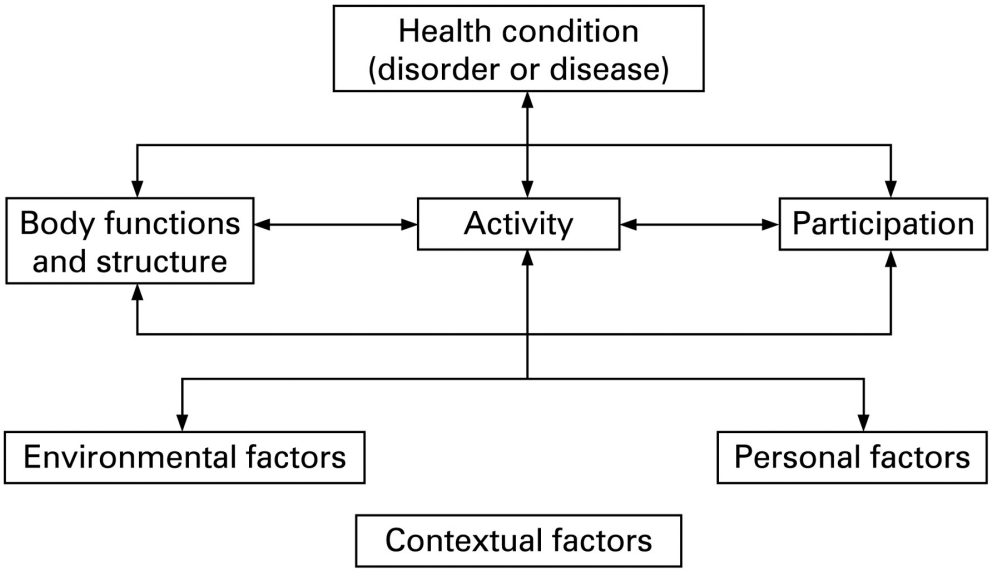
Figure 2.5 The biopsychosocial model of health and illness



Source: Engel, 1977

The ICF defined functioning and disability as multi-dimensional concepts, relating to (i) body functions and structure, (ii) the activities people do and the life areas in which they participate, and (iii) the factors in their environment that affect these experiences. Within the ICF, a hierarchy of classifications and codes were provided for each of these components. In this model, an individual's functioning or disability was conceived as a dynamic interaction between health conditions and personal and environmental factors (WHO, 2001) (Figure 2.6).

Figure 2.6 Diagram of interactions between the components of ICF



Source: WHO, 2001

The ICF organised information in two sections, (i) function and disability, and (ii) contextual factors, to encourage and facilitate a broader understanding of human functioning (WHO, 2001).

(i) Functioning and disability

The ICF domains were summarised at three levels (body, individual and societal) as body structures and functions, activities and participation, which also indicated positive functioning (Table 2.1). In the ICF, disability is an umbrella term for any negative functioning in these three levels which are referred to as impairments, activity limitation and participation restriction (WHO, 2001). Impairment was defined as problems in body function and structure, such as a significant deviation or loss (WHO, 2001). Activity limitations were defined as difficulties that an

individual may have in executing tasks (WHO, 2001). These tasks could be any activities related to the individual's life and encompasses the use of purposeful body functions. Participation restrictions were defined as problems an individual may experience in life situations when interacting with society and/or environment which may enable or restrict participation (WHO 2001). Thus, participation restriction is the result of a complex interaction between the individual (including the consequences of a health condition) and the environment (Stucki et al., 2002; Grimby et al., 2001).

The ICF indicates that both concepts (activity limitation and participation restriction) can be measured with reference to either capacity or performance and judged against accepted population standards (i.e. what is normally expected from someone of a specific age and gender) (WHO 2001). In the ICF, *capacity* is defined as a construct which describes an individual's ability to execute a task or an action in a standardised environment, and it is useful to indicate the highest probable level of functioning that a person can reach in the domain that is being evaluated (i.e. actual ability). To evaluate the individual's full capacity, a standardised environment is necessary to remove the impact of environmental factors. Thus, capacity reflects the individual's ability adjusted to the environment. On the other hand, *performance* refers to what individuals do in their current environment (Jette, 2002). Therefore, "*the gap between capacity and performance reflects the difference between the impacts of current and uniform environments, and thus provides a useful guide as to what can be done to the environment of the individual to improve performance*" (WHO, 2001:p.15).

The ICF recommends judging the capacity and performance of individuals against population standards (i.e. what is expected of a similar individual without the similar impairment). However participation restriction cannot be the same for each person due to changing roles, environments and personal factors, thus judging against a population standard does not reflect the subjective dimension of functioning and disability (Ueda and Okawa 2003; Harwood et al., 1994). However, taking the participant's perception is a highly relevant dimension for clinical practice as perceived disability may identify care needs. It is also difficult to define a population standard for judging participation, because different needs direct whether participation will occur at all in some areas of life (e.g. older adults who have sufficient financial means to allow them to retire may no longer choose to work) (Peronboom and Chorus, 2003).

Table 2.1 The ICF components and definitions

Level	Functioning	Definition	Disability	Definition
Body	Body structures and functions	Anatomical parts of the body such as organs, limbs and their components. Physiological components of body (including psychological functions)	Impairments	Problems in body function or structure such as significant deviation or loss
Individual	Activities	Execution of a task or action by an individual	Activity limitation	Difficulties an individual may have in executing activities
Societal	Participation	Involvement in life situations	Participation restriction	Problems an individual may experience in involvement of life situations

Source: ICF (WHO, 2001)

To further aid a common language and approach to research, different domains of disability were also outlined in the ICF; this was a single list of domains and sub-domains that are proposed to cover the full range of life areas. However, the ICF does not direct whether these domains refer to activity limitation or participation restriction (Table 2.2).

Table 2.2 The ICF concepts in context

Body	
Function	**Structure**
Mental Functions Sensory Functions and Pain Voice and Speech Functions Functions of the Cardiovascular, Haematological, Immunological and Respiratory Systems Functions of the Digestive, Metabolic, Endocrine Systems Genitourinary and Reproductive Functions Neuromusculoskeletal and Movement-Related Functions Functions of the Skin and Related Structures	Structure of the Nervous System The Eye, Ear and Related Structures Structures Involved in Voice and Speech Structure of the Cardiovascular, Immunological and Respiratory Systems Structures Related to the Digestive, Metabolic and Endocrine Systems Structure Related to Genitourinary and Reproductive Systems Structure Related to Movement Skin and Related Structures
Activities and Participation	
Learning and Applying Knowledge General Tasks and Demands Communication Mobility Self Care Domestic Life Interpersonal Interactions and Relationships Major Life Areas Community, Social and Civic Life	
Environmental Factors	
Products and Technology Natural Environment and Human-Made Changes to Environment Support and Relationships Attitudes Services, Systems and Policies	

Source: ICF (WHO, 2001)

(ii) Contextual factors

The ICF includes personal and environmental factors to set an individual's function in the context of their life (WHO, 2001); these contextual factors *"represent the complete background of an individual's life and living"* (Murray, 2002). Personal factors (i.e. characteristics that exist independently from the presence or absence of disease or the functional state) are not classified in the ICF framework, and refer to attributes such as age, sex, educational background, social class, culture, past experiences, personal character traits, lifestyle, coping styles and occupation (Jette, 2002). Environmental factors encompass the physical, social and attitudinal environment in which people live and conduct their lives (Table 1.2) (WHO, 2001). The model proposes five categories; 'Products and Technology' (e.g. any product, instrument, equipment or technical system used by a disabled person, especially produced or generally available, preventing, compensating, monitoring, relieving or neutralizing disability), Natural Environment and Human-Made Changes to Environment' (e.g. animate and inanimate elements of the natural environment, and components of that have been modified by people, as well as characteristics of human populations within that environment), 'Support and Relationships' (e.g. people or animals that provide practical physical or emotional support, nurturing, protection, assistance and relationships to other persons, in their home, place of work, school or at play or in other aspects of their daily activities), and 'Services, Systems and Policies' (e.g. systems and services that provide benefits, and policies govern and regulate the systems that organize, control and monitor services, structured programmes and operations in various sectors of society). Environmental factors can impact the individual's life positively or negatively during

life situations. The environment can be viewed as immediate (e.g. physical features of the environment, social environment) or societal (e.g. formal and informal social structures, services and systems). Particular environments may have a specific impact on an individual, regardless of their health condition (WHO, 2001).

Strengths and limitations of the ICF

The ICF framework is based on a biopsychosocial model which integrates the medical and social models and allows users to record the impact of health conditions on human functioning at biological, individual, and societal levels (Reed et al., 2005). In addition, the ICF also includes personal and environmental factors to encourage acknowledgement of their influence on an individual's function and disability. This is an important addition as both personal and environmental factors may act as barriers or facilitators to participation (Allan et al., 2006).

The ICF also provides a clear definition of the three levels of disability, offering ''*a unified and standard language and framework for the description of health and health-related states*'' (WHO, 2001:p. 3). This terminology allows the communication of health information across professional disciplines; the presence of a common framework and language across disciplines facilitates inter-professional collaboration (Giacomini, 2004).

The neutrality of the ICF definitions allows the framework to be applied to all populations, allowing comparisons across health conditions. However the flexible

nature of this framework has also been criticised, as the definitions offered may not be sufficiently clear to lead the standardisation of such information (Bornman, 2004; Stucki et al, 2002). It is also being suggested that the lack of clarity between the concepts of activity limitation and participation restriction prevents clear application of this framework (Fougeyrollas and Beauregard, 2001).

2.2.4 Models of participation developed in Occupational Therapy

The author of this thesis is an occupational therapist and this profession has developed models of participation and function to direct practice and research. Occupational therapy (OT) is an allied health-care profession that aims to promote health by enabling individuals to perform meaningful and purposeful activities to develop, recover, or maintain their daily living (World Federation of Occupation Therapy (WFOT), 2011). The theoretical models of disability relate closely to the OT practice of supporting health and participation in life through engagement in occupation (American Occupational Therapy Association (AOAT), 2002). The Canadian Model of Occupational Performance (CMOP) was developed by the Canadian Association of Occupational Therapists, and illustrates the relationship between person, occupation (activities of daily living) and environment (Fearing et al., 1997). This model suggests that all these three levels (person, occupation and environment) are interdependent and the change in one area affects all others (Ward et al., 1996). The model is applied in practice by the accompanying Canadian Occupational Performance Process Model (COPM), which describes the therapeutic process from a client's perspective (Clarke, 2003). Model of Human Occupation (MOHO) is another occupational therapy model developed in 1985.

MOHO is a conceptual model of practice that evolved from Reilly's *Occupational Behavior Model* and *General System Theory* (Reily, 1974). This model aimed to explore what motivates individuals in establishing everyday routines and how the environment influences these behaviours using concepts such as volition, habituation, performance capacity and environmental context (Kielhofner et al, 2002). Its application in clinical practice aids the therapist to understand that there are multiple factors within the person and the environment that influence each other. Thus a change in any one factor will spontaneously result in a change in one's motivation, behavior, and/or performance (Cole, 2008). MOHO has both structured and unstructured assessments. The Model of Human Occupation Screening Tool (MOHOST) is an assessment that addresses the majority of MOHO concepts, and helps the therapist to gain an overview of the client's occupational functioning. Criticisms around the use of MOHO, are the lack of consideration around the influence of the environment on human behaviour, and appreciation of the dialectic process between the human and the environment (Haglund and Kjellberd, 1999). However the MOHOST assessment went through a number of revisions by Kielhofner and colleagues periodically and subsequently its validity was supported by using both classical and modern test theories (Ay-Woan Pan et al., 2010).

These models use terms specific to the OT profession and require specialist training in application for clinical and research practice. This creates a barrier for other health-care and research practitioners to interpret and compare information, and isolate the use of these models to OTs only. OTs involvement in inter-agency

and inter-disciplinary work is increasing, and the use of generic models and frameworks that complement OT philosophy and framework could prove beneficial for the future of multidisciplinary working (College of Occupational Therapists (COT), 2004; Baum, 2002). The biopsychosocial approach taken in the ICF framework complements the person-centred approach that is central to OT philosophy and beliefs (Brintnell, 2002; College of Occupational Therapists, 2002; Law and Baum, 2001). Current OT textbooks include chapters that compare OT models to the ICF (Atwal and Jones, 2009; Kielhofner, 2008; Davis, 2006; Christiansen et al., 2005), and the WFOT has incorporated the ICF into the definition and description of OT (WFOT, 2011).

2.2.5 Overview of models of disability

The disability models discussed in this section were developed over time, utilising criticisms and constantly evolving social, cultural and environmental demands to create a better model. The Nagi model brought together a way to classify the impact of health conditions into different levels, and subsequent revisions have included environmental factors. Nevertheless, these models were not able to offer a framework in which the consequences of health conditions could be classified, or provide domains of disability where an individual's participation in life situations could be assessed. Thus, several models of disability were developed over the years, but none of these were universally adopted. The ICF framework was launched globally in 2001 by the WHO with this intention.

The ICF framework is the most recently developed model, developed to organise information on the disability process, and consist of, body functions / impairments, activity, participation, personal and environmental factors. The use of the ICF framework is promoted in OT to encourage inter-disciplinary collaboration through use of common terminology, and supports the design and organisation of epidemiological studies, which can provide evidence for the holistic OT philosophy and patient-centred interventions.

One of the main advantages of the ICF framework is its capacity to provide a standardised method for collecting and presenting health data (Wilkie et al., 2005). This could address the complications created by the use of different terminologies for the same concept within the literature and/or the same terminology referring to different concepts respectively (e.g. the difference between functional limitation and activity limitation; self-care and self-management). These differences could be observed in different studies as well as government legislation and policies (Simeonsson et al, 2000).

As the philosophy of epidemiology is based on the approach that the frequency of occurrence of a health outcome in a population is governed by the interaction of a large number of different factors or determinants, the use of clear terminology to differentiate between different concepts is an important step in building the epidemiology of self-care disability in older people. In the context of this thesis, being able to clearly differentiate between self-care disability and other disabilities, such as locomotor disability, is of great importance. This allows a clear construct

to be operationalized to allow description of the course of self-care restrictions in community-dwelling older people and its links with joint pain, health, socio-demographic and environmental factors which can help guide the development of future interventions, services and policies to better older people's lives.

Despite criticisms, the ICF is an accepted tool internationally. There are growing numbers of implementations of the framework around the globe, in health information systems and surveys (Madden et al., 2005). The ICF provides a framework to direct data collection in population surveys by offering clear definitions for constructs. Consistent adherence to these definitions will allow comparisons between studies, and build the epidemiology of the health outcome of interest (e.g. self-care restriction). The different domains offered in the ICF permit different types of disability such as self-care to be explored using a standard definition. The ICF framework also allows data to be organised into relevant sections such as impairments, activities, personal and environmental factors, providing a framework for investigating associations and potential pathways to the consequences of health conditions. In the ICF, the locus of problem is not only the individual, and includes a wide range of factors that could be linked to self-care disability in older adults. This could help to expand the knowledge of potential strategies to manage self-care in populations (Table 2.3).

Table 2.3 A critical review of the models of participation and disability

The conceptual models of participation and disability
Nagi Model (Nagi, 1965)
Strengths
• It was the first disablement model to recognise that environment, family, society, and community factors may influence disability. • It has changed the perception of disability away from a focus on physical limitations to interaction between the individual and the environment. • It provided a basis for future models.
Limitations
• It was based on a uni-dimensional (pathology-based) model of disability. • It does not account for impairments and functional limitations not due to pathology (e.g. obesity, or sedentary life style) (McKeough 2009).
Institute of Medicine (IOM) Model (Brandt and Pope, 1997; Pope and Tarlow, 1991)
Strengths
• Proposed three interacting risk factors as an addition to the Nagi model; biological, environmental (social and physical), and lifestyle/behavioural that affects each component of the disabling process: pathology, impairment, functional limitation, and disability. • Included the impact on quality of life as a new component in disabling process. • Focused on the effects of the environment in producing or reducing disability. • The revised model (1997) provided clarity in describing disability and included bidirectional arrows to show interaction between different levels.
Limitations
• Disability was depicted in the 1991 model as a linear process. • The earlier model (1991) gave a “limited characterisation of the environment and the interaction of the individual with the environment.
The National Centre for Medical Rehabilitation Research (NCMMR) Model (1993)
Strengths
• Added ‘societal limitation’ to the disablement process • Included personal factors as a potential influence on an individual’s response to a life situation. • Highlighted that the barriers between individuals and environment could be reduced or eliminated by public policies and services.
Limitations
• The NCMRR model was a linear model of disablement. • It did not account for the social or physical environment. • It did not offer an adequate working model for practice and research on its own due to use of broad definitions when describing different levels in the proposed disablement process.

The conceptual models of participation and disability
The Disablement Process Model (Verbrugge and Jette, 1994)
Strengths
• It described how chronic and acute conditions affect functioning in specific body parts, mental function and daily life, and the role of personal and environmental factors in disablement. • Encouraged research into the impact of risk factors (intra and extra-individual factors) on impairment, functional limitation, disability and the disablement process. • Suggested that it may be better to measure 'actual disability' rather than intrinsic disability (without personal or equipment assistance).
Limitations
• Although it is proposed as a socio-medical model of disability, it has been criticised for ignoring 'impairment' by emphasising the effects of social and environmental factors.
The (ICIDH) Model (WHO, 1980)
Strengths
• It was the first attempt by WHO to provide a common language to describe the consequences of health and disease. • It was linked with the International Classification of Diseases (ICD), which aimed to provide a standard diagnostic tool for epidemiology to monitor the incidence and prevalence of diseases and other health problems.
Limitations
• It was criticised for being a medical model; it implied a linear relationship (i.e. impairment causes disability which then causes handicap). • It did not implicitly outline the role of social and environmental factors on an individual's function. • Its linear approach failed to show that the body, individual and societal levels were distinctive. • Introduced the use of the term handicap, which resulted in people being labelled as 'handicapped'.
The International Classification of Functioning (ICF) Model (2001)
Strengths
• The emphasis was on health and functioning, not on disability. This allowed researchers to explore pathways. • Based on a biopsychosocial model of health, it was a departure from previous linear, cause-effect based approaches to the consequences of health. • It was the first model to categorise environmental factors, which allowed the consideration of societal consequences on disability in a greater clarity. • The framework included the psychosocial dimensions as well as the biological aspects of health conditions. • Shifted the focus from the pathological processes to the level of health and participation. • Provided clear definitions for different domains, offering an international language for use in research and clinical practice.

The conceptual models of participation and disability
Limitations
• Its emphasis on health rather than disability meant that the model does not provide a clear pathway to disability, or offer a model of disablement process, instead promote a new language to define the consequences of health conditions which might be interpreted as introducing further complexity to disability literature. • The interpretation and categorisation of the concepts of activity and participation had been widely criticised for the difficulty in differentiating the two concepts. The ICF describes them conceptually different but provides a single combined list of life areas that are not necessarily linked to one or another. • Personal factors were not clearly defined due to its wide variability.
Canadian Model of Occupational Performance (CMOP) (Fearing at al., 1997)
Strengths
• Illustrated the relationship between person, occupation (ADL) and environment with a three dimensional model; suggesting that a change in one area automatically affects the others. • With the person at its centre, the model conveys Occupational Therapy's (OT) client centred perspective. • Designed to demonstrate change in a client's self-perception of occupational performance over the course of occupational therapy, thus, aiding the therapy in the rehabilitation process. • Applied in practice through an accompanying outcome measure; Canadian Occupational Performance Measure (COPM) designed to help clients identify, prioritise, and evaluate important issues they encounter in occupational performance.
Limitations
• Through its use of terminology specific to OT and the need for specialist training in application to the clinical and research practice, it creates a barrier for other health-care/ research professionals to interpret the results of this assessment and compare information with other studies.
The Model of Human Occupation (MOHO) (Kielhofner et al., 2002)
Strengths
• MOHO emphasised that to understand human occupation, it is important to understand the physical and social environments in which the occupation is performed and conceptualised human occupation as a product of three interrelated components; volition, habituation, and performance capacity, taking a person centred stance. • It is applied in clinical practice and research by both structured and unstructured assessments such as the Model of Human Occupation Screening Tool (MOHOST) to provide the therapist an overview of the client's functioning.
Limitations
• It has been criticised for its lack of consideration around the role of environmental factors on human behaviour and impact of this on the occupational performance. • Similar to CMOP, this model is not openly accessible to those who are not occupational therapists.

2.3 The ICF model of self-care

Differences in definitions and measurement of self-care across studies highlight the need for use of a common language and a consistent approach to define and quantify self-care restrictions in populations. The ICF offers a definition and a model of self-care to encourage a consistent approach. In this framework self-care is presented as one domain of functioning that warrants particular attention to understand how common it is and the factors linked with restriction (WHO, 2003).

The ICF defines self-care as *"caring for oneself, washing and drying oneself, caring for one's body and body parts, dressing, eating and drinking, and looking after one's health"* (WHO, 2001). Each of the sub-domains of self-care is also defined within the ICF framework to avoid ambiguity and provide guidance for analysis (D510; Washing oneself, D520; Caring for body parts, D530;Toileting, D540; Dressing, D550; Eating, D560; Drinking, D570; Looking after one's health) (Table 2.4). Having clear definitions of self-care allows differentiation from other forms of disability such as locomotor disability and other constructs such as self-maintenance (i.e. management of health). The ICF offers a biopsychosocial model of self-care that accounts for the context of an individual's life when assessing disability.

The ICF does not propose whether self-care should be considered as "Activities" or "Participation", or in other words, whether it should be considered as functioning at the level of the individual or society. One of the clear strengths of the ICF framework is that it encourages a biopsychosocial approach to understanding "disability". The framework encourages a wider approach to investigating factors

that are associated with self-care restriction and in particular the role of environmental factors. For example an older person with joint pain may experience difficulty bending to wash, dress and pick things up. In this case access to environmental facilitators such as a grab-rail by a bath or shower cubicle can assist transfers, whilst dressing aids such as button hooks can enable those with grip problems to put on and take off shirts and trousers. Similarly, those who are in receipt of personal help and assistance for personal care activities such as washing and dressing or caring for body parts may feel that their needs in self-care have been met, hence, may not be disabled by their limitations.

The model of self-care provided by the ICF offers opportunities to develop the epidemiology of self-care using a common language and a consistent approach. Therefore, this model was adopted as a conceptual framework in this thesis to investigate the course of self-care restriction and its links with joint pain in community-dwelling older people.

Table 2.4 The self-care and its components in the ICF framework

D5- Self-care Domain	
Sub-domain	Definition
D510 - Washing one-self	Washing and drying one's whole body, or body parts, using water and appropriate cleaning and drying materials or methods, such as bathing, showering, washing hands and feet, face and hair, and drying with a towel.
D520 - Caring for body parts	Looking after those parts of the body, such as skin, face, teeth, scalp, nails and genitals that require more than washing and drying.
D530 - Toileting	Planning and carrying out the elimination of human waste (menstruation, urination and defecation), and cleaning oneself afterwards.
D540 - Dressing	Carrying out the coordinated actions and tasks of putting on and taking off clothes and footwear in sequence and in keeping with climatic and social conditions, such as by putting on, adjusting and removing shirts, skirts, blouses, pants, undergarments, saris, kimono, tights, hats, gloves, coats, shoes, boots, sandals and slippers.
D550 - Eating	Carrying out the coordinated tasks and actions of eating food that has been served, bringing it to the mouth and consuming it in culturally acceptable ways, cutting or breaking food into pieces, opening bottles and cans, using eating implements, having meals, feasting or dining.
D560 -Drinking	Taking hold of a drink, bringing it to the mouth, and consuming the drink in culturally acceptable ways, mixing, stirring and pouring liquids for drinking, opening bottles and cans, drinking through a straw or drinking running water such as from a tap or a spring; feeding from the breast.
D570 - Looking after one's health	Ensuring physical comfort, health and physical and mental well-being, such as by maintaining a balanced diet, and an appropriate level of physical activity, keeping warm or cool, avoiding harms to health, following safe sex practices, including using condoms, getting immunizations and regular physical examinations.

Source: International Classification of Functioning (WHO, 2001)

Chapter 3
The impact of osteoarthritis on self-care in older adults: a systematic review

3.1 The burden of musculoskeletal conditions in older adults

The prevalence of musculoskeletal conditions is high and they are the most common cause of disability in older adults (Woolf and Pfleger, 2003). Musculoskeletal conditions are rarely fatal and prevalence rises with age (Verbrugge, 1995). With population ageing there will be an increasing number of older adults with these conditions. Despite the large and growing impact, identifying and managing musculoskeletal conditions has not been a health care priority in the United Kingdom (UK) or other western countries (i.e. in Europe or the United States). Initiatives, such as the Bone and Joint Decade (1998), have raised awareness of musculoskeletal diseases, but there is still a need to better understand the full burden of these conditions on the individual and society (Woolf and Pfleger, 2003). This includes recognising the frequency, incidence, causes, progression and consequences to inform preventative and management strategies.

3.2 Osteoarthritis

Osteoarthritis is the most common musculoskeletal condition in older adults (Arthritis Care, 2004; Arthritis Research Campaign, 2002; Scott et al., 1998). In the UK in 2000 it was estimated that there were just over three million consultations to general practice and over one hundred thousand admissions to hospital for

osteoarthritis (Arthritis Research Campaign, 2002). It is strongly associated with age and is expected to have an increasing impact on health and social care needs (Woolf and Pfleger, 2003).

3.2.1 Definition of osteoarthritis

"*The name osteoarthritis was adopted from three Greek words meaning bone, joint, and inflammation*" (Mosby's Medical Dictionary, 2009: osteoarthritis). It can be defined by two different but overlapping syndromes; the disease and the clinical syndrome of joint pain and disability (Moskowitz, 2009). As a disease, osteoarthritis is defined as a non-inflammatory disorder of synovial joints that is characterised by focal areas of damage to the articular cartilage, remodelling of underlying bone and the formation of osteophytes (i.e. new bone at joint margins), and mild synovitis (Dequeker and Luyten, 2008; National Collaborating Centre for Chronic Conditions, 2008). In osteoarthritis the disease processes do not only affect the articular cartilage, but involve the entire joint, including the subchondral bone, ligaments, capsule, synovial membrane, and periarticular muscles (Brandt et al., 2008).

The articular cartilage is whitish in colour, elastic and very strong due to its components; which consist mostly of water (nearly 65%), proteoglycans, and collagens. Cells embedded throughout the cartilage called chondrocytes are responsible for synthesising proteins that make up cartilage, as well as the enzymes that break down the cartilage maintaining the balance of repair and degradation. A number of enzymes are produced by chondrocytes called

metalloproteinases (Lane and Wallace 2002). Normally, these enzymes are found in very low concentrations in cartilage with normal levels of their inhibitors (tissue inhibitors of metalloproteinases (TIMPs)) (i.e. "*naturally occurring small proteins which inhibit metalloproteinases so that they do not break down too much cartilage*" (Lane and Wallace 2002:p.32). However, in osteoarthritis, there is a change in this metabolic balance, so the levels of these enzymes increases and TIMPs decrease, breaking down the cartilage faster than the chondrocyte can repair, resulting in a loss of cartilage (Lane and Wallace 2002). Therefore, the disease process in osteoarthritis usually starts with inflamed and swollen cartilage when the joint loses proteoglycan molecules, other tissues and water. Cartilage loses its elasticity and fluid, and cracks starts to appear on the surface. In this process, the cartilage hardens and becomes more prone to further damage with continuous usage and loading. Over time, large amounts of the cartilage can be lost, leaving the ends of the bone within the joint unprotected. As the body reacts to the loss of cartilage, clusters of damaged cells or fluid-filled cysts form on the bony areas or near the splits in the cartilage. This may also happen within the bone marrow itself, which results in swelling. The marrow is rich in nerve fibres. These changes may cause pain in those with osteoarthritis. Bone cells may respond to damage by multiplying, growing, and forming dense, misshapen plates around exposed areas (i.e. osteophytes) causing limitation in joint movements and pain (Simon, 2009).

Definition and diagnosis of osteoarthritis has proven to be challenging (Peat et al. 2005). Due to the complex nature of OA, the clinical presentation and outcomes

can be extremely variable, both between individuals and at different joint sites (Doherty et al., 2001). Osteoarthritis can present itself as a symptom free but mechanically altered joint, or symptoms may be experienced but without radiographic change (Dahaghin et al., 2005). More often than not, the natural repair process that takes place in the joint fails to compensate for the damage, and this results in joint failure (NICE, 2008). Therefore, radiographic change only identifies those with severe osteoarthritis and not those present with the clinical symptoms of pain and stiffness (Wenham and Conaghan, 2009). The National Institute for Health and Clinical Excellence (NICE) guidelines state that the presence of radiological change is not required for the diagnosis of osteoarthritis, and the complaint of joint pain and functional limitation is sufficient (Table 3.1). Joint pain is a recommended starting point for population-based studies of osteoarthritis and its impact (Peat et al., 2001). The most commonly affected joints are the knees, hips, and the small joints of the hand (WHO, 2003).

Table 3.1 The GDP diagnostic criteria for osteoarthritis

i.	persistent joint pain which is worse with use
ii.	aged 45 years and over
iii.	morning stiffness lasting no more than half hour

Source: NICE, 2008

3.2.2 Prevalence of osteoarthritis

The reported prevalence of osteoarthritis in the literature varies due to different definitions of osteoarthritis (e.g. joint pain or radiographic osteoarthritis (Jacobson et al., 2004) (Table 3.2). However, osteoarthritis at individual joint sites (e.g. knee, hip and hand), no matter how it is defined, increases with age (Arthritis and Musculoskeletal Alliance 2005). In population studies, more people report multiple joint pains than pain at a single site (Conaghan and Nelson, 2009).

The prevalence of radiographic osteoarthritis is reported to be higher in women than men, particularly in those aged 50 years and over with hand and/or knee osteoarthritis (WHO, 2003). Radiographic osteoarthritis of the knee affects about a quarter of adults aged 50 years and over in the community (Peat et al., 2001). However the prevalence estimates vary according to the diagnostic criteria and the age of the sample in each study (Table 3.2). Evidence suggests that radiographic osteoarthritis is more common in those who have had the condition longer and have more persistent symptoms. However this also depends on the applied definition (Bedson and Croft, 2008). Duncan et al. (2007) reported that there is a steady association between severity of pain, stiffness and physical function, and the presence of radiographic knee osteoarthritis. Peat et al (2006) suggest that concordance between symptoms and radiographic osteoarthritis seems greater with more advanced structural damage.

Joint pain is common in adults aged 50 years and over in the general population (Thomas et al., 2004:a). The most common site of peripheral joint pain is the knee

(19%; 95% CI 18, 21), and the prevalence of knee pain among women aged 75 and over is estimated to be 35% (defined as pain in the past month lasting for more than a week) (Urwin et al., 1998). However the reported frequencies of joint pain are varied, due to differences in definitions used to measure joint pain (Table 3.2).

Table 3.2 Standardised prevalence rates of knee osteoarthritis

Source	Diagnosis	Age	Prevalence
Steven et al 1992	Symptomatic	16-99	6.50
Badley et al 1992	Self-reported	16-99	9.84
Forsberg et al 1992	Radiographic	67-92	53.87
Bagge et al 1992	Radiographic	67-92	43.01
Mannoni et al 2003	Symptomatic	65-99	29.80
Picavet et al 2003	Self-reported	25-99	11.90
Andrianakos et al 2003	Symptomatic/ Radiographic	19-99	6.55
Salaffi et al 2005	Symptomatic	18-91	5.39
Horvath et al 2006	Self-reported pain	14-69	28.30
Tamm et al 2008	Radiographic	34-55	3.74
Fernandez-Lopez et al 2008	Symptomatic	20-99	11.72
Quintana et al 2008:a	Symptomatic/ Radiographic	60-89	71.10
Quintana et al 2008:b	Symptomatic	60-90	40.39
Quintana et al 2008:b	Self-reported	60-90	35.12

Source: Data extracted from the Musculoskeletal Health in Europe Report (2012)

Hand pain is also common in older adults in the general population (Dziedzic et al., 2007; Arthritis and Musculoskeletal Alliance (ARMA), 2005; Arthritis Care, 2004; Hochberg et al., 2000; Urwin et al., 1998). One study estimated the prevalence of hand pain as 12% in adults aged 45 years and over (defined as pain in the past month lasting for more than a week) (Urwin et al., 1998). Another study

estimated the prevalence of hand pain and as ~30% in those aged 50 years and over in the general population (participants were asked whether they had experienced any recent pain, specifically *"in the past month any ache or pain that lasted for one day or longer in your hands"*) (Dziedzic et al., 2007). It was suggested that prevalence of hand pain was higher in women (Dziedzic et al., 2007; Dahaghin et al., 2005).

3.2.3 The impact of osteoarthritis on self-care in older people

The impact of osteoarthritis is broad and is associated with many outcomes. The extent of pain severity is associated with increasing mobility problems (Wilkie et al., 2006) and is a predictor of future disability in activities of daily living (ADL) (Davis et al., 1991). According to WHO (2003), about 80% of those with osteoarthritis have limitation in movement and a quarter have limitations in ADL. Studies suggests that joint pain can affect mobility, participation and the psychosocial functioning of the individual, leading to increased dependency in carrying out ADL (Verbrugge and Juarez, 2001; Dunlop et al., 2001; Hochberg et al., 1995). Knee pain was found to be associated with severe difficulties in conducting ADL in those aged 50 years and over (Jinks et al., 2002), and older adults with joint pain are more likely to have participation restriction, than those without (Wilkie et al 2007:a). Reduced quality of life is linked to joint pain through its impact on self-esteem, independence and its considerable effect on personal relationships (Conaghan and Nelson, 2012). Depression is also common amongst those with osteoarthritis, and is linked to activity limitation and participation restriction (Wilkie e al., 2005; Machado et al., 2008).

Studies suggest that personal factors such as psycho-social dynamics and mental health status should be taken into account when attempting to understand the predictors of functional decrease in those with joint pain (Gignac et al., 2000; Yelin et al., 1987). Environmental factors such as social support and exercise are positively associated with protection against poor functional outcome (Sharma et al., 2003). However many studies focus on the individual (i.e. measuring activity limitation) and not the individual's interaction with the environment.

Despite the research indicating links between joint pain and future self-care disability, the extent and mechanisms of restriction in self-care in those with joint pain is fragmented. Differences in the terminologies used to define self-care and joint pain further adds to the variation in research findings. There is a need to conduct a systematic review of the literature to identify whether there are any studies which have specifically explored the links between self-care restriction and joint pain and identified the determinants of self-care restrictions in community-dwelling older adults with joint pain/ osteoarthritis.

3.3 Aims and objectives

The aim of the systematic review was to explore the current literature on restricted self-care in community-dwelling adults aged 50 years and over in the general population and its links with joint pain/ osteoarthritis.

The objectives of the review were to (i) determine if self-care restriction is associated with joint pain in community-dwelling adults aged 50 years and over in

the general population, and (ii) identify the determinants of restricted self-care in community-dwelling adults aged 50 years and over with joint pain/osteoarthritis.

3.4 Methods

3.4.1 Search strategy

Systematic reviews are conducted to identify relevant studies, synthesise information, and to present an objective summary of the results with due consideration of any limitations in the evidence (Davies and Crombie, 2001). Systematic reviews are formal processes which use explicit methods to perform a thorough literature search and critical appraisal of individual studies to identify the valid and applicable evidence (Moher et al., 2007).

The search strategy was designed to be comprehensive and thorough with the aim of identifying all relevant studies for the research question. Through an eliminatory literature search, keywords were identified to capture the International Classification of Function's (ICF) (WHO, 2001) definition of self-care. A similar approach was taken to identify keywords for 'restriction', such as limitation and disability. In order to include all studies that capture the population aged 50 and over, keywords to represent age groups in numbers and words were used. To ensure the in-depth search of the specialised literature, the search strategy was divided into two stages to meet the reviews objectives. (i) To determine whether self-care restriction was associated with joint pain in community-dwelling adults aged 50 years and over, general population studies were identified. (ii) To explore the determinants of restricted self-care in community-dwelling adults aged 50

years and over with joint pain/osteoarthritis, studies in joint pain/ osteoarthritis populations were identified. For the general population, related terms were also identified through the literature review. For the joint pain population, both medical terms and clinical references were used to gather the studies of joint pain and osteoarthritis. Where necessary, keywords were truncated to yield all results covering varied forms of the word. For example, when a search using the word 'limit' was truncated, this yielded results for the variation of this term such as 'limited' and 'limitation' to ensure that the keywords used in the search were comprehensive.

To capture all studies published to date, titles were retrieved by a two stage computerised search of the Cochrane Library, Medical Literature Analysis and Retrieval System Online (Medline), Excerpta Medica Database (Embase), Cumulative Index to Nursing and Allied Health Literature (CINAHL), King's Fund (Her Majesty's Inspectorate of Constabulary (HMIC)), Allied and Alternative Medicine (Amed), Psychological Information Database (PsychINFO), Applied Social Sciences Index and Abstracts (ASSIA), Ageline-CSA, Social Services Abstracts and British Nursing Index from earliest (1900) to January 2009. Keywords with Medical Subject Headings (MeSH) and text words were used in following order to retrieve the target literature (Table 3.3).

Table 3.3 Search strategy

Stage (i) General population	
1	(“self care” OR “self-care” OR “self maintenance” OR “self-maintenance” OR “self reliance” OR “self-reliance” OR “personal care” OR “personal-care” OR “activities of daily living” or “daily living activities” or ADL or IADL or PADL or ADLS AND restrict* or limit* or disab*).ti,ab
2	(wash* OR dress* OR “putting on clothes” OR “taking off clothes” OR “putting on footwear” OR “taking off footwear” OR bath* OR shower* OR grooming OR drying OR combing OR shaving OR brushing OR clean* OR walk* OR toilet* OR feeding OR drinking OR “meal preparation” OR “meal-preparation” OR cooking) AND (restrict* or limit* or disab*).ti,ab
3	(“older adults” OR “over 50” OR “over fifty” OR “over 65” OR “over sixty five” OR eld* OR age* OR geriatric OR middle age*).ti,ab
4	(“community dwelling” OR “community-dwelling” OR “lives at home” OR “lives at-home” OR “lives alone” OR “lives-alone” OR “general population”) .ti,ab
5	(“joint pain” OR arthrit* OR osteoarthrit* OR osteoarthrosis OR OA OR gonarthrosis OR coxarthrosis) AND (pain OR complain*).ti,ab
6	(hip OR knee OR hand OR thumb OR foot) AND (pain) .ti,ab
7	Combine 1 OR 2
8	Combine 3 AND 4
9	Combine 7 AND 8
Stage (ii) Joint pain population	
10	Combine 5 OR 6
11	Combine 3 AND 7
12	Combine 10 AND 11

3.4.2 Selection criteria

First of all, the author reviewed the titles of all identified publications for potential relevance to self-care and osteoarthritis. Two observers (Yeliz Prior (YP) and Ross Wilkie (RW)) then independently reviewed the titles of all identified publications for potential relevance to the ICF’s definition of self-care used in this thesis. This process was repeated for both stages of the search. Selection criteria were developed to select publications that were relevant to the objectives of this review. Inclusion criteria were:

i. Method: Epidemiological studies (i.e. cross-sectional, case-control or prospective/cohort)

ii. Population of interest: Community-dwelling adults aged 50 and over

iii. Exposure: Joint pain/ Osteoarthritis

iv. Comparison: General population

v. Outcome: Limitations/ Restrictions in self-care (i.e. washing oneself, caring for body parts, dressing, eating and drinking and toileting)

vi. Fully published papers in the English language

Following their review of study titles, the two reviewers (YG and RW) met to discuss which papers were relevant to the objectives of the systematic review. Disagreements were resolved during this consensus meeting. Once agreement on the titles was reached, corresponding abstracts were retrieved and both reviewers independently applied the selection criteria to abstracts, or to full papers when the information provided on abstracts were not sufficient.

Following the review of abstracts of full papers, full articles of all relevant studies were retrieved and the inclusion criteria were applied to these studies independently to ensure they met the systematic review objectives. A further meeting was held by reviewers to discuss the inclusion of these studies and finalise the selection process.

3.4.3 Quality assessment and data extraction

Differences in methodological quality across studies can indicate that the results of some studies are more likely to be affected by bias than others. Bias tends to be a much greater problem in observational studies (Bonita et al., 2006). Thus, assessing quality and susceptibility to bias is essential when interpreting research findings and conducting systematic reviews (Sanderson et al., 2007). Bias is defined in epidemiology as *"an error in design or execution of a study, which produce results that are consistently distorted in one direction because of non-random factors"* (Bayona and Olsen, 2004: p15).

There are three major biases in observational studies; confounding, selection and information bias (Hennekens and Buring, 1987). Confounding bias occurs when *"all or part of the apparent association between the exposure and outcome is in fact accounted for by other variables that affect the outcome and are not themselves affected by the exposure"* (Porta, 2008 p:49). Selection bias is a distortion in the estimate of association between the risk factor and disease that results from the methods used during the selection of participants. Selection bias could occur either because the sampling frame is sufficiently different from the target population, or because the sampling procedure cannot be expected to deliver a sample that is a mirror image of the sampling frame (Silman and Macfarlane, 2002). Information bias is an estimate arising from systematic measurement error or misclassification of subjects on one or more variables, risk factor or disease status (Bayona and Olsen, 2004).

Although tools for assessing quality in clinical trials are well-described, notably less attention has been given to tools assessing the quality of observational epidemiological studies (Sanderson et al., 2007). A recent review, considered 121 critical appraisal tools for allied health research, and concluded that there is no agreed 'gold standard'. At the time of this review, no tool has been adopted for widespread use within systematic reviews. Quality assessments in addition to assessing the susceptibility to bias, can also consider issues around sample size, power calculations and ethical approval. However it is important to differentiate between the quality of reporting and the quality of the design, conduct and analysis of a given study (Huwiler-Muntener et al., 2002). A number of consensus statements have encouraged higher quality of reporting, including recommendations for reporting systematic reviews (The Quality of Reporting of Meta-analyses (QUOROM)) (Moher et al., 1999) and observational epidemiological studies (Strengthening the Reporting of Observational studies in Epidemiology (STROBE)) (Von Elm et al., 2007). These tools aimed to assist the author of reports, not the reader who would like to assess the validity of the research (Sanderson et al., 2007). The following assessment tools have been proposed to assess the quality of research studies in peer-reviewed journals.

Critical Appraisal Skills Programme (CASP)

The Critical Appraisal Skills Programme (CASP) was developed by the Public Health Resource Unit of the National Health Service (NHS) (2006). This tool considered three broad issues; i) are the results of the study valid? ii) what are the results? and iii) will the results help locally? (Bradley and Burls, 1999). The primary

aim was to help the reviewer to think systematically when appraising systematic reviews, thus this tool was not designed to assess individual studies. There are 10 questions in total, of which two are screening questions, advising the reviewer to complete the remaining questions if the answer to both these questions are 'yes'. Reviewers are asked to record a "yes", "no" or "can't tell" to most of the questions, with prompts after each question. Screening questions ask whether there is a clearly focused question; include the right type of study; identify all relevant studies; assessed the quality of the included studies; if the results of the studies combined, was it reasonable to do so; how are the results are presented and what is the main result; how precise are the results; can the results be applied to the local population; were all important outcomes considered, and finally should policy or practice change as a result of the evidence contained in this review? (Public Health Resource Unit, 2008).

Strengthening the Reporting of Observational Studies in Epidemiology (STROBE)

The STROBE statement was developed by a group of methodologists, researchers, and editors to improve the quality in reporting of observational studies by facilitating critical appraisal and interpretation of studies by reviewers (Malta et al., 2010).

This statement restricts their recommendations mainly to three study designs (cohort, case-control and cross-sectional studies) and provides a checklist of items that should be included in reports of observational studies. This consists of 22 points to summarise the title and abstract, introduction, methods, results and

discussion sections of the studies (Vandenbroucke et al, 2007). The statement makes recommendations for each section. For example, it recommends that the methods of a study should present the key elements of the study design early in the paper and describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection. It provides clear instructions on the need to describe the participants (i.e. for a cross-sectional study, the eligibility criteria, and the sources and methods of selection of participants should be presented); to clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers; give sources of data and details of methods of assessment for each variable of interest; to describe any efforts to address potential sources of bias; to explain how the study size was arrived at; to explain how quantitative variables were handled in the analyses and how the statistical methods followed should be summarised. In the results section, it again provides detailed instructions on how to report the participants at each stage of the study; to give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders; to report numbers of outcome events or summary measures; to give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval), and report other analyses done (e.g. analyses of subgroups and interactions, and sensitivity analyses). The Strobe Statement also gives pointers for how to report the discussion and any other information such as funding (Sanderson et al., 2007). The STROBE group stress that the aim is to provide guidance on how to report observational research well, and that the recommendations are not prescriptions for designing or conducting studies. They

also add that the checklist is not an instrument to evaluate the quality of observational research (The Strobe Initiative, 2009) (Table 3.4).

Table 3.4 STROBE Statement—Checklist of items that should be included in reports of cross-sectional studies (an extract)

	Item no	
Title and abstract	**1**	**Recommendation** a) Indicate the study's design with a commonly used term in the title or the abstract b) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background and Rationale	**2**	Explain the scientific background and rationale for the investigation being reported
Objectives	**3**	State specific objectives, including any pre-specified hypotheses
Methods		
Study design	**4**	Present key elements of study design early in the paper
Setting	**5**	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	**6**	Give the eligibility criteria, and the sources and methods of selection of Participants

Source: The Strobe Statement, 2009

Quality in Prognosis Studies (QUIPS-LBP) tool

The QUIPS-LBP tool was designed for systematic reviews of prognostic studies through international expert consensus (Hayden et al., 2006). Originally developed to provide criteria and guidance for assessing the risk of potential biases in low back pain prognosis studies, this tool considers bias related to study participation,

study attrition, prognostic factor measurement, outcome measurement, confounding measurement and account bias related to analysis.

The QUIPS-LBP does not offer a scoring system to appraise studies. Instead, it allows the overall quality of the research to be comprehensively evaluated by recognising flaws in the study which may have resulted in bias (Wynne-Jones et al., 2010; Hayden et al., 2008). The reviewer is asked to consider if the study methods satisfy each general statement for the six biases assessed by the tool and explain why they chose their rating under 'comments' (Table 3.5). There are six sections and 36 questions with five possible ratings as: "Yes", "Partly", "No", "Unclear" and "Not relevant" with a summary at the end of every section. Where the majority of domains are given a "no" rating this suggests that the methodological quality of that domain is poor. Where the majority of domains are given a rating of "unclear" or "partly", this indicates a moderate risk of bias, which is difficult to assess due to the lack of detail with regards to the methods reported in the study. Finally, the "yes" rating indicates a low risk of bias, suggesting that the reporting of the methodological quality is sufficient to exclude the possibility of bias in the study (see appendix). Although originally developed for back pain studies, the QUIPS-LBP tool could be used to assess bias for other conditions (Hayden et al., 2007).

Table 3.5 The layout of the QUIPS-LBP: Quality Appraisal Exercise (an extract)

Study (First author, year):	
Bias related to Study Participation	
1. The source of population or population of interest is adequately described for key characteristics. ☐ Yes ☐ Partly ☐ No ☐ Unclear ☐ Not relevant	***Comments:*** For example, what are the 'key characteristics; that need to be described for the source population?

Source: Data from the original QUIPS Quality Appraisal Exercise (Hayden et al., 2006)

The Quality Assessment Process

The most suitable tool to assess the quality of studies was the QUIPS-LBP tool (Hayden et al., 2007) (Table 3.5). This was both due to the use of expert consensus in development of this tool and the ease of practical application as it listed a structured series of questions to identify and score possible bias and confounding (Hayden et al., 2007). The QUIPS-LBP tool was adapted for use in this study by making minor adjustments to allow application to both cross-sectional and longitudinal studies (e.g. question 13 asks whether the study provides a clear description of the prognostic factor measured – including dose, level, duration of exposure, and clear specification of the method of measurement. This heading was changed to 'factors measured', and the section on the study attrition was not applied to cross-sectional studies).

Two reviewers (YG, RW) independently assessed the quality of each study using the QUIPS-LBP (Quality in Prognosis Studies) tool. Each study was given

individual scores at the end of the assessment in the overall summary section. A third reviewer was consulted to resolve any disagreements (Roger Beech (RB)). A descriptive summary of quality assessment was presented for each study according to the QUIPS quality appraisal exercise tool in the results section (Table 3.9).

Data extraction

Each study's detail on the study population (setting, sampling frame, sample size, response rate), outcome and the associations with other factors were extracted and presented as a narrative summary table in the results section (Table 3.8).

3.4.4 Strength of the evidence

To establish possible associations between joint pain and restricted self-care, important factors such as temporal relationship (i.e. does joint pain occur before activity limitations), plausibility, dose-response relationship (i.e. does increased pain results in increased restriction) and the consistency of possible associations across studies were considered. It was understood that the strength of these associations might be dependent on the relative prevalence of other possible causes (Bonita et al., 2006), thus the evidence acquired for or against the cause and effect relationship might be discordant. Nevertheless following criteria ensures that the systematic review maintains a methodical manner (Van Der Windt et al., 2000).

3.5 Results

3.5.1 Search Strategy

Search 1: Self-care and joint pain in the general population

The number of citations identified in each database was documented in "Reference Manager" (Table 3.6 and Table 3.7) and each reference was archived electronically. In total 9765 citations were identified and retrieved during the first stage of the search. 9731 citations did not meet the inclusion criteria as they were not relevant to the review (e.g. search terms yielded results from studies of brain injury, psychological disorders and other literature as well as studies of self-management of health conditions). Two reviewers read the remaining 34 abstracts and 19 abstracts were excluded for not meeting the inclusion criteria. The remaining 15 papers were retrieved and read by two reviewers and further 13 papers were excluded in this stage because they did not meet the inclusion criteria (i.e. either because of the study design (i.e. not an epidemiological study), definition of self-care (e.g. inclusion of mobility or IADL items) and joint pain (i.e. not all musculoskeletal pain is due to OA) or differences in sampling frames (i.e. not meeting the criteria of aged 50≥). Two papers were identified for review.

Search 2: Self-care in the joint pain population

During the second stage of the search, 988 citations were retrieved and 973 citations were excluded for not meeting the inclusion criteria. Of the remaining 15 abstracts, 14 abstracts were excluded for not meeting the inclusion criteria, leaving

one paper. The flow diagram in figure 3.1 describes the number of abstracts accepted and rejected by two reviewers during the selection procedure. A total of three studies were finally included in the review.

Figure 3.1 Flow diagram of papers accepted and rejected in the review

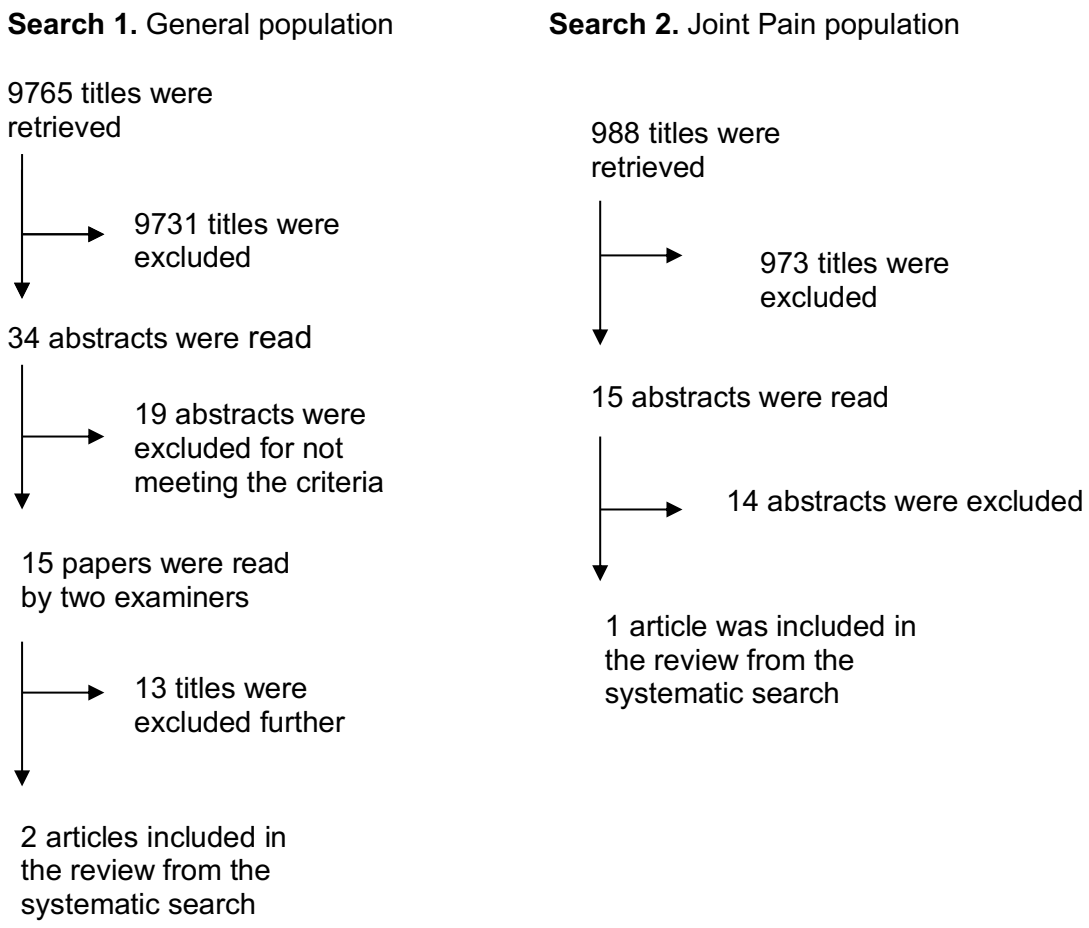


Table 3.6 Search 1: General population

Date of Search	Database	Host/System Used	Years Searched	Numbers of documents obtained	Number of Duplicates	Total after removal of duplicates
15.12.2008	Cochrane Library	Wiley-Interscience	All years	396	0	396
15.12.2008	ASSIA	CSA-Illumina	All years	172	0	568
15.12.2008	Ageline	CSA-Illumina	All years	1685	1	2253
16.12.2008	Social Services Abstracts	CSA-Illumina	All years	753	2	3004
17.12.2008	Embase	NHS Library	All years	2620	278	5346
17.12.2008	HMIC	NHS Library	All years	83	29	5400
08.01.2009	Medline	CSA-Illumina	All years	4364	2326	7438
07.01.2009	CINAHL	NHS Library	All years	2581	432	9587
07.01.2009	Amed	NHS Library	All years	233	154	9666
07.01.2009	Psychinfo	NHS Library	All years	979	92	9758
07.01.2009	British Nursing Index	EPSCO	All years	15	7	9765

Table 3.7 Search 2: Joint pain population

Date of Search	Database	Host/System Used	Years Searched	Numbers of documents obtained	Number of Duplicates	Total after removal of duplicates
26.01.2009	Cochrane Library	Wiley-Interscience	All years	291	0	291
15.12.2008	ASSIA	CSA-Illumina	All years	66	0	357
15.12.2008	Ageline	CSA-Illumina	All years	24	0	381
16.12.2008	Social Services Abstracts	CSA-Illumina	All years	319	1	699
17.12.2008	Embase	NHS Library	All years	94	3	790
17.12.2008	HMIC	NHS Library	All years	2	0	792
08.01.2009	Medline	CSA-Illumina	All years	156	37	911
07.01.2009	CINAHL	NHS Library	All years	80	28	963
07.01.2009	Amed	NHS Library	All years	16	12	967
07.01.2009	Psychinfo	NHS Library	All years	14	9	972
07.01.2009	British Nursing Index	EPSCO	All years	19	3	988

3.5.2 Articles Identified

The three articles selected for the review are summarised below;

(i) General population studies:

Effect of Arthritis in Middle Age on Older-Age Functioning (Covinsky et al., 2008)

This study aimed to examine whether symptomatic arthritis in middle age predicts early onset of functional difficulties that are associated with loss of independence in older adults (Covinsky et al., 2008). Participants were those who took part in the 1992 Health and Retirement Study (HRS), as they were considered to be an ideal cohort to address whether arthritis in mid-life leads to earlier onset of late-life disabilities. The study design was a prospective longitudinal study. 7543 participants aged 50 to 62 at baseline, reporting no difficulty in mobility or ADL function were enrolled in the study (Covinsky et al., 2008).

This study looked at the links with symptomatic arthritis defined by self-reported pain, stiffness or swelling in joints, use of medications or other treatments for their arthritis or rheumatism, or consultation with a doctor for arthritis in the previous 12 months. The primary outcome was time to persistent difficulty in one of five activities of daily life (ADLs) (bathing, dressing, transferring from a bed to a chair or out of chair, using a toilet, or eating) or mobility. Participants were classified as having difficulty with ADLs if they reported difficulty in one of these items. Difficulty with carrying out ADLs and mobility were assessed by interview every two years. Participants were classified as having persistent difficulty only if they reported a specific difficulty on two consecutive waves (participants who reported difficulty on one wave and died before the next wave was also classified as having persistent

difficulty). Kaplan-Meier curves were constructed to compare the time to persistent difficulty with mobility or ADL function in participants with or without arthritis at baseline. Proportional hazards survival analysis was used to calculate the unadjusted and adjusted hazard ratios for the association between arthritis and subsequent mobility or ADL difficulty. Analyses were adjusted for other comorbid conditions, body mass index, exercise, and demographic characteristics to determine independent associations between arthritis and mobility or ADL difficulty (Covinsky et al., 2008).

At baseline 29% of the participants had symptomatic arthritis. Participants with symptomatic arthritis were older, more likely to be female, of low socio-economic status and higher BMI than those who did not report arthritis. They were also more likely to have other comorbidities such as hypertension, diabetes mellitus, cancer, lung disease, and depressive symptoms. They were also more likely to have persistent difficulty in mobility and ADL function across the 10 year period than those who did not have symptomatic arthritis (Covinsky et al., 2008). The authors conclude that middle-aged adults with symptomatic arthritis had a greater risk for developing mobility and ADL difficulties that lead to loss of independence in late life (Covinsky et al., 2008).

Arthritis Prevalence and Activity Limitations in Older Adults (Dunlop et al., 2001)

This study aimed to evaluate the prevalence of arthritis and activity limitations among older Americans by assessing their demographic, ethnic, and economic characteristics. Data was utilised from the Asset and Health Dynamic Survey

Among the Oldest Old (AHEAD) study, a national probability sample of community-dwelling adults born before 1924, and analysed cross-sectionally (Dunlop et al., 2001).

The case definition of arthritis was defined as symptomatic arthritis that has been severe enough for participants to visit a doctor within the last 12 months prior to this study. The study compared the activity limitation experience of people with arthritis, with people reporting other conditions. Activity limitations included self-reported functional limitations in basic ADL or instrumental ADL (IADL) tasks and physical activity limitations. ADL limitations were having difficulty or receiving help in the tasks of dressing, toileting, bathing, or eating, and reports of using a device, having difficulty, or receiving help in the tasks of walking across a room or transferring in and out of bed. IADL limitations were defined as difficulties or receiving help with hot meal preparation, shopping, using the telephone, taking medication, or managing money. Functional limitations were categorised as no limitations, or limitations in only IADL, one to two ADL, or three or more ADL. Physical activity limitations were related to having difficulties in walking several blocks, climbing one flight of scales, pulling / pushing heavy objects, carrying ten pounds, or picking up a dime (Dunlop et al., 2001).

All analyses were weighted and adjusted for the complex sampling design to provide appropriate statistical tests based on the sample size to reflect the probability sample of the national population. Logistic regression was used to calculate adjusted rates for selected population characteristics. The estimated logit

from these analyses was used to obtain estimates of adjusted rates and proportions. The standard error of the adjusted rate, used to calculate the associated confidence interval, was estimated by delta method, and statistical testing was done at a nominal 5% alpha significance level (Dunlop et al., 2001).

The prevalence of arthritis in older people ranged from 25% in non-Hispanic whites to 40% in non-Hispanic blacks and 44% in Hispanics. Increased prevalence of arthritis was associated with less education, lower income and less wealth. The prevalence of ADL limitations in those with arthritis was 29%, 30% and 37% respectively for non-Hispanic whites, non-Hispanic blacks and Hispanics, and increased to 48%, 57% and 56% in those with arthritis who also report other chronic conditions (Dunlop et al., 2001). The authors concluded that non-Hispanic blacks and Hispanic older adults reported higher rates of arthritis than non-Hispanic whites, and Hispanics reported higher frequency of ADL limitations than non-Hispanic whites (Dunlop et al., 2001).

(ii) Joint pain study

Longitudinal Study of Joint Pain in Older People (Donald and Foy, 2004)

This study aimed to describe the natural history of joint pain in older people. The study recruited participants as part of a randomised controlled trial (RCT) evaluating the benefit of targeted nurse visits. 4804 participants aged 75 years and over from 12 UK General Practices (GP) were enrolled in the study. Participants were followed for a year in 1998 (Donald and Foy, 2004).

The postal version of the Elderly At Risk Rating Scale (EARRS), which consists of 20 domains to include activity and mobility, personal ADLs, mental health, support at home and questions to include joint pain, were sent to all participants identified by nurses at the 12 GP practices. EARRS was originally designed for nurse interview, thus it required minor modifications. The presence of joint pain was measured by recording the participant's response to the question "regarding joint pains, do you i) have no trouble at all? ii) have only occasional pains? iii) have pain some of the time? iv) have pains a lot of the time? v) have pains virtually all of the time? (Donald and Foy, 2004). This was categorised to 'no pain' (no or occasional pain); "episodic" pain some of the time and "constant pain" for pain 'a lot' or 'all' of the time. Multiple regression modelling was used to examine for associations (Donald and Foy, 2004).

Joint pain was reported by 83% of the participants. The prevalence of constant pain was 26% and was higher in women and in those over the age of 85. Pain increased with age in women. Joint pain was associated with disability and dependency across a wide range of problems. Pain was associated with a threefold increase in likelihood of dependency for ADL. Over 1 year, 18% acquired or had increased frequency of pain and 14% had reduced frequency of pain. Resolution was associated with preserved indoor mobility, and functional recovery (Donald and Foy, 2004). The authors concluded that joint pain is very common in older people, fluctuates over time, and strongly associated with psychological factors and disability (Donald and Foy, 2004).

Table 3.8 Data extraction from the identified articles

STUDIES	Effect of Arthritis in Middle Age on Older Age Functioning	Arthritis Prevalence and Activity Limitations in Older Adults	A Longitudinal Study of Joint Pain in Older People
Publication Year and Journal	2008. 56:23-28. Journal of American Geriatric Society	Jan 2001. Vol. 44, No. 1, pp 12-221. American College of Arthritis & Rheumatology	June 2004. 43:1256-1260, Journal of Rheumatology
Authors	Covinsky, K.E., Lindquist, K., Dunlop, D.D., Gill, T.M., Yelin, E.	Dunlop, D.D., Manheim, L.M., Song, J., Rowland, W.C.	Donald, I.P., and Foy, C.
Methods	Prospective Longitudinal Study	Cross-sectional	Prospective Longitudinal Study
Definition of self-care	Participants were classified as having difficulty with ADLs if they reported difficulty with bathing, dressing, transferring from a bed to a chair or out of a chair, using a toilet, or eating.	ADL limitations included reports of having difficulty or receiving help in the tasks of dressing, toileting, bathing, or eating, and reports of using a device, having difficulty, or receiving help in the tasks of walking across a room or transferring in and out of bed.	Personal activities of daily living was assessed in personal hygiene and dressing dependency
Definition of arthritis	Participants were asked, ‘‘Have you ever had, or has a doctor ever told you that you have, arthritis or rheumatism?’’	A person was considered to have arthritis if an affirmative response was given regarding seeing a doctor within 12 months for arthritis or rheumatism or if a person reported a joint replacement that was not associated with a hip fracture.	Cases were identified by the response to the question; Regarding joint pains, do you (i)have no trouble at all (ii) have only occasional pains (iii) have pains some of the time (iv)have pains a lot of the time (v)have pains virtually all of the time

STUDIES	Effect of Arthritis in Middle Age on Older Age Functioning	Arthritis Prevalence and Activity Limitations in Older Adults	A Longitudinal Study of Joint Pain in Older People
Setting	The Health and Retirement Study, a nationally representative sample of people aged 50 to 62 in the United States at baseline who were followed for 10 years.	Data were based on the AHEAD (Asset and Health Dynamic Survey Among the Oldest Old), a national probability sample of older Americans living in the community.	12 general practice populations in UK, with predominance of rural towns. All the practices had less then 5% ethnic minority on their list.
Sampling Frame	Participants enrolled in 1992 in the first wave of HRS who reported no difficulty in mobility or ADL function in baseline were used.	People born 1923 or earlier (70 years or older) who participated in 1993 AHEAD study.	All patients aged 75 and over on 1 May 1998 in 12 practices were identified and sent the postal version of Elderly At Risk Rating Scale (EARRS)
Sample Size	n= 7,543	n= 7,447	n= 4,804
Response Rate	80%	80%	80%
Mean Age	56 years	77 years	81 years
Female	51%	62%	58%
Prevalence of self-care restriction	Not reported	29%- Non-Hispanic Whites 30%- Non-Hispanic Blacks 37%- Hispanics (those with arthritis)	Not reported
Prevalence of Joint Pain/ OA	29%	24%- Non-Hispanic Whites 40%- Non-Hispanic Blacks 44%- Hispanics	83%

STUDIES	Effect of Arthritis in Middle Age on Older Age Functioning	Arthritis Prevalence and Activity Limitations in Older Adults	A Longitudinal Study of Joint Pain in Older People
Key Findings	Participants with arthritis were more likely to reach the primary outcome measure of persistent difficulty with mobility or with ADL function (34% vs 18%). It was found that middle-aged persons with arthritis were at higher risk for developing mobility and ADL difficulties that lead to loss of independence in late life.	Ethnic differences were found in the arthritis prevalence rates among older adults. Arthritis prevalence rates among non-Hispanic blacks and Hispanics were more than 50% higher than among non-Hispanic whites. Across all ethnic groups, the rates of ADL limitations increased with the presence of arthritis and other conditions, with the highest rates of ADL limitations being among older people with arthritis and other conditions.	The prevalence of constant pain was 26% and higher in women. Disability, measured in EARRS questionnaire, was found to be far stronger predictor of adverse outcomes (what is the outcome) than joint pain.

3.5.3 Methodological quality

The results of the quality appraisals are presented in the Table 3.9. This table shows an overall rating for each study to summarise the rating of individual items under the six main sections of the QUIPS-LBP assessment.

Table 3.9 Overall summaries of the QUIPS-LBP ratings for each study

QUALITY IN PROGNOSIS STUDIES (QUIPS-LBP): QUALITY APPRAISAL				
		Effect of Arthritis in Middle Age on Older Age Functioning	A Longitudinal Study of Joint Pain in Older People	Arthritis Prevalence and Activity Limitation in Older Adults
		OVERALL RATINGS FOR EACH SECTION		
1	Bias related to study participation	partly	unclear	partly
2	Bias related to study attrition	unclear	unclear	unclear
3	Bias related to prognostic factor measurement	yes	yes	partly
4	Bias related to outcome measurement	yes	yes	yes
5	Bias related to confounding measurement and account	yes	partly	partly
6	Bias related to analysis	partly	partly	partly

Effect of Arthritis in Middle Age on Older-Age Functioning

The reviewers agreed that this study did not describe the sampling frame and recruitment clearly, expecting readers to be familiar with the HRS sampling strategy. Baseline participants were recruited on the basis of not reporting any difficulty in mobility or ADL function. However, environmental factors such as use of aids and adaptations were not measured. This could potentially have influenced the absence or presence of ADL difficulties reported. Participants were interviewed every two years to assess these difficulties and participants were classified as having persistent difficulty if they reported difficulty on two consecutive waves. This two-year gap between interviews and the definition of 'persistence' could be problematic due to participants' readiness to report symptoms of disability. There were no clear outlines of the interview process, which could be an important source of bias, raising questions about the validity and reliability of this outcome measure.

The study provides data for the first two years with regards to response rate and study attrition. However, the sample was followed for 10 years. This implies that the number of responders had not changed in the subsequent years, which may be questionable. Additionally, participants who were lost at follow-up were not clearly described. Discrepancies were noted with regards to censoring exercise, as whether they have used partial data on censored participants or not was not clearly stated.

Arthritis Prevalence and Activity Limitations in Older Adults

Reviewers agreed that the inclusion and exclusion criteria for the study participation were not adequately described in this study. It was not clear in the paper that the study population was the correct representation of the target population. The term 'community-dwelling adults' was not clearly defined. It has been noted that some studies use this term for people living in supported housing schemes.

The study did not provide enough information for the characteristics of those, who were lost to follow-up and/or non-responders to judge whether the remaining responders were a representative sample of older adults in the general population. It was difficult to identify whether an adequate proportion of the sample had complete data for all relevant outcome periods, as there was no mention of missing data. In the statistical analysis, figures were weighted and adjusted, suggesting there may have been some imputation. However, there was no mention of this in the study. The conceptual framework within the Arthritis Prevalence and Activity Limitations in Older Adults study drove an examination of the differences in limitation with ethnicity but the results indicated that socio-economic factors may also be the predictor of the outcome.

Longitudinal Study of Joint Pain in Older People

The reporting of the study design was complex due to references made to the randomised controlled trial (RCT) evaluating the benefit of targeted nurse visits. It was stated that all patients over 75 years of age in twelve practices were enrolled

in this study. However, the levels of joint pain or the problems that these participants were having were not described. Data were collected using EARRS (Donald, 1997) but the conceptual basis for the inclusion of this assessment was not established within the study. EARRS was not designed for a postal survey. The study suggested that the results for the nurse interview versus postal questionnaire were tested on feedback from 30 patients residing in a day care hospital, indicating good overall agreement. However this was a relatively small sample, derived from hospital patients, compared to 4804 general population sample, which subsequently carried out this postal questionnaire as a self-assessment. Again, it is questionable whether this small sample was representative of the general population of older adults living in the community.

The study stated that no specific instructions were included within the questionnaire regarding whether to include or exclude back pain, suggesting that participants were left to identify the difference between joint pain and back pain. Therefore, a potential assumption may be that this sample will include those with back pain, and this may have increased the prevalence of joint pain as well as strengthening associations with other factors.

Important confounders besides age and gender were not included in this study. The attempts to collect information on dropouts were not described. Results were presented without supporting data and, an important proportion of the information seems to be missing.

3.5.4 The association between self-care restriction and joint pain in community-dwelling older people

This systematic review involved a thorough search of the literature to identify observational studies that explored the relationship between limitation in self-care activities and joint pain in community-dwelling older adults in the general population. Despite finding a number of studies that have reported the prevalence, onset, persistence and other factors associated with ADL limitations in community-dwelling older adults in the general population (e.g. Gill et al., 2007:a-b, 2006:a-b, 2003, 2002:a-b, 1998; Hardy and Gill, 2004; Naik et al., 2004), and studies that have examined associations between joint pain and poor functional outcomes (e.g. Wood et al., 2008; Machado et al, 2008; Grothle et al., 2008; Dziedzic et al., 2007; Corti and Rigon, 2003; Peat et al, 2001), there were only two studies which specifically examined the relationship between limitation in self-care activities and joint pain in community-dwelling older adults in the general population.

As highlighted earlier in this chapter, the definition of osteoarthritis and self-care restrictions varies across studies, and this was observed whilst doing this study. This further evidenced in the two identified studies in which definitions of self-care problems (i.e. how they defined limitation / disability) and joint pain differed. Covinsky and colleagues (2008) study considered transferring from a bed or chair or out of chair as one of the five ADLs, and Donald and Foy (2004) considered dressing dependency and personal hygiene only. Whilst one study made no distinctions between OA and rheumatoid arthritis, and defined symptomatic arthritis as pain, stiffness and swelling of joints (Covinsky et al., 2008), the other study measured the frequency of joint pain as no pain, episodic, and constant pain

(Donald and Foy, 2004). Notably the study population in Donald and Foy's study was much older than the other (50≥ CF 75≥).

Donald and Foy's Longitudinal Study of Joint Pain (2004) found that joint pain fluctuates in frequency over time and is strongly related to disability as well as psychological factors. One in five adults with constant pain were housebound compared to 6% in those with without pain. Pain was associated with a threefold increased likelihood of dependency for ADL. In examining the relapsing and remitting nature of joint pain, sadness and dressing dependency were found to be predictors of acquiring joint pain, which was suggested that these may be early markers of functional decline, which frequently accompanied new joint pain (Donald and Foy, 2004).

Although these studies adjusted the associations between self-care activities and joint pain for various other factors such as age and gender, psychological and other health and socio-demographic factors, there was no clear rationale or consistency behind choosing these individual factors across the two studies. These studies measured self-care as difficulty (i.e. at the level of the individual) and haven't considered self-care as a biopsychosocial construct. Thus, following this review, the question asked at the beginning (i.e. "are people with joint pain more likely to have self-care restriction?") was still not answered.

3.5.5 Determinants of self-care restrictions in older adults with joint pain

The systematic review identified one study that specifically examined the determinants of self-care restrictions in community-dwelling older adults with joint pain. However, this study defined self-care as an ADL; it measured limitation in dressing dependency and personal hygiene only, which is at the level of an individual (i.e. environmental factors were not considered). Although this study offers some insight into the relationship between joint pain and self-care disability in older people, it does not clearly identify the determinants of self-care restrictions in older people. An approach that considers the many potential individual and contextual determinants may provide a better understanding of self-care restriction.

3.5.6 Summary of results

Following a two stage comprehensive systematic search of the literature through eleven electronic databases to identify observational epidemiological studies investigating associations between self-care restrictions and joint pain in community-dwelling older adults in the general population and the determinants of self-care restrictions in older adults with joint pain, only three studies were included in the review. The overall methodological quality of these studies ranged from being moderate to low risk of bias.

The conclusion from the systematic review is that evidence of the extent and mechanisms of self-care restriction in community-dwelling older adults remains limited to date. Information on self-care in older adults in the general population is

fragmented. Limitation in specific self-care tasks (based on an individual's capacity) was associated with joint pain, but there were no studies which have focused on self-care as an outcome of the individual and environmental factors. There were no studies which identified the determinants of self-care restriction in older adults with joint pain.

3.6 Discussion

Despite the comprehensive search of the literature, this review was only able to identify three relevant epidemiological studies, indicating that links between self-care restrictions and joint pain were an under-researched area. However, the limited number of studies identified could be due to the variety of terms used to describe self-care restrictions in the literature, and however carefully selected, the keywords used in this review to find these studies may have not been exhaustive. The inclusion and exclusion criteria were strictly applied to identify only observational studies that referred to self-care. This review found that measurement of self-care in studies varied with some self-care tasks being measured.

The main aim behind this review, which was to identify studies which could describe and explain the relationship between self-care and joint pain in community-dwelling older adults, may have potentially narrowed the results. The fact that only epidemiological studies were included in this review may have led to the exclusion of a substantial qualitative study, thereby impacting on the findings. Although qualitative studies cannot provide quantitative estimations of the

prevalence and patterns of such cases, they may identify important factors that contribute to the occurrence of self-care restrictions through exploration of the view and experiences of older adults with joint pain. Equally, there may have been studies conducted in languages other than English. As English was a selection criterion, this could have led to the exclusion of studies conducted in other languages. However there is little evidence that not including non-English language research results in biased estimates (Pham et al., 2005).

The search in this review included 11 bibliographic databases from the time of their inception until January 2009. However the search did not cover any grey literature or contact any local experts with regards to unpublished studies or thesis. At the time this thesis is written, there may be other studies of self-care restriction and joint pain conducted, and / or in the process of being peer reviewed for publishing, which may have had an impact on the results of this review.

This review utilised a standardised assessment tool to review studies to aid consistency of reviewers' observations and reduce the inter-rater bias. Inter-rater bias refers to the consistency in which multiple reviewers evaluate the same data using the same scoring criteria (Bailey, 1998) at a specified time (Stemler, 2004). This concept suggests that the behaviour of reviewers contains a degree of subjectivity, thus the judgements made will depend upon the reviewers' interpretation of the criteria. A good quality assessment aims to reduce this subjectivity by providing clear instructions (Tierney and Marielle 2004; Mertler, 2001). The quality assessments of these studies were individually and

independently carried out using the QUIPS-LBP tool (Hayden, 2007) by three reviewers (YG, RW and RB). Prior to the full review, one paper was selected to facilitate a consistent approach to the review and judgement of the different forms of bias. During the consensus meetings, reviewers 'explained' their choice of particular rating in the comments section; differences in opinions were explored, and agreement on ratings was achieved. The QUIPS-LBP tool was developed through international expert consensus, and aim to provide a criteria and guidance for assessing the risk of potential biases in low back pain prognosis studies (Hayden, 2007). However, the use of such a tool could be controversial and, in the absence of empirical evidence to support the 'quality' in observational studies, the assumptions behind equal weighting of scores could be deemed as questionable (Mallen et al., 2007).

The methods used in the three studies varied in terms of study setting, sample frames, outcome measures, and use of statistical analysis. Therefore, there isn't clear empirical evidence of an association between self-care restriction and joint pain or of the potential determinants of self-care restriction in older adults with joint pain (Table 3.10).

3.7 Conclusion

There have been a number of studies that have described the impact of osteoarthritis in older adults. Despite this, the systematic search described in this chapter identified two papers that empirically examined the link between self-care and joint pain. Only one study was identified that explored self-care in older adults

with joint pain. Following this review, it is still unclear if self-care restriction is associated with joint pain. The frequency of self-care restriction and its potential determinants in older adults is also unclear.

A barrier to research on self-care is the inconsistent approach to definitions and measurement. The ICF offers an opportunity for a consistent approach to self-care research through the proposal of a standard definition and framework. It also offers a broader approach which views self-care within a biopsychosocial model where restriction is not only dependent on joint pain and physical function but also on psychosocial and environmental factors. As the conceptual model of restrictions in self-care restriction suggests that the potential determinants may be multi-factorial, the links with comorbidities, impairments, activity limitations, socio-economic and environmental factors should be taken into account.

There is a need to investigate the prevalence and patterns of restricted self-care in older adults in the general population, the links with joint pain and the potential determinants in older adults with joint pain. Using the ICF to define self-care and provide a framework to classify potential determinants, this thesis describes an observational study in community-dwelling older adults.

Table 3.10 Summary of key findings

- Although a number of studies described the impact of joint pain in older adults, only two studies examined the link between self-care and joint pain empirically.
- Only one study explored self-care restrictions in older adults with joint pain.
- Following this review, it is still unclear if self-care restriction is associated with joint pain. The frequency of self-care restriction and its potential determinants in older adults is also unclear.
- The inconsistent approach to definitions and measurement of self-care creates a barrier for research.
- The ICF offers an opportunity for a consistent approach to self-care research though the proposal of a standard definition and framework, providing a biopsychosocial model where restriction is not only dependent on joint pain and physical functions but also on psychosocial and environmental factors.
- There is a need to investigate the prevalence and patterns of restricted self-care in older adults in the general population, the links with joint pain and the potential determinants in older adults with joint pain.

Chapter 4

North Staffordshire Osteoarthritis Project (NorStOP): The survey overview and sample analysis

4.1 Introduction

Each study described in this thesis uses data collected in the North Staffordshire Osteoarthritis Project (NorStOP); a population based prospective cohort study which collected information using postal questionnaires. Cohort, cross sectional, and case-control studies are often referred to as observational studies as the data is collected through observations, and no interventions performed (Mann, 2003). Cohort studies are useful for investigating prevalence, incidence, cause and prognosis of health outcomes in populations observed over time (Mann, 2003, Schlesselman, 1982). Cohort studies can provide data on potential causes with data being collected prior to the outcome (Mann, 2003). However, a key limitation of cohort studies is loss to follow-up, particularly when the intervals between follow-ups is over a long periods of time, which can introduce bias to the study findings.

Secondary analysis involves the use of an existing dataset to address new research questions. It is a popular way to investigate research questions when resources (such as time and funding) restrict new primary data collections (Clarke and Cossette, 2000). It is regarded as an efficient way of producing data to support population health (Bibbs, 2007). This chapter will examine the suitability of the NorStOP dataset to meet the objectives of this thesis and answer the main

study questions by reviewing the study design, the psychometric properties of the data collected, and the sample derivation.

4.2 Study design

4.2.1 Setting and sampling

The aim of NorStOP was to study the impact of joint pain / osteoarthritis in adults aged 50 years and over in the general population (Thomas et al., 2004:b). The main objectives were to "*(i) determine the impact these syndromes have on activity and participation levels in older people, (ii) to determine factors which predict prognosis over time with respect to change in pain, activity and participation, and (iii) to determine frequency and predictors of health care use by sufferers of these syndromes through prospective linkage of self-completion survey instruments with primary care records*" (Thomas et al, 2004-b: p.7).

NorStOP recruitment was divided into three sub-cohorts (NorStOP^1, NorStOP^2, and NorStOP^3). NorStOP^1 was set up as a population study only; NorStOP^2 and NorStOP^3 were organised to provide a sampling-base for a clinical epidemiology study of knee pain (CAS-K; Peat et al., 2004) and the hand pain and problems respectively (CAS-HA; Myers et al., 2007). This thesis uses data collected in NorStOP^1 only.

To obtain a representative sample of older adults, NorStOP recruited patients from general practice (GP) registers. In the UK, 98% of the British population are registered with a GP (Bowling, 1997). At the time of this study there were 101

general practices in North Staffordshire and 16 of these practices formed the General Practice Research Network. Those practices taking part in this study were fully computerised. All practice staff required to enter a code for each contact as part of READ classification of morbidity and event coding, which is widely implemented within the National Health Service. The READ classification was originally developed by Dr James Read (Read, 1991), and it was structured similarly to the International Classification of Diseases. The data kept in these practices were also audited annually to assess the quality and completeness of the data. Audits were undertaken by the Primary Care Sciences Research Centre Health Informatics team (Wilkie, 2005).

At baseline, three practices from the North Staffordshire Research Consortium were recruited to the study. These three practices were located in Stoke-on-Trent and one in Newcastle-under-Lyme, both urban areas, which are rated as some of the poorest in England (Experian, 2012). Contact details of all adults aged 50 years and over were taken from each research practice, and were checked by GPs from the practices for exclusions (n=11309). These exclusions were; (i) patient is unable to complete the questionnaire due to illness; (ii) patient is known to have severe learning disabilities or a severe psychological disorder; and (iii) the patient has indicated previously that they would not like to take part in research projects.

The baseline phase of the study was a two-stage mailed survey; firstly the participants were mailed the “Health Survey Questionnaire”, which collected

information on socio-demographics, general health, physical function, participation, and bodily pain. Following this, those consenting to further contact and reported pain and/or problems in the hand, hip, knee or foot in the last year were mailed the “Regional Pains Survey Questionnaire”, which focused on these four joint areas. At both stages, questionnaires were mailed with a letter from the GP practice and a study information leaflet, with reminders to be sent to non-responders after two and four weeks (Thomas et al., 2004: b).

Throughout the mailing process the Keele General Practice Research Partnership (KGPRP) staff maintained the checks on the database for deaths and departures. Details such as date of birth and gender given on the returned questionnaires were checked against the GP records to ensure that correct person had completed the questionnaire (Wilkie, 2005; Muller, 2010). If a date of birth on a questionnaire differed to the data on the GP records, the information given by the participant was used as the correct data once it was established that the correct person had completed the questionnaire. The gender of the participants was checked against the name of the respondent in the GP lists if the NorStOP baseline Health Survey questionnaire was inconsistent.

4.2.2 Data administration

The Arthritis Research Primary Care Centre (ARPCC) at Keele University has data security systems and policies in place to meet legal requirements and obligations set by the Data Protection Act and follow General Medical Council (GMC), Caldecott Guardian and British Computer Society standards and guidelines

(Wilkie, 2005). Personally identifiable data that was held during mailing was stripped from research databases as soon as it was feasible. Individuals in the sample were allocated a unique study number. All questionnaires and survey data were anonymised by separating them from all contact details prior to any analysis (Wilkie, 2005).

Survey questionnaires were designed and processed using Tele*form*™ version 7.0 (Cardiff Software Inc, 1998). Once the questionnaires were scanned into computers, Optic Mark Recognition (OMR) technology was used to recognise marked choices for multiple choice questions, and Optic Character Recognition (OCR) and Intelligent Character Recognition (ICR) to recognise machine print and hand-writing. The automatic data entry system was organised using three linked software modules: Designer, Reader, and Verifier. Protocols were devised to facilitate data processing prior to scanning, and checks were conducted to ensure data accuracy. The system reviewed those items that could be interpreted erroneously (e.g. hand-writing) during the data process by the Reader and Verifier modules according to the validation criteria set during the design stage. These procedures were continuously monitored to ensure high levels of data accuracy (Wilkie, 2005).

The “Health Survey Questionnaire” included a body manikin, which the automatic data entry system could not process. Thus, body manikin related data was entered manually, using a transparent overlay to define pain areas (Figure 4.1) into a

Microsoft Access database. The manikin data entry was checked by another data clerk to identify errors, which were later corrected in the database (Muller, 2010).

The processed data was then exported to a SPSS® file and checked for anomalies in the full data set. In this process, where date of birth was missing, the signature on the questionnaire was checked against the name on the mailing list to make sure that the correct person filled the questionnaire. Then, the date of birth was copied from the mailing list to the questionnaire database. The same procedure was followed for the missing values of gender. If there were any unreasonable values of height and weight (e.g. heights indicated as greater than 8 feet or weight indicated as less than 3 stones) these were scored as missing. Occupations which could not be coded using the Office for National Statistics (ONS) classification of occupation (ONS, 2000; ONS, 2001) were checked against the original questionnaire to identify data entry errors (Wilkie, 2005).

4.2.3 Ethical approval and informed consent

Epidemiological research involves collecting an extensive amount of data on participants to describe physical, environmental and behavioural factors. Thus, researchers need to consider the ethical implications of their projects. The World Medical Association (WMA) has developed the Declaration of Helsinki as a statement of ethical principles for medical research involving human participants, including research on human material. They also detail data consent policies and more explicit guidelines for conducting research (Declaration of Helsinki, 1964). Following this, ethical guidelines have been formulated to protect the rights and

privacy of research participants, and to provide a standard for ethical dignity and professional conduct in research and practice. This ethical stance is located within a legal framework that includes the Human Rights Act and Data Protection Act. At the national level, the NHS National Patient Safety Agency (NPSA) includes the National Research Ethics Service (NRES) which developed a process to streamline ethical approval for NHS research projects. These guidelines demand the practice of obtaining informed consent from research participants. Researchers are expected to conduct all research in accordance with these guidelines to advance high standards in quality of research, and to cultivate public confidence, support and participation in these studies. Thus, securing ethical approval helps to maintain ethical standards of research practice, protect participants from harm, protect participants' rights, provide reassurance to the public, and protect researchers from unjustified criticism and harm.

Ethical approval for the NorStOP baseline study was gained from the North Staffordshire Local Research Ethics Committee (REC number: 1351) to conduct the study. Ethical approval for the 3 years follow-up was gained separately (REC number: 05/Q2604/20) and a substantial amendment was made to this application for the 6 years follow-up study.

At baseline, returned health survey questionnaires were taken as consent to be part of the baseline study. The Health Survey questionnaires were sent to participants with a study information sheet to explain the rationale for the study and at baseline, participants were asked to complete a consent form giving / not

giving permission for researchers to access their medical records and contact them again in the future for follow-up studies. At 3 and 6 years follow-up studies consent was again requested for permission for further contact.

4.2.4 Follow-up of the NorStOP cohort

Participant attrition is a concern in longitudinal studies as loss of participants may result in subsequent bias on findings (Ahern and Le Brocque, 2005). Thus, recruitment and follow-up methods in longitudinal studies should be designed to maximise the retention of these participants (Young et al., 2006).

3 years follow-up

The baseline responders who consented to further contact were eligible for the follow-up study at 3 years. Prior to the mailing, health informatics staff from the KGPRP checked the current practice registers to identify those who were no longer registered with the current practice. They also scrutinised the National Health Service Strategic Tracing Service (NHSSTS) to determine whether the person died or had changed their address. These checks were undertaken in two-weekly intervals throughout the mailing process. NHSSTS was not always able to identify the new addresses of those who had departed, thus these participants could no longer be followed-up. The same two-stage mailing process (Health Survey and the Regional Pains Survey) was repeated as per baseline sample, reminders for each stage were sent at 2 weeks (postcard only) and 4 weeks (a further questionnaire and a letter from the GP) respectively.

6 years follow-up

The same procedures for recruitment and mailing at baseline and 3 years were followed at the 6 years follow-up study, with one exception. Participants who were no longer registered with the practices were not traced using NHSSTS. This is because using NHSSTS was found to excessively lengthen the mailing process and not necessarily provide improved response rates (Muller, 2010).

4.2.5 The Health and Regional Pains Survey Questionnaire Contents

The Health Survey Questionnaire was designed by the NorStOP project team to measure a range of individual, health and contextual variables to allow the exploration of the consequences of health in populations. The survey instrument included previously well-validated questionnaires, a pain manikin and specifically developed single items. The Regional Pains Survey questionnaire included single items and validated questionnaires to explore hip, knee and foot pain, and hand pain or problems only.

One of the intentions of the ICF was to facilitate categorisation of health and contextual variables. The instruments included in the surveys and from which data was used in the analyses in this thesis were categorised in to ICF in the following section (Table 4.1). Additional variables included in the survey to investigate other research questions are not described in this thesis. A critical summary of the outcome measures used in this study is presented in Table 4.3 and 4.4 for ease of reference, and a synopsis of the threats to the validity and reliability of large scale self-report survey data is provided in Table 4.5.

Table 4.1 Health & Regional Pains Survey Questionnaire contents

ICF category	Measurement topic	Measurement method	Details	Scoring
Health conditions	■Self-reported health conditions	Single item	"Do you suffer from any of the following? Chest problems Heart problems Diabetes	 Yes/ No Yes/ No Yes/ No
Impairments	■Self-reported impairments	Single items	"Thinking back over the past 3 months have you suffered from any of the following?" Falls Memory problems Cough with spit Breathless when walking Dizziness Weakness in arms/ legs Deafness Problems with eyesight Raised blood pressure	 Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No
	■Extent of bodily pain in the last 4 weeks	Single item	"In the past 4 weeks have you had pain that has lasted for one day or longer in any part of your body?" "If so, please shade in the body chart, any pain that has lasted for one day or longer in the past 4 weeks	 Yes/ No 0-44 areas
	■Selected joint pains in the last year	Single item	Have you had pain in and around your Hands Hips Knees Feet (adapted from Jinks et al., 2001)	 Yes/ No Yes/ No Yes/ No Yes/ No

■ Health Survey Questionnaire items

Table 4.1b Health & Regional Pains Survey Questionnaire contents

ICF category	Topic	Method	Details	Scoring
	Joint pain severity and stiffness for hand*	Scale	Australian/Canadian Osteoarthritis Hand Index (AUSCAN) (Bellamy et al., 2002)	None to moderate Severe to extreme
	Joint pain severity and stiffness for hip and knee*	Scale	Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) (Bellamy et al., 1988)	None to moderate Severe to extreme
	Joint pain severity for foot*	Scale	Foot Disability Index (FPDI) (Garrow et al., 2004)	None of the time/ On some days/ On most-every day(s)
	Joint pain chronicity*	Single item	Joint pain chronicity	< 3 months 3 months +
	■Anxiety	Scale	Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)	(0-7) (8-10) (11+)
	■Depression	Scale	Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)	(0-7) (8-10) (11+)
	■Cognition and alertness	Scale	Functional Limitations Profile – Cognitive and Alertness behaviour subscale (Bergner et al., 1981)	(0) (22.5-100) (0.1-22.4)

■ Health Survey Questionnaire items

* Regional Pains Survey Questionnaire items (measured at baseline, 3YFUP and 6YFUP)

Table 4.1c Health & Regional Pains Survey Questionnaire contents

ICF category	Topic	Method	Details	Scoring
Body structures	■Body Mass Index (BMI)	Single item	Height Weight	(<20) (20-24.9) (25-29.9) Obese (≥30)
Activity Limitation	■Physical functioning	Scale	MOS SF-36 Physical Functioning subscale (Ware & Sherbourne, 1992)	(90.1-100) (70.1-90) (35.1-70) ≥35
Personal factors	■Socio-demographic characteristics	Single item	Age	50-59; 60-69; 70-79; 80+ yrs
			Gender	Male; Female
		Single Item	Occupational class	Non-manual Manual
			Educational attainment "Have you gained qualifications through study as an adult?'	Yes/ No
	■Social networks	Scale	Berkman and Syme Social Network Index (Berman & Syme, 1979)	High Med/ high Med/Low
		Single item	Have a confidant	Yes/ No
Environmental factors	■┼ Help and assistance	Single items	Receipt of help and assistance from family/ friends and/or health/ social care professionals in: • Washing and bathing • Looking after your skin, teeth, hair, nails • Putting on and taking off clothes • Using a toilet • Eating and drinking	No need help Yes, receive help Yes, don't receive help Yes, receive help*
	■┼Aids and adaptations	Single items	Use of aids and adaptations for: • Washing and bathing • Looking after your skin, teeth, hair, nails • Putting on and taking off clothes • Using a toilet • Eating and drinking	Yes/No

■ Health Survey Questionnaire items
┼ This variables were measured at Health Survey Questionnaire at 6 years follow-up only
* Receive help from family/ friends and/ or from health professionals/ social services

Health Conditions

Self-reported health conditions

The baseline Health Questionnaire included 12 single items to measure the experience of health problems and symptoms. Three out of twelve single items were defined as health conditions in accordance with the ICF framework. These were three of the most common chronic health conditions (apart from osteoarthritis) in the older UK population (chest problems, heart problems and diabetes). Each item had a simple yes/no response option. A count variable was created by adding up the occurrence of these conditions; this variable was categorised by combining adjacent numbers of health conditions into one category if their univariable estimates of association were similar (0, 1 and 2-3).

Impairments

Self-reported impairments

Again with reference to the ICF, the remaining nine items from the twelve single items in the Health Questionnaire were considered to measure impairments (falls, difficulty remembering, cough with spit, breathlessness when walking, dizziness, weakness in limbs, deafness, problems with eyesight, and raised blood pressure). Each item had a simple yes/no response option. A count variable was created by adding up the occurrence of these conditions. This variable was categorised, combining adjacent numbers of impairments into one category if their univariable estimates of association were similar (0, 1-3, 4-5 and 6-9).

Peripheral Joint Pain

Joint pain is the most common symptom of osteoarthritis in older adults (Felson et al., 2000). For population studies of older adults, joint pain is the most appropriate way to define osteoarthritis (Peat et al., 2001). Single items were included in the questionnaire to identify the presence of peripheral joint pain (hand, hip, knee and foot). Participants were asked whether they had suffered from pain for one day or more in the last year for each joint site (hand, hip, knee and foot). Response options were yes/ no (Jinks et al., 2001).

Joint-specific characteristics

Joint specific characteristics were measured in the Regional Pain Survey questionnaire at baseline, 3 and 6 years follow-up. Hand pain severity and stiffness were measured using Australian/Canadian Osteoarthritis Hand Index (AUSCAN) by 6 items (5 pains and 1 stiffness) that capture a combination of common symptoms in hand osteoarthritis (Bellamy et al., 2002). AUSCAN is a valid and reliable measure of hand problems in a community-dwelling population of older adults and was highlighted to have performed well both for its internal reliability and for its relationship with the external constructs (Dziedzic et al., 2007).

Lower limb pain and stiffness were measured using the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) for those with hip and knee pain (Bellamy et al., 1988). Scores for both hand and lower limb pain severity and stiffness ranged from 1 (none) to 5 (severe). Previously knee pain has been assessed in population surveys by a number of measurements such as Short

Form 36 (SF-36) (Ware and Sherbourne, 1992), Health Assessment Questionnaire (HAQ) (Fries et al., 1980), and Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC). WOMAC is a disease specific, self-administered instrument and was developed for use as an outcome measure in people with hip and knee osteoarthritis (Bellamy et al., 1988). Items are reported as subscales of pain, stiffness and physical function. WOMAC was found to be a reliable disease-specific measure for use in large epidemiological surveys, with good test-retest reliability for pain (ANOVA ICC: 0.88 p>0.74) in the general older adult population (Jinks et al., 2002).

Foot pain was measured using the Foot Disability Index (FPDI) (Garrow et al., 2004). This is a self-complete questionnaire that consists of 19 items to investigate function, pain intensity and appearance, each of which has three possible response categories: none of the time / on some days / on most or every day (s). Only the items that measured pain intensity were used in this analysis (10 and 14 to 17).

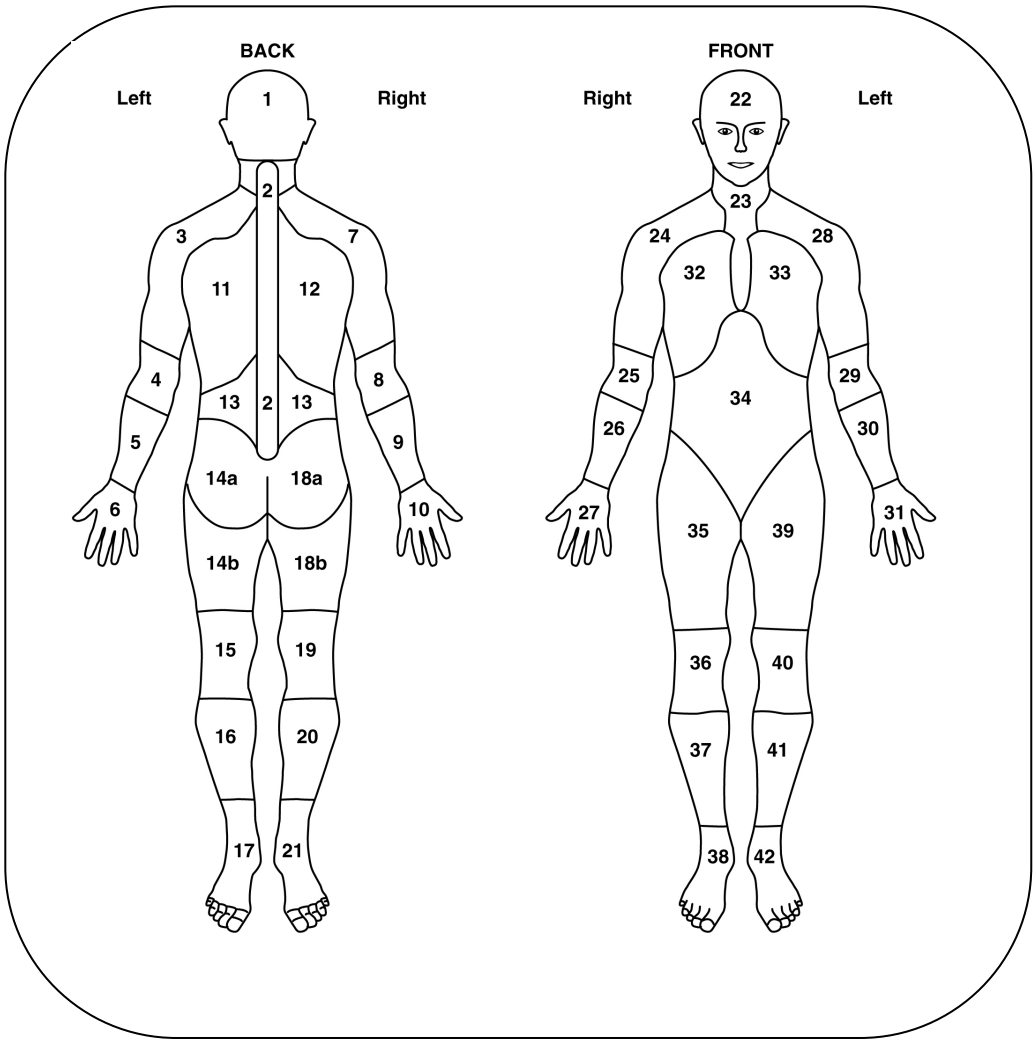
Chronicity of pain for hand, hip, knee and foot was measured by asking participants the number of days of hand/hip/knee/foot pain they have had in the last 12 months. The answer options were: less than 7 days / 1 to 4 weeks / >1 months but <3 months / 3 months or more. Joint pain chronicity was calculated by categorising those who reported 3 months or more hand / hip / knee / foot pain as having chronic pain as it is recommended by the criteria established by the

International Association for the Study of Pain (IASP) (Merskey and Bogduk, 1994).

Bodily pain

Bodily pain was assessed to measure musculoskeletal comorbidity using a single item and a body manikin. Participants were asked “In the past 4 weeks have you had pain that has lasted for one day or longer in any part of your body?” and those responding positively were asked to shade their painful areas on a full body manikin. This manikin was separated into 44 mutually exclusive areas and a transparent template was used to mark the borders (Lewis et al., 2002) (Figure 4.1). Those responding negatively to the pain item and not shading the manikin were categorised as the ‘no pain’ group, and those responded positively to the pain item and shaded the manikin were considered to have pain in shaded areas. The bodily pain variable was derived from this variable to capture pain which was not linked to hands, hips, knees or feet pain. The areas included were mutually exclusive. The areas excluded were respectively knee pain (15, 19, 36, 40); foot pain (17, 21, 38, 42); hand pain (6, 10, 27, 31); hip pain (35, 39, 14a if 44 is +ve; 18a if 45 is +ve) (see Fig 4.1). Bodily pain was categorised by combining adjacent numbers of bodily pain into one category if their univariable estimates of association were similar (0; 1-4; 5-9; 10).

Figure 4.1 The pain manikin



General Health Characteristics

The Medical Outcomes Study (MOS) Short Form (SF) 36 is a generic health status instrument (Ware et al., 1993). The SF-36 has been recommended for use in primary care research for its succinctness and the quality of its psychometric testing (Ware, 2000; Brazier et al., 1992). The SF-36 Health Survey was developed with an aim to capture physical and mental health, functioning and well-being under one succinct instrument (Ware and Sherbourne, 1992). The eight

domains of health represent the most frequently measured concepts in health surveys and those most affected by disease and treatment (Ware, 1995; Ware et al., 1993). These domains are Physical Functioning (PF); Role-Physical (RP); Bodily Pain (BP); General Health (GH); Vitality (VT); Social Functioning (SF); Role-Emotional (RE); and Mental Health (MH). The selected questionnaire items characterise various pointers of health, including behavioural function and dysfunction, distress and well-being, objective reports and subjective ratings, and both favourable and unfavourable self-evaluations of general health status (Ware et al., 1993). The questions include asking participants to rate their health, problems experienced as a result of their physical and mental health, and the amount of time their physical health or emotional problems interfered with their social activities (such as visiting friends and relatives). The usefulness of the SF-36 in postal surveys of older adults has received criticism due to items being frequently left blank on questionnaires by respondents (Mallinson, 1998). However, later studies which assessed the practicality and validity of using the SF-36 in community-dwelling older people recommended the use of SF-36 to obtain population scores in this population group (Walters et al., 2001; Nante et al., 1999).

The SF-12 Health Survey was developed as a shorter alternative to the SF-36 Health Survey for use in large-scale studies, particularly when overall physical and mental health are the outcomes of interest (Stewart & Ware, 1992). The SF-36 and SF-12 and Health Surveys measure the same eight health domains, and each survey provides psychometrically-based physical component summary (PCS) and

mental component summary (MCS) scores. The PCS and MCS scores have a range of 0 to 100 and were designed to have a mean score of 50 and a standard deviation of 10 in a representative sample of the US population. This norm-based score allows comparison among the three surveys and across the studies published in the past 20 years. The SF-12 Health Survey uses just 12 questions to measure functional health and well-being from the patient's point of view. Previous studies recommended the SF-12 Health Survey to be a practical, reliable, and valid measure of physical and mental health, with less respondent burden (Jenkinson and Layte, 1997). In this study the SF-12 score for Physical Health (PCS) and Mental Health (MCS) was used to describe the health characteristics of the responders, and scores were expressed as means with standard deviations.

Anxiety and Depression

The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983), was used to measure anxiety and depression. This was developed to identify the presence and severity of relatively mild mood disorders (anxiety and depression) in non-psychiatric hospital outpatients. It has been validated for use as a self-completed questionnaire (Herrmann, 1997; Lisspers et al., 1997). The HADS consists of 14 items (7 relating to the anxiety subscale and 7 relating to the depression subscale) with a four point response scale (from 0 representing absence of symptoms, to 3 representing maximum symptomatology). Scores can range from 0-21 on each subscale, higher scores indicating greater depression or anxiety, with cut-off points suggested between 0-7 (non-cases), 8-10 (borderline cases) and >11 (definite cases) (Pallant and Bailey, 2005). The scores were

calculated separately for anxiety and depression for the purpose of this thesis and categorised using the suggested cut-off points (Sackley et al., 2009; Mallen et al. 2006; Mallen et al., 2005).

Cognitive Complaint

Cognitive complaint, which is the subjective reporting of perceived cognitive impairment, is common and more frequently encountered in older age and females (Westoby et al., 2009) was measured using the Sickness Impact Profile (SIP) Cognitive and Alertness subscale (Bergner et al., 1981) at all three time points (baseline, 3 and 6 years follow-ups). This is a ten item scale which was designed to measure sickness related changes in normal life (Bergner et al., 1981) and has been previously administered as a postal questionnaire (Trigg and Wood, 2003). The response options were a simple yes / no, and responses contribute to a summation of a weighted score, which is then converted to a percentage value, with higher scores indicating poorer function. Raw scores were categorised according to the sample distribution, using quartiles. 53% of the responders had a score of 0 (no cognitive impairment category) and the third quartile (75th percentile: 22.4) was divided into two categories as high (22.5-100) and low levels (0.1-22.4) of cognitive impairment. No cognitive impairment category was used as a reference category as higher scores indicates higher levels of cognitive impairment.

Body Structures

Body Mass Index

Studies suggest that weight problems are associated with osteoarthritis (Felson et al., 1997; Schouten et al., 1992) and obesity could be an important predictor of activity limitation and participation restriction in older people (McDonough and Jette, 2010). Therefore body mass index (BMI), an anthropometric measure to determine if people are at healthy weight, was used to calculate self-reported height and weight scores of the responders. Participants were asked to provide their height and weight using a preferable unit (either metric or imperial) at each time point to calculate BMI. This score was categorised into standard BMI groups which were used in previous studies of disability (WHO, 2004) as <20 (underweight), 20-24.99 (healthy body weight) 25-29.99 (overweight), >30 (obese). Healthy body weight (20-24.99) was used as a reference category.

Activities

Activity limitation

Activity limitations are difficulties that people may have in executing tasks (WHO, 2001). Activity limitation was assessed using the Physical Functioning subscale (PF-10) of the SF-36 Health Survey Questionnaire (Ware and Sherbourne, 1992), which was measured in NorStOP at all three time points. MOS SF-36 were used in previous population studies to measure activity limitation (Fransen et. al., 2002), and its use in primary care has been recommended (Ware, 2000; Jenkinson and Lyte, 1996). PF-10 consists of ten items to assess the extent of activity limitations

in a variety of physical activities. A criticism of the PF-10 is that the two items in this scale actually measure participation restriction (Wilkie 2005). Participants were asked *"Does your* health *now limit you in these activities? If so, how much?"* The activity items were; i) vigorous activities (such as running, lifting heavy objects, participating in strenuous sports); ii) moderate activities (such as moving a table, pushing a vacuum cleaner, bowling or playing golf); iii) lifting or carrying groceries; iv) climbing several flights of stairs; v) climbing one flight of stairs; vi) bending, kneeling or stooping; vii) walking more than a mile; viii) walking half a mile; ix) walking 100 yards; x) bathing and dressing yourself. The answer options were: yes limited a lot / yes limited a little / no, not limited at all. The scores for the ten items were summed and normalised so that the total score ranges from 0-100, with higher scores indicating better physical functioning. Following initial empirical work, raw scores were categorised using quartiles into lowest limitation (90.1-100), 3rd highest limitation (70.1-90.0), 2nd highest limitation (35.1-70.0), highest limitation (≥35.0).

Contextual Factors

Personal factors:

Age and gender

Participant's age was derived from the date of birth provided in the questionnaire and categorised into 10 year age bands (50-59, 60-69, 70-79 and 80 and over) as recommended in previous studies (Thomas et al., 2004:b; Schoenborn, 2000).

Ethnicity

Ethnic origin was measured using a single item in the baseline Health Survey questionnaire as 'White British / European', 'Afro Caribbean', 'Chinese', 'Asian', 'African', or 'Other'. However its distribution was not sufficiently diverse to include this factor in the analysis (i.e. 99.4% of the responders were white).

Socio-economic status

Individual's socio-economic status was measured in three domains as occupational class, educational attainment and perceived adequacy of income:

i) Occupational class

Occupational class was assessed by asking participants *"If working what is your job title"* and *"If you are not working, or are retired, what was your last job title?"* and classified according to the Standard Occupational Classification (Office for National Statistics (ONS) (2000) (Table 4.2)). These categories were further revised to *non-manual* (higher managerial, higher professional, lower managerial / professional, intermediate occupations), *manual* (lower supervisory / technical, semi-routine occupations, routine occupations) and *self-employed* (Small employers and own account workers) occupations (Muller, 2010). The *self-employed* category was excluded from the analysis due to ambiguity of this classification as it was not possible to identify the nature of their job (i.e. manual or non-manual).

Table 4.2 Categories of individual socio-economic classification

1	Higher managerial and professional occupations
	a) Large employers and higher managerial roles
	b) Higher professional occupations
2	Lower managerial and professional occupations
3	Intermediate occupations
4	Small employers and own account workers
5	Lower supervisory, craft and related occupations
6	Semi routine occupations
7	Routine occupations
8	Never worked and long term unemployed

Source: Office for National Statistics, 2010

Educational attainment

Educational attainment was measured by a single item, asking participants *"have you gained qualifications through study as an adult?"* With answer options *yes* or *no*. Having adult qualifications (yes) was used as a reference category.

Perceived adequacy of income

Perceived adequacy of income was measured using a single item which asked *"Thinking about the cost of living as it affects you, which of these descriptions best describes your situation".* The answer options were: 'find it strain to get by from week to week / have to be careful with money / able to manage without much difficulty / quite comfortably off' (Thomas, 1999). This measure was developed by Thomas (1999) and it measures participants' financial circumstances without revealing the details of the responders' income. Although measuring income adequacy has been previously criticised for the inherent variability of individuals

subjective evaluation (Ballantyne and Marshall, 2001), it has been validated by a study comprised persons aged 50 years and older in 12 countries from the Survey of Health, Ageing and Retirement in Europe as an objective economic indicator in predicting household financial distress (Litwin and Sapir, 2009).

The Berkman and Syme Social Network Index

The Berkman and Syme Social Network Index was originally constructed in 1979 to summarise the relationship between increasing social isolation and mortality (Berkman and Syme, 1979) and was used in this analysis to measure participants' social network status. The use of the Berkman and Syme Social Network Index is supported in population studies of adults to explore the role of social integration and support (Handley et al., 2012; Kearney et al., 2011; Shelton et al., 2011; White et al., 2009). The nine item version consists of asking the participants questions such as the number of children they have, number of children they see at least once a month, number of close relatives and friends, the number of religious meetings and/or community groups they attend to measure participants' social network status. Raw index scores were categorised as *"low / medium / medium high / high"* with high scores indicating better social ties.

Having a confidant

Participants were asked *"Is there any one special person you know that you feel close to; someone you feel you can share confidences and feelings with?*" The answer options were "*Yes* or *No*" (Michael et al., 2001).

Participation

Self-care

The Keele Assessment of Participation (KAP) was developed to measure participation for NorStOP. It includes one item that measures self-care restriction and the following section reviews the potential for this item to be used to meet the objectives of this thesis.

Table 4.3 Psychometric properties of the outcome measurement scales used in this study

Name of measure / scale	Reliability / Repeatability	Validity	Ability to detect change	Strengths	Cautions
Australian/ Canadian Osteoarthritis Hand Index (AUSCAN) (Bellamy et al., 2002)	Inter-observer and Intra-observer reliability were found to be 'substantial' and 'moderate' respectively.Two sources of data were used; first, a two-staged cross-sectional postal survey of older adults population using self-complete questionnaires; second, through the completion of AUSCAN by participants in a pilot study of clinical assessment of hand problems [median agreement beyond chance (kappa) was 0.75 (range: -0.03, 0.93) and 0.57 (range: -0.02, 1.00)] (Dziedzic et al., 2007).	The index has been subject to validation studies which have supported the clinimetric qualities such as the internal consistency, construct validity, factor structure, responsiveness and clinical relevance (Bellamy et al., 2002).	It is suggested that this scale should successfully detect changes in both pain and function, even when pain and loss of function do not occur concurrently (Allen et al., 2006).	The patient self-completed AUSCAN Indices are reliable, valid and responsive and can be recommended as primary outcome measures for future population-based studies.	Self-completed AUSCAN represent only the perspective of the participant. Additionally, it appears to pool aspects of long-term outcome and disease activity. It may be more appropriate to separate measures of disease activity from the long-term outcome (Kloppenburg et al., 2007).

Name of measure / scale	Reliability / Repeatability	Validity	Ability to detect change	Strengths	Cautions
Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) (Bellamy et al., 1988)	Overall, test-retest reliability of the WOMAC pain subscale has been variable across studies but generally meets the minimum standard; test-retest reliability has been more consistent and stronger for the physical function subscale, but the stiffness subscale has shown low test-retest reliability (McConnell et al., 2001).	Developed with the use of expert opinion, reviews of existing instruments, and surveys of patients with hip and/or knee osteoarthritis. High correlations and overlapping items between the pain and physical function subscales may pose measurement problems (Pua et al, 2009; Stratford and Kennedy, 2004).	It is suggested that activity overlap on the pain and function subscales limits the physical function subscale's ability to detect change over time (Stratford and Kennedy, 2004).	It is accepted as one of the most widely used self-report measures of lower extremity symptoms and function, and had been studied over 30 years in various contexts and populations. It has shown sufficient psychometric properties to be applied in population studies (Jinks et al., 2002).	The reliability of the pain subscale has been variable across studies, albeit meeting the minimum requirements. The reliability of the physical functioning scale reported to be more consistent and stronger than the pain subscale.
Foot Pain and Disability Index (FPDI) (Garrow et al., 2004)	The construct of FPDI structure (pain intensity, functional limitation and appearance) was verified through confirmatory factor analysis in a general population of adults. Internal consistency for the three constructs was good	The FPDI was found to be a valid measure for use in community-dwelling older adults (Roddy et al., 2009; Roddy and Muller, 2009). A good level of agreement was	It is suggested to have a good ability to detect differences in disability levels reported by community subjects with and without current foot pain (Garrow et al., 2000).	Research into foot pain and function in the general population using postal questionnaires had been hindered by the lack of instruments to measure foot-related disability. FPDI, as a validated measure has potential to fill	The appearance subscale consists of only two items, which makes the scoring problematic (Muller and Roddy, 2009).

Name of measure / scale	Reliability / Repeatability	Validity	Ability to detect change	Strengths	Cautions
	(Cronbach's alpha 0.74, 0.92 and 0.77, respectively). Test–retest repeatability for the individual constructs ranged from fair to substantial (Roddy et al., 2009).	reported when compared with similar items on the ambulation sub-scale of the Functional Limitation Profile questionnaire (Garrow et al., 2000).		this gap.	
Hospital Anxiety and depression Scale (HADS) (Zigmond & Snaith, 1983)	Satisfactory or good item total correlations observed for anxiety and depression subscales (Herrmann, 1997). HADS was found to perform well in assessing the symptom severity of anxiety disorders and depression in both primary care patients and in the general population (Bjelland et al., 2002).	The concurrent validity was reported to be good to very good (Bjelland et al., 2002).	Re-test reliability shows a high correlation up to two-weeks, which decreases with longer term intervals; showing HADS is stable enough to withstand situational influences (Herrmann, 1997).	The scale is well accepted by general population and hospital patients, with response rates ranging from 95-100% in well-motivated study participants (Herrmann, 1997).	It is important to emphasise that anxiety and depression identified by self-report methods are only valid for screening purposes; definitive diagnosis must rest on the process of clinical examination.
MOS SF-36 Physical	The reliability of the scale and the summary measure	Previously has been validated for use as a generic-	It is suggested that SF-36 is sensitive to changes in health in	The SF-36 has proven useful in surveys of general	Mallinson (2002) proposed in a qualitative

Name of measure / scale	Reliability / Repeatability	Validity	Ability to detect change	Strengths	Cautions
Functioning Subscale (Ware and Sherbourne, 1992)	has been estimated using both internal consistency and test-retest methods. Published reliability statistics have exceeded the minimum standard of 0.70 recommended for measures used in group comparisons in more than 25 studies (Tsai, Bayliss, & Ware, 1997).	health related quality of life measure in general populations (Garratt et al., 1993; Brazier et al., 1992), and in selected populations with knee osteoarthritis (Brazier et al., 1999).	general populations (Busija et al., 2008; Hemingway et al., 1997).	and specific populations, comparing the relative burden of diseases, and in differentiating the health benefits produced by a wide range of different treatments (Ware, 2000).	assessment of the questionnaire that there are problems in which the respondents interpret the questions and suggested further research should explore differences in interpretation between different social groups. Schroder et al. (2011) reported that the structure of self-rated health in patients with severe Functional Somatic Syndromes (FSS) (e.g. fibromyalgia) differed from people in the general population.
Functional Limitations Profile (FLP) Cognitive and Alertness	Adapted from the Sickness Impact Profile (SIP), this scale is a widely used health status	Not tested.	Not tested.	Unlike the SF-36, the FLP uses weights expressing the severity of individual items, which have	SIP measures behavioural impacts of sickness in terms of dysfunction and does not assess

Name of measure / scale	Reliability / Repeatability	Validity	Ability to detect change	Strengths	Cautions
behaviour subscale (Bergner et al., 1981)	measure. Previous studies support the measurement properties of this measure in population studies (Bruin et al., 1992; Carter et al., 1976), however there is no evidence of psychometric testing to support these assumptions.			been derived from previous research (Fitzpatrick et al., 1998).	levels of positive functioning. FLP-Cognitive and alertness subscale needs to be further tested to confirm its psychometric validity and reliability.
Berkman and Syme Social Network Index (Berkman and Syme, 1979)	There is no evidence of formal pychometric testing to support the use of Berkman and Syme Social Network Index in general population studies.	Not tested.	Not tested.	The index measures the level of social integration, taking into account number as well as relative importance of different ties. Thus, intimate ties are given more weight than group affiliations (Eng et al., 2002).	It is a lengthy scale, thus, it is not always used as an index to obtain a total score. Instead, different items are included/ excluded in studies. This causes difficulty when comparing results across studies.
Keele Assessment of Participation (KAP) (Wilkie et al., 2005)	Internal consistency was not examined. Mean observed agreement over a 4-week period for dichotomised responses was 90%.	Cognitive and semi-structured interviews examined face validity, responder burden and content validity and found	Responsiveness and ability to detect minimum clinically importance difference has not been tested.	The instrument measures participation comprehensively and can be applied to the general population as a generic measure of	It has not been tested sufficiently to evaluate its appropriateness for evaluating interventions. Further

Name of measure / scale	Reliability / Repeatability	Validity	Ability to detect change	Strengths	Cautions
	Kappa ranged from 0.20 to 0.71.	that the instrument comprehensively measured participation. Demonstrated high levels of agreement with Reintegration to Normal Living Index and Impact of Participation and Autonomy.		participation. Its brief and concise design minimises the responder burden.	psychometric testing required for its responsiveness. The brevity of the instrument is at the expense of detail.

Table 4.4 Strengths and weaknesses of the specifically developed single items in the survey

Self-reported health conditions and impairments	
Strengths: • Allows the measurement of the presence or absence of common health conditions and symptoms in older adults and is classified in-line with the International Classification of Functioning (ICF).	*Weaknesses:* • The response option (yes / no) for each item does not measure the severity of these symptoms. • Participants are asked to think back over the past 3 months, this might introduce recall bias. • Low agreement was found when self-reported morbidity was compared with computerised general practice consultation records 2-years prior to the survey (Barber et al., 2009)
Selected peripheral joint pain	
Strengths: • It is adapted from a previously validated measure of knee pain (Jinks et al., 2001).	*Weaknesses:* • Participants are asked to think back over the past year to remember if they had suffer from pain for each joint site; as participants may not recall the pain for specific joint site, this might introduce recall bias. • Self-reported joint pain may be arising from causes other than Osteoarthritis (e.g. bursitis, tendonitis).
Joint Pain Chronicity	
Strengths: • The criteria for chronic pain (≥3 months) is based on the recommendations of the International Association for the Study of Pain (IASP) (Merskey and Bogduk, 1994).	*Weaknesses:* • Participants are asked to remember the number of days of hand/hip/knee/foot pain they have had in the last 12 months. This might be difficult to recall, which may impact on the precision of these estimates (recall bias).
Self-reported height and weight	
Strengths: • This score is categorised into standard Body Mass Index (BMI) groups which were used in previous studies of disability (WHO, 2004), allowing comparisons with the wider literature.	*Weaknesses:* • It relies on the self-reported health and weight measurements of the responders, which may have been subject to recall / information bias. • There is an on-going discussion in the literature whether BMI is a reliable measure of body fatness for people.

Single item which asked patients to indicate their occupation or if retired their previous occupation; this was coded to provide data on Occupational Class	
Strengths: • Responses to this measure were classified according to the Standard Occupational Classification (Office for National Statistics (ONS) (2000).	*Weaknesses:* • Participants were classified into categories based on their answer to the question "If working what is your job title" and "If you are not working, or are retired, what was your last job title?" As the study population consist of older people who may have been involved in variety of roles throughout their working life, there is a potential for misclassification of their occupational class.
Perceived adequacy of income	
Strengths: • This measure was originally developed by Thomas in 1999 and it measures the responder's financial circumstances without revealing the details of their income. • It has been validated as an objective economic indicator in predicting household income by a multinational study (Litwin and Sapir, 2009).	*Weaknesses:* • It is "subjective" and can be influenced by negative appraisal.
Educational Attainment	
Strengths: • Identifies whether participants gained qualifications as an adult; providing another level of socio-economic measure to the survey data.	*Weaknesses:* • This item does not specify the type of qualifications gained through study as an adult, thus it might be misinterpreted depending on what the participant considers these are, which may result in misclasification.
Extent of bodily pain	
Strengths: • Use of pain drawings which were than scored for the presence or absence of pain in each of 45 body areas has been tested in a previous study by margolis et al (1986) and scorers achieved a high rate of inter-rater agreement with relatively little training. • This method has been shown to be repeatable (Lacey et al 2005).	*Weaknesses:* • Those, who responded "*Yes*" to the pain item but did not shade any areas on the manikin, were excluded from analyses. Those who responded "No" to the pain item but shaded at least one area on the manikin were also excluded from analyses. This may have influenced the results.

Receipt of help and assistance from family/ friends and/or health/ social care professionals+	
Strengths: • This item breaks down daily activities into individual tasks such as 'washing and bathing' and 'using toilet' to aid to recall the difficulties participants may experience, thus require help when carrying out specific tasks.	*Weaknesses:* • Validity has not been tested. • Participants were asked to recall the details of how they conducted daily daily activities in the past 4-weeks and whether they have had any help from family and friends or a health / social care professional. This may have resulted in recall / information bias. • Participants may have had a tendency to response this item positively to appear in a better light, (i.e. social desirability bias).
Use of aids and adaptations+	
Strengths: • This item lists commonly used aids and appliances when conducting the essential activities of daily living with an easy 'yes / no' option to aid the participants to recall the information.	*Weaknesses:* • Validity has not been tested. • Although a selection of aids and adaptations are provided in the questionnaire, this list is not exhaustive. Thus, participants might use alternative tools/ methods to help with their daily activities that are not represented in this list. This could result in misclassification. • Some items such as 'aids to help you wash and dress' may be open to different interpretations as what these aids might be. Again, this may also cause misclassification. • Participants were asked to recall the details of how they conducted daily daily activities in the past 4-weeks and whether they have used any aids and appliances to help with these activities. This may have been difficult to remember, thus, resulted in recall / information bias.

+This measures are detailed in Chapter 8

Table 4.5 A summary of the potential threats to the validity and reliability of self-reported survey data

Acquiescence bias (Watson, 1992)	❖ Refers to the tendency to respond positively. ❖ Negatively and positively worded items should be evenly distributed to reduce this bias. ❖ The process and interpretation of the data should be conducted with caution.
Extreme and moderate response bias (Couch and Keniston, 1960)	❖ Reflects the tendency for subjects to respond consistently using particular sections of the data. ❖ Demographic factors may influence extreme responding. ❖ Can be controlled by altering the response format.
Negative affectivity bias (Watson et al., 1987)	❖ Negative affectivity markedly inflates the associations between variables. ❖ If identified, can be controlled by statistical methods.
Social desirability bias (Paulhus, 1991)	❖ Refers to the tendency to answer self-report items in such a way as to deliberately or unconsciously represent oneself in a favourable light.
Sampling bias (Lijmer et al., 1999)	❖ It is a consistent error that arises due to the sample selection. ❖ It means the data collected may not be accurate, or represent the target sample.
Response bias (Porta, 2008)	❖ Systematic error due to differences in characteristics between those who choose or volunteer to take part in a study and those who do not.
Information bias (Sanderson et al., 2007)	❖ Bias in an estimate arising from measurement errors. ❖ Also referred to as observational bias and misclassification. ❖ The occurrence of information bias may not be independent of the occurrence of selection bias.
Recall bias (Rothman et al., 2008)	❖ It occurs when the way a respondent answers a question is affected not just by the correct answer, but also by the respondent's memory.
Measurement bias (Porta, 2008)	❖ It occurs when surveys do not measure what they intended to measure. ❖ This results from flaws in the instrument, question wording, question order, interviewer error, timing and question response options.

4.2.6 Keele Assessment of Participation Restriction (KAP)

The Keele Assessment of Participation (KAP) was developed as a self-complete instrument to provide estimates of participation restriction in population surveys (Wilkie, 2005). This was the first instrument developed specifically to measure participation restriction in population surveys (Magasi and Post, 2010). The KAP was developed to measure participation in line with the conceptual model proposed in the ICF. In the ICF, participation is seen as the outcome of a complex relationship between an individual's health condition, personal factors, and the external factors of the environment in which the person lives (WHO, 2001). The KAP consists of 11 items to measure participation restriction in different aspects of life (Table 4.6), reflecting the domains proposed to capture participation (Wilkie et al., 2005). Each of the 11 items are an aggregated measure and so responders must consider a number of relevant tasks when responding to one item. Each item is qualified by an individual's judgement of their performance because the occurrence of participation restriction is best perceived by the individual who experiences it, rather than describing deviation from an established normative standard (Wilkie et al., 2005). The cognitive testing of the KAP demonstrated that when individuals answered these questions they considered personal and environmental factors relevant to them and how these contribute to either preventing or facilitating participation. This was in line with the intended conceptual model and provided support for face validity of participation restriction (Wilkie, 2005).

One of the KAP items provides an aggregated measure of self-care (i.e. puts the self-care tasks such as washing, toileting, dressing, feeding, maintaining health under one umbrella). It is phrased to capture the individual's perception of their self-care needs being met. 'During the past 4 weeks, my self-care needs (examples are washing, toileting, dressing, feeding, maintaining health) have been met, **as and when I have wanted**' (response options: *all the time / most of the time / some of the time / a little of the time / none of the time*) (Table 4.3). The conceptual model means that individuals will consider the interaction between the individual and their environment when responding.

Table 4.6 Keele Assessment of Participation

1	During the past 4 weeks, I have moved around in my home, **as and when I have wanted***
2	During the past 4 weeks, I have moved around outside my home, **as and when I have wanted***
3	During the past 4 weeks, my **self-care** needs (examples are washing bathing, toileting, dressing, feeding, maintaining health) have been met, **as and when I have wanted***
4	During the past 4 weeks, my home has been looked after, **as and when I have wanted***
5	During the past 4 weeks, my things (belongings) has been looked after, **as and when I have wanted***
6	Do you have relatives or any other people who depend on you? (Yes/ No) ┼ If yes, during the past 4 weeks, were those people looked after **as and when you have wanted?***
7	During the past 4 weeks, I have met and spoken to other people, **as and when I have wanted***
8	During the past 4 weeks, I or someone else on my behalf, have managed my money, **as and when I have wanted***
9	Do you choose to take part in paid or voluntary work? (Yes/No) ┼ If yes, during the past 4 weeks, have you taken part in paid or voluntary work **as and when you wanted***
10	Do you choose to take part in education or training courses? (Yes/No) ┼ If yes, during the past 4 weeks, have you taken part in education or training courses **as and when you have wanted?***
11	Do you choose to take part in social activities? (Yes/No) ┼ If yes, during the past 4 weeks, have you taken part in social activities **as and when you have wanted?***

*Response options: All the time/ most of the time/ some of the time/ a little of the time/ none of the time. ┼ Filter questions were added following pre-testing stage (Wilkie et al., 2005)

Psychometric testing and development of the instrument

Pre-pilot studies: face validity, responder burden and content validity

The review criteria suggested by the Scientific Advisory Committee of the Medical Outcomes Trust (Lohr et al., 1996) were used to inform and guide the development and testing of the KAP (Wilkie et al., 2005). The psychometric properties of the instrument were tested in two interview studies (cognitive interviews (n=11); qualitative interviews (n=4)) and a pilot study. Cognitive interviews examined face validity, responder burden and content validity (Wilkie, 2005). For this, purposive a convenience sample of adults aged 50 years and over was selected as a representative of older people with participation restrictions across a range of life areas (n=11). Participants completed the draft version of the KAP measure and were timed and observed for any difficulties they encountered during completion of the instrument. During this process, semi-structured interviews and open-ended probing were used to explore deeper meaning and interpretation of questions (Wilkie, 2005). Analysis of face validity reflected on the way items were completed with reference to the conceptual model of participation restriction. Responder burden was assessed by observing the difficulties and problems faced by participants when completing the KAP. Content validity was tested using the participant's opinions on the comprehensiveness of the KAP, considering whether it captured their own involvement in life situations (Wilkie, 2005). Qualitative interviews further tested the face and content validity of KAP in a different sample of participants (n=4) purposively sampled from a rheumatology ward to represent those with range of health conditions and restrictions. Semi-structured in-depth individual interviews were undertaken by an experienced

qualitative researcher to explore participants' accounts of the impact of joint pain, and the comprehensiveness of the KAP was examined through exploring the impact of joint pain on individuals in relation to the domains captured by the KAP instrument. For this, the interviewer was provided with the WHO definition of the domains covered by the questionnaire, from which the questions for the interview were generated (Wilkie, 2005).

Results of the pre-pilot studies

The cognitive interview participants were divided into two categories. A healthy group (3 participants who had no complaints of joint pain or any other health problems) and an unhealthy group (8 patients receiving treatment on rheumatology ward in a local district general hospital). With regards to face validity, all items were understood and answered as intended, and all questions were regarded as appropriate and relevant by participants. Considering responder burden, there were no observed difficulties in completing the questionnaires, and for the content validity no additional items were highlighted by participants (Wilkie, 2005; Wilkie et al., 2005).

The qualitative interview participants also found the items relevant, felt able to communicate the problems they were having, and reported that the instrument was presented in an acceptable format. All restrictions mentioned in the interviews could be mapped to a domain of the KAP (Wilkie, 2005; Wilkie et al., 2005).

Pilot questionnaire

The KAP was included in the survey instrument mailed to a random sample of 1461 adults aged 50 years and over, drawn from one GP register within the North Staffordshire General Practice Consortium. The inclusion of the KAP in this population based cross-sectional study allowed the meaning of responses to the filter questions, completion rates, and missing data to be examined as well as the distribution of KAP items in terms of restrictions to be observed (Wilkie, 2005).

Of 1461 questionnaires mailed, 1117 responded with completed questionnaires (adjusted response rate 71.7%). The completion rates for all KAP items were reasonably high; the completion of the KAP self-care item was 98.9% (n=1106). Of those, 53% of responders had no participation restriction and 5% reported restriction in self-care (Wilkie, 2005; Wilkie et al., 2005).

Face validity and conceptual discrimination

The measurement model for filter questions was based on the assumption that responders who answered 'no' to the filter questions did not or could not have participation restriction in that domain (e.g. if they answered 'no' to the filter question 'have any dependents' they would not have participation restriction in 'looking after others'). Thus, to examine the correctness of this assumption, those 'no' responses indicating no participation were matched with corresponding frequency items. To support the assumption, participants who answered 'no' to the filter questions would be expected to indicate that they do not take part at all in the matched task (Wilkie, 2005). To establish conceptual discrimination, KAP items

were matched to other survey items from the same domain (e.g. self-care with self-care) that were intended to capture participation restriction measured from the perspective of the society (as opposed to person-perceived approach taken in KAP).

The proportion of responders who indicated 'no' in a filter question and also indicated that they did not participate in the corresponding task ranged from 64% for those who answered item 6 to 98% for those who answered item 10; this proportion was 98.9% for the self-care item (Table 4.6). There was no distinct association between person-perceived participation restriction and the frequency with which people engaged in activities in these domains. The observed agreement between the KAP self-care item and the paired question about the frequency (take a bath – most days or less) was 40%, indicating conceptual distinctions between person-perceived participation restriction and society-perceived participation restriction (Wilkie, 2005).

Repeatability of the KAP

Responders who gave permission for further contact were randomly designated to two groups and sent further questionnaires to address (i) the repeatability of the KAP, and (ii) validity of the KAP compared to items measuring participation derived from other instruments. Responses to the first and second wave of the KAP were then compared for both the main and filter questions. The repeatability of the KAP was examined by calculating the proportion of participants with agreement and agreement beyond chance (kappa K) for dichotomous variables.

Repeatability was assessed for the original five response options for each item, and the categories of 'none' and 'any' participation restriction (Wilkie, 2005).

Of possible 314 who responded at baseline, 196 returned a repeat questionnaire four weeks later (adjusted response rate 62.4%). For the four filter questions the mean observed agreement was 87.5%, and the chance corrected agreement ranged from moderate to substantial. The mean observed agreement for the five response options to each participation item was 75.1% (range: 68%-83%), and the chance corrected agreement was highest for the item which refers to mobility within the home (K_w= 0.64; with 95% CI 0.54-0.74) and the lowest for the item referring to managing money (K_w= 0.34; CI 0.09-0.56). Better repeatability was seen for the dichotomised response (mean agreement: 90.4%; range: 85.3-94.4%), with chance corrected agreement ranging from slight to substantial. The mean observed agreement for the five response options to KAP self-care item was 82.1%, and the chance corrected agreement ranged from slight to moderate (K_w= 0.45; CI 0.33-0.55). Better repeatability was seen for the dichotomised response (mean agreement: 93.9%; range: 85.3-94.4%), with chance corrected agreement ranging from slight to moderate (K_w= 0.37; CI 0.23-0.51) (Wilkie et al., 2005).

Construct validity sub-studies

Convergent validity and discriminant validity

To examine construct validity of the KAP, a similar construct to that of the KAP was needed. During the mapping process two instruments were identified as containing a reasonable proportion of items that measured participation restriction

which could be deemed to capture similar construct to the KAP (Impact on Participation and Autonomy (IPA) (Cardol et al., 2001) and the Reintegration to Normal Living (RNL) (Wood-Dauphinee et al., 1988)). These instruments were used to examine the convergent and discriminative validity. The original response options were replaced with a uniform scale to allow responders to indicate how often they performed the participation task, and response scale for each item was dichotomised to indicate 'participation' and 'participation restriction' (Wilkie, 2005).

There were 102 responders who completed both KAP and RNL, and 104 responders completed both KAP and IPA. The mean percentage agreement for the 10 pairs of corresponding items (convergent validity) between KAP and RNL was 79.3% (range: 72-84%), and the mean percentage agreement for the KAP and IPA (23 items) was 76% (range: 74-97%). The highest observed agreement between items of the KAP and the RNL was for self-care, and lowest agreement was for looking after dependants.

Mean agreement between the 60 pairs of non-corresponding items (discriminant validity) between the KAP and RNL was 76% (range: 57-89%) and the mean agreement for the 160 pairs of non-corresponding items between the KAP and IPA was 82.8% (range: 66-97%), suggesting that individual's perception does not simply reflect the frequency of participation restriction. The high levels of agreement within some of the matched pairs also suggest that participation frequency may be more influential on the perception of participation restriction for some tasks than others.

Interpretation and summary

The findings of the pilot studies support the validity and practicality of applying the KAP in a population survey to estimate participation restriction. These studies have shown that KAP items are comprehendible, can be completed in line with the conceptual model, and relevant and understandable by potential responders. The face validity test suggests that KAP captures person-perceived participation and the construct says that this differs from frequency. KAP items also have presented good convergent validity when compared with other constructs of participation restriction (RNL and IPA), with participation restriction correlating with items selected both for their correspondence and their difference to the items measured by KAP.

However, it was difficult to interpret the levels of chance-corrected agreement for the KAP self-care item and the categories of amount of participation restriction due to the effects of low prevalence. This is because Kappa statistics rely on a comparison between the observed and the expected agreement. When the prevalence of participation restriction is low, the possible agreement above chance can only be small due to high expected agreement; which then makes it difficult to achieve even moderate kappa values (Sim and Wright, 2005). Also the changes that occurred in the prevalence of participation restriction in the repeat mailing were not investigated. Thus, it is unknown whether these changes were due to a random bias or a systematic error as the levels of repeatability for other questionnaires included in the survey did not suggest any change in status of the concepts they were measuring. The change in prevalence could be due to several

factors such as the fluctuating nature of participation restriction, or the variance in the responder's appraisal of an item as person-perceived measures may be influenced by contextual factors (Wilkie, 2005). Although the issues with the repeatability of KAP can introduce a level of uncertainty to the longitudinal analysis in this thesis, it would be reasonable to accept that any participation restriction measured from a person-perspective rather than the societal norm will have variable estimations in between measurements due to change in personal and environmental factors over time.

The KAP's performance in validity and reliability tests indicated that it can be used as an aggregated measure to identify and provide estimates of participation restriction in postal surveys of population of adults aged 50 years and over. Thus, as a validated measure of participation, the KAP offers a good opportunity to measure self-care as participation from an individual's perspective, along with other components of NorStOP which offer the potential to look at health, joint pain and contextual factors and their links with self-care in line with the ICF framework.

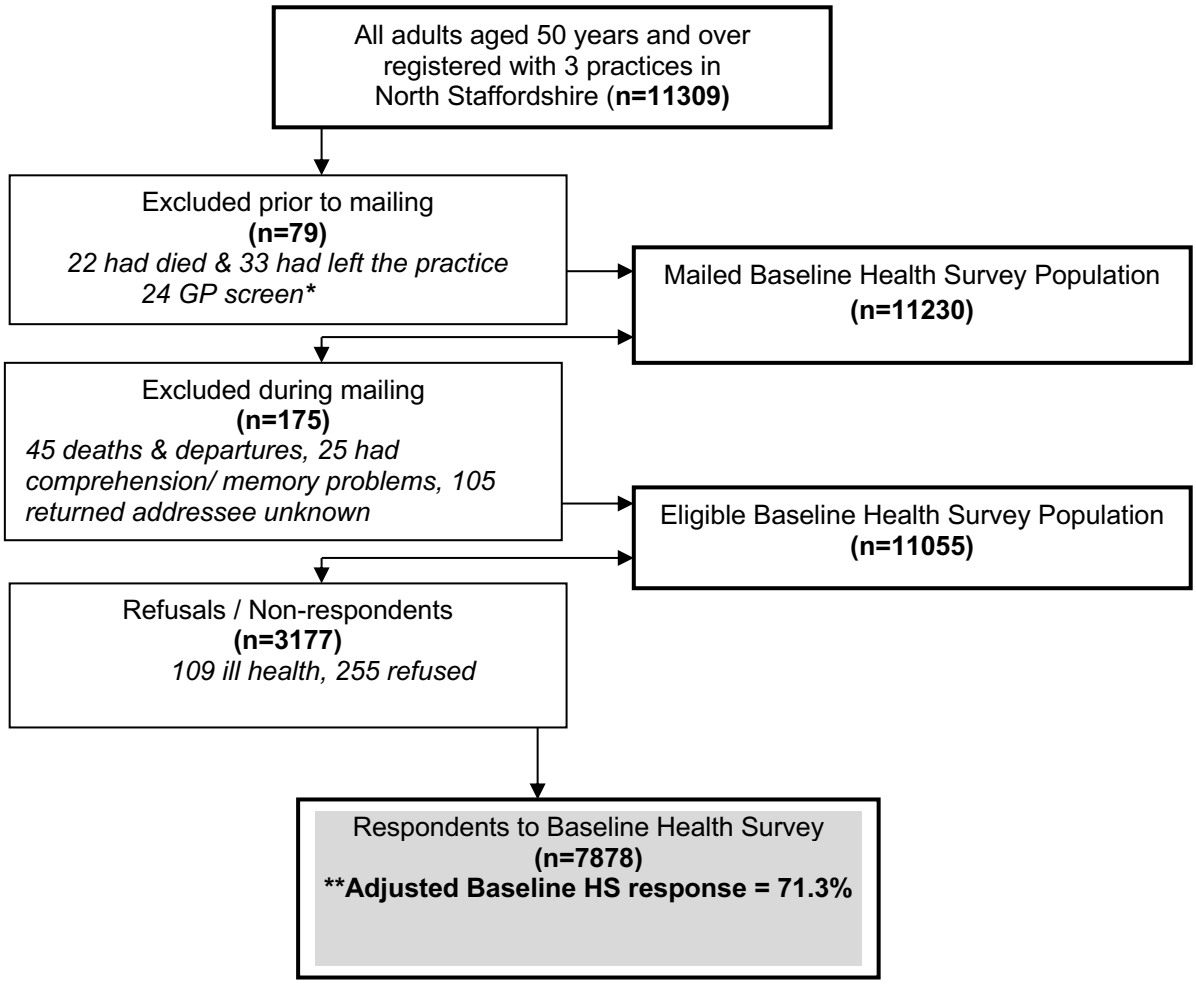
4.3 Response to NorStOP

4.3.1 Baseline survey response

11309 people aged 50 years and older from the three general practices were identified as eligible for the NorStOP study by the KGPRP staff, and 11230 people were mailed after 79 people were excluded prior to mailing (22 had died, 33 had left the practices, 6 were unwilling to take part in the study and 18 had a severe psychiatric disorder, illness or learning difficulties) the Health Survey Questionnaire.

Following the mailing of the first wave of the questionnaires, 175 further exclusions were made due to: subsequent deaths and departures from the practice (n=45), returned questionnaires with addressee unknown (n=105), and those with comprehension / memory problems (n=25). During the mailing 255 people refused to take part in the survey, 109 had ill health and 2813 did not respond. Thus, 7878 responded to the Health Survey Questionnaire from the possible 11055 people, giving the adjusted response of 71.3% (Thomas et al., 2004:b) (Figure 4.2).

Figure 4.2 Flowchart of response to NorStOP study at baseline



* **GP screen** - 6 were identified by their GP as unwilling to take part and 18 were stated to have a severe psychiatric disorder, illness or severe learning disabilities, hence unable to complete the questionnaire.

** **Adjusted baseline response** - Adjusted response refers to the response rate calculated with those who were excluded from the mailing process, for example through death, stroke, dementia or incorrect address information, removed from the denominator.

4.3.2 Response at 3 years and 6 years follow-ups

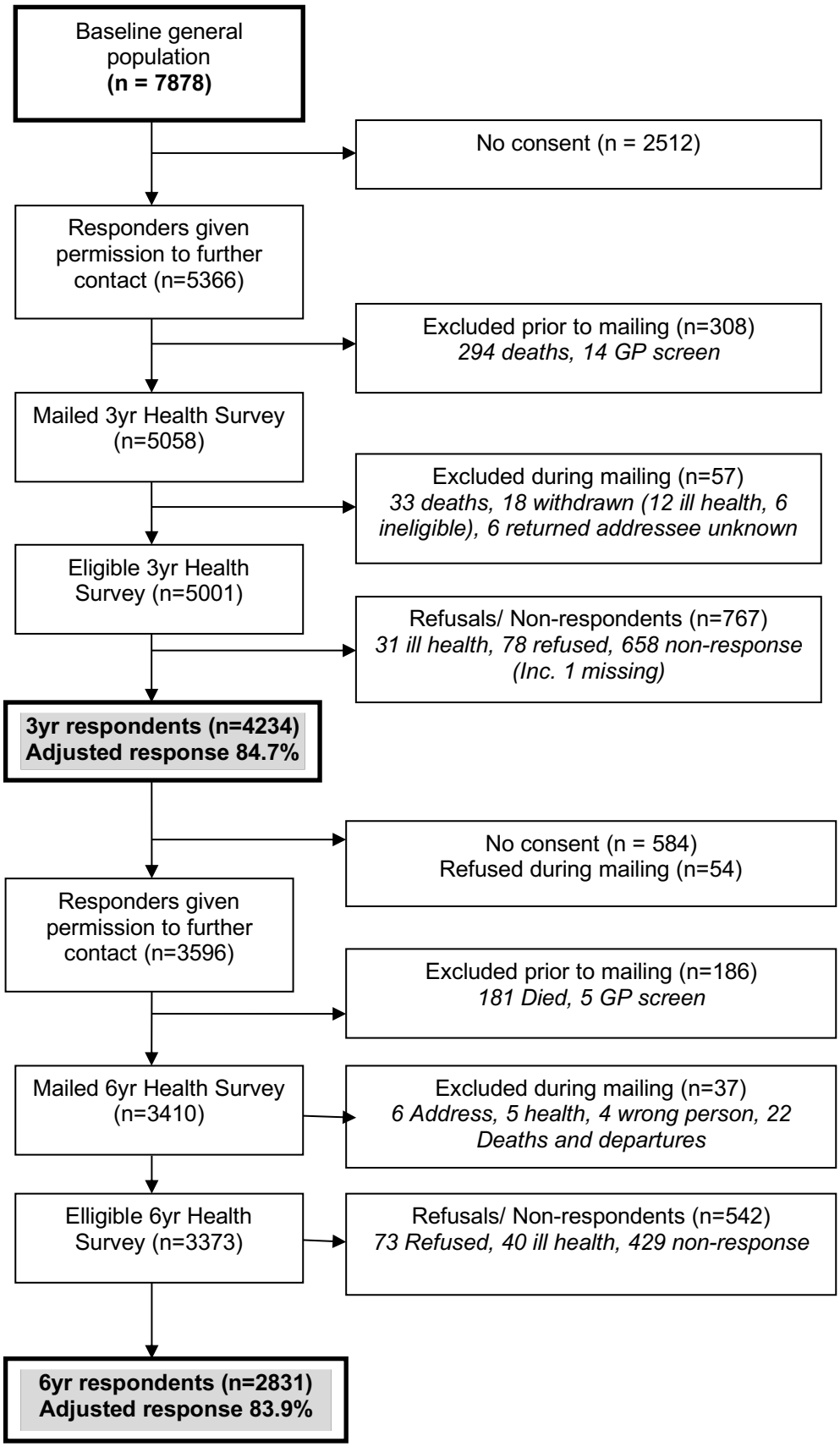
3 years follow-up

In the baseline study, 5366 people gave permission for further contact; of these 308 were excluded prior to mailing due to deaths and GP screenings and 5058 were mailed 3 years Health Survey Questionnaire. Of these, 57 were excluded during mailing due to death or departure, 31 dropped out due to being unable to complete the questionnaire due to ill health, 78 refused to return a questionnaire, 658 did not respond and 4234 returned Health Survey questionnaires. The adjusted response rate for 3 years follow-up was 84.7% (Thomas et al., 2007) (Figure 4.3).

6 years follow-up

Of the 4234 responders at three years, 3596 responders gave permission for further contact. Of this group 186 people were excluded prior to mailing at 6 years (181 died, 5 were screened as non-eligible by GPs) and 3410 people were mailed the Health Survey questionnaire. Following mailing, 37 people were excluded (change of address n=6; ill health n=5; wrong person n=4; deaths and departures n= 22), leaving 3373 eligible participants. Of those 542 did not respond (refusals n=73; ill health n= 40; non-response n=429). Completed questionnaires were received from 2831 people (adjusted response rate 84%) (Figure 4.3).

Figure 4.3 Study consort from baseline to 6 years follow-up



4.3.3 Completeness of the data

Completeness is an important attribute of data quality (Nagurney et al., 2005).The ultimate objective of data quality assessment is to fully understand the characteristics of the data set and determine strategies for the data analyses. Table 4.7 shows the levels of missing data associated with the key variables from the NorStOP baseline, 3 and 6 years follow-up studies used in this thesis. The levels of missing data on the KAP self-care item was very low, less than 2% at each time point. There were higher levels of missing data in certain constructs such as the SF-12 Physical and Mental Health Component, SF-36:PF10 Physical Functioning scale and the SIP Cognitive Alertness Score, where multiple items were required in order to construct a score.

Table 4.7 Levels of missing data among items and scales within the NorStOP at baseline, 3 years and 6 years follow-up studies

Item/ Scale	**Baseline** (n=7878)	**3 years** (n=4234)	**6 years** (n=2831)
	%	**%**	**%**
KAP Self-care item	1.9	1.9	1.2
SF36-PF10 Physical functioning scale	6.8	4.5	1.6
Hospital Depression Score (HAD)	2.4	1.8	1.4
SIP Cognitive Alertness Score	6.6	5.0	8.5
Perceived Adequacy of Income	2.8	1.6	1.8
Educational attainment	2.7	1.9	1.6
SF-12 Physical Health Component (PCS)	14.7	11.0	10.2
SF-12 Mental health Component (MCS)	14.7	11.0	10.2

4.4 The impact of non-response at baseline and attrition across the six years

4.4.1 Responders compared to non-responders at baseline

At baseline, a further 175 (1.5%) people were excluded following mailing and 3177 (28%) did not respond. There was a significant difference in the age and gender of responders, non-responders and those excluded (both p<0.001). Response was higher in the 60-69 and 70-79 age groups, and in women compared with men (71.8 % cf 68.2%). Exclusions were common amongst the oldest age group (80+ years) and non-response were higher in the youngest age groups (50-59 years). Proportionately there were more males in the non-responder (30.0% cf 26.9%) and exclusions (1.8% cf 1.3%) groups compared to women (Table 4.8).

Table 4.8 Age and gender distribution of respondents, exclusions, and non-responders of NorStOP Health Survey at baseline

Overall n=11230	**Exclusions** n=175* (%)	**Responders** n=7878 (%)	**Non-responders** n=3177(%)	┼**P-value**
Age groups				
50-59	53 (1.4)	2521 (65.6)	1273 (33.1)	
60-69	28 (0.5)	2352 (74.4)	783 (24.8)	
70-79	40 (1.4)	2030 (75.6)	602 (22.4)	
80+	52 (3.4)	975 (63.1)	519 (33.6)	p<0.001
Gender				
Females	81 (1.3)	4416 (71.8)	1651 (26.9)	
Males	94 (1.8)	3462 (68.2)	1526 (30.0)	p<0.001

***** Numbers do not add up due to missing data in exclusions
┼ Chi-squared test (X^2)

4.4.2 The NorStOP compared to the local and national population

Table 4.6 shows the comparison of the NorStOP responders to the population of England and Staffordshire by age, gender and ethnicity. This table shows that the age structure of the Staffordshire population is very similar to the population of England. Although the Staffordshire population had less than 10% of adults who were 80 years and older, compared to the English national population where adults 80+ years comprise 11.3% of the total population. However the NorStOP responders comprised a higher proportion of adults in the 80+ years category (12.2%) than the Staffordshire population, making the distribution of this age group closer to the English national sample. The proportion of those in the 60-79 years old groups was higher in the NorStOP responders compared to England and Staffordshire populations. Thus, indicating a possible response bias by age. However this difference is more likely to be related to the sampling frame than to the bias in the response to the survey.

Again, the gender structure of England and Staffordshire was very similar within each age group. There were slightly higher percentages of females in the NorStOP responders compared to the Staffordshire and England populations, but this difference was not markedly higher to suggest a response bias by gender.

The proportion of those who were white was markedly higher in the Staffordshire population and NorStOP responders compared to the English national population in each age group. This underlines that the NorStOP cohort is not representative of England as a whole in terms of ethnicity, however the effect of such bias is likely

to be insignificant due to the small proportion of non-white people overall aged 50 years and over in England (Table 4.9).

Table 4.9 Comparison of the NorStOP responders to those of England and Staffordshire population by age, gender and ethnicity proportions

	50-59	60-69	70-79	80+
Age:	**%**	**%**	**%**	**%**
England[a]	38.4	28.3	22.0	11.3
Staffordshire[a]	40.6	28.7	21.0	9.7
NorStOP responders[b]	32.2	30.8	24.9	12.2
Female:	**%**	**%**	**%**	**%**
England[a]	50.5	51.9	56.5	68.0
Staffordshire[a]	49.7	51.0	56.0	68.4
NorStOP responders[c]	53.9	52.7	57.1	69.5
Ethnicity (white):	**%**	**%**	**%**	**%**
England[a]	95.3	95.1	97.3	98.5
Staffordshire[a]	98.7	98.7	99.5	99.4
NorStOP responders[d]	99.3	99.5	99.5	99.6

[a]Calculated from 2001 Census: standard tables downloaded from Nomis https://www.nomisweb.co.uk/home/Census2001.asp, accessed on 19 February 2009; [b]Age group at baseline responders to NorStOP Health Survey Questionnaire; [c]Gender at baseline responders to NorStOP Health Survey Questionnaire stratified by age group; [d]Ethnicity (white) at baseline responders to NorStOP Health Survey Questionnaire stratified by age group

4.5 Sample analysis

4.5.1 Descriptive characteristics of responders at baseline

Demographic and socio-economic characteristics

The survey responders at baseline had a mean age of 66.3 years (SD: 10.3); and the mean age was slightly higher for female responders compared to male responders (Mean age: 66.9 years (SD:10.6) cf 65.5 years (SD:9.8)). Just over half of the baseline sample were women (56%), and majority were from white ethnic backgrounds (99.4%). The slight increase in the proportion of women in this sample could be related to the evidence suggesting that women are more likely to respond to population surveys than men (Moore and Tarnai, 2002; Gannon et al., 1971). The ethnic homogeneity of this population could be explained by the fact that although black and minority ethnic groups make up over 16% of the population of England, this reduces to 8% in those aged 60 and over (ONS, 2009).

One in four responders at baseline lived alone, and 67% were married. Recent research also suggests a significant increase in the numbers of older people living alone in the recent years (Cambridge CHPR (Centre for Housing & Planning Research) (2010)), with women being more likely to fall into this category (Blood, 2010).

In terms of socio-economic status, the majority of responders had manual occupations (68.5%) and only 14% would describe their perceived adequacy of income as being 'comfortable'. 81.9% consider their income 'difficult to get by' with

or that they ‘had to be careful’, and 3.9% found it to be ‘a strain’. The local economy of the North Staffordshire area has traditionally been dominated by coal mining, heavy manufacturing industries and the ceramics industry. The historically recent decline of these industries has had a significant impact upon the socio-economic dynamics of its population. Thus, the North Staffordshire area is known to be highly deprived in relation to health and employment compared to the rest of the country (Health and Social Profile of Staffordshire (Adults) 2010). However, the Department of Work and Pensions (Households Below Average Income) (2011) reports that 1.7 million pensioners (14%) live below the poverty line in the UK and 8% of pensioners are in persistent poverty (DWP, 2012). Previously the National Statistics for England reported that participants in lower income quintiles were more likely to report high prevalence of chronic diseases (National Statistics (The information centre) 2005).

In terms of level of education amongst responders, over 70% of participants report not having adult qualifications. Education is associated with material resources in Britain; people who are only educated up to secondary level are associated with a low level of material resources, whilst those who progress to further education (adult qualifications) come to be associated with attaining higher levels of resources (Burholt and Windle, 2006) (Table 4.10).

Table 4.10 Descriptive characteristics of NorStOP Health Survey baseline responders (n=7878): demographic and socio-economic characteristics

Age Mean (SD)		
	Overall	66.3 (10.3)
	Female	66.9 (10.6)
	Male	65.5 (9.8)
Female n (%)		4416 (56.1)
Ethnicity (white) n (%)		7633 (99.4)
Marital Status † n (%)		
	Married	5197 (66.8)
	Separated	55 (1.0)
	Divorced	440 (5.7)
	Widowed	1559 (20.0)
	Cohabiting	116 (1.5)
	Single	411 (5.3)
Live alone n (%)		1915 (24.3)
Occupational class* n (%)		
	Manual	4619 (68.5)
	Non-manual	2119 (31.4)
Perceived adequacy of income † n (%)		
	Comfortable	1083 (14.1)
	Little difficulty	3094 (40.4)
	Have to be careful	3179 (41.5)
	Strain	302 (3.9)
Higher educational attainment † n (%)		
	YES	2204 (28.8)
	NO	5460 (71.2)

†Totals do not add up to the 7878 due to the missing values
* Totals do not add up to 7878 due to the removal of the self-employed category

Health characteristics

The mean SF-12 PCS and MCS scores of responders were 40.7 (SD: 12.5) and 48.8 (SD: 11.2) respectively. Physical health and mental health are linked; individuals with mental health problems are at increased risk of a range of physical problems and conditions and poor physical health is also associated with the increased risk of developing mental health problems (Coalition Government's

Public Health White Paper Healthy Lives, Healthy People (2010). In terms of anxiety and depression, the majority of responders were not anxious or depressed (59.6% and 77.3% respectively). Of those with anxiety, 21.9% were borderline and 18.5% were deemed to be “definite” cases. Of those with depression, 14% were borderline and 9.7% were deemed as definite. This is similar to the findings of the Health Survey for England which studies chronic diseases and the health of older people in England. It reported that approximately 10-15% of the population aged 65 and over have depression, which is severe in 3-5% of older people (National Statistics (The information centre) 2005). Depression can also co-occur with cognitive impairment and pain (Sherbourne et al, 2009; Fishbain et al., 1997; Magni et al., 1993). Of those with cognitive impairment, 21.6% reported low levels and 24.9% had reported high levels. However, over half of responders had no cognitive impairment (53.5%). A previous population survey of community-dwelling older adults in the UK also reported high levels of cognitive impairment among community-dwelling adults. However the sample population was aged 75 and older in this study (Rait and Jones, 2005). In terms of joint pain, 43.8% reported hand pain, 51.5% reported knee pain, 33.1% reported hip pain, and 38.3% reported foot pain in the last 12 months. These estimates are comparable with previous studies of joint pain in community-dwelling older people. As mentioned in earlier chapters, the definition and measurement of joint pain is varied vastly across the studies. For example the prevalence of hand pain has been reported to be in the regions of 12% to 30% (Dziedzic et al., 2007; Urwin et al., 1998) and the prevalence of knee pain was reported to be in the regions of 19% (Urwin et al., 1998) and 47% (Jinks et al., 2004).

Over 40% of responders were overweight, 17% were obese, and less than 5% were underweight. It is reported that a quarter of the UK adult population is obese and nearly two thirds are beyond the threshold for being overweight in the UK. Obesity rates increase with age (up to the age of 70 years) and decline thereafter (Peeters et al., 2003). The most prevalent health problems experienced were breathlessness when walking (35.5%), followed by weakness in arm and leg (34%) and raised blood pressure (31%). A Health Survey conducted in New Zealand reported that increasing BMI and waist circumference were related to increased prevalence of cardiovascular disease, diabetes, high blood pressure and osteoarthritis (Turley et al., 2006). The Health Survey of England (2005) also reported that hypertension, arthritis, and having had a joint replaced were more common in overweight or obese adults, supporting the view that health problems and multiple conditions are interrelated (Table 4.11).

Table 4.11 Health characteristics of baseline responders to NorStOP Health Questionnaire (n=7878)

SF-12 Physical Component Score	
(0-100) Mean (SD)	40.7 (12.5)
SF-12 Mental Component Score	
(0-100) Mean (SD)	48.8 (11.2)
HAD* Anxiety † n (%)	
Non cases	4564 (59.6)
Borderline cases	1679 (21.9)
Definite cases	1414 (18.5)
HAD* Depression † n (%)	
Non cases	5932 (77.3)
Borderline cases	1077 (14.0)
Definite cases	669 (8.7)
Cognitive Alertness †† n (%)	
None	3936 (53.5)
Low level	1588 (21.6)
High level	1832 (24.9)
Body Mass Index (BMI) n (%)	
20 – 24.99	2744 (36.5)
25 – 29.99	3070 (40.9)
>30	1339 (17.8)
<20	1355 (4.7)
Peripheral Joint Pain n (%)	
Hand pain	3449 (43.8)
Knee pain	4060 (51.5)
Hip pain	2608 (33.1)
Foot pain	3020 (38.3)
Selected health problems n (%)	
Chest problems	1698 (21.6)
Heart problems	1410 (17.9)
Deafness	1467 (18.1)
Eyesight+	1688 (21.4)
Raised blood pressure	2445 (31.0)
Diabetes	643 (8.2)
Falls	1007 (12.8)
Difficulty remembering things	2148 (27.3)
Cough with spit	1460 (18.5)
Breathlessness when walking	2797 (35.5)
Dizziness/ unsteadiness	1931 (24.5)
Weakness in arm/leg	2677 (34.0)

* Totals do not add up to the 7878 due to the missing values
† Hospital Anxiety and Depression Scale (Non cases: 0-7, Borderline cases: 8-10, Definite cases: 11+)
†† Functional Limitations Profile, Cognitive and Alertness behaviour subscale (None: 0, high levels: 22.5-100, low levels: 0.1-22.4)
+Excluding need for spectacles

4.5.2 Responders compared to lost at follow-up at 3 years

Of 7878 responders at baseline, 3644 (46%) did not return a questionnaire at 3 year follow-up. Of those lost at follow-up, 2512 (69%) did not consent to further participation, 365 (10%) were excluded from the study and 767 (21%) did not respond to the 3 years follow-up questionnaire (Figure 4.3).

Compared to those lost to follow-up, responders at 3 years were younger (M= 64.3 SD= 9.3), had better physical and mental health (Mean PCS: 42.0 (12.4); Mean MCS: 49.6 (11.1)), better physical functioning (Mean: 64.5 (30.4)), less depression and lower levels of cognitive impairment ($p \leq 0.001$). There were no significant differences between responders and those who were lost to follow-up in terms of gender ($p=0.149$). However, there were significant differences in the socio-economic status of the responders and those lost to follow-up. Proportionately, fewer responders found their income to be of strain (3.5%) and, responders tended to possess adult qualifications (35.6%) ($p \leq 0.001$) (Table 4.12). These differences indicate that the responders at 3 years were characteristically different from those lost to follow-up, which may affect the estimates of frequency of self-care restriction and the strength of association with other factors in the longitudinal estimates.

Table 4.12 Responders versus loss to follow-up at 3 years

n= 7878		Total loss to follow-up		n= 3644	
	Responders	Non-response	Non-consent	Excluded	
	n=4234	n= 767	n= 2512	n= 365	Significance test
Age					
Mean (SD)	64.30 (9.3)	63.4 (10.2)	69.4 (10.6)	74.5 (9.9)	p≤ 0.001
Gender n (%)					
Female	2350 (55.5)	390 (50.8)	1518 (60.4)	158 (43.3)	
Male	1884 (44.5)	377 (49.2)	994 (39.6)	207 (56.7)	p= 0.149
SF-12 PH					
0-100: Mean (SD)	42.0 (12.4)	40.9 (12.5)	39.4 (12.4)	32.8 (11.4)	p≤ 0.001
SF-12 MH					
0-100: Mean (SD)	49.6 (11.1)	48.5 (11.0)	47.9 (11.2)	44.4 (11.7)	p≤ 0.001
HAD depression score* ┼n (%)					
Non cases	3411 (82.0)	573 (76.9)	1731 (71.6)	217 (61.0)	
Borderline cases	484 (11.6)	105 (14.1)	413 (17.2)	72 (20.2)	
Definite cases	263 (6.3)	67 (9.0)	272 (11.2)	67 (18.8)	p≤ 0.001
Cognitive Alertness┼┼ n (%)					
None	2308 (57.4)	371 (52.1)	1133 (49.4)	124 (37.2)	
Low -level	859 (21.4)	163 (22.9)	495 (21.6)	71 (21.3)	
High-level	852 (21.2)	178 (25.0)	664 (29.0)	138 (41.4)	p≤ 0.001
Activity limitation (PF-10)					
0-100: Mean (SD)	64.5 (30.4)	63.8. (31.6)	55.5 (33.3)	38.0 (32.8)	p≤ 0.001
Perceived adequacy of income n (%)					
Comfortable	660 (15.8)	122 (16.3)	252 (10.5)	49 (13.9)	
Little difficulty	1729 (41.5)	283 (37.9)	939 (39.3)	143 (40.5)	
Be careful	1631 (39.1)	297 (39.8)	1107 (46.3)	144 (40.8)	
Strain	147 (3.5)	45 (6.0)	93 (3.9)	17 (4.8)	p≤ 0.001
Higher educational attainment n (%)					
YES	1481 (35.6)	238 (32.0)	395 (16.4)	90 (25.0)	
NO	2674 (64.4)	505 (68.0)	2011 (83.6)	270 (75.0)	p≤ 0.001

* Numbers do not add up due to missing data

┼ Hospital Depression Score (Non cases: 0-7, Borderline cases: 8-10, Definite cases: 11+)

┼┼ Functional Limitations Profile, Cognitive and Alertness behaviour subscale (None: 0, high levels: 22.5-100, low levels: 0.1-22.4)

4.5.3 Responders compared to loss to follow-up at 6 years

Of 4234 responders at 3 years, 2831 had responded (67%) to the six year follow-up questionnaire. 1403 (33%) were lost at follow-up. Of those who were lost at follow-up, 638 (45%) did not consent to take further part in the study at 3 years. A further 223 (16%) were excluded from the study and 542 (39%) did not respond to the six year follow-up questionnaire (Figure 4.3).

Again, the difference between the responders and those lost at follow-up at 6 years were statistically significant for demographic, health and socio-economic characteristics (Table 4.10). Responders at 6 years were younger (Mean age 65.9 (8.6)), predominantly female (65.4%) ($p=0.043$), with better physical and mental health (Mean PCS: 43.2 (12.1); Mean MCS: 50.1 (10.9)), higher physical functioning (Mean: 61.9 (29.5)) ($p\leq0.001$), less depression ($p\leq0.001$) and lower levels of cognitive impairment ($p\leq0.001$). Responders had the higher proportion of people with higher educational achievement (40.4%) ($p\leq0.001$) and those whose income was comfortable (16.7%) compared to those who were lost to follow-up at 6 years ($p=0.024$) (Table 4.13). Thus, the cohort at 6 years was a healthier cohort compared to those who were lost to follow-up. This cohort was used to study the empirical differences between two things in community-dwelling older people with joint pain. First, task-specific activity limitation and self-care restriction. Second, the link between environmental facilitators and self-care restriction (Chapter 8). A healthier cohort may affect the estimates of self-care restriction and task-specific activity limitation, and the strength of associations with other health, socio-

demographic and environmental factors at the cross-sectional study of older adults with joint pain at 6 years.

Table 4.13 Responders versus loss to follow-up at 6 years

n= 4234		Total loss to follow-up n= 1403			
	Responders n=2831	Non-response n= 542	Non-consent n= 638	Excluded n= 223	Significance test
Age					
Mean (SD)	65.9 (8.6)	67.1 (9.9)	70.9 (9.5)	74.5 (9.4)	p≤ 0.001
Gender n (%)					
Female	1598 (56.4)	291 (53.7)	374 (58.6)	87 (39.0)	
Male	1233 (43.6)	251 (46.3)	264 (41.4)	136 (61.0)	p= 0.043
SF-12 PH					
0-100: Mean (SD)	43.2 (12.1)	39.1 (12.2)	38.8 (11.9)	33.8 (10.9)	p≤ 0.001
SF-12 MH					
0-100: Mean (SD)	50.1 (10.9)	47.4 (11.4)	47.1 (11.2)	46.7 (10.8)	p≤ 0.001
HAD depression score*┼					
Non cases	1737 (82.0)	312 (75.4)	320 (71.1)	108 (65.1)	
Borderline cases	235 (11.1)	55 (13.3)	81 (18.0)	31 (18.7)	
Definite cases	146 (6.9)	47 (11.4)	49 (10.9)	27 (16.3)	p≤ 0.001
Cognitive alertness┼┼ n (%)					
None	1053 (53.8)	165 (44.0)	170 (44.9)	49 (35.0)	
Low -level	482 (24.6)	103 (27.5)	102 (26.4)	35 (25.0)	
High-level	424 (21.6)	107 (28.5)	115 (29.7)	56 (40.0)	p≤ 0.001
Physical Functioning					
0-100: Mean (SD)	61.9 (29.5)	51.2 (32.3)	48.6 (31.6)	36.6 (28.2)	p≤ 0.001
Perceived adequacy of income n (%)					
Comfortable	463 (16.7)	67 (12.7)	81 (13.3)	29 (14.0)	
Little difficulty	1168 (42.0)	212 (40.2)	264 (43.5)	90 (43.5)	
Be careful	1085 (39.0)	230 (43.6)	249 (41.0)	85 (41.1)	
Strain	63 (2.3)	19 (3.6)	13 (2.1)	3 (1.4)	p= 0.024
Higher educational attainment n (%)					
YES	1126 (40.4)	168 (31.5)	115 (18.5)	72 (33.6)	
NO	1659 (59.6)	365 (68.5)	508 (81.5)	142 (66.4)	p≤ 0.001

* Numbers do not add up due to missing data
┼ Hospital Depression Score (Non cases: 0-7, Borderline cases: 8-10, Definite cases: 11+)
┼┼ Functional Limitations Profile, Cognitive and Alertness behaviour subscale (None: 0, high levels: 22.5-100, low levels: 0.1-22.4)

4.6 Discussion

4.6.1 Representativeness of the general population

The use of general practice registers provided a representative sample of older adults in the general population who were not involved in other similar research at the time of the baseline survey. The sampling frame (n=11309) was similar in demography (age and gender) to the population of England, albeit there were differences in ethnic background.

A repeat mailing strategy was used in NorStOP to increase the response rate, as this method was previously successful in population studies (Nakash et al., 2006; Jinks et al., 2001). Acceptable response rates depend on many factors and an acceptable response rate for self-completed surveys is reported to be between 65-75% (Bowling, 2002; Sitzia and Wood 1998). The response to the NorStOP Baseline Health Questionnaire was 71%, which is within the suggested range. The sample analysis identified that non-response was higher in the youngest (50-59 years) age group, whereas exclusions were higher in the oldest age group (80+) compared to the mailed sample. However, there was no evidence of responders at the baseline Health Survey questionnaire been different than those in the England population in terms of age groups and gender. The proportion of white adults was slightly higher in responders at baseline compared to the English population, especially in the 50-79 age groups. However, considering that both the responders at baseline and the population of England's ethnicity was ≥95% white, this is unlikely to cause a biased sample in terms of the study sample's representativeness of the general population. Thus, the findings from the NorStOP

cross-sectional sample at baseline can be generalised to the national population with careful consideration.

4.6.2 Study attrition

Despite the two-stage mailing process being repeated at each follow-up and support of NHSSTS to boost response rates, there was a significant reduction in sample size from baseline to 3 and 6 years follow-up. In particular a reduction in the proportion of males aged 70 years and over from lower socio-economic backgrounds and with poorer health. This anticipated bias may affect results of the longitudinal analysis at 3 years by underestimating the onset and persistence of self-care restriction and weakening the associations with known risk factors. However there is potential to use statistical methods, for example imputation, to assess the effect of attrition over time.

4.6.3 Data quality

NorStOP was a large population survey, administered as a self-completed postal survey. Postal surveys are a simple, cost efficient way of reaching a widely dispersed population, many of whom would not normally attend a healthcare setting (Bates and Rogstad, 2000). Self-completion postal surveys eliminate interviewer bias (i.e. the researcher can't influence the respondents' answers by using verbal or facial expression to affirm or reject a particular answer). However, this also means that the researcher has no control over whether the intended person fills in the survey; anyone at the mailing address may have picked the form up and filled it in. However, problems completing the questionnaire due to specific

health problems such as reduced sight and physical functioning may have required help from a significant other or a friend to complete the questionnaire which may have introduced bias to the response by encouraging / discouraging certain answers.

To minimise human error in data entry, the questionnaire data were scanned and processed using the Tele*form*™ software package (Cardiff Software Inc., 1998) with the exception of the pain manikins, where the data were entered manually into a Microsoft Access database, using a transparent overlay to define pain areas. The data entry accuracy was audited through manually checking one in ten questionnaires for errors. Jinks et al (2003) reported that these processes enable accurate survey data transfer to be attained with Tele*form*™ in a study which evaluated a computer-assisted data entry procedure (including Tele*form*™) for large-scale mailed surveys.

The missing data amongst the important variables such as the KAP self-care item, HADS scores, perceived adequacy of income and educational attainment were less than 3.0% across the 6 years follow-up. However, there were some instances of higher levels of missing data (≥5%). In particular where multiple items were required to calculate an overall score, such as SF-12 Physical and Mental Health scores. Thus, reducing the sample size available for the analysis. Issues with missing covariate data is explored in a later chapter.

4.6.4 Measurement of self-care restriction using KAP

Traditionally, self-care was measured as an individual's capacity to perform specific tasks of daily living (e.g. difficulty and dependence in washing and bathing, dressing and toileting (see Chapter 1 and 2)). In contrast, the KAP measures self-care as a biopsychosocial construct in line with the ICF model, where self-care is an outcome involving the interaction between the individual and their environment. It measures self-care from the individual's perspective and the individual judges whether their self-care needs are *"met as and when I wanted"*. There are no other published instruments to measure self-care as participation restriction, despite it being argued as a principal component of health-related quality of life (Wilkie et al., 2004; Wilkie et al., 2005). This is important as most health measurement instruments do not separate participation restriction from activity limitation (Wilkie et al., 2004; WHO, 2001). The philosophical concept and theoretical rationale behind the KAP, along with its simple format for application in epidemiological studies provides a good foundation to describe and investigate the extent of self-care restrictions in the community-dwelling older adults.

The test of construct validity demonstrated that there was some distinction between person-perceived participation restriction and the frequency with which people engaged in activities in these domains. The observed level of agreement between the self-care item and the paired question about frequency suggested that participants reported some specific functional limitations without indicating participation restriction in the corresponding item. This was because limitation was not considered important or severe enough to influence participation (Wilkie et al.,

2005). The response to NorStOP across 6 year follow-up also shows that less than 2% of data in KAP self-care item were missing, suggesting a high rate of data completeness.

Although KAP appears to be a good measure of self-care restriction in population surveys, it is not without limitations. The aggregated nature of the KAP self-care item means that the specific nature of the restriction (e.g. washing and bathing, dressing) cannot be not identified. In developing the epidemiology of self-care restriction and associated factors in a population of older adults, this may not be a problem, but to develop clinical interventions for rehabilitation purposes, more information into the specific restrictions would be needed, such as to establish needs for specific dependencies in order to provide environmental facilitators (e.g. help and assistance in washing, aids and appliances for cooking).

Levels of kappa statistics need to be considered with percentage agreement and the low prevalence of certain items when judging the repeatability of the KAP. The assessment of repeatability suggests that person-perceived restriction may not be stable over time, but the other psychometric tests indicate that the KAP measures the construct at each time point. The prevalence of limitation in self-care tasks such as bathing is reported to be in the range of 29-40% in older adults (Gill et al., 2009: Gill et al., 2006:a; Naik et al., 2004). In contrast the prevalence of self-care restriction measured by the KAP in the pilot study was lower, which may indicate differences in the constructs (limitation in capacity at the level of the individual versus person-perceived participation including the use of environmental factors)

(Wilkie et al., 2005). Attrition bias also may have resulted in reduced estimates of participation restriction in self-care in the study sample compared to the “true” prevalence of these restrictions in the general population of older adults. However statistical methods can further assess the extent of this on observed estimates.

4.7 Conclusions

Secondary analysis of the NorStOP dataset provides a practical, cost-effective, and suitable method of accessing a large population survey containing data that can be used to investigate self-care restrictions and joint pain in community-dwelling older people. The strength of using NorStOP is that it contains the KAP which measures participation in line with the ICF construct of participation and includes a number of variables to examine the associations with health conditions, activities, personal and environmental factors and joint pain. The limitation is the study attrition; this is an inevitable occurrence in studies where people are followed up over a long period of time. Thus, the issues with the selective loss to follow-up at three and six years will be considered in the following chapters for their potential to affect the analysis.

Table 4.14 Summary of key findings

- This chapter examined the suitability of the NorStOP dataset to meet the objectives of this thesis by reviewing the study design, the psychometric properties of the data collected, and sample derivation.

- The Health Survey instrument included previously validated questionnaires; a pain manikin and specifically developed single items. The Regional Pains Survey included single items and explored hip, knee and foot pain and hand pain and problems only.

- The KAP's performance in validity and reliability tests indicated that it can be used as an aggregated measure to identify and provide estimates of participation restriction in postal surveys of population of adults aged 50 years and over. Thus, as a validated measure of participation, the KAP offers a good opportunity to measure self-care as participation from an individual's perspective.

- Response to the NorStOP Health Survey Questionnaire was n=7878 at baseline (adj. response 71.3%); n=4234 at three years follow-up (adj. 87.7%); and n=2831 at six years follow-up (adj. 83.9%) studies.

- There was no evidence of significant difference between the age and gender distribution of the responders at baseline and the England population. Thus, the findings from this cross-sectional sample can be generalised to the national population with careful consideration.

- Despite the two-staged mailing process being repeated at each follow-up, and support of the NHSSTS to boost response rates, there was a significant study attrition from baseline to three and six years follow-up, particularly with a reduction in the proportion of males aged 70 years and over, from lower socio-economic backgrounds and with poorer health. Employing statistical methods such as imputation may help to minimise the effects of attrition in longitudinal analysis of this data.

- The missing data amongst the important variables such as the KAP item, HADS scores, perceived adequacy of income and educational attainment were less than 3% across the six years follow-up.

- The strength of using NorStOP is that it contains the KAP, which measures participation in line with the ICF, and includes a number of variables to examine the associations with health conditions, activities, personal and environmental factors and joint pain.

Chapter 5

The prevalence and distribution of restricted self-care and associated factors in the general population at baseline

5.1 Introduction

Cross-sectional studies are used to estimate prevalence and examine the relationship between the outcome of interest, and other explanatory factors in a defined population, at a specific time point (Porta, 2008). First of all it is important to quantify the size and nature of a problem within specific populations. Prevalence is used to quantify the size of a health problem in populations, and is defined as *the number of events of a given condition, in a given population at a chosen time* (Porta, 2008). When this term is used to refer to the total number of people with a specific condition at a specific point time, it is called the 'point prevalence'. When it is used to refer to observing the total number of people with a condition *at any time during a specified period*, it is called the 'period prevalence' (Porta, 2008). Prevalence estimates of conditions in the general population play an important role in public health policy making and service provision (Valanis, 1999). Understanding how prevalence may differ with demographic factors, such as age and gender, can help to generate hypotheses on causation. Identifying factors that are associated with self-care restriction can contribute further to the generation of hypotheses on causal mechanisms and provide some insight into potential prevention and intervention strategies. This is a key component in building the epidemiology of self-care, however, it is important to emphasise that the temporal

sequence of cause and effect cannot be determined in cross-sectional studies (Porta, 2008).

Self-care, as a form of participation in which the role of environmental factors is acknowledged, has not been examined before in population studies; hence there are no estimates of prevalence or empirical studies of the associations with self-care restriction. This study sets out to test this conceptual model of self-care (i.e. that self-care restriction will be associated with health and contextual factors). Age, female gender, physical inactivity / limitation, lower income, excessive weight and mental health problems are factors commonly associated with poor functional outcomes (Leroux et al., 2005: Woolf and Pfleger, 2003; Badley and Ibanez, 1994). Previous research into specific limitations in self-care activities (e.g. bathing) reported that the capacity to carry out this activity independently depends on more than one factor and can be multiply determined by both physiological and psychological factors (Mullick 2005; Naik et al., 2004). Emotional distress and physical limitation are key factors independently linked to limitation in self-care activities such as bathing and dressing (Verbrugge and Jette, 1994). The role of joint pain is explored specifically in this study. With an ageing population, and the expected rise in the number of people with musculoskeletal conditions, understanding the link with self-care is important.

This chapter describes the cross-sectional analysis of the North Staffordshire Osteoarthritis Project (NorStOP) baseline data. This includes the methods and results for studies that: (i) estimate the prevalence of person-perceived restricted

self-care in the general population of adults aged 50 years and over; (ii) describe the distribution of self-care restriction with age and gender; (iii) determine the associations between self-care restriction and selected health conditions, impairments, activity limitation and other contextual factors, with a specific focus on joint pain.

5.2 Aims and objectives

Using cross-sectional analyses of the baseline data from the NorStOP in community-dwelling adults aged 50 years and over the aims of this work are to:

i. Estimate the four-week period prevalence of person-perceived self-care restriction and its distribution by age and gender
ii. Investigate the strength of cross-sectional associations between restricted self-care and selected health conditions, impairments, activity limitation and contextual factors with a specific focus on joint pain
iii. Derive a parsimonious model of factors which are independently associated with restricted self-care
iv. Examine factors that may explain the relationship between joint pain and self-care restriction

5.3 Methods

5.3.1 Dataset

The analyses described in this chapter uses data collected at baseline in the NorStOP study. Participants were community-dwelling adults aged 50 years and over in the general population who responded and completed the Keele Assessment of Participation (KAP) self-care item at baseline (n=7725).

5.3.2 Outcome

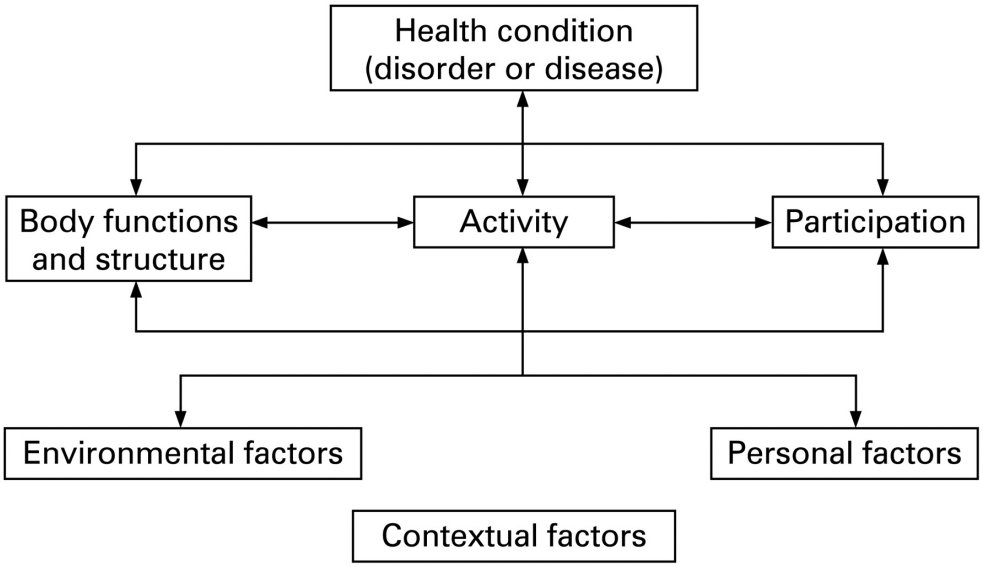
As outlined in chapter 4, the self-care item from the KAP was used to define participation and participation restriction. The item asks *"During the past 4 weeks, my self-care needs (examples are washing, toileting, dressing, feeding, maintaining health) have been met, as and when I have wanted".* The answer options were *"All the time / Most of the time / Some of the time / A little of the time / None of the time".* Those who answered "*All the time"* and *"Most of the time" were* classed as *restricted*, those who answered "*Some of the time", "A little of the time", and "None of the time"* were classed as *not restricted* in self-care; this provides a dichotomous outcome variable.

5.3.3 Covariates

The ICF framework was used to guide the cross-sectional analysis of the baseline data. Covariates included in the study were classified according to the ICF model of human function and disability (see Chapter 4). As the diagram shows, in the ICF disability and functioning are viewed as outcomes of interactions between health conditions (diseases, disorders and injuries) and contextual factors (Figure 5.1).

Contextual factors considered in this study were the *internal* personal factors such as age, gender and socio-economic characteristics. *External* environmental factors were not measured in NorStOP at baseline.

Figure 5.1 ICF Model of Human Function and Disability (WHO, 2001)



Source: WHO, 2001

5.4 Statistical analysis

The statistical analysis conducted in this study was designed and planned by the author of this thesis with the advice of the supervisory team. The analysis was performed by the author using SPSS Statistics Version 17.0 and Stata Version 11.0.

5.4.1 Prevalence of person-perceived self-care restriction and its distribution by age and gender

Prevalence of restricted self-care was calculated by dividing the number of responders who reported restriction in self-care by the number of responders who completed the self-care (KAP) item and reported as a percentage.

Prevalence of restricted self-care was calculated overall and within age and gender groups to assess for potential confounding. Differences in prevalence of restricted self-care within age groups were determined using Pearson *Chi-squared* test for trend and by percentage difference with 95% confidence intervals for gender.

To explore the effect of gender on the distribution of restricted self-care with age, the prevalence of restricted self-care for each age group was stratified by gender.

Age standardisation using indirect method

Age is one of the most common and important confounding factors in health studies as it is more often than not related to both the outcome of interest and the independent variable (Hennekens and Buring, 1987). Standardisation methods are used to enable valid comparisons between groups studied at different places and / or times (Wells, 2002). Age standardisation is a method that removes the confounding effect of age in order to make unbiased comparisons (Field, 2005). The two most common standardisation techniques used in the literature are the *direct* and *indirect* methods. Both methods are similar in principal, as they are based on taking a weighted average of category specific rates. However, the *direct method* is generally used for comparisons between two populations, and the *indirect method* is used when the age-specific rates for the study population are not known but the total number of events is known, or when calculating rates for small populations where fluctuations in age-specific rates can affect the reliability of rates calculated using the direct method (Armitage and Berry, 1994) (Table 5.1).

Table 5.1 Age standardisation methods

Direct method	Indirect method
$SR= (SUM (r_i * P_i))/SUM P_i$	$SR=(C/SUM(R_i *p_i))*R$

SR is the age-standardised rate for the population being studied
ri is the age-group specific rate for age group i in the population being studied
Pi is the population of age group i in the standard population
C is the observed number of events* in the population being studied
SUM(Ripi) is the expected number of events in the population being studied
Ri is the age-group specific rate for age group i in the standard population
pi is the population for age group i in the population being studied
R is the crude rate in the standard population
* 'Events' can include deaths, incident or prevalent cases of disease or other conditions, or health care utilisation occurrences.

Source: Australian Institute of Health and Welfare (AIHW) Knowledgebase, 2005

The age and gender structure of England differs to that of NorStOP (Chapter 4). Indirect standardisation was used to compare the actual number of self-care restriction with the number expected in the population of England and Wales, as the census data were not available only for England. The observed prevalence of restricted self-care in NorStOP was adjusted using the most recent available estimates of the national population for England and Wales at the time this thesis was undertaken (Census 2001). Calculation was applied to age groups stratified by gender respectively. Figures in each group were added together and divided by the total number to acquire the total (final) standardised prevalence estimate of restricted self-care in people aged 50 years and over in the general population.

The NorStOP population who responded to the KAP self-care item at each age band was shown in column (a). The number of people who reported restricted self-care in each age band was shown in column (b). The age-specific prevalence was calculated and shown in column (c).

Rate/ 1000 person-years

= (Observed number of cases/ number in NorStOP population) x 1000

= ((b)/ (a)) x 1000

To compare the prevalence of restricted self-care in the NorStOP sample to the population of England and Wales, whose age distributions may differ, the observed rate was adjusted to the reference population using UK Census (2001) data. Age group specific rates, which occurred in the study population, were applied to the appropriate age groups in the England and Wales population, and

the number of cases would have been expected if the study population rates were identical to national rates were calculated as below:

Expected number of cases

= Prevalence (per 1000 individuals) in the study population x (number of people in the national population/ 1000)

= (c) x (d)

This was calculated for each age-group stratified by gender and the results were shown in column (e).

The standardised rate

= (Total expected number of cases/ Total national population) x 1000

= (Total (e)/ Total (d)) x 1000

The combined standardised prevalence rate

$$= \frac{\text{(total expected male cases + total expected female cases)}}{\text{(total standard male population + total standard female population)}} \times 1000$$

5.4.2 Factors associated with restricted self-care in the general population

Following prevalence estimates, factors associated with restricted self-care in the general population were investigated through a set of univariable and multivariable logistic regression analyses. These were conducted by the author using SPSS Version 17.0.

When carrying out a univariable analysis it is important to understand that the relationship between two variables could be confounded by another factor (Henneken and Buring, 1987). A confounder variable is associated with both the probable cause and the outcome (Jordan et al, 1998). In order to control the potential effects of confounding, multivariable techniques were used to assess independent associations with restricted self-care. Therefore each variable that was associated with restricted self-care in the univariable analysis was adjusted for age and gender, and then all other associated factors in the multivariable analysis, to identify their independent association with restricted self-care using a backward-stepwise logistic regression.

Logistic regression method was used to investigate the associations between self-care restriction and selected covariates, and adjust for potential confounders, because the dependent variable was binary / dichotomous and all independent variables were binary or categorical (Field, 2005; Jordan et al., 1998). Logistic regression is used for the prediction of the probability of occurrence of an event by fitting data to a logistic function (Agresti, 2007). Logistic regression is carried out through a logistic or logit transformation that is used to link the dependent variable to the set of other predictive or explanatory variables (Tranmer and Elliot, 2008). As both the dependent variable and explanatory variables were categorical, the logit modelling was used. The logit modelling is represented as:

$$y = \text{logit}(p) = \text{Log}\left[p / (1 - p) \right]$$

Predictive variables were also coded 1 for exposed and 0 for non-exposed. The model can be represented as below:

$$p_i = p\,(y=1 \mid X = x_i)$$

$$\text{Log}\,(p/1\text{-}p) = \text{logit}\,(p) = \beta_0 + \beta_1 x_i$$

In the above formula, p_i represents the probability of having self-care restriction and x_i is the predictive variable (e.g. gender). Therefore the parameter β_0 gives the log odds of a study participant having self-care restriction in non-exposed (when $x_i = 0$) and β_1 shows how this odds differ in exposed (when $x_i = 1$) (Tranmer and Elliot, 2008).

This logistic regression model was also used to assess the association of self-care restriction with a number of variables ($x_i, x_2, x_3 \ldots x_i$), by calculating corresponding odd ratios from the model coefficients ($\beta_1, \beta_2, \ldots \beta_i$) to estimate independent associations with restricted self-care in the multivariate analysis.

Odds ratios with 95% confidence intervals (CI) were used to determine the direction and strength of associations between self-care restriction and selected covariates. Odds ratios can be calculated using 2 x 2 tables as below:

		Exposure	
		Yes	No
Self-care restriction	Yes	a	b
	No	c	d
		n^1	n^2

The odds ratios were calculated as the ratio of self-care restriction within the exposed group, to the odds of self-care restriction within the non-exposed group (Field, 2005).

Odds of self-care restriction in the exposed $= (a/ n^1) / (c/ n^1)$
$= a / c$

Odds of self-care restriction in the non-exposed $= (b/ n^2) / (d/ n^2)$
$= b / d$

Odds of ratio of the self-care restriction
among the exposed to the non-exposed $= (a/c) / (b/d)$
$= ad / bc$

A ratio of 1.0 represents that the odds of self-care restriction in both exposed and non-exposed groups are the same; hence there is no difference between the two groups. However when this ratio is over 1.0 it is indicative of a positive association with the independent variable, meaning that the odds of having self-care restriction is higher in the exposed than the non-exposed. The opposite is true when a ratio is less than 1.0, therefore the odds of having self-care restriction would be lower in the exposed than the non-exposed (i.e. the exposed are less likely to have self-care restriction) (Silman and Macfarlane, 2002). In order to assess the precision of these estimates, confidence intervals (CI) were calculated to provide information on the boundaries, within which we believe the true value of the population mean will fall.

Cross-tabulations of restricted self-care were performed with each variable. Associations were presented as odds ratios with 95% confidence intervals, first unadjusted and then adjusted for age and gender and all other variables that were associated with restricted self-care from self-reported health conditions and impairments, activity limitation and contextual factors.

Table 5.2 Variables included in the multivariable analysis

ICF component	Variable	Categories
Personal Factors	Age*	0-59, 60-69, 70-79, 80+
	Gender*	Male, Female
	BMI	Normal, underweight, overweight, obese
Health Condition	Number of health conditions	0,1,2-3
Impairment	Number of Impairments	0, 1-3, 4-5, 6-9
	Number of non-OA body pain areas	0, 1-4, 5-9, 10+
	Number of joint pains	0,1,2,3,4
	Anxiety	Non-case, borderline case, definite case
	Depression	Non-case, borderline case, definite case
	Cognitive impairment	None, low level, high level
Activity limitation	SF-36 physical functioning scale	Lowest level, 3rd highest, 2nd highest, highest
Contextual factors	Occupational Class	Non-manual Manual
	Higher educational attainment	YES NO
	Perceived adequacy of income	Strain Be careful Little difficulty Comfortable
	Have a confidante	YES NO
	Berkman and Syme Social Network Index	High Medium high Medium Low

* Age and gender included as potential confounders

5.4.3 Parsimonious model of key factors associated with restricted self-care

Variables included in the multivariable analysis were factors that were significantly associated with restricted self-care in the univariable analysis after adjusting for age and gender ($p < 0.05$). These factors were also checked for collinearity with other variables in the model, using 2 x 2 tables. It is suggested, that highly correlated variables could result in increased variance, hence a loss of significance in multivariable analysis (Field, 2005). Backwards-stepwise binary logistic regression was used to select / remove variables from the multivariable model. This approach was chosen as it is suggested that in statistical models each parameter introduced to the model adds some uncertainty to it (Harrell, 2001). Excessively complex models suffer from over fitting and have poor predictive power (Hosmer and Lemeshow, 1995).

The fixed statistical level rule was predetermined for the removal from the model as $p=0.05$, and for re-entry to the model as $p=0.01$. Recommended values in the literature for a decision rule range from 0.15 to 0.20 (Hosmer and Lemeshow, 1989). These somewhat narrow values were chosen for providing precision in these estimates and acquiring the most parsimonious model of factors. In order to achieve the maximum available sample size, the variables that remained associated with restricted self-care following adjustment for all other factors were included in the parsimonious model. This was achieved by running the backward-stepwise model and then, when it had found the final set of predictors, refitting the model as a parsimonious model of key factors associated with restricted self-care. Adjusted odds ratios with

95% confidence intervals were calculated to determine the strength of association for each variable.

Validity of the parsimonious model

Model assumptions play an important part in determining the quality of associations, therefore when a model satisfies its underlying assumptions, estimates would be more accurate (Field, 2009). It is also important to consider that the performance of the model could be overestimated on the sample of participants that were used to construct the analysis, resulting in an optimistic prediction of the outcome (Harrell, et al., 2001 and 1996; Houwelingen and Le Cessie, 1990).

Calibration and discrimination are often used in studies with binary outcomes to measure performance (Steyerberg et al., 2010). Calibration refers to the ability of a predictive model to match predicted and observed rates across the entire spread of the data. A predictive model, in which the number of observed cases supports the number of cases predicted by the model, indicates good calibration. Good calibration is crucial for attaining a realistic risk adjustment (Houwelingen and Le Cessie, 1990). A common measure of calibration used is the Pearson Goodness-of-fit test. The Pearson Goodness-of-fit test provides the sum of differences between the observed and the expected frequencies of outcome (counts of observations); each squared and divided by the expectation. The resulting value can be compared to the chi-squared distribution to determine the goodness of fit (Laub and Kuhl, 2005).

Models which can differentiate between people with and without the expected outcome are considered to have good discrimination (Cook, 2008). For binary outcomes, discrimination can be quantified by the c-index which is the area under the receiver operating characteristic (ROC) curve (Steyerberg et al., 2000). The c-index is based on the ranks in individuals with and without the outcome and ranges from 0.5 (no predictive ability) to 1 (perfect predictive ability), with higher values indicating better discrimination (Pepe, 2003). The c-index is obtained by plotting sensitivity against 1-specificity for different cut-off points for the predicted risk.

Internal validity of the parsimonious model was conducted using the original baseline sample employed in this study (NorStOP^1). The external validity of the parsimonious model was tested in the NorStOP^2 for comparison of the results with an alternative sample population. The NorStOP^2 sample was another sub-cohort of NorStOP. Participants in NorStOP^1 were recruited during March and April 2002 and used as the main sample in this thesis. Participants in the NorStOP^2 study sample were recruited between July 2002 and June 2003 with an aim to provide a sampling-base for a clinical epidemiology study of knee pain and problems (CAS-K; Peat et al., 2004) (see Chapter 4).

Validation was carried out in following stages:

i) Apparent performance:

Apparent performance is defined as the estimate of a model performance from the full, original sample (Steyerberg, 2009). The apparent performance is deemed to be optimistic because both the development and the testing of the model is carried out on the same data. Multivariable logistic regression was used to perform estimates. The dependent variable was self-care restriction measured by the KAP self-care item. Coefficients were the variables from parsimonious model of key factors associated with restricted self-care. ORs with their respective 95% confidence intervals were used to summarise the contribution of the each predictor in the model. The fitting of the model to the data was assessed using Pearson Chi Squared statistic (X^2). Large values of X^2 and small p-values indicate a lack of fit of the model (Donati et al., 2004). The c-index (ROC curve) was used as a summary measure to evaluate how accurately the model discriminated between respondents with or without restricted self-care.

ii) Bootstrap performance:

The bootstrap method was introduced by Efron in 1979 as a resampling procedure for estimating the distribution of statistics based on independent observations. Bootstrapping is a computer intensive method for a resampling technique. It repeatedly generates samples from an underlying population by extracting samples with substitution from the original data, of the same size as the original dataset (Efron and Tibshirani, 1993). Each of these resamples will

randomly differ from the original sample. As the cases in these resamples vary, the statistic calculated from one of these resamples will also have different values (Cugnet, 1997).

The bootstrapping approach was conducted using Stata 11 as below;

Step 1. An empirical probability distribution, F_n, was constructed from the original sample by placing a probability of 1/n at each point, x^1, x^2-x_n of the sample. This is the empirical distribution function of the sample, which is the nonparametric maximum likelihood estimate of the population distribution, F.

Step 2. Resample was drawn from the empirical distribution function, F_n, as a random sample of size *n* with replacement.

Step 3. The X^2 and c-index statistics (T_n*) were calculated for the resample

Step 4. Steps 2 and 3 was repeated *B* (500) times

Step 5. The relative frequency histogram was constructed from the B number of T_n*s by placing a probability of 1/B at each point, T_n^{*1}, T_n^{*2} . . . , T_n^{*B}. The distribution obtained was the bootstrapped estimate of the sampling distribution of T_n. This distribution was then used to make inferences about the model calibration and discriminative powers, which was estimated by T_n*.

(Efron and Tibshirani, 1993)

iii) Split-sample performance:

In the split-sample (reduced sample, e.g. two-thirds of the sample) approach the data is split into two sets and the first part is used to develop the model and the second part is used to measure its performance. Thus, model performance is tested on similar yet independent datasets (Steyerberg et al., 2001). Split-sample performance was carried out in Stata 11 by randomly selecting 65% of the data. The performance of the parsimonious model was then tested on this sample using multivariable logistic regression to obtain odds ratios with 95% confidence intervals. HL X^2 statistic and ROC curve (c-index) were also obtained.

iv) Expected optimism:

Expected optimism of the parsimonious model was calculated as the difference between the estimated bootstrap and the test performance (iv= (ii – iii)).

v) Optimism corrected performance:

The optimism corrected performance of the parsimonious model was calculated as the difference between the estimated apparent performance (i) and the optimism (iv) (v= i - (ii – iii)). It is understood that the bigger the absolute difference, the bigger the optimism (Steyerberg et al., 2003).

5.4.4 Factors explaining the relationship between joint pain and self-care restriction

The relationship between joint pain and self-care restriction may be explained in addition to confounders, by mediators or moderators (Wilkie et al., 2007: a-b; Machado et al., 2008). "*A variable that occurs in a causal pathway from an independent variable to an outcome variable and causing variation in the outcome variable and itself is caused to vary by the original independent variable is called an intermediate variable*". This can also be known as a mediator (Porta, 2008, p.131). A factor that modifies the measure of effect of an assumed causal factor is referred as the moderator or modifying factor (Porta, 2008). The ICF model suggests that contextual factors can influence the relationship between participation restriction, health conditions, impairments and activity limitation (WHO, 2001). Thus, it may be plausible to assume that these factors may be mediating / moderating the relationship between joint pain and self-care restriction.

Multivariable logistic regression was used to test the hypothesis that each of the variables that were included in the parsimonious model influence the association between joint pain and restricted self-care following the methods proposed by Baron and Kenny (1986). This method suggests that if the relationship between variable x (e.g. pain) and outcome y (e.g. self-care restriction) is significantly reduced when adjusted for variable z (e.g. depression), variable z can be considered as a potential mediator (i.e. it explains some of the mechanism between pain and participation restriction). The "potential mediators" were the variables from the parsimonious model.

The relationship between the number of pain sites and self-care restriction were adjusted for each separately.

5.5 Results

5.5.1 Prevalence and age and gender distribution of restricted self-care

At baseline, 7725 (98%) responders completed the KAP self-care item in returned questionnaires (n=7878). 886 (11.5%; 95% confidence interval (CI): 10.8, 12.2) participants reported restricted self-care. There was a linear trend with increasing age ($p \leq 0.001$) and restriction was higher in women (% difference 2.3 %; CI: 0.8, 2.7) (Table 5.3).

Table 5.3 The 4-week period prevalence of restricted self-care; overall and stratified by age and gender

	Restricted in self-care
Overall	886 (11.5%)
Age group	
50-59	174 (7.0%)
60-69	216 (9.3%)
70-79	280 (14.2%)
80+	216 (22.9%)
Gender	
Female	540 (12.5%)
Male	346 (10.2%)

When stratified by gender in each age group it was noted that there were a high proportion of older females. However, the difference in the prevalence of self-care restriction between men and women aged 80+ was not significant (% difference 5.0 % (95% confidence interval -0.6, 10.3)).

Age standardisation

There were differences between the age and gender structures of NorStOP and the population of England and Wales. To remove the effect of differences in age, standardisation calculations were carried out using indirect standardisation. Calculations were done both for age groups and gender.

The observed rate of self-care restriction (overall) in adults aged 50 years and over in the general population (study population) was 11.5% and the standardised (England and Wales population) overall rate of restricted self-care was 11.2%. In females the observed prevalence of self-care was 12.4% and the standardised rate was 12.3%. The observed rate of prevalence in males was 10.2% and 9.8% in the standardised population (Table 5.4 & 5.5).

These results indicate that the observed prevalence rate of restricted self-care in the NorStOP population is generalisable to the population of adults aged 50 years and over in England and Wales based on the age and gender structure.

Table 5.4 Standardisation of the prevalence of restricted self-care by age groups

	a	b	c	d	e
Age Group	**NorStOP Population**	**Observed Restricted self-care**	**Observed prevalence b/a x 1000**	**England and Wales Population /1000**	**Expected Restricted self-care**
Females					
50-59	1332	95	71	3306	234,726
60-69	1249	122	97	2487	241,239
70-79	1133	170	150	2152	322,800
80+	622	153	246	1475	362,850
Total	4336	540	564	9420	1,161,615
Males					
50-59	1158	79	68	3248	221,479
60-69	1066	94	88	2351	207,314
70-79	843	110	131	1677	218,861
80+	322	63	196	716	140,049
Total	3389	346	483	7992	787,703

Table 5.5 The standardised prevalence of restricted self-care

Observed estimates in NorStOP		**Standardised to England and Wales**	
Overall		**Overall**	
11.5%		11.2%	
Female	**Male**	**Female**	**Male**
12.4%	10.2%	12.3%	9.8%

5.5.2 Factors associated with self-care restriction

Associations between health conditions / impairments and restricted self-care

i) Health conditions

All health conditions were significantly associated with restricted self-care in the univariable analysis. Adjusting for age and gender did not reduce the

strength of the relationship, suggesting age and gender did not confound the association between restricted self-care and number of health conditions (Table 5.6). There was a dose and response relationship between restricted self-care and an increase in numbers of conditions. (2-3 health conditions adj. OR: 3.1; 95% CI 2.5, 3.8). In the multivariable analysis, there was no significant relationship between health conditions and self-care restriction when adjusted for other associated factors.

ii) Impairments

All self-reported impairments were significantly associated with restricted self-care in the univariable analysis before and after adjusting for age and gender. There was a dose-response relationship between restricted self-care and increasing numbers of impairments (for 6-9 impairments adj. OR: 14.8; 95% CI 9.7, 22.4). When adjusted for all other factors associated with self-care in the multivariable analysis, these associations were no longer statistically significant (Table 5.6).

iii) Body mass index

Only obesity was significantly associated with restricted self-care in the univariable analysis after adjusting for age and gender (adj. OR: 2.1; 95% CI 1.7, 2.5). However, BMI was not associated with restricted self-care once adjusted for other variables in the multivariable analysis (Table 5.6).

iv) Anxiety

Anxiety was significantly associated with restricted self-care in the univariable analysis. There was a trend with self-care restriction and increasing anxiety; the odds of reporting restricted self-care was four and a half times higher in those with definite cases compared to non-cases (adj. OR for definite cases: 4.5; 95% CI 3.8, 5.4). When adjusted for other factors associated with restricted self-care, associations were no longer statistically significant (Table 5.6).

v) Depression

Depression was significantly associated with restricted self-care in the univariable analysis before and after adjusting for age and gender. There was a trend with self-care restriction and increasing depression. The odds of reporting self-care restriction were almost ten times higher for definite cases of depression comparing to non-cases (adj. OR for definite cases: 9.8; 95% CI 8.0, 11.9). Associations remained statistically significant in the multivariable analysis (adj. OR for definite cases: 3.3; CI 2.4, 4.6) (Table 5.6).

vi) Cognitive complaint

Cognitive complaint was significantly associated with restricted self-care in the univariable analysis. The odds of reporting self-care restriction in those individuals with high levels of cognitive impairment were five times higher than those who had scored zero (none) (adj. OR for high levels: 5.1; 95% CI 4.3, 6.2). Adjusting for other variables associated with restricted self-care reduced the odds of reporting restricted self-care in those with both high and low levels

of cognitive impairment, but associations remained statistically significant (adj. OR for high levels: 1.7; CI 1.3, 2.3) (Table 5.6).

vi) Peripheral joint pain

Restricted self-care was significantly associated with the site, number, and pattern of peripheral joint pain in the univariable analysis. A dose-response relationship was observed between comorbid joint pain and self-care restriction. The odds of reporting self-care restriction increased with the increasing number of peripheral joint pain, and when multiple sites of joint pain were reported (adj. OR: 5.0; 95% CI 3.9, 6.5 for four joint pains). (adj. OR for Multiple LL: 2.7; CI 1.6, 2.9 and adj. OR for Hand+LL: 3.0; CI 2.4, 3.8). Therefore only the number of peripheral joint pain was included in the multivariable analysis. However, associations with restricted self-care were not significant when adjusted for other factors (Table 5.7).

vii) Bodily pain (pain elsewhere other than hand, hip, knee or foot pain)

Restricted self-care was significantly associated with bodily pain in the univariable analysis. There was a dose-response relationship between bodily pain and restricted self-care. The odds of reporting self-care restriction in those individuals who reported ten or more sites of pain elsewhere were five times higher than those who reported no bodily pain (adj. OR: 5.1; 95% CI 4.0, 6.5). In the multivariable analysis there was no significant relationship between bodily pain and restricted self-care (Table 5.7).

Associations between activity limitation and restricted self-care

The strongest association with self-care restriction in the univariable analysis was with activity limitation. There was a positive trend between the association with restricted self-care and activity limitation. The odds of reporting self-care restriction in people with highest activity limitation scores were 13 times higher than those with lowest levels of activity limitation (adj. OR: 13.3 95% CI: 9.2, 19.1). Associations remained statistically significant in the 2nd highest and highest categories after adjusting for other variables in the multivariable analysis (adj. OR for highest: 7.6 95%CI: 4.2, 13.6) (Table 5.8).

Associations between contextual factors and restricted self-care

i) Socio-demographic factors

Age

Age was significantly associated with restricted self-care in the univariable analysis before and after adjusting for gender. There was a positive trend with increase in age and restricted self-care. Strongest associations occurred in those who were 80 years of age and older (adj. OR 3.9; 95% CI 3.1, 4.8). Associations with age and restricted self-care remained significant in the multivariable analysis for those 70 years and older (adj. OR for 80+: 1.7; CI 1.2, 2.5) (Table 5.9).

Gender

Female gender was significantly associated with restricted self-care before and after adjusting for age in the univariable analysis, albeit the association

was not strong (adj. OR: 1.2 95% CI 1.0, 1.3). Gender was not significantly associated with restricted self-care in the multivariable analysis once adjusted for other associated factors (Table 5.9).

ii) Socio-economic factors

Occupational class

Occupational class was significantly associated with restricted self-care in the univariable analysis after adjusting for age and gender. The odds of reporting restricted self-care in those who were in the manual jobs category were twice as high compared to those in the non-manual jobs category (adj. OR 2.3; 95% CI 1.9, 2.8). Associations were not statistically significant in the multivariable analysis once adjusted for other factors in the model (adj. OR 1.2; CI 0.7, 2.0) (Table 5.9).

Educational attainment

Educational attainment was significantly associated with restricted self-care in the univariable analysis. The odds of reporting restricted self-care in those with no adult qualifications was twice as high comparing to those who gained adult qualifications (adj. OR: 2.3 95% CI 1.9, 2.8). Associations reduced but remained statistically significant in the multivariable analysis (adj. OR: 1.5 CI 1.1, 2.0) (Table 5.9).

Perceived adequacy of income

Perceived adequacy of income was significantly associated with restricted self-care in the univariable analysis before and after adjusting for age and

gender (adj. ORs for strain: 9.5; 95% CI 6.2, 14.5). In the multivariable analysis, associations remained statistically significant for those who had to 'be careful' and find it 'strain' to get by (adj. ORs for strain: 2.6; CI 1.3, 5.0) (Table 5.9).

iii) Social networks

Social networks

Social network scores were significantly associated with restricted self-care in the univariable analysis before and after adjusting for age and gender. The odds of reporting self-care restriction was three times higher in those with 'low' social network scores compared to those with 'high' scores (adj. OR: 2.7; 95% CI 1.9, 2.8). However, associations were not statistically significant when adjusted for other factors in the multivariable analysis (Table 5.9).

Having a confidant

Having a confidant was significantly associated with restricted self-care before and after adjusting for age and gender, albeit the association was not strong (adj. OR: 1.4; 95% CI 1.1, 1.8). Associations were not statistically significant when adjusted for other factors in the multivariable analysis (Table 5.9).

Table 5.6 Associations between restricted self-care and selected health conditions and impairments; Univariable associations adjusted for age and gender and Multivariable associations adjusted for all other variables associated with restricted self-care

Health conditions & Impairments	Total n	Restricted n (%)	Crude ORs (95%CI)	Adj. OR (95% CI) (Age and Gender)	Adj. OR (95% CI) for all other variables
Health conditions					
0	4872	392 (8.0)	1	1	◊ Removed due to non-significant association
1	2160	325 (15.0)	2.0 (1.7, 2.4)	1.9 (1.6, 2.2)	
2-3	693	169 (24.4)	3.7 (3.0, 4.5)	3.1 (2.5, 3.8)	
Impairments					
0	1432	42 (2.9)	1	1	◊ Removed due to non-significant association
1-3	4509	392 (8.7)	3.2 (2.3, 4.4)	2.8 (2.0, 3.9)	
4-5	1562	368 (23.6)	10.2 (7.3, 14.2)	8.1 (5.8, 11.2)	
6-9	222	84 (37.8)	20.1 (13.4, 30.3)	14.8 (9.7, 22.4)	
Body Mass Index (BMI)+					
20 – 24.99	2695	273 (10.1)	1	1	◊ Removed due to non-significant association
25 – 29.99	3016	288 (9.5)	0.9 (0.8, 1.1)	1.1 (0.9, 1.3)	
<20	345	57 (16.5)	1.8 (1.2, 2.4)	1.3 (0.9, 1.8)	
>30	1316	205 (15.6)	1.6 (1.3, 2.0)	2.1 (1.7, 2.5)	
HAD ┼ anxiety score					
None case					◊ Removed due to non-significant association
Borderline	4486	302 (6.7)	1	1	
Definite	1645	228 (13.9)	2.2 (1.9, 2.7)	2.3 (1.9, 2.7)	
	1393	317 (22.8)	4.1 (3.4, 4.8)	4.5 (3.8, 5.4)	
HAD ┼ depression score					
Non cases	5833	335 (5.7)	1	1	1
Borderline	1046	255 (24.4)	5.2 (4.4, 6.3)	4.9 (4.1, 5.9)	2.2 (1.6, 2.9)
Definite	662	260 (39.3)	10.6 (8.8, 12.8)	9.8 (8.0, 11.9)	3.3 (2.4, 4.6)
Cognitive complaint ┼┼					
None	3863	193 (5.0)	1	1	1
Low levels	1559	170 (10.9)	2.3 (1.9, 2.8)	2.2 (1.8, 2.7)	1.6 (1.1, 2.2)
High levels	1803	426 (23.6)	5.9 (4.9, 7.1)	5.1 (4.3, 6.2)	1.7 (1.3, 2.3)

*Numbers do not add up due to missing data

+BMI (20–24.99:Normal, 25–29.99:Overweight <20:Underweight >30:Obese

┼ Hospital Anxiety and Depression Scale (Non cases: 0-7, Borderline cases: 8-10, Definite cases: 11+)

┼┼ Functional Limitations Profile, Cognitive and Alertness behaviour subscale (None: 0, high levels: 22.5-100, low levels: 0.1-22.4)

◊ Removed in the backward-stepwise logistic regression due to non-significance

Table 5.7 Associations between restricted self-care and selected health conditions and impairments; Univariable associations adjusted for age and gender and Multivariable associations adjusted for all other variables associated with restricted self-care in the univariable analysis

Health conditions & Impairments	Total n■	Restricted n (%)	Crude ORs (95%CI)	Univariable Associations Adj. ORs (95% CI)	▲Multivariable Associations Adj. ORs (95% CI)
Site of peripheral joint pain					
Hand pain					
NO	4128	329 (8.0)	1	1	~ Not included in the analysis
YES	3379	519 (6.9)	2.0 (1.8, 2.4)	2.0 (1.7, 2.4)	
Hip pain					
NO	4943	411 (8.3)	1	1	-
YES	2558	427 (16.7)	2.2 (1.9, 2.5)	2.1 (1.8, 2.5)	
Knee pain					
NO	3536	267 (7.6)	1	1	-
YES	3995	583 (14.6)	2.0 (1.8, 2.4)	2.0 (1.7, 2.3)	
Foot pain					
NO	4553	347 (7.6)	1	1	-
YES	2959	496 (16.8)	2.4 (2.1, 2.8)	2.3 (2.0, 2.7)	
Number of peripheral joint pain					
0	1730	102 (5.9)	1	1	◊ Removed due to non-significant association
1	1767	120 (6.8)	1.2 (0.9, 1.5)	1.2 (0.9, 1.5)	
2	1622	171 (10.5)	1.9 (1.5, 2.4)	1.9 (1.4, 2.4)	
3	1275	197 (15.5)	2.9 (2.3, 3.7)	2.7 (2.1, 3.5)	
4	880	218 (24.8)	5.3 (4.1, 6.8)	5.0 (3.9, 6.5)	
Pattern of peripheral joint pain					
No joint pain	1730	102 (5.9)	1	1	~ Not included in the analysis
Hand only	403	25 (6.2)	1.0 (0.7, 1.6)	1.0 (0.7, 1.6)	
Single LL*	1364	95 (7.0)	1.2 (0.9, 1.6)	1.2 (0.9, 1.6)	
Multiple LL	947	121 (12.8)	2.3 (1.8, 3.1)	2.7 (1.6, 2.9)	
Hand+ LL	2380	465 (46.4)	3.1 (2.5, 3.9)	3.0 (2.4, 3.8)	-
Bodily Pain					
0	2675	193 (7.2)	1	1	◊ Removed due to non-significant association
1-4	2588	247 (9.5)	1.4 (1.1, 1.6)	1.4 (1.1, 1.7)	
5-9	1232	192 (15.6)	2.4 (1.9, 2.9)	2.5 (2.0, 3.1)	
10+	595	155 (26.1)	4.5 (3.6, 5.7)	5.1 (4.0, 6.5)	

*LL (lower limb)
~ Not included due to high correlation with another variable in the multivariable analysis
■ n= for univariable associations
▲ denominator (overall n=) for multivariable analysis was n=4357
◊ Removed in the backward-stepwise logistic regression due to non-significance

Table 5.8 Associations between restricted self-care and activity limitation; Univariable associations adjusted for age and gender and Multivariable associations adjusted for all other variables associated with restricted self-care in the univariable analysis

Activity Limitation	Total n■	Restricted n (%)	Crude ORs (95%CI)	Univariable Associations Adj. ORs (95% CI)	▲Multivariable Associations Adj. ORs (95% CI)
Activity limitation score*					
lowest	1318	34 (2.5)	1	1	1
3rd high	1953	60 (3.0)	1.2 (0.8, 1.8)	1.4 (0.7, 1.7)	1.4 (0.8, 2.7)
2nd high	1732	126 (6.8)	2.8 (1.9, 4.1)	2.6 (1.7, 3.8)	1.9 (1.0, 3.5)
highest ≥35	1437	565 (28.2)	15.2 (10.7,21.7)	13.3 (9.2, 19.1)	7.6 (4.2, 13.6)

* PF-10 Physical functioning score: lowest (90.1-100), 3rd highest (70.1-90.0), 2nd highest (35.1-70.0), Highest (≥35.0)
■ n= for univariable associations
▲ denominator (overall n=) for multivariable analysis was n=4357

Table 5.9 Associations between restricted self-care and contextual factors; Univariable associations adjusted for age and gender and Multivariable associations adjusted for all other variables associated with restricted self-care in the univariable analysis

Contextual factors	Total n■	Restricted n (%)	Crude ORs (95%CI)	Univariable Associations Adj. ORs (95% CI)	▲Multivariable Associations Adj. ORs (95% CI)
Age					
50-59	2316	174 (7.5)	1	1	1
60-69	2099	216 (10.2)	1.4 (1.1, 1.7)	1.4 (1.1, 1.7)	1.1 (0.8, 1.5)
70-79	1696	280 (16.5)	2.2.(1.8, 2.7)	2.2 (1.8, 2.7)	1.4 (1.0, 1.9)
80+	728	216 (29.6)	4.0 (3.2, 5.0)	3.9 (3.1, 4.8)	1.7 (1.2, 2.5)
Gender					◊ Removed due to non-significant association
Male	3043	346 (11.3)	1	1	
Female	3796	540 (14.2)	1.3 (1.1, 1.4)	1.2 (1.0, 1.3)	
Occupational Class					◊ Removed due to non-significant association
Non-manual	2094	120 (5.7)	1	1	
Manual	4530	590 (13.0)	2.5 (2.0, 3.0)	2.3 (1.9, 2.8)	
Higher Educational attainment *					
Yes	2181	114 (5.2)	1	1	1
No	5345	731 (13.7)	2.9 (2.3, 3.6)	2.3 (1.8, 2.8)	1.5 (1.1, 2.0)
Perceived Adequacy of Income					
Comfortable	1065	41 (3.8)	1	1	1
Little difficulty	3044	256 (8.4)	2.3 (1.6, 3.2)	2.2 (1.6, 3.0)	1.5 (0.9, 2.5)
Be careful	3115	459 (14.7)	4.3 (3.1, 6.0)	4.2 (3.0, 5.8)	2.1 (1.3, 3.4)
Strain	295	67 (22.7)	7.3 (4.9, 11.1)	9.5 (6.2, 14.5)	2.6 (1.3, 5.0)
Social Networks					
High	1249	72 (5.8)	1	1	◊ Removed due to non-significant association
Medium high	682	56 (8.2)	1.5 (1.0, 2.1)	1.4 (1.0, 2.0)	
Medium	2663	274 (10.3)	1.9 (1.4, 2.5)	1.7 (1.3, 2.2)	
Low	1529	264 (17.3)	3.4 (2.6, 4.5)	2.7 (2.0, 3.6)	
Have a confidant					◊ Removed due to non-significant association
YES	6839	751 (11.0)	1	1	
NO	724	107 (14.8)	1.4 (1.1, 1.8)	1.4 (1.1, 1.8)	

* Educational attainment yes = Have adult qualifications, no= Do not have adult qualifications
■ n= for univariable associations
▲ denominator (overall n=) for multivariable analysis was n=4357
◊ Removed in the backward-stepwise logistic regression due to non-significance

5.5.3 Derivation of the parsimonious model of key factors associated with restricted self-care

A parsimonious model of key factors associated with restricted self-care was derived from the multivariable analysis using backward-stepwise logistic regression. The final fitted model (n=6506) included key variables independently associated with restricted self-care, which were age, activity limitation, depression, cognitive alertness, perceived adequacy of income and educational attainment.

Strongest associations occurred between restricted self-care and the highest activity limitation score (adj. OR: 7.6; 95% CI 4.2, 13.6). This was followed by definite cases of depression (adj. OR: 3.8; CI 3.0, 4.9) and inadequacy of income (adj. OR for strain: 2.5; CI 1.5, 4.1). The risk of reporting self-care restriction for those with high levels of cognitive impairment was nearly twice as high as those with no cognitive impairment (adj. OR high levels: 1.8; CI 1.4, 2.3). Age was also independently associated with restricted self-care. Those who were 80 years and older had twice the odds of reporting self-care restriction than those who were up to 59 years of age (adj. OR for 80+: 1.9; CI 1.4, 2.5). Those who did not have adult qualifications were also more likely to have self-care restrictions even after adjusting for all other factors. However the association was not as strong as in other key factors (adj. OR: 1.1; CI 1.0, 1.5) (Table 5.10).

Table 5.10 Final (re-fitted) parsimonious model of key factors associated with restricted self-care in older adults in the general population

Overall n=6506	Total n	Restricted n (%)	Adjusted ORs for all covariates (95% CI)
Age			
50-59	2229	174 (7.8)	1
60-69	1991	216 (10.8)	1.3 (1.0, 1.7)
70-79	1599	280 (17.5)	1.6 (1.2, 2.0)
80+	687	216 (31.4)	1.9 (1.4, 2.5)
Activity limitation			
lowest (90.1-100)	1266	34 (2.6)	1
3rd highest (70.1- 90)	1864	60 (3.2)	1.1 (0.7, 1.8)
2nd highest (35.1-70)	1645	126 (7.6)	1.9 (1.1, 3.0)
highest ≥35	1731	565 (32.6)	5.6 (3.6, 8.7)
Depression┼			
Non cases (0-7)	5105	335 (6.6)	1
Borderline cases (8-10)	857	255 (29.7)	2.1 (1.7, 2.6)
Definite cases (≥11)	544	260 (47.8)	3.8 (3.0, 4.9)
Cognitive complaint ┼┼			
None (0)	3531	193 (5.4)	1
low levels (0.1-22.4)	1410	170 (12.0)	1.5 (1.2, 1.9)
high levels (22.5-100)	1565	426 (27.2)	1.8 (1.4, 2.3)
Perceived adequacy of income			
Comfortable	943	41 (4.3)	1
Little difficulty	2659	256 (9.6)	1.6 (1.1, 2.4)
Be careful	2658	459 (17.2)	2.1 (1.4, 3.0)
Strain	246	67 (27.2)	2.5 (1.5, 4.1)
Higher educational attainment			
Yes	1968	114 (5.8)	1
No	4538	731 (16.1)	1.1 (1.0, 1.5)

┼ Hospital Depression Score (HAD)

┼┼ Functional Limitations Profile, Cognitive and Alertness behaviour subscale

Validation of the parsimonious model

i) Internal validity

The apparent performance of the parsimonious model was determined using the original baseline sample of NorStOP1 (n=6506). The Hosmer and Lemeshow goodness of fit test (HL) suggested that the parsimonious model was not a good fit for the data (Pearson's X^2 = 684.20, p= 0.0007). However, the area under the ROC curve was 0.83 (95% CI 0.81, 0.85), which indicated an 83% probability of those with self-care restriction having higher predicted probability than those without self-care restriction, for a random pair of cases with or without self-care restriction. Bootstrapping improved the goodness of fit significantly (Pearson's X^2 = 284.36, p=1.00: c-index= 0.83 (CI 0.81, 0.85), and the split-sample performance yielded similar, but improved results to the apparent performance of the model (Pearson's X^2 = 546.22, p=0.07: c-index= 0.82 (CI 0.80, 0.84)). The expected optimism of the model was 0.01, suggesting that the parsimonious model had very low levels of optimism. The optimism corrected performance of the model was 0.82, proposing that this model has a reasonable power in predicting self-care restriction in those aged 50 and over in the general population (Table 5.11).

Table 5.11 Internal validity (NorStOP[1]) of the parsimonious model

Overall n= 6506	Apparent ORs 95% CI	Bootstrap ORs 95% CI	Split-sample ORs 95% CI
Age groups			
50-59	1	1	1
60-69	1.3 (1.0, 1.7)	1.3 (1.0, 1.7)	1.6 (1.9, 2.3)
70-79	1.6 (1.2, 2.0)	1.6 (1.2, 2.0)	1.7 (1.3, 2.4)
80+	1.9 (1.4, 2.5)	1.9 (1.4, 2.5)	2.0 (1.4, 2.9)
Activity limitation			
lowest	1	1	1
3rd highest	1.1 (0.7, 1.8)	1.1 (0.7, 1.8)	1.0 (0.5, 1.6)
2nd highest	1.9 (1.2, 3.0)	1.9 (1.2, 3.0)	1.5 (1.0, 2.5)
highest	5.6 (3.6, 8.7)	5.9 (3.7, 9.3)	4.8 (2.9, 7.9)
Depression ┼			
Non cases (0-7)	1	1	1
Borderline (8-10)	2.1 (1.7, 2.6)	2.1 (1.7, 2.6)	2.0 (1.5, 2.6)
Definite (≥11)	3.8 (3.0, 4.9)	3.8 (3.0, 5.0)	3.2 (2.3, 4.4)
Cognitive complaint ┼┼			
None (0)	1	1	1
low levels (0.1-22.4)	1.5 (1.1, 1.9)	1.5 (1.1,1.9)	1.6 (1.2, 2.1)
high levels (22.5-100)	1.8 (1.4, 2.3)	1.8 (1.4, 2.3)	1.9 (1.4, 2.6)
Perceived adequacy of Income			
Comfortable	1	1	1
Little difficulty	1.6 (1.1, 2.4)	1.6 (1.1, 2.4)	2.1 (1.2, 3.5)
Be careful	2.1 (1.4, 3.0)	2.1 (1.4, 3.1)	2.7 (1.6, 4.5)
Strain	2.5 (1.5, 4.2)	2.5 (1.5, 4.3)	3.8 (2.0, 7.3)
Higher educational attainment			
Yes	1	1	1
No	1.1 (1.0, 1.5)	1.1 (0.8, 1.6)	1.1 (0.7, 1.7)
Goodness of fit test			
Pearson X^2	684.20	284.36	546.22
P value	≤0.001	1.00	0.07
c-index	0.83 (0.81, 0.85)	0.83 (0.81, 0.85)	0.82 (0.80, 0.84)

┼ Hospital Depression Score (HAD)
┼┼ Functional Limitations Profile, Cognitive and Alertness behaviour subscale

ii) External validity

The external validity of the parsimonious model was tested on the NorStOP[2] dataset with sample size of n=5022. In the apparent performance HL test showed that the model was a reasonable fit for the data (Pearson's X^2 = 531.66, p= 0.60). The area under the ROC curve was 0.83 (95% CI 0.79, 0.83), again suggesting the model had a good discriminative power in identifying those with high and low risk of reporting self-care restriction. Bootstrapping improved how the model fitted the data (Pearson's X^2 = 309.60, p=1.00: c-index= 0.82 (CI 0.79, 0.83)) and the split-data sample method had similar results to the apparent model, albeit the model calibration was even lower (Pearson's X^2 = 471.89, p=0.34: c-index= 0.80 (CI 0.77, 0.82)).

The expected optimism of the model was 0.02, suggesting that the model was not optimistic. The optimism corrected performance of the model was 0.81, indicating that the external validity of the parsimonious model was similar to the model tested on the original data (internal validation). Thus, this model had a reasonable predictive power on different population sample, and therefore the model could be used in other populations to estimate restricted self-care in adults aged 50 years and over in the general population (Table 5.12).

Table 5.12 External validity (NorStOP[2]) scores of the parsimonious model

Overall n= 5022	Apparent ORs 95% CI	Bootstrap ORs 95% CI	Split-sample ORs 95% CI
Age groups			
50-59	1	1	1
60-69	1.2 (1.0, 1.6)	1.2 (1.0, 1.7)	1.4 (1.0, 2.0)
70-79	1.3 (1.0, 1.8)	1.3 (1.0, 1.8)	1.4 (1.0, 2.1)
80+	1.8 (1.3, 2.5)	1.8 (1.3, 2.6)	2.0 (1.4, 3.0)
Activity Limitation			
lowest	1	1	1
3rd highest	1.0 (1.0, 1.6)	1.0 (1.0, 1.6)	1.0 (0.6, 1.8)
2nd highest	1.7 (1.1, 2.7)	1.7 (1.1, 2.7)	1.6 (1.0, 2.7)
highest	4.8 (3.1, 7.5)	4.8 (3.1, 7.7)	4.1 (2.4, 6.8)
Depression ┼			
Non cases (0-7)	1	1	1
Borderline (8-10)	2.1 (1.6, 2.7)	2.1 (1.6, 2.7)	2.1 (1.5, 3.0)
Definite (≥11)	4.6 (3.5, 6.2)	4.6 (3.5, 6.2)	4.5 (3.1, 6.3)
Cognitive complaint ┼┼			
None (0)	1	1	1
low levels (0.1-22.4)	1.5 (1.1, 2.0)	1.5 (1.1, 2.0)	1.4 (1.0, 2.0)
high levels (22.5-100)	1.5 (1.2, 2.0)	1.5 (1.2, 2.0)	1.3 (1.0, 1.8)
Perceived adequacy of Income			
Comfortable	1	1	1
Little difficulty	1.0 (0.7, 1.4)	1.0 (0.7, 1.4)	1.1 (0.7, 1.8)
Be careful	1.5 (1.0, 2.9)	1.5 (1.0, 2.1)	1.5 (1.0, 2.3)
Strain	1.8 (1.1, 3.0)	1.8 (1.1, 3.0)	2.4 (1.3, 4.3)
Higher educational attainment			
Yes	1	1	1
No	1.0 (0.7, 1.5)	1.0 (0.7, 1.5)	1.0 (0.6, 1.4)
Goodness of fit test			
Pearson X^2	531.66	309.60	471.89
P value	0.60	1.00	0.34
c-index	0.83 (0.79, 0.83)	0.82 (0.79, 0.83)	0.80 (0.77, 0.82)

┼ Hospital Depression Score (HAD)

┼┼ Functional Limitations Profile, Cognitive and Alertness behaviour subscale

5.5.4 Factors explaining the relationship between joint pain and self-care restriction

Univariable analysis showed strong associations between joint pain and restricted self-care. However joint pain was not independently associated with restricted self-care and was not included in the parsimonious model.

A multivariable logistic regression was fitted to examine the associations between joint pain and self-care restriction adjusted for each factor from the parsimonious model to assess for potential mediation. The association between the number of joint pains and restricted self-care remained after adjustment for each factor. The association between the number of joint pains attenuated most with adjustment for activity limitation and the depression. There was no attenuation when adjusted for age and educational attainment (Table 5.13).

Table 5.13 Multivariable analysis of the associations of joint pain and restricted self-care adjusted for parsimonious factors

		Association with restricted self-care ORs (95% CI)
Peripheral Joint Pain by number Crude n=7274		
	0	1
	1	1.2 (0.9, 1.5)
	2	1.9 (1.5, 2.4)
	3	2.9 (2.3, 3.7)
	4	5.3 (4.1, 6.8)
Peripheral Joint Pain by number Adjusted for age n=7274	0	1
	1	1.2 (0.9, 1.5)
	2	1.8 (1.4, 2.4)
	3	2.7 (2.1, 3.5)
	4	5.0 (3.9, 6.5)
Peripheral Joint Pain by number Adjusted for activity limitation n=6890		
	0	1
	1	0.8 (0.6, 1.1)
	2	0.9 (0.7, 1.2)
	3	1.0 (0.8, 1.4)
	4	1.3 (1.0, 1.8)
Peripheral Joint Pain by number Adjusted for depression n=7116		
	0	1
	1	1.1 (0.8, 1.5)
	2	1.6 (1.2, 2.0)
	3	2.0 (1.5, 2.6)
	4	2.9 (2.2, 3.8)
Peripheral Joint Pain by number Adjusted for cognitive alertness n=6891		
	0	1
	1	1.1 (0.8, 1.4)
	2	1.4 (1.1, 1.9)
	3	1.9 (1.5, 2.5)
	4	3.2 (2.5, 4.3)
Peripheral Joint Pain by number Adjusted for perceived adequacy of income n=7096	0	1
	1	1.1 (0.9, 1.5)
	2	1.8 (1.4, 2.3)
	3	2.7 (2.1, 3.5)
	4	4.3 (3.3, 5.6)
Peripheral Joint Pain by number Adjusted for educational attainment n= 7115		
	0	1
	1	1.2 (0.9, 1.6)
	2	1.9 (1.5, 2.5)
	3	2.9 (2.3, 3.8)
	4	5.3 (4.1, 6.9)

5.5.5 Summary of results

The overall prevalence of restricted self-care was 11.5% in community-dwelling older adults in the general population. There was a linear trend with increasing age, and self-care restrictions were higher in women.

Self-reported health conditions, impairments, activity limitation and contextual factors were significantly associated with restricted self-care in the univariable analysis, after adjusting for age and gender. The strongest associations occurred with self-reported impairments, activity limitation and depression. Restricted self-care was associated with each peripheral joint pain; the association with joint pain increased with the increasing number of joint pains. However joint pain was not independently associated with self-care restriction once adjusted for other factors. This is because it co-occurs with other health and socio-demographic factors that are strongly associated with self-care, such as activity limitation and depression. Age, depression, cognitive alertness, activity limitation, educational attainment and perceived adequacy of income were included in a parsimonious set of statistically significant and independently associated factors with restricted self-care. This model was validated using bootstraping and split-data methods both for internal and external validation. The optimism corrected performance of the model proposed that this model had a reasonable power in predicting self-care restriction in those aged 50 years and over in the general population.

5.6 Discussion

5.6.1 Principal findings

Prevalence and distribution of person-perceived self-care restriction

One in ten community-dwelling older adults in the general population was restricted in self-care. Prevalence increased with age, and was higher in women. Individuals who are older and with higher levels of self-care restriction may not have been able to complete this self-complete postal questionnaire due to their severe activity limitation and / or psychological impairments. Age standardisation of the observed prevalence rates of the study to the England and Wales population confirmed that the study was generalisable to the wider national population (observed: 11.5% cf standardised: 11.2%). However, the generalisability of the results to other populations may be limited by differences in the socio-economic characteristics and contextual factors, which may vary across different populations. The study population resided in urban areas of the North Staffordshire area in England, where the local population is highly disadvantaged, both in terms of health deprivation and employment, when compared to the rest of the country. This is partially due to the historic decline of traditional industries (Comprehensive Area Assessment, 2009). More than half of the Stoke-On-Trent population were reported to be in the most deprived national quintile (Association of Public Health Observatories, 2010).

7725 people completed the self-care item out of 7878 participants at baseline. Those who did not complete the self-care item (1.9%) did not differ from those who completed the self-care item in terms of age and gender. As this was a small proportion of the sample, the potential effects of the missing data in the statistical analysis could be considered to be minor.

The study population was highly heterogeneous (99.4% white). Consequently the results of this study could not be generalised to other ethnic groups. However, there is no empirical evidence to suggest that the prevalence of restricted self-care might be different in other ethnic groups or in rural populations.

Associated factors with restricted self-care in older people

The study findings provide empirical support for the ICF model of participation restriction. Restrictions in self-care were associated with bodily, personal and contextual factors. Activity limitation measured by PF-10 scale had the strongest association with restricted self-care both in the univariable and multivariable analysis. However, there were previous concerns about linking the measurement components of PF-10 (physical functioning scale) to the ICF's domain of activity limitation in population surveys. Previous studies questioned the measurement validity of PF-10, suggesting that this instrument does not necessarily differentiate between the participation restriction and activity limitation domains of ICF (Ayis et al., 2010; Pollard et al., 2006; Wilkie, 2005). Also, the PF-10 had items such as measuring limitation in bathing or dressing, which would expectedly have high correlations with self-care restriction. Nevertheless, in this secondary analysis of a

large dataset, the PF-10 was the most suitable available instrument to measure activity limitation. Although there may be some correlations between the measurement properties of PF-10 and the KAP self-care item, it is appreciated that the ICF framework implies that activity limitation is one component that may lead to participation restriction. Although this study does not completely confirm this it does suggest that for those who are restricted in self-care, most have activity limitation and indicates that this may be a key mechanism for restriction.

The strong associations with depression, cognitive alertness and perceived adequacy of income could be the result of negative reporting bias, which is a major problem in the assessment of health care outcomes (McGauran et al., 2010). Responders with poorer backgrounds and depression may generally be less satisfied with their quality of life (Moore et al., 2005) and have a negative perception of their needs being met 'as and when they have wanted' (Wilkie, 2005). Previous research also suggested that cognitive impairment and depression co-occurs with pain (Sherbourne et al, 2009; Fishbain et al., 1997; Magni et al., 1993).

Those who perceived their incomes as inadequate were nearly three times more likely to report self-care restriction compared to those who were comfortable with their income even after adjusting for all other health and contextual factors in the multivariable analysis. Social disadvantages have been previously associated with disability in those with chronic conditions (Grundy, 2000). It was reported that failure to afford a reasonable standard of living could have an impact on an

individual's health status (i.e. diet, housing, access to health and social services) and may result in an increase of reporting psychological disorders such as anxiety and depression (Emerson et al., 2006). In a recently published report, the equality profile of older people with high support needs was examined, and this highlighted that a higher proportion of people who used support services were from disadvantaged backgrounds (Blood and Bamford, 2010). It is important to acknowledge that given the two key factors independently associated with restricted self-care are socio-economic factors in this study, it would be reasonable to conclude these factors play an important role in the participation restriction process.

Age was another factor that remained significantly associated with restricted self-care in the parsimonious model after adjusting for other key factors. Restriction was higher in the oldest age group (80+). This supports the literature review conducted in Chapter 1 which suggests that ageing population is associated with increase in prevalence of chronic health conditions and disability (Denton and Spencer, 2010; Martin et al., 2010; Nusselder et al., 2006; Wilkie et al, 2006; Gill et al, 2006:a).

A simple method proposed by Baron and Kenny (1986) was used to examine the potential mediation of the link between the number of joint pains and self-care restriction. Using this method, mediation was identified if the strength of association was reduced with the addition of a third variable. The limitations to this approach were that a formal test for mediation (e.g. Sobel's test) was not used and

newer techniques are now being used to examine how extensively mediation is being quantified (for example using structural equation modelling). However following the approach outlined by Baron and Kenny, the results suggest that the link between joint pain and restricted self-care in older people is potentially mediated by activity limitation and depression. Previous studies have highlighted that activity limitation (broadly defined in studies to include limitations in walking, bathing, transferring, dressing and personal care) is on the causal path both for joint pain and participation restriction (Arola et al., 2010; Corti and Rigon 2003) and this provides empirical support for the proposed ICF model of participation.

The strength of the association between joint pain and self-care restriction also attenuated with the addition of cognitive complaint and to a lesser extent with perceived adequacy of income. It could be hypothesised that, once older adults have pain, cognitive impairment or an inadequate income may prevent them from managing the joint problem or from adapting to continue to manage their self-care as they would like to. Further testing is required to explore these relationships further.

The elimination of health conditions and impairments from the parsimonious model is explained by the high correlation between these variables and remaining predictors in the model. Depression was highly correlated with anxiety, other health conditions and impairments in the 2X2 tables, and the same was true for the peripheral joint pain (by site, count and/or pattern) and activity limitation. It is important to recognise that the result of this analysis does not indicate that

variables taken out of the model are not important factors associated with restricted self-care in older people. Similarly, correlations between other health conditions and impairments and activity limitation could have contributed to the strength of relationship between activity limitation and restricted self-care as strong links were retained between these factors in the multivariable analysis.

5.6.2 Comparison with other studies

Previous studies of self-care estimated the prevalence of limitations in older people to be in the region of 29% to 40% (Gill et al., 2009: Gill et al., 2006: a; Naik et al., 2004). Self-care was measured in this study as one form of participation and from the perspective of participants deciding if their needs were met “as and when they wanted”. Therefore, it is understood that an individual may experience task-specific activity limitation in self-care (e.g. difficulties in getting in and out of bath) but access to environmental facilitators may enable them to self-care (e.g. fitting a bath seat, handrails, or non-slip mats or receiving personal help and assistance). This may explain the gap between the observed prevalence estimates of self-care restriction when compared to other population studies of ADL limitations / dependency.

Age characteristics of the study sample had demonstrated agreement to previous studies’ findings on the associations of increasing age with increased prevalence of chronic conditions and comorbidity (Palacios-Cena et al., 2012; Tsang et al., 2008; Cigolle et al., 2007; Schafer et al., 2002). This study observed strong links between co-morbid health, number of peripheral joint pains and restricted self-

care. The risk of self-care restriction increased with increasing numbers of peripheral joint pain. Similarly, the odds of reporting self-care restriction was increased in those with peripheral joint pain by pattern, when multiple sites of joint pain were taken into account. Previous research supports this finding by stating that dose-response deterioration in general health status is associated with each extra joint pain sites that is symptomatic (Dawson et al., 2004). Multiple joint pains might also result in an increased severity of pain, which was previously related to functional limitations (Van Dijk et al., 2008). Van Dijk and colleagues (2008) studied comorbidity, limitations in activities and pain in patients with osteoarthritis of the hip and knee, and found morbidity count and severity is associated with increased pain and limitations in activities. This cross-sectional study was conducted in the Netherlands, and participants (n=288) were recruited from three rehabilitation centres and two hospitals. However this study excluded those over the age of 85 years. Limitations in activities were measured using WOMAC and SF-36 physical functioning domains. Relationship between comorbidity and limitation in activities were determined using multivariate linear regression analysis. As opposed to this study, dependent variables were WOMAC and SF-36 physical functioning scores, and the Visual Analogue Scale (VAS) pain score. This study was characteristically different than the NorStOP study as it was conducted on a sample of participants that originated from Orthopaedic department listings as opposed to the general population. Further, participants mean age was 66; somewhat younger than the mean NorStOP sample age. However, findings from this thesis and Van Dijk et al's study were congruent. Both pointed out the

relationship between comorbidity and activity limitation in older adults with osteoarthritis.

A recent study into musculoskeletal comorbidities in cardiovascular disease, diabetes and respiratory disease aimed to quantify the contribution of comorbidity to activity limitations in populations (Slater et al., 2011). This study stated that comorbid arthritis significantly increased the risk of activity limitations. The study population recruited through the Canadian Community Health Survey was different to the NorStOP population in terms of demographic and socio-economic status; they were younger (20+ cf 50+), with higher income and education levels. Nevertheless, the results pointed to the same finding; that chronic musculoskeletal conditions play an important role in activity limitations in those with other conditions such as cardiovascular disease, diabetes and respiratory disease. An earlier study by Adamson and colleagues (2004) examined the association of chronic degenerative diseases with locomotor activity limitation and social participation among older British women. The study was a cross-sectional survey of 4286 women aged 60-79 years from 23 towns in England, Scotland and Wales. The prevalence of locomotor activity limitation and difficulties with social participation increased with increasing age and with increasing number of chronic diseases.

Depression, measured by the Hospital Anxiety and Depression Scale, was also strongly associated with restricted self-care in older people in this thesis. Previously it was reported that people with depressive thoughts and feelings are

more limited in activities and more restricted in participation (Muller, 2009; Bresling et al., 2006). Most previous research into depression has been conducted through longitudinal studies. A recent study by Machado et al. (2008) examined the role symptoms, activity limitation and depression play in social participation of older adults with osteoarthritis. Participants were 184 community-dwelling adults aged ≥55 years with physician diagnosis of osteoarthritis and they were interviewed at two time points 18 months apart. Measures of activity limitation and participation restrictions were derived by factor analysis of questions about difficulties experienced in daily life. This study found that the relationship between physical symptoms and difficulties in participation was partially mediated by activity limitation and depressive symptoms. Findings suggested that these factors act as a pathway to subsequent participation restrictions.

Another study investigated the relationship between major depression, subclinical depressive symptomology and activity limitation over a four year period in adults aged 18 to 60 years. A brief diagnostic interview was used to gather information on major depression, activity limitations, health conditions and other socio-demographic characteristics. This study found that major depression had a significant adverse impact and leads to limitation in daily activities (Breslin at al., 2006).

An earlier study carried out by Gureje and colleagues (2001) examined the persistent pain syndromes among primary care patients across 15 sites in 14 countries. In this study, 3197 randomly selected primary care patients completed

baseline and 12-month follow-up assessments of pain and depressive symptoms. This study found a strong and symmetrical relationship between persistent pain and depression and stated that the impairment of daily activities was the central component of this relationship (Gureje et al., 2001).

Similarly, the odds of reporting self-care restriction in those individuals with low levels of cognitive alertness score were five times higher than those who were classified as non-cases. The suggestion of strong associations between cognitive impairment and participation restriction was also advocated by previous research, although the direction of the causal association remains to be investigated further (Wilkie et al., 2007:a; Jagger et al., 2005). Buchner and Larson (1987) found that people with cognitive impairment were more susceptible to falls and at higher risk of developing mobility problems. It could be assumed that people with a high risk of falls may restrict activities such as bathing to avoid such risk. It was also suggested that cognitive impairment may also impede the individual's ability to make appropriate self-care decisions (Cameron et al., 2010).

5.6.3 Limitations

This study was based on cross-sectional data. In cross-sectional studies, a purposeful sample of a population is used to estimate the relationship between an outcome of interest and population parameters as they are presented at a particular period of time (Porta, 2008). Since both the outcome and the variables are measured at a single time point, these studies cannot determine cause and effect relationships.

This study was based on self-reported data with varying time periods. It is possible, that some variables (e.g. pain in the last year) might be affected by information or recall bias (Porta, 2008). Similarly, mild problems such as pain, symptoms and activity limitation could also go unreported due to the responders' differing perceptions.

This study was a secondary analysis of the data collected for a general health survey that included questionnaires to investigate self-reported health conditions, activity limitations, participation restriction and contextual factors based around the individual's life. Whilst there were disadvantages to conducting a secondary analysis using this large dataset, (such as lack of familiarity with data, absence of key variables (e.g. environmental variables), and dealing with the complexity of data) there were many more advantages. First of all it was cost effective; it saved time as data was already collected. This allowed sufficient time for a detailed, intensive statistical analysis to answer complex questions. Secondly, it is based upon a high-quality dataset featuring a large and representative sample of general population. The survey response (71.3%) provided results which were representative of the target population (Mangione, 1995). Nevertheless the sample analysis highlighted differences in the non-responders and the responders in terms of age and gender, as there was a greater response from females and in the middle age groups (60-69 and 70-79) (Chapter 4). This could suggest that the oldest age group, which may be the one with most self-care restrictions according to the results of this study, may have been under represented in this survey. Therefore the observed prevalence of restricted self-care may actually be an

underestimation of the correct prevalence in the general population. It is possible that the non-response in the oldest age groups could be due to the study method of collecting data through a postal survey. It can be hypothesised that the prevalence of restricted self-care in individuals who were unable to complete the survey due to activity limitation and / or physical or psychological impairments could be significantly higher.

The parsimonious model was derived from 6506 participants, due to missing data (17%) in six covariates measured. The age and gender structure of these 6506 people were significantly different than the age and gender structure of those who were missing. Proportionately, those included in the parsimonious model were younger compared to those who responded at baseline but had missing covariate data ($p \geq 0.001$), and had fewer women ($p \geq 0.001$). Considering that this study established that self-care restriction increased with age and was higher in women based on the general population of older adults at baseline, associations between the key covariates identified with parsimonious model and self-care restriction may have been an underestimation due to missing data. The model was also solely based on a statistical decision, where inclusion and exclusion of predictors to the model was dependent on the statistical significance level. Rather strict significance values (0.05 for removal and 0.01 for re-entry cf 0.15 and 0.20 recommended by Hosmer and Lemeshow, 1989) were used in the multivariable model due to high levels of significance with all variables at the univariable analysis. This could have resulted in an elimination of other important factors from the model. However, the

internal and external validation of the parsimonious model suggested that the model had a reasonable predictive power.

5.7 Conclusions

Person perceived self-care restriction is reported by one in ten persons over the age of 50 years in the general population and increases with age. It is associated with joint pain, although much of this relationship may be explained by other factors, such as activity limitation and contextual factors. To understand how self-care restriction may occur in older adults with joint pain, a focused analysis within this group is required. Prevalence increases with increasing age and is higher in women. Self-care restriction is associated with a number of factors including health conditions, impairments, activity limitation and contextual factors, providing support for the ICF model of participation; the proposed model of self-care in this thesis.

Whilst the findings reported in this chapter are useful for identifying how common self-care restrictions are in community-dwelling older people and associated factors, the cross-sectional analysis cannot ascertain patterns of occurrence and / or clearly identify potential predictors. The following chapters describe longitudinal analyses of self-care restriction.

Table 5.14 Summary of key findings

- This chapter reported the baseline cross-sectional analyses of the NorStOP, with an aim to estimate the prevalence of self-care restriction in older people in the general population, and determine the associations between self-care restriction and health conditions, impairments, activity limitation and other contextual factors.

- The prevalence of self-care restriction was 11.5% (95% CI: 10.8, 12.2). There was a linear trend with increasing age ($p \leq 0.001$) and restriction was higher in women (% difference 2.3%; CI: 0.8, 2.7).

- The results of the age standardisation indicated that the observed prevalence of restricted self-care in the NorStOP population is similar to the estimated prevalence in England and Wales population.

- Self-reported health conditions, impairments, activity limitation and contextual factors were significantly associated with restricted self-care in the univariable analysis, after adjusting for age and gender.

- A parsimonious model of key factors associated with restricted self-care was derived from the multivariable analysis using backward-stepwise logistic regression. These key factors were age, activity limitation, depression, cognitive alertness, perceived adequacy of income and educational attainment.

- Joint pain was not independently associated with self-care restriction once adjusted for other factors, therefore was not identified as a key factor in the parsimonious model. One explanation for this is that joint pain co-occurs with other health and socio-demographic factors that are strongly linked to self-care.

- The internal and external validity of the parsimonious model was tested using the apparent, bootstrap and split-sample techniques and the model had a reasonable power in predicting self-care restriction in those aged 50 years and over in the general population.

- As cross-sectional analysis cannot ascertain patterns of occurrence and/or clearly identify potential predictors, following chapters describe longitudinal analysis of self-care restriction.

Chapter 6
Person-perceived self-care restriction in the middle and old age: risk of onset and persistence over a 3 years period

6.1 Introduction

The previous chapter described the prevalence of person-perceived self-care restriction and its relationship with joint pain in the general population through a set of cross-sectional analyses. The next stage in building a picture of the epidemiology of restricted self-care is to describe the 'natural history', in terms of onset and persistence of self-care restrictions in older people. Studying 'natural history' aims to yield information about the course of a disease or condition and generally requires longitudinal methods. Although 'natural history' is broadly defined as the course of a disease from pathological onset to resolution in epidemiology, these stages vary vastly across human conditions. Thus, more often than not the term 'natural history' refers to a model or framework that incorporates social and cultural interactions as well as the biological and healthcare processes involved in the disease process (Porta, 2008). In this thesis, self-care restriction is the health-related outcome of interest, not a disease or health condition. It is assumed in this chapter that the concept of 'natural history' can be applied also to such health-related states.

This is the first study to examine self-care as defined in the International Classification of Functioning (ICF) and there is no estimate of its natural history (i.e. in terms of the onset and persistence of self-care restriction). For comparison,

there are studies which have reported the rate of onset and persistence of dependency and / or loss of independence in self-care tasks; definitions that would be classed under the umbrella term of activities of daily living (ADLs) (e.g. dressing, eating, toileting) and instrumental activities of daily living (IADL) (e.g. meal preparation, grocery shopping, using the telephone, taking medications and managing money) in older adults. Despite conceptual differences between ADL and person-perceived self-care restriction these may nevertheless provide useful information on the natural history of self-care disability in general.

The Index of Independence in Activities of Daily Living, (Index of ADL), was developed by Katz and colleagues (1963) from observations of a large number of activities performed by a group of patients with fracture of the hip, to use as a measure of function which could be used to evaluate chronically ill and aging populations. The index ranks individuals according to adequacy of their performance. This adequacy is expressed as a grade (A, B, C, D, E, F, G, or Other) which summarises overall performance in bathing, dressing, toileting, transferring, continence and feeding (Table 6.1). This scale has been extensively used in studies of the natural history of disease and results of treatments.

Table 6.1 Index of Independence in Activities of Daily Living

These specific definitions for ranking appear below the index	
A	Independent in feeding, continence, transferring, going to toilet, dressing, and bathing
B	Independent in all but one of these functions
C	Independent in all but bathing and one additional function
D	Independent in all but bathing, dressing, and one additional function
E	Independent in all but bathing, dressing, going to toilet, and one additional function
F	Independent in all but bathing, dressing, going to toilet, transferring and one additional function
G	Dependent in all six functions
Other	Dependent in at least two functions, but not classifiable as C,D,E, or F

Source: Katz et al. 1963 page: 95

Over the years, a number of instruments measured ADL, although a few of them considered those with musculoskeletal conditions. Of those, the most commonly used instrument in arthritis is the Stanford Health Assessment Questionnaire (HAQ) (Bruce and Fries 2003; Fries et al., 1980). The HAQ was developed as a comprehensive measure of outcome in patients with a wide variety of rheumatic diseases, including osteoarthritis. The domain of disability is assessed in the HAQ by eight categories of dressing, arising, eating, walking, hygiene, reach, grip, and other common activities. There are four possible response options to rate difficulty in functioning, which range from 0-3 (without any difficulty (0), with some difficulty (1), with much difficulty (2), and unable to do (3)). The scoring system used in the HAQ reflects the disease activity, which is expressed as the degree of difficulty in performing ADLs. Each of the disability items has a corresponding aids / devices variable that is used to identify what type(s) of assistance, if any, is used to help with these activities. Again, the scoring system used for this range from 0 (No assistance is needed) to 3 (The patient usually needs BOTH a special device and

help from another person). However, the inclusion of environmental facilitators in HAQ increases the disability scores, as it assumes the more help is needed/ used by individuals the more dependent they are.

Latterly, Kempen and Suurmejer developed the Groningen Activity Restriction Scale (GARS) to measure both ADL and IADL disability in community based studies with respect to the aid and services provided by professional home help and district nursing agencies (Kempen and Suurmeijer 1990). The GARS included 18 items (e.g. for ADL: dressing, getting in and out the bed, washing, toileting, feeding, using stairs, walking outdoors, take care of feet and toenails; for IADL: prepare breakfast / lunch / diner, do light / heavy household activities, wash and iron, make the beds and do the shopping) and five response options for each item to gauge what responders are able to do and not do independently. The response options ranged from: (1) yes, I can do it fully independently without any difficulty; (2) with some difficulty; (3) with great difficulty; (4) no, I cannot do it fully independently, I can only do it with someone's help; (5) No, I cannot do it at all, and I need complete help (Suurmeijer et al., 1994). One disadvantage of the GARS is that it is not taking the use of aids and adaptations into account which may promote independent function in older people, and similar to the HAQ, the disability score of the individuals increase with the increased use of environmental facilitators to function.

Another ADL measure developed originally in Sweden specifically for the use in Occupational Therapy (OT) is the Evaluation of the Daily Activity Questionnaire

(EDAQ) (Nordenskiold et al., 1996). This measure encompasses 14 domains: where the level of difficulty is measured in personal and IADL (6-14 activities in each: 138 activities in total). Each of these domains has two sections: section (A) is scored without aids, alternate methods or help, and section (B) is scored with aids or alternate methods. As opposed to HAQ and GARS, the scoring system in EDAQ reflects the use of aids and assistance as an improvement in function. However, although this instrument's strength lies in the large number of domains it covers to provide a thorough OT assessment, it has been criticised for the potential responder burden for being too comprehensive (Archenholtz and Dellhag, 2008).

Previous studies of the onset of ADL disability have suggested that the disability process follows a complex and sometimes transient course (Stuck et al, 1999; Norburn et al., 1995). Reynolds and Silverstein (2003) investigated the role of various factors in the onset of ADL and IADL to examine the onset of disability both in the aggregate, and as an individual phenomenon. They did so in order to develop a long term strategy for better targeted home and community based services. In this study, participants were considered as 'dependent' or 'disabled' if they could not perform such activities without help. This study confirmed that the onset of ADL and IADL disability is a complex process, predicted by a variety of different factors. Amongst factors associated with the onset of ADL disability, the strongest predictors were identified as increasing age, being female and having arthritis.

In a series of studies involving a cohort of 754 community-dwelling adults aged 70 years and over who provided monthly reports of disability by telephone interview, Gill and colleagues revealed the high incidence of episodes of disability, their recurrent nature, and the effects of persistent episodes of disability. Over a median follow-up of 51 months, they found that over half the cohort experienced an episode of disability (dependence or difficulty in bathing, dressing, walking, or transferring) (Hardy and Gill, 2004). Of those, 81% recovered (i.e. regained independence in all 4 ADLs measured) within a year of their initial disability episode and a majority of these maintained independence for at least 6 months. This study concluded that disability is a recurrent rather than enduring condition and suggested interventions to maintain independence after recovery are needed (Hardy and Gill, 2004).

In a further analysis within the same cohort, but focused on bathing disability (defined as the 'inability to wash and dry one's whole body without personal assistance'), the authors reported that over the course of 6 years, 58.4% had at least one episode of bathing disability, and 34.0% had multiple episodes (Gill et al., 2006: a). The incidence of bathing disability was higher in women, in those who were physically frail, and in those aged 80 years and over. The fact that many of these incident episodes of bathing disability occurred in the absence of disability in other ADL domains (e.g. dressing, transferring, walking) suggested that bathing disability may be a 'sentinel event'. This study concluded that given the recurrent nature of bathing disability, the focus for intervention must not be solely on the prevention but also restoration and maintenance of independent bathing in older

people who become disabled (Gill et al., 2006:a). In a subsequent study of bathing disability and the risk of long-term admission to a nursing home, participants were followed up with monthly telephone interviews for a median of 75 months. The study determined the occurrence of persistent disability in bathing (defined as present for at least 2 consecutive months) and the time to the first long-term nursing home admission (defined as longer than 3 months). The authors found that the occurrence of persistent disability in bathing was independently associated with the risk of a long-term nursing home admission (Gill et al., 2006: b).

Balzi and colleagues (2010) measured factors potentially associated with high risk of ADL disability in a population of older adults (≥65) in a prospective cohort study at baseline (n=1155), and at 3 years (n=897) follow-up studies. The 'incidence' of disability was defined as a new ADL disability at 3 years follow-up in those participants without ADL disability at baseline. Worsening disability was defined as increased ADL disability in those who already had ADL disability at baseline. Of those participants who were free of ADL disability at baseline, 8.4% developed ADL disability, and of those who were already disabled, 51.0% had a worsening ADL disability over a 3 years follow-up.

From this small and limited selection of studies, it can be assumed that, like estimates of prevalence, estimates of the rate of onset and persistence of self-care disability are likely to vary depending on the definition used and the population studied. Direct comparisons between the current study and the existing literature

will therefore be difficult. In addition, the studies by Gill and colleagues illustrate that the period of follow-up and the frequency of repeated measurement can yield very different estimates of the episode incidence of self-care disability and that this will differ from estimates of cumulative incidence such as those provided by Balzi and colleagues. The 3 years period of follow-up from Balzi and colleagues is the same as that used in the current thesis and, although the measure of self-care disability in this thesis is different, we might nevertheless hypothesise from these previous studies that: (a) the state of self-care restriction is reversible and therefore a proportion of those reporting self-care restriction at baseline will report no such restriction at 3 years follow-up ('back-transitions'), (b) the rate of onset of self-care restriction will be lower than the rate of persistence, (c) the rate of onset will be higher in women and in older age groups. It must also be assumed that the cumulative incidence of self-care restriction at 3 years will under-estimate the episode incidence of self-care restriction.

6.2 Aims and objectives

The overall aim of this study was to describe the longitudinal course of self-care restriction in older people in the general population over a three year period. Using baseline and 3 years data from the NorStOP in community-dwelling adults aged 50 years and over the objectives of these analyses were:

i. To estimate the risk of onset and persistence of self-care restriction at 3 years

ii. To describe the relationship between the risk of onset and risk of persistence of self-care restriction at 3 years and baseline demographic, socio-economic and health characteristics

iii. To explore the direction and strength of association between the risk of onset and risk of persistence of self-care restriction at 3 years and the site, number, and pattern of peripheral joint pains at baseline

6.3 Methods

6.3.1 Dataset

The analyses described in this chapter use data collected at baseline and 3 years in the NorStOP study. Participants were adults aged 50 years and over in the general population who responded and completed the Keele Assessment of Participation (KAP) self-care item at baseline and 3 years follow-up. Of those 7725 responders who completed KAP self-care item at baseline, 5425 consented to further contact, 4089 (75%) of whom were successfully followed up at 3 years.

6.3.2 Outcome

Longitudinal studies involve following participants over time, measuring an outcome variable and risk factors, at least at two different points in time (Jewell and Hubbard, 2006). Incidence is defined as number of new cases in a specified population in a given period and may be measured as a frequency count, a rate, or a proportion (Porta, 2008). The incidence rate is defined as the rate at which new events occur in a population, and the cumulative incidence is defined as the

proportion of people presenting with the onset of a health-related event during a specified time interval (Porta, 2008). In this study participants were followed at two time points with a 3 years interval. Therefore, it was not possible to measure the incidence of episodes of self-care restriction, as it was not possible to observe the timing of the event or change in state. Therefore, instead of incidence, the term '*onset*' was used in this study to refer to *the risk of self-care restriction at 3 years in people free of self-care restriction at baseline*. '*Persistence'* was defined as *the risk of self-care restriction at 3 years in people reporting self-care restriction at baseline*. These two variables – onset and persistence of self-care restriction at 3 years – were used as outcome variables in multivariable analyses investigating baseline determinants.

6.3.3 Covariates

Demographic, socio-economic and health characteristics

Longitudinal studies comprise of studying the same group of individuals over an extended period of time and are an efficient way to discover associations between factors that are not visibly related. Examining the demographic, socio-economic and health characteristics of the study cohort can highlight these associations with the outcome and provide further information on risk factors.

Demographic and socio-economic variables used in this analysis were selected for their associations with restricted self-care at baseline. Age and gender were used to estimate the distribution of the onset and persistence of restricted self-care in the general population of adults aged 50 years and over. In order to describe the

relationship between the risk of onset and risk of persistence of self-care restriction, and the baseline socio-economic and health characteristics of those responders at 3 years, participants were described using perceived adequacy of income (find it strain to get by from week to week / have to be careful with money / able to manage without much difficulty / quite comfortably off), educational attainment (whether they had gained qualifications through study as an adult) along with the health characteristics using 12-item Health Survey (SF-12) physical and mental health component scores. A linear trend in self-care restriction with increasing age was observed at baseline and self-care restriction was higher in women. Individuals' perceived adequacy of income and educational attainment were found to be independently associated with self-care restriction in the multivariable analysis where other socio-economic factors such as occupational class were eliminated from the parsimonious model at baseline. These variables were described in detail in Chapters 4 and 5.

Joint pain

Peripheral joint pain was included in this study to explore the direction and strength of associations between the risk of onset and risk of persistence of self-care restriction at 3 years. Peripheral joint pain was defined as pain in the past year in hand, hip, knee, and / or foot. This was analysed in three ways: by site (each site – yes/no), as a simple count of the number of peripheral joint areas reported as painful (0-4) and by pattern (no pain, hand only, single lower limb, multiple lower limb, hand+ lower limb).

6.3.4 Statistical Analysis

The primary analyses were conducted on cases with complete data at baseline and 3 years. Estimates of the onset and persistence of self-care restriction at 3 years were expressed as percentages, overall, and stratified by age and gender. Differences in onset and persistence between males and females were tested using *chi-squared* test. Differences between age groups (50-59, 60-69, 70-79, 80+ years) were tested using *chi-squared* test for trend.

Relationship with baseline socio-economic and health characteristics

Descriptive characteristics such as socio-economic (adequacy of income and educational attainment) and health characteristics (SF-12 physical and mental health scores) of the study participants were cross-tabulated using frequencies and percentages to compare those with the onset of self-care restriction against those who remained free of restriction. Differences between the groups were tested using *chi-squared* for non-parametric variables (e.g. educational attainment and perceived adequacy of income) and the *independent samples t-test* for parametric variables (e.g. PCS and MCS scores). These were expressed as p-values. The analyses were repeated comparing those with persistent self-care restriction to those who recovered from self-care restriction at 3 years.

Relationship with selected peripheral joint pain at baseline

Those who reported onset and persistence of restricted self-care at 3 years were cross-tabulated with joint pain by site, pattern and number at baseline. Links between the onset and persistence of restricted self-care at 3 years and joint pain

by site, pattern and number at baseline were investigated using univariable and multivariable logistic regression analysis (adjusting the associations for all joint specific characteristics) as this method was highlighted as the most appropriate method in the previous chapter (Chapter 5). Associations were presented as odds ratios with 95% confidence intervals.

Sensitivity analysis

Missing data is common in longitudinal analyses due to various factors such as missing items on the questionnaire, non-response and study attrition. There is increasing recognition that studies which restrict analysis to participants with complete data can be biased and improvident (Spratt et al., 2010). Multiple imputation (MI) is increasingly endorsed in epidemiology to adjust for the bias and data loss that may occur in analyses limited to study participants with complete data (Spratt et al., 2010). MI is a technique that allows for uncertainty about the missing data by creating several copies of the dataset in which missing values are substituted by imputed values sampled from an earlier predictive distribution that is estimated from the observed data (Rubin, 1996; Schafer, 1997).

As described in chapter 4, the extent and the characteristics of the study attrition at NorStOP 3 years sample could introduce bias to the longitudinal analyses results. Therefore MI was utilised in this study in an attempt to understand and control this possible bias by examining whether the estimates based on partial and complete datasets had differed.

Missing data mechanisms are categorised into three categories: (i) missing completely at random (MCAR); here the assumption is that the attrition is independent of both observed and unobserved data, (ii) missing at random (MAR); attrition depends on the observed data, but not on unobserved data, and (iii) missing not at random (MNAR); attrition depends on unobserved data (Twisk and Vente, 2002). It not possible to distinguish between MAR and MNAR from the observed data alone, but the MAR assumption can be made more plausible by including more explanatory variables in the analysis (White et al., 2010). The missing data mechanism is important, as different types of missing data require different types of analysis. Under MAR assumption, a set of covariates *X* is observed and the missing values, $Y_{mis,}$ depend on the observed variables *X*. There is no statistical test to prove this assumption, however a common approach to see if MAR assumption is plausible, is to conduct univariable and multivariable logistic regression to determine if covariates *X* were associated with Y_{mis} (outcome variable) (Vargas-Chanes et al., 2003). In the preliminary analysis conducted, baseline values of the key factors associated with restricted self-care were predictive of the missing outcome data at 3 years, suggesting covariate dependent missingness. The assumption regarding the lack of association with unobserved quantities in this dataset meant the data was MAR, since the missingness can actually be predicted (but is random after controlling for missingness due to observed quantities) (Horton and Kleinman, 2007). Under the MAR assumption, identifying the variables for the imputation process is an important step and the number of variables included in the imputation process affects the quality of the sensitivity analysis. This is because MI's ability to reduce bias in a given analysis

depends on the measured variables that are associated with both the manner in which data are missing and the outcome variable (Engels and Diehr, 2003). Therefore, only six variables from the parsimonious model developed at baseline were selected to be included in the imputation process (age, activity limitation (PF10), depression (HADs), cognitive complaint (SIP), perceived adequacy of income and educational attainment.

Two major approaches to MI were identified by the author to create multiply imputed datasets. The first approach identified was the approach taken by Stata's *mi imputes* command. This assumes the joint distribution of all variables in the imputation model to be multivariate normal. The second approach identified was based on each conditional density of a variable given other variables, a user-written *ICE* (imputation by chained equations approach) programme (Royston, 2005; 2007; 2009). As the pattern of missingness was deemed to be arbitrary in this dataset, an *ICE* programme was used for imputation. An advantage of the *ICE* approach is that variables are not assumed to have a multivariate normal distribution (Von Hippel, 2007). *ICE* is used to perform multivariable imputation via chained equations, and the *mim* command analyses multiply imputed data by performing data analysis and combining these individual analyses using Rubin's combination rules (Rubin, 1987). Recommendations for the number of imputations vary in the literature, from 5 to 50 depending on the amount of missing data (Graham et al., 2007). For the sensitivity analysis different m sets of imputations were carried out (5; 20; 30; 40) to see if different results were acquired. As results

were similar and the power of the analysis decreased with the number of imputations, 20 m sets was decided as the optimum amount of imputation.

MI analysis using *ice* consisted of three phases: (i) imputation - creating multiply imputed data, (ii) analysis of imputed datasets, and (iii) combining of estimates from imputed datasets using Rubin's combination rules.

i) Imputation:

The original baseline general population sample to draw imputations from was identified after 365 people were omitted from the dataset according to their 3 year exclusion status (308 were excluded prior to mailing, 33 died, 6 changed address, 6 ineligible, 12 ill). Those who were not restricted in self-care at baseline formed the sample to impute for the *onset of self-care restriction* at 3 years (n=6571). Those who were restricted in self-care at baseline formed the sample to impute for the *persistence of self-care restriction* at 3 years (n=796). The unknown missing data were replaced by 20 independent simulated sets of values drawn from the predictive distribution of the missing outcome data, conditional on the observed parsimonious variables data to create multiply imputed datasets at 3 years using *ICE*.

ii) Analysis of imputed datasets:

Following the completion of imputations, each imputed dataset for the onset and persistence of self-care restriction at 3 years were analysed separately. The regression coefficients were estimated from each imputed dataset with 95%

confidence intervals. The results of these m imputations were examined to ensure that the distributions looked reasonable after imputation, and that they were not out of range of the original values.

iii) Combining of estimates from imputed datasets:

In the last step the multiply imputed estimates were combined into an overall estimate with 95% confidence interval using Rubin's rule of combination which allows the variance of estimates between different imputed datasets to be taken into account. The combined variance incorporates both within-imputation variability (uncertainty about the results from one imputed dataset) and between imputation variability (reflecting the uncertainty due to the missing information) (White et al., 2011).

6.4 Results

6.4.1 Onset self-care restriction at 3 years: complete-case analysis

Based on complete case analysis, there were 4089 potentially eligible respondents at 3 year follow-up, of whom 3770 were free of self-care restriction at baseline (Figure 6.1).

250 (6.6%; 95 % CI 5.9, 7.5) reported the onset of self-care restriction at 3 years (Fig: 6.1). There was a linear trend with increasing age (p≤0.001) but no difference between men and women (Table 6.2).

Figure 6.1 Flowchart of the onset and persistence of self-care restriction in the general population over a 3 years period

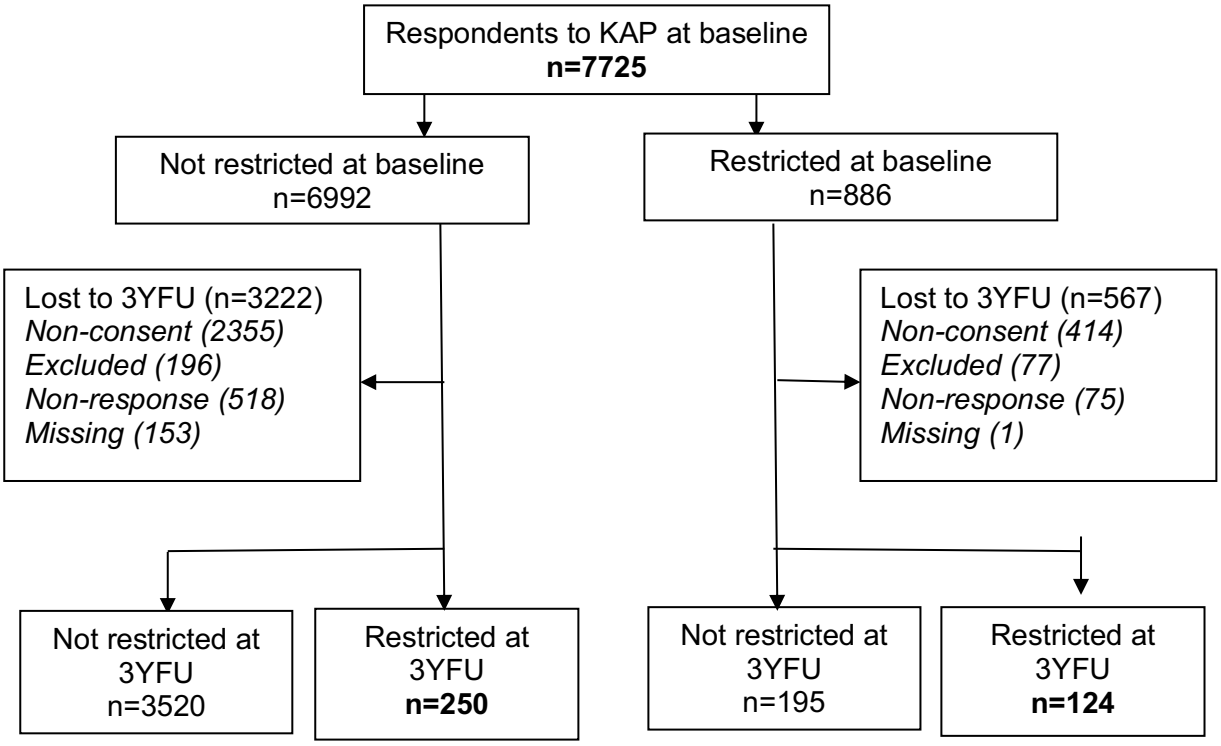


Table 6.2 Onset of restricted self-care at 3 years; overall and stratified by age and gender

		N	Onset n (%)	P-value
Overall		3770	250 (6.6)	
Gender				
	Female	2070	141 (6.8)	
	Male	1700	109 (6.4)	p=0.336
Age group				
	50-59	1452	61 (4.2)	
	60-69	1272	79 (6.2)	
	70-79	828	74 (8.9)	
	80+	218	36 (16.5)	p≤0.001

6.4.2 Persistence of self-care restriction at 3 years

Of 319 eligible respondents who reported self-care restriction at baseline and were successfully followed up at 3 years, 124 (38.9%; 95% CI 33.7, 44.3) reported self-care restriction again at 3 years follow-up (Fig: 6.1). Persistent self-care restrictions were higher in men (Table 6.3). The risk of persistent self-care restriction at 3 years was unexpectedly low in 80+ year olds, resulting in no overall trend with age.

Table 6.3 Persistence of restricted self-care at 3 years; overall and stratified by age and gender

		N	Persistence n (%)	P-value
Overall		319	124 (38.9)	
Gender				
	Female	202	70 (34.7)	
	Male	117	54 (46.2)	p=0.042
Age group				
	50-59	86	33 (38.4)	
	60-69	103	42 (40.8)	
	70-79	83	35 (42.2)	
	80+	47	14 (29.8)	p=0.536

6.4.3 Association with baseline socio-economic and health characteristics

Onset of self-care restriction

The crude risk of onset of self-care restriction at 3 years was associated with lower socioeconomic status - as measured by educational attainment and perceived financial strain - at baseline. For example, the risk of onset was four times higher among individuals who felt that they were under financial strain, compared to those who rated themselves as 'comfortably off' (Table 6.4). Those who experienced the onset of self-care restriction at 3 years tended to have lower (unadjusted) physical and mental health scores at baseline than those who remained free of self-care restriction at follow-up (Mean (SD) SF-Physical Component Score (0-100): 32 (11) vs 42 (12), p<0.001; Mean (SD) SF-Mental Component Score (0-100): 44 (12) vs 50 (11), p<0.001).

Table 6.4 Onset of self-care restriction at 3 years follow-up, by socio-economic status at baseline

		N	Onset n (%)	P-value
Overall		3770	250(6.6)	
Adequacy of Income				
	Comfortable	445	17 (3.8)	
	Little difficulty	1183	76 (6.4)	
	Be careful	1101	105 (9.5)	
	Strain	91	11 (12.1)	p≤0.001
Higher educational attainment	**No**	2318	182 (7.9)	
	Yes	1395	60 (4.3)	p≤0.001

Persistence of self-care restriction

Similar to the onset analysis, the crude risk of persistence of self-care restriction at 3 years was associated with the perceived financial strain at baseline. The risk of persistence was 2.5 times higher among individuals who stated financial strain than those who described themselves as comfortable, but there was no relationship with educational attainment (Table 6.5). Those who had persistent self-care restriction at 3 years had lower (unadjusted) physical health scores at baseline than those who remained free of self-care restriction at follow-up, but there was no significant difference in mental health scores between those recovered and those had persistent self-care restriction at 3 years (Mean (SD) SF-Physical Component Score (0-100): 27 (10) vs 29 (9), p=0.040; Mean (SD) SF-Mental Component Score (0-100): 38 (11) vs 41 (12), p=0.105).

Table 6.5 Distribution of the persistence of self-care restriction at 3 years by socio-demographic and health characteristics

		N	Persistence n (%)	P-value
Overall		319	124 (38.9)	
Adequacy of Income				
	Comfortable	16	4 (25.0)	
	Little difficulty	69	23 (33.3)	
	Be careful	168	65 (38.7)	
	Strain	26	16 (61.5)	p=0.050
Higher educational attainment	No	251	97 (38.6)	
	Yes	56	20 (35.7)	p=0.402

6.4.4 Association of the onset of self-care restriction with joint pain at baseline

Individuals with pain at each of the selected peripheral joint areas were at higher risk of onset of self-care restriction at 3 years compared to those without that pain (Hand pain= Crude OR 1.7 95% CI 1.3, 2.3; Hip pain= OR 2.1 CI 1.6, 2.6; Knee pain= OR 1.9 CI: 1.4, 2.4; Foot pain= OR 2.0; CI 1.5, 2.6) (Table 6.6).

The number of painful peripheral joint areas at baseline was associated with the onset of self-care restriction within each category (Table 6.7). For example, the odds of self-care restriction at 3 years was 3.3 times higher in individuals reporting pain in the hand, hip, knee and feet at baseline compared with people reporting pain in none of these areas (Four painful joint areas = OR 3.3; CI 2.2, 4.9).

Pattern of joint pain at baseline was also associated with the onset of self-care restriction at 3 years in each category level but only for those with patterns involving multiple joint areas (Table 6.8). Neither isolated hand pain nor single-site lower limb pain were associated with an increased risk of self-care restriction at 3 years (Hand pain only= OR 1.1; CI 0.6, 2.2; Single lower limb pain= OR 1.0; CI 0.6, 1.6).

Table 6.6 Onset of self-care restriction at 3 years and site of joint pain at baseline

3 years response to KAP self-care item of those who were not restricted at baseline n= 3770*		Onset of self-care restriction at 3 years		
		No	Yes	
		n	n	OR (95%CI)
Hand pain				
	No	1938	103	1
	Yes	1513	141	1.7 (1.3, 2.3)
Hip pain				
	No	2349	123	1
	Yes	1111	120	2.1 (1.6, 2.6)
Knee pain				
	No	1723	85	1
	Yes	1739	160	1.9 (1.4, 2.4)
Foot pain				
	No	2218	115	1
	Yes	1243	129	2.0 (1.5, 2.6)

* Cells do not add to 3770 due to missing data

Table 6.7 Onset of self-care restriction at 3 years and number of painful joint areas at baseline

3 years response to KAP self-care item of those who were not restricted at baseline n= 3770		Onset of self-care restriction at 3 years		
		No	Yes	
		n	n	OR (95%CI)
Number of painful joint areas				
	None	832	32	1
	One	867	44	1.0 (0.7, 1.6)
	Two	791	49	1.3 (0.8, 1.9)
	Three	556	56	2.0 (1.4, 3.0)
	Four	329	53	3.3 (2.2, 4.9)

* Cells do not add to 3770 due to missing data

Table 6.8 Onset of self-care restriction at 3 years and pattern of joint pain at baseline

3 years response to KAP3 of those who were not restricted at baseline n= 3770	Onset of self-care restriction at 3 years		
	No	Yes	
	n	n	OR (95%CI)
Pattern of joint pain			
No pain	977	48	1
Hand pain only	199	11	1.1 (0.6, 2.2)
Single lower limb	668	33	1.0 (0.6, 1.6)
Multiple lower limb	409	36	1.8 (1.1, 2.8)
Hand and lower limb	1267	122	2.0 (1.4, 2.8)

* Cells do not add to 3770 due to missing data

6.4.5 Association of the persistence of self-care restriction with joint pain at baseline

Individuals with hip, knee, or foot pain at baseline appeared to have a slightly higher risk of persistent self-care at 3 years, although this was statistically non-significant (Hip= Crude OR 1.5 95% CI 0.9, 2.5; Foot= OR 1.4; CI 0.9, 2.3) (Table 6.9).

People with the four painful peripheral joint areas at baseline had higher odds of reporting self-care restriction at 3 years compared with people reporting no painful joint areas. However the relationship was statistically non-significant (Table 6.10).

The pattern of joint pain at baseline was associated with persistence of self-care restriction at 3 years, but only for those with patterns involving multiple joint areas. However, again these associations were not statistically significant due to small sample size (Table 6.11).

Table 6.9 Persistence of self-care restriction at 3 years and site of joint pain at baseline

3 years response to KAP3 of those who were restricted at baseline n= 319		Persistence of self-care restriction at 3 years		
		No	Yes	
		n	n	OR (95%CI)
Hand pain				
	No	64	41	1
	Yes	124	80	1.0 (0.6, 1.6)
Hip pain				
	No	87	42	1
	Yes	101	76	1.5 (0.9, 2.5)
Knee pain				
	No	51	26	1
	Yes	138	94	1.3 (0.8, 2.3)
Foot pain				
	No	74	37	1
	Yes	116	84	1.4 (0.9, 2.3)

* Cells do not add to 3770 due to missing data

Table 6.10 Persistence of self-care restriction at 3 years and number of painful joint areas at baseline

3 years response to KAP3 of those who were restricted at baseline n= 319	Persistence of self-care restriction at 3 years		
	No	Yes	
	n	n	OR (95%CI)
Number of painful joint areas			
None	16	7	1
One	27	15	1.2 (0.4, 3.8)
Two	33	22	1.5 (0.5, 4.3)
Three	55	28	1.2 (0.4, 3.1)
Four	50	45	2.0 (0.8, 5.4)

* Cells do not add to 3770 due to missing data

Table 6.11 Persistence of self-care restriction at 3 years and pattern of joint pain at baseline

3 years response to KAP3 of those who were restricted at baseline n= 319	Persistence of self-care restriction at 3 years		
	No	Yes	
	n	n	OR (95%CI)
Pattern of joint pain			
No pain	30	14	1
Hand pain only	6	3	1.1 (0.2, 4.9)
Single lower limb	21	12	1.2 (0.5, 3.2)
Multiple lower limb	26	22	1.8 (0.8, 4.2)
Hand and lower limb	112	73	1.4 (0.7, 2.8)

* Cells do not add to 3770 due to missing data

6.4.6 Sensitivity analysis

Analyses of each imputed set demonstrated that the distribution of data was reasonable after imputation and they were not out of range of the original values. When 20 sets of imputations were combined using Rubin's rules, the estimated frequency of onset of restricted self-care at 3 years was 7.9% (95% CI 7.1; 8.6) (compared to the observed estimate of 6.6%). The estimated frequency of persistence of self-care restriction at 3 years was 39.8% (CI 35.6; 44.0) (compared to the observed estimate of 38.9%).

6.4.7 Summary of results

In this study, the incidence of self-care restriction at 3 years in people aged 50 years and over was estimated to be 6.6%. In those already reporting restriction at baseline, 38.9% reported self-care restriction again 3 years later, implying persistent restriction. The net effect of these changes on the prevalence of self-care restriction over 3 years within this cohort was a small increase (7.8% at baseline to 10.9% at 3 years follow-up). An increase in the prevalence of self-care restriction over time is consistent with the observed cross-sectional association between self-care restriction and increasing age reported in Chapter 5. However, selective loss to follow-up appears likely in the current study and both onset and persistence are likely to be under-estimated in the complete-case analysis.

Individuals who were older, of lower socioeconomic status, and who were reporting worse physical and mental health at baseline were at increased risk of onset of self-care restriction at follow-up. The presence of peripheral joint pain at

baseline, particularly multiple joint pains, was also associated with an increased risk of onset of self-care restriction, but there were no significant associations with persistence. The risk of persistent self-care restriction at 3 years appeared to be higher among men, those with poorer physical health, and those under financial strain. But persistence was not related to age, educational attainment, or mental health. Lower numbers were available for the analysis of persistence than the analysis of onset, limiting the precision of the former estimates.

6.5 Discussion

Critical comparison against previous studies

In the study where Balzi and colleagues measured factors potentially associated with high risk of ADL disability at baseline and 3 years follow-up, the 'incidence' of disability was defined as a new ADL disability at 3 years follow-up in those participants without ADL disability at baseline. This is consistent with the risk of onset of self-care restriction at 3 years in the study undertaken in this chapter. Their estimated onset of ADL disability was 8.4% (Balzi and colleagues 2010), somewhat similar to the estimated onset of self-care restriction in this study (6.6%). However, it is important to bear in mind that the outcome of interest in Balzi and colleague's study was ADL disability (reported need for help of another person in performing at least one ADL), and was not person-perceived participation in self-care (self-care needs met as and when wanted with or without help and assistance) as measured in the NorStOP study.

Balzi and colleagues (2010) also reported worsening disability (defined as increased ADL disability in those who already had ADL disability at baseline) in their study of *risk factors for disability in older persons over 3 years follow-up*, which can be compared to the estimation of persistent self-care restriction (defined as continued existence or occurrence of restricted self-care in those reporting self-care restrictions at baseline) in the NorStOP study reported in this chapter. Their estimation of 'worsening disability' was 51.0% over a 3 years follow-up, compared to the NorStOP study estimation of persistent self-care restriction of 38.9%. The persistence of self-care restriction was measured using KAP, an aggregated measure of self-care, which was dichotomised. This dichotomy did not allow accounting for the worsening of the scores over a 3 years follow-up. Also, fewer numbers were available for the analysis of persistence in the follow-up, limiting the precision of the estimates.

Another prospective cohort study investigated ADL function (bathing, dressing, walking and transferring) monthly in a sample of community-dwelling adults aged 70 and older, over a five year period. It reported that 81% recovered within a year and maintained independence for at least 6 months (Hardy and Gill, 2004). The recovery rate from self-care restriction at 3 years in the NorStOP population was 61.1%. However, participants in this study were assessed monthly as opposed to the 3 years interval in the NorStOP study, and were in the study for longer (5 years cf 3 years). The NorStOP study may have missed the resolved cases of persistent self-care restriction in this long interval, as this study stated that recovery from disability in essential ADLs among community-dwelling older adults is common,

albeit often brief in duration (Hardy and Gill, 2004). Gill and Hardy's study also took a different approach than the study described in this chapter. They sought to determine the rate of and time to recovery of independent function (defined as not being dependent on carrying out ADL tasks) in community-dwelling older persons who become newly disabled (dependent) in ADLs (bathing, dressing, walking, and transferring). Their measure of ADL included walking as well as self-care tasks, and their data collection methods involved comprehensive home assessments at baseline, 18, and 36 months and monthly telephone interviews for up to 53 months. Comprehensive assessments were completed by trained research nurses using standard instruments. During monthly interviews participants were assessed for each ADL by asking "at the present time, do you need help from another person to perform the task?" Participants who needed help with or were unable to complete one or more of the ADL tasks were considered disabled. Dissimilar to the NorStOP study, participants were not asked about eating, toileting, or grooming on the basis that disability in these ADLs is uncommon without concurrent disability on bathing, dressing, walking, or transferring (Gill at al., 1995; Gill et al., 1995a). However, considering that the methods and approach of this study differ to the NorStOP study, the rates of recovery reported may conceptually explain what is deemed to be an over-optimistic recovery from self-care restriction in this study, as this process is underlined to be transitory.

Other studies that have investigated the level and time course of ADL disability have acknowledged that disability can both increase and decrease over time, and that recovery is quite often followed by decline due to non-linear process of

disability (Nusselder et al., 2006). Therefore recovery or persistence based on two measurements may not reflect permanent change. Nusselder, Caspar and Mackenbach identified 9 trajectories of disability ranging from entirely non-disabled (1) to severely disabled (8 and 9). A person reporting only difficulty in carrying an object would just fit into 'entirely non-disabled' group. Had this person been unable to carry out a task, or had other difficulties, they would then fit into one of the trajectories with disability. Severely disabled persons would be those with at least some difficulty in all disability items (including ADLs), or who had great difficulty, or who was unable to do several items. This study also found significant association between the trajectories of disability and age; those who were younger than 65 years of age were associated with lower risk of almost all trajectories of disability and death.

In terms of the critical comparison with the previous studies which investigated the socio-demographic and health differences and the risk of self-care restriction, Covinsky and colleagues' study (2008) offers interesting comparisons. This prospective longitudinal study examined whether symptomatic arthritis in middle age predicts the earlier onset of difficulties with ADLs (Covinsky et al., 2008). Symptomatic arthritis was measured at baseline according to self-report, by asking participants "Have you ever had, or has a doctor ever told you that you have, arthritis or rheumatism?" The outcome measure was persistent difficulty with ADL tasks and these tasks were bathing, dressing, transferring from a bed to a chair or out of chair, using a toilet, or eating. Those with arthritis were more likely to develop persistent difficulty in ADL function over a 10 year follow-up. Those with

both arthritis and another chronic condition (e.g. depression) were at markedly greater risk for developing difficulties with ADL. Again, the outcome of interest in this study was 'difficulty' in selected self-care activities, which mostly consisted of self-care tasks (other than for transferring) as opposed to 'restriction' in aggregated measure of self-care. The definition of joint pain was also different, as it was restricted to a form of arthritis being presented. Nevertheless, both results suggest that middle aged adults with joint pain are at a greater risk of reporting difficulties and/or restrictions in self-care activities as they age, especially when these adults have a declining mental health.

Limitations

i. Selective loss to follow-up

Loss to follow-up introduces imprecision and the potential for bias (Hennekens and Buring, 1987). Although the sample size for complete case analysis in the this study was relatively large (n=3147), estimates for the onset and persistence of self-care restriction at 3 years were based on 250 and 124 cases respectively, causing imprecision of stratified estimates and odds ratios in multivariable analyses.

Selective loss to follow-up was addressed in this study by sensitivity analysis using multiple imputation. The estimates based on multiple imputation were slightly higher than those from the complete case analysis, suggesting that those lost at follow-up were at higher risk of onset and persistence of self-care restriction. The MI approach was chosen as a suitable method following a set of preliminary

analyses on missing data. This involved the usual exploratory data techniques, such as examining means and standard deviations, and graphing distributions. Also, it was important to understand not just how much data was missing, but the patterns of the missing values. Patterns of missing data were explored using the baseline values. It is important to understand the pattern of missing values as the patterns of missingness may suggest why these values are missing. If a variable that has more missing values than others, it is important to consider why this may be the case. The pattern of missingness influences the type of imputation that can be used. Factors identified in the parsimonious cross-sectional model at baseline (see Chapter 5) were included as covariates in the MI as they were identified as independently associated with self-care restriction at baseline, and were strongly correlated with the missingness in the preliminary analysis. It is suggested that the number of variables entered in the MI increases the accuracy of the estimates (Twisk and Vente, 2002). Inclusion of these variables which were highly correlated with the self-care restriction was made on the assumption that the missingness mechanism was MAR. But if this assumption was not completely true and the data was missing not at random (MNAR), in which the probability of missingness depends upon the value of variables that may themselves be missing (Sterne et al., 2009), then using imputation would still give biased estimates.

Although it is not possible to measure the adequacy of MI in correcting responder bias empirically, it is no longer acceptable to ignore missing values in longitudinal surveys as analysis of complete cases is deemed to be potentially misleading and inefficient. MI is increasingly used and it has been suggested that correctly and

carefully applied imputation methods should reduce bias and increase precision (Spratt et al., 2010). Nevertheless, the author acknowledges that application of MI is not simple, and the MI approach used in this study may not be less biased than the complete case analysis.

ii. Long interval – unobserved episodes of self-care restriction

Due to the long interval between baseline and the 3 years follow-up study, it was not possible to observe changes in the participants' self-care status (restricted yes / no) that occur and resolve in this time period. The effect is that the true incidence rate of episodes of self-care restriction is likely to be much higher than the onset at 6.6% at 3 years. The use of the dichotomous definition for self-care restriction meant that it was not possible to further quantify the amount of change in self-care restriction. For example, those with persistent self-care restriction may not be static but actually experience a worsening of the severity of restriction over time.

iii. Generalisability

The study population at baseline was representative of the general population in England in terms of age and gender. However, at 3 years follow-up those who were in the older age groups and female had higher rates of loss to follow-up, leaving a cohort that was younger with more males compared to baseline. This means that the estimates of the onset and persistence of self-care restriction is likely to be lower than the true rates in the local and national population, but this does not necessarily mean that the study results are not generalisable. The generalisability of the study findings also depends on factors that determine self-

care restriction (e.g. age, physical limitation, depression, lower socio-economic status), and whether the study population is representative of the local and national population for these characteristics. The sensitivity analysis resulted in a small increase in the estimated risk of onset and persistence and was in agreement with the findings of the wider literature on the onset and persistence of ADL disability and links with joint pain. Thus, study findings are compatible with previous research findings; albeit the estimated rates of the onset and persistence of self-care restriction in the local and national population is expected to be higher.

iv. Crude analyses

Analyses that investigated links between the onset and persistence of self-care restriction and pattern, site and number of peripheral joint areas at baseline were crude analyses and established that people with joint pain, in particular with multiple joint pains, have a higher risk of onset and persistence of self-care restriction over the following three years than people without joint pain. The next chapter will examine the association between the onset and persistence of self-care restriction and peripheral joint pain in more detail, considering specific joint characteristics and exploring other factors that modify this relationship.

6.6 Conclusions

Self-care restriction, as measured by the KAP, appears to be an unstable state, with evidence of a substantial majority of people with self-care restriction at one point in time reporting a ‘back-transition’ 3 years later. Study results suggest that people with joint pain, particularly with multiple joint pain areas, and those with

lower socio-economic backgrounds may be at a higher risk of self-care restriction. To identify factors that predict the onset and persistence of self-care restriction in those with joint pain, further analyses within this group is required. The next chapter describes such analyses.

Table 6.12 Summary of key findings

- This chapter described the longitudinal course of self-care restriction in older people in the general population over a three year period, using baseline and three years follow-up data from the NorStOP.
- The onset and persistence of self-care restriction at three years was 6.6% (95% CI: 5.9, 7.5) and 38.9% (CI: 33.7, 44.3) respectively.
- Individuals who were older, of lower socio-economic status, and who were reporting worse physical and mental health at baseline were at increased risk of onset of self-care restriction at follow-up.
- Persistent self-care restriction at three years was higher among men, and those under financial strain.
- The presence of peripheral joint pain, particularly multiple joint pains, was also associated with an increased risk of onset of self-care restriction, but there were no significant associations with persistence.
- In order to identify factors that predict the onset and persistence of self-care restriction in those with joint pain, next chapter describes further analysis within this group.

Chapter 7
Potential predictors of the risk of onset and persistence of restricted self-care in older people with joint pain

7.1 Introduction

The previous chapter (Chapter 6) estimated the risk of onset and persistence of self-care restriction at 3 years in older adults in the general population. The results have shown that older adults with peripheral joint pain, particularly multiple peripheral joint pain, were at a higher risk of reporting self-care restrictions. The next set of analyses focus on those with joint pain to ascertain the potential determinants of restricted self-care in this population.

Persistent pain is commonly experienced by older adults with osteoarthritis, and may result in mobility problems when the pain is severe (Wilkie et al. 2006; Arthritis Research Campaign 2002). The WHO (2003) suggest that eight out of ten people with osteoarthritis experience some kind of physical limitation, and that one in four cannot perform activities of daily living (ADL) due to pain in the small joints of hands and fingers hindering the conduct of these activities. Associations between joint pain/arthritis and future self-care disability were reported in previous studies of ADL (Covinsky et al., 2008; Song et al., 2006; Donald and Foy, 2004; Stuck 1999; Dunlop et al., 1998; Davis et al., 1991; Yelin and Katz, 1990). Earlier studies emphasised the negative influences of joint pain on participation, indicating that pain associated with osteoarthritis is an important predictor of future disability in activities of daily living (Davis et al., 1991). They also highlighted the importance of studying other factors such as psycho-social factors and mental health status to

understand the predictors of functional decrease in those with joint pain (Gignac et al., 2000; Yelin et al., 1987).

A study conducted by Dunlop et al (1998) assessed the longitudinal impact of joint impairment (calculated as presence/absence of tenderness, deformity and/or limitation of lower spine, hips, knees, ankles, feet and upper spine as well as wrist, elbow, shoulder, distal and proximal hand regions) on overall disability and domain-specific thresholds for ADL that are associated with use of long-term care. In a longitudinal study, using 484 adults aged 65 years and older, lower-extremity joint impairment was found as a strong risk factor for future disability associated with the use of long-term care in older adults. One study showed that one-fifth of the population aged over 50 had severe difficulty with activities of daily living due to knee pain. They found strong associations between difficulty in functioning and joint pain duration (Jinks et al., 2002). In another study, in which 4804 participants aged 75 years and over from a UK General Practice (GP) population were followed up for over a year in 1998, it was reported that some degree of joint pain (defined as those pains older people perceived as related to their joints) was reported by 83%, and joint pain was associated with a three-fold increased likelihood of dependency for activities of daily living (Donald and Foy, 2004).

The conceptual model adhered to in this thesis suggests that a range of comorbid health conditions, impairments, and personal and environmental factors may influence the risk of self-care restriction (WHO, 2001). Song and colleagues (2006) examined the population impact of arthritis on disability incidence among older

Americans aged 65 and over using the longitudinal data (1998-2000) from the Health and Retirement Study (HRS); a national probability sample of elderly Americans (n=7758). In this study, older adults who had baseline arthritis had a substantially higher incidence of ADL disability (inability to perform activities of daily living) compared with those without arthritis (9.3% cf 4.5%). Even after adjusting for all other risk factors (demographics, health factors, health behaviors, and medical access) arthritis remained as an independent and significant predictor for developing ADL disability (Song et al., 2006). A subsequent study conducted by Covinsky and colleagues (2008) using the same HRS cohort (n=7543) examined whether symptomatic arthritis (those reporting pain, stiffness and swelling in their joints, were currently taking medications or other treatments for their arthritis or rheumatism, or had seen a doctor for their arthritis or rheumatism in the previous 12 months) in middle age (defined as aged 50+) predicts the earlier onset of ADL difficulties (difficulty with bathing, dressing, transferring from a bed to a chair or out of a chair, using a toilet, or eating). This study also reported that participants with arthritis were more likely to report persistent difficulty with ADL function even after adjusting for other socio-demographic and health factors. Following this, using the same cohort, Covinsky and colleagues (2009) examined the relationship between functional limitations and pain, and reported that participants with significant pain were at much higher risk of reporting functional limitations.

The understanding of the determinants of the relationship between joint pain and ADL disability has evolved with successive studies. In 2008, Machado et al

examined the roles that factors such as activity limitation and depression played on participation restriction in older adults. This study highlighted the importance of making allowances for both physical and psychological consequences of OA, suggesting activity limitation and depressive symptoms mediated the relationship between physical symptoms and subsequent participation restrictions (Machado et al., 2008).

To summarise, previous studies have identified joint specific characteristics (e.g. pain severity) as important risk factors, which increased poor physical functioning and predict future ADL disability in older adults. Other health and psycho-social factors (e.g. depression) could also influence the relationship between joint pain/arthritis and participation restriction, supporting the use of biopsychosocial model when investigating the consequences of health conditions. Thus, this chapter investigates the course of self-care restriction in older people with joint pain. Building on the findings reported in the previous chapter, the analysis will examine the associations between the risk of onset and persistence of self-care restriction and key factors independently associated with restricted self-care in older people at baseline, and test the predictive ability of the parsimonious model to determine whether joint specific characteristics make an additional contribution to the prediction of future self-care restriction.

7.2 Aims and Objectives

The overall aim of this chapter was to identify potential predictors of the onset and persistence of restricted self-care in older adults with joint pain. By investigating the association between joint specific characteristics and the key factors identified as being associated with restricted self-care, this would establish whether the risk profile of those with joint pain differs from the general population. Using baseline and 3-year data from the NorStOP in community-dwelling adults aged 50 years and over with joint pain at baseline the objectives were:

i. To examine the association between risk of onset and of persistence of self-care restriction at 3 years and joint specific characteristics at baseline, such as pain severity, stiffness and chronicity

ii. To investigate links between risk of onset and persistence of self-care restriction at 3 years and individual factors that were independently associated with restricted self-care in the cross-sectional analyses at baseline (‘the parsimonious model’)

iii. To test the extent to which the parsimonious model predicts the risk of onset and persistence of self-care restriction at 3 years and to determine whether joint-specific characteristics make an additional independent contribution to the prediction of future self-care restriction

7.3 Methods

7.3.1 Dataset

This chapter used NorStOP baseline and 3-year follow-up data. The eligibility criteria were:

- ✓ Responded to NorStOP baseline Health Survey
- ✓ Reported hand, hip, knee or foot pain in the past 12 months
- ✓ Consented to further contact
- ✓ Responded to 3-year follow-up Health Survey
- ✓ Completed the Keele Assessment of Participation (KAP) item at baseline and 3-year follow-up

Of the 4089 participants included in the analysis described in chapter 6, 3147 met these criteria.

7.3.2 Outcome

As in chapter 6, the outcome variables were (i) onset of self-care restriction at 3 years and (ii) persistence of self-care restriction at 3 years. The term 'onset' is used to define the reporting of self-care restriction at 3 years in people who were free of self-care restriction at baseline. 'Persistence' is used to define the reporting of self-care restriction at 3 years in people who were restricted in self-care at baseline.

7.3.3 Covariates

Joint-specific characteristics

For each of the four selected peripheral joint sites, (hand, hip, knee, foot) variables on the chronicity and severity of pain, as well as the severity of stiffness (hand, hip, knee only) from the baseline Regional Pains Survey were used.

The Pain and Stiffness subscales of the Australian/Canadian Osteoarthritis Hand Index (AUSCAN: Bellamy et al., 2002) were used for ***severity of hand pain and hand stiffness***. The Pain subscale comprises 5 items (*how much pain do you have in your hands –a) at rest, b) when gripping, c) when lifting, d) when turning, e) when squeezing?*). Each item has the following response options: 'none', 'mild', 'moderate', 'severe' or 'extreme'. Hand stiffness comprises 1 item, (*how severe is stiffness in your hands after first wakening in the morning?)* with the same item response options as for the Pain items. For these analyses, hand pain and stiffness were each dichotomised into 'non-severe' (no items rated as 'severe' or 'extreme') or 'severe' (one or more items rated as 'severe' or 'extreme').

The Pain and Stiffness subscales of the Western Ontario & McMaster Universities Osteoarthritis Index (WOMAC: Bellamy, 1988) were used for ***severity of hip pain and severity of hip stiffness***. The Pain subscale comprises 5 items (*walking on a flat surface / going up or downstairs / at night while in bed / sitting or lying / standing upright*). Each item has the following response options: 'none', 'mild', 'moderate', 'severe' or 'extreme'. Hip stiffness comprises 2 items, (*how severe is your stiffness after waking in the morning? / how severe is your stiffness after*

sitting, lying or resting in the day?) with the same item response options as for the Pain items. Hip pain and stiffness were each dichotomised into 'non-severe' (no items rated as 'severe' or 'extreme') or 'severe' (one or more items rated as 'severe' or 'extreme').

A separate WOMAC was completed for knee pain, scored and dichotomised as above, giving two variables: ***severity of knee pain*** (non-severe, severe), ***severity of knee stiffness*** (non-severe, severe).

The severity of foot pain was measured using the Pain Intensity subscale of the Manchester Foot Pain & Disability Index (FPDI: Garrow et al., 2003). This subscale comprises 5 items (*because of pain in my feet: my feet are worse in the morning / my feet are more painful in the evening / I get shooting pains in my feet / I am unable to carry out my previous work / I no longer do all my previous activities).* Each item is rated as 'none of the time', 'on some days', or 'most/every day'. Foot pain was dichotomised into 'non-severe' (no items were rated as 'most/every day') or 'severe' (one or more items were rated as 'most/every day').

Chronicity of hand, hip, knee and foot pain were each defined as pain present for less than 3 months (non-chronic) or 3 months or more (chronic) in the past 12 months.

Each participant was classed as having non-severe or severe joint pain, as having non-severe or severe joint stiffness (hand, hip, knee only), and as having chronic

or non-chronic joint pain. For participants with joint pain in only one site, these values were for that site. For participants with multiple joint pains (e.g. hand and knee joint pain) the highest value from their site-specific measures was used. For example, if hand pain was classed as non-severe from AUSCAN and knee pain was classed as severe from WOMAC, that participant would be classed as having severe pain.

Variables in the parsimonious model

In the cross-sectional analysis of the baseline data (Chapter 5), a parsimonious model of factors independently associated with restricted self-care in older people in the general population, was derived and validated for use in the general population of adults aged 50 years and over. The factors were:

i. age: categorised as 50-59, 60-69, 70-79, and 80≥
ii. activity limitation: measured using the PF-10 subscale of the SF-36 (0-100: Ware & Sherbourne, 1992) and categorised into tertiles (rather than quartiles as used in the baseline analysis). Categories were highest limitation: ≥35; 2nd highest limitation: 35.1-70.0; and lowest limitation: 70.1-100 respectively. This allowed a better distribution of scores in each category as the population at 3 years follow-up was much smaller than the baseline population due to study attrition
i. depression: measured using the Hospital Anxiety and Depression Scale (0-21: Zigmond & Snaith, 1981) and categorised into none (0-7), borderline (8-10), and definite (11-21) cases

ii. cognitive complaint: measured using the cognitive and alertness behaviour subscale of the Functional Limitation Profile (FLP) (0-100: Bergner et al., 1981) and categorised into three groups (no cognitive impairment (0) / high levels of cognitive impairment (22.5-100) / low levels of cognitive impairment (0.1-22.4)) based on distribution of scores

iii. perceived adequacy of income: a single item with four response options (find it strain to get by from week to week / have to be careful with money / able to manage without much difficulty / quite comfortably off) (Thomas 1999)

iv. educational attainment: a single item asking about qualifications gained through study as an adult (yes/no).

7.3.4 Statistical Analysis

Onset and persistence of self-care restriction at 3 years in older adults with joint pain

In this chapter, the estimates of the risk of onset and persistence of self-care restrictions were based on those with joint pain, which is 76% of the general population sample used in Chapter 6 for the onset analysis (n=2857 cf n=3770), and 91% of the general population sample used in Chapter 6 for the persistence analysis (n=290 cf n=319). Estimates were expressed as percentages.

Association of the risk of onset and persistence of self-care restriction at 3 years with joint-specific characteristics at baseline

Cross-tabulations of onset and persistence of self-care restriction at 3 years with joint-specific characteristics (joint-specific pain severity, stiffness severity and chronicity) at baseline were performed. The direction and strength of associations between joint-specific characteristics, the risk of onset, and risk of persistence of self-care restriction were examined using logistic regression to identify which factors at baseline predicted self-care status at 3 years. Results were summarised as crude odds ratios with 95% confidence intervals, and then adjusted for all covariates (factors in the parsimonious model).

Factors associated with the risk of onset and persistence of restricted self-care

At first, associations between the risk of onset and persistence of restricted self-care at 3 years and each of the factors from the parsimonious model, and joint specific characteristics were investigated using univariable logistic regression. Then, associations between self-care restriction at 3 years and the factors from the parsimonious model were adjusted for the other factors in the model using multivariable logistic regression. The association between the risk of onset and persistence of restricted self-care at 3 years and the parsimonious model was then adjusted for the joint specific characteristics by including joint pain severity, stiffness, and chronicity. Associations were presented as odd ratios with 95% confidence intervals, first unadjusted then adjusted for the non-pain model, and then fully adjusted for the pain model in the multivariable analysis.

Testing the predictive ability of the non-pain and pain models

The predictive power of the parsimonious model was validated at baseline, using both internal and external validation methods (see Chapter 5). In this study, the extent to which the parsimonious model predicts the risk of self-care restriction at 3 years was investigated using multivariable logistic regression. Furthermore, the effects of the addition of joint specific characteristics to this model were also examined using multivariable logistic regression. Previously it was suggested that adjusting for pain may improve models of disability, strengthening associations once the model accounted for pain that was frequent or severe (Adamson et al., 2003).

An important feature of the prediction model is assessing the goodness of fit. This examines the agreement between observed probabilities and predicted probabilities. It is suggested that a predictive model in which the number of observed cases supports the number of cases predicted by the model, indicates good calibration. Good calibration is crucial for attaining a realistic risk adjustment (Van Houwelingen and Le Cessie, 1990). The calibration method performed in this study to examine how well the method fitted the data was the Pearson Goodness-of-fit test. The Pearson Goodness-of-fit test provides the sum of differences between observed and expected outcome frequencies (counts of observations); each squared and divided by the expectation. The resulting value can be compared to the chi-squared distribution to determine the goodness of fit (Laub and Kuhl, 2005). This calibration method was explained in detail in Chapter 5.

The c-index is a measure of discrimination, which is commonly quantified by a measure of concordance. It has the ability to correctly classify participants into high-risk and low-risk groups (Steyerberg et al., 2001). The c-index is the area under the receiver operating characteristic (ROC) curve for binary outcomes, based on the ranks ranges from 0.5 to 1, with higher values indicating better discrimination (Harrell, 2001 et al., 1996; Pepe, 2003). The c-index measure was explained in detail in Chapter 5.

In order to test the equality of the c-index obtained from applying the un-adjusted and adjusted parsimonious model (for joint specific characteristics) to the same sample, the c-index were compared executing *roccomp* command in Stata 11, using the original outcome variables (onset and persistence of self-care restriction at 3 years) as the reference variable, and the predicted probabilities of the un-adjusted and adjusted parsimonious model as classification variables. When a significant probability value is obtained, it suggests that two models are different in their predictive ability (Steyerberg et al., 2001).

The key difference between calibration and discrimination is that the discrimination reveals the ability of a given model to distinguish a status (with case / without case), while calibration measures how much the estimated values of a predictive model match the observed proportion of the event (Tripepi et al., 2009).

Predictive performances of the un-adjusted and adjusted parsimonious model were tested using multivariable logistic regression. Odds ratios with their

respective 95% confidence intervals were used to summarise the contribution of each predictor in the model. Pearson χ^2-statistic and c-index were obtained for each model and for between models using Stata 11.

7.4 Results

7.4.1 The risk of onset and persistence of self-care restriction at 3 years in those with joint pain

Based on 2857 people with joint pain who were not restricted in self-care at baseline, 215 (7.5%; 95% CI 6.6, 8.6) reported the onset of self-care restriction at 3 years and of the 290 people with joint pain and self-care restriction at baseline, 115 (39.7%; CI 34.2, 45.4) reported persistence of self-care restriction at 3 years.

7.4.2 Association of the onset of self-care restriction at 3 years with joint specific characteristics at baseline

In the univariable analysis there were strong associations between the risk of onset of self-care restriction at 3 years and the joint specific characteristics at baseline. The strongest association occurred in those with extreme to severe joint pain. The odds of the onset of self-care restriction at 3 years was 3 times higher in individuals reporting severe to extreme joint pain at baseline compared to those reporting none to moderate pain. This was followed by severe to extreme stiffness of the hand, hip and knee joints. The odds of self-care restriction at 3 years were 2.7 times higher in individuals reporting severe to extreme stiffness at baseline compared to those reporting none to moderate stiffness. Chronicity of joint pain at baseline was also associated with reporting onset of self-care restriction at 3

years. The odds of reporting self-care restriction at 3 years in those with chronic pain at baseline were 1.9 times higher compared to those with duration of joint pain with less than 3 months (Table 7.1).

Table 7.1 Joint-specific characteristics at baseline and onset of self-care restriction at 3 years

3 year response to KAP self-care item of those who were not restricted at baseline	Onset of self-care restriction at 3 years		
	No	Yes	
	N	n	OR (95%CI)
Joint pain severity			
Non-severe	1505	68	1
Severe	920	124	3.0 (2.1, 4.0)
Joint pain stiffness			
Non-severe	1975	127	1
Severe	342	59	2.7 (1.9, 3.7)
Joint pain chronicity			
<3 months	768	38	1
3 months+	1619	154	1.9 (1.3, 2.8)

*cells do not add to 215 due to missing data

7.4.3 Factors associated with the onset of self-care restriction at 3 years

In the univariable analysis, all factors from the parsimonious model at baseline were significantly associated with the risk of onset of self-care restriction at 3 years (Table 7.2). The parsimonious model was a good fit for the data (Pearson's X^2= 350.33 p= 0.88), and was able to moderately discriminate between those with and without the onset of self-care restriction at 3 years (c-index: 0.76, 95% CI 0.72, 0.80). The adjusted model for the joint specific characteristics was not a good fit for the data (Pearson's X^2= 951.41 p= 0.01). However, the model was still able to discriminate between cases with or without self-care restriction at 3 years (c-index: 0.73, CI 0.7, 0.80). Therefore, the addition of joint specific characteristics to the parsimonious model did not improve discrimination (Pearson's X^2= 2.34 p= 0.13).

Table 7.2 Predicting the onset of self-care restriction at 3 years, multivariable analysis

		Unadjusted	Adjusted	Fully adjusted
		OR (95%CI)	OR (95%CI) ‡	OR (95%CI) ‡‡
Age	50-59	1	1	1
	60-69	1.5 (1.0, 2.1)	1.0 (0.7, 1.6)	1.1 (0.7, 1.7)
	70-79	2.1 (1.4, 3.0)	1.1 (0.7, 1.8)	1.2 (0.7, 2.0)
	80+	4.1 (2.6, 6.7)	1.6 (0.8, 2.9)	2.1 (1.1, 4.1)
Activity limitation score (PF 10)				
	lowest (70.1-100)	1	1	1
	2nd highest (35.1-70.0)	3.6 (2.3, 5.5)	2.6 (1.6, 4.2)	2.2 (1.3, 3.8)
	highest ≥35	8.2 (5.4, 12.4)	4.8 (2.9, 7.9)	3.4 (1.9, 6.1)
Hospital depression (HAD) Score				
	Non cases (0-7)	1	1	1
	Borderline cases (8-10)	2.4 (1.6, 3.5)	1.1 (0.7, 1.7)	1.0 (0.6, 1.7)
	Definite cases (11+)	5.1 (3.4, 7.7)	2.5 (1.5, 4.1)	2.3 (1.0, 4.0)
Cognitive complaint				
	No cognitive impairment	1	1	1
	Low levels	2.3 (1.6, 3.3)	1.7 (1.1, 2.6)	1.9 (1.2, 3.0)
	High levels	3.9 (2.7, 5.5)	1.8 (1.2, 2.7)	1.9 (1.2, 3.1)
Perceived adequacy of income				
	Comfortable	1	1	1
	Little difficulty	1.7 (1.0, 2.9)	1.4 (0.8, 2.6)	1.3 (0.7, 2.4)
	Be careful	2.6 (1.6, 4.5)	1.6 (0.8, 2.8)	1.5 (0.8, 2.7)
	Strain	3.5 (1.6, 7.7)	1.6 (0.6, 3.9)	1.1 (0.4, 3.2)
Higher Educational attainment				
	Yes	1	1	1
	No	2.1 (1.5, 3.0)	1.5 (1.0, 2.1)	1.5 (1.0, 2.4)
Joint pain severity				
	Non-severe	1	-	1
	Severe	3.0 (2.1, 4.0)	-	1.4 (0.9, 2.2)
Joint pain stiffness				
	Non-severe	1	-	1
	Severe	2.7 (1.9, 3.7)	-	1.2 (0.8, 1.9)
Joint pain chronicity				
	<3 months	1	-	1
	3 months+	1.9 (1.3, 2.8)	-	0.9 (0.6, 1.4)
Goodness of fit test				
	Pearson X^2	-	350.33	951.41
	P value	-	0.88	0.01
	c-index	-	0.76 (0.72, 0.80)	0.76 (0.73, 0.80)

‡ Adjusted for the parsimonious model factors
‡‡ Adjusted for the parsimonious model and joint specific characteristics (joint pain severity, joint pain chronicity and hand, hip and knee stiffness)

7.4.4 Association of the persistence of self-care restriction at 3 years with joint specific characteristics at baseline

Associations between the risk of persistence of self-care restriction at 3 years with joint specific characteristics at baseline had similar patterns with the associations of the onset of restricted self-care at 3 years. Again, in the univariable analysis, all joint-specific characteristics at baseline were significantly associated with the persistence of self-care restriction at 3 years. The odds of self-care restriction at 3 years were two times higher in individuals reporting severe to extreme joint pain at baseline compared with people reporting none to moderate pain, 1.7 times higher in those reporting severe to extreme stiffness compared to those with none to moderate stiffness, and 1.4 times higher in those with chronic joint pain at baseline compared to those with pain lasting 3 months or less (Table 7.3).

Table 7.3 Joint-specific characteristics at baseline and persistence of self-care restriction at 3 years

3 year response to KAP self-care item of those who were restricted at baseline	Persistence of self-care restriction at 3 years		
	No	Yes	
	n	n	OR (95%CI)
Joint pain severity			
Non-severe	36	14	1
Severe	118	90	2.0 (1.0, 3.8)
Joint pain stiffness			
Non-severe	80	41	1
Severe	71	61	1.7 (1.0, 2.8)
Joint pain chronicity			
<3 months	27	14	1
3 months+	124	91	1.4 (1.0, 2.8)

7.4.5 Factors associated with the persistence of self-care restriction at 3 years

In the univariable analysis most factors from the parsimonious model were associated with the persistence of self-care restriction at 3 years, with the exception of 80+ category within age groups, 2nd highest score category in the activity limitation (PF10), and the absence of higher educational attainment (Table 7.4). Although these associations were mostly insignificant, this may be due to small numbers in each category.

In the multivariable analysis, the parsimonious model was a good fit for the data (Pearson's X^2 = 124.39 p= 0.22). The c-index was 0.68 (95% CI 0.54, 0.70), suggesting that data is consistent with a model that has got a poor discriminative ability. Adjusting the parsimonious model for joint-specific characteristics resulted in a slight improvement in c-index value (0.69; CI 0.62, 0.77), but reduced the goodness of fit (Pearson's X^2 = 162.84 p= 0.11).

Comparing c-indexes for the unadjusted and adjusted parsimonious model suggested there were no statistical difference between the models in terms of their predictive ability (Pearson's X^2 = 1.56 p= 0.21).

Table 7.4 Predicting the persistence of self-care restriction at 3 years, multivariable analysis

	Unadjusted	Adjusted (non-pain model)	Fully adjusted
	OR (95%CI)	OR (95%CI) ‡	OR (95%CI) ‡‡
Age			
50-59	1	1	1
60-69	1.1 (0.6, 2.1)	1.2 (0.6, 2.7)	1.1 (0.5, 2.6)
70-79	1.3 (0.7, 2.5)	1.4 (0.6, 3.2)	1.2 (0.5, 2.9)
80+	0.7 (0.3, 1.5)	0.5 (0.2, 1.6)	0.6 (0.2, 2.0)
Activity limitation score (PF 10)			
lowest (70.1-100)	1	1	1
2nd highest (35.1-70.0)	0.9 (0.3, 2.9)	0.8 (0.2, 3.2)	0.5 (0.1, 2.4)
highest ≥35	2.2 (0.9, 5.5)	2.0 (0.7, 6.2)	1.1 (0.3, 4.1)
Hospital depression (HAD) score			
Non cases (0-7)	1	1	1
Borderline cases (8-10)	1.8 (1.0, 3.4)	1.9 (0.9, 4.0)	2.4 (1.1, 5.5)
Definite cases (11+)	2.6 (1.4, 4.6)	1.8 (0.9, 4.0)	2.4 (1.1, 5.4)
Cognitive complaint			
No cognitive impairment	1	1	1
Low levels	1.1 (0.5, 2.3)	0.6 (0.3, 1.5)	0.7 (0.3, 1.7)
High levels	1.8 (1.0, 3.4)	0.8 (0.4, 1.9)	0.8 (0.3, 2.0)
Perceived adequacy of income			
Comfortable	1	1	1
Little difficulty	1.5 (0.4, 5.2)	1.8 (0.4, 8.1)	2.2 (0.5, 10.3)
Be careful	1.9 (0.6, 6.1)	1.8 (0.4, 7.8)	1.8 (0.4, 8.2)
Strain	4.8 (0.2, 19.1)	4.5 (0.8, 24.6)	3.5 (0.6, 20.1)
Higher educational attainment			
Yes	1	1	1
No	1.0 (0.6, 1.9)	1.1 (0.5, 2.9)	1.3 (0.6, 2.9)
Joint pain severity			
Non-severe	1	-	1
Severe	2.0 (1.0, 3.8)	-	1.2 (0.4, 3.8)
Joint pain stiffness			
Non-severe	1	-	1
Severe	1.7 (1.0, 2.8)	-	1.4 (0.7, 2.9)
Joint pain chronicity			
<3 months	1	-	1
3 months+	1.4 (1.0, 2.8)	-	0.9 (0.3, 2.4)
Goodness of fit test			
Pearson X^2	-	124.39	162.84
P value	-	0.22	0.11
c-index (95%CI)	-	0.68 (0.54, 0.70)	0.69 (0.62, 0.77)

‡ Adjusted for the parsimonious model factors

‡‡ Adjusted for joint specific characteristics (joint pain severity, joint pain chronicity and hand, hip and knee stiffness)

7.5 Summary of results

All joint specific characteristics were associated with the risk of onset and persistence of self-care restriction at 3 years in the univariable analysis. People with severe pain or stiffness were at a higher risk, as were those with more chronic peripheral joint pain symptoms.

Older age, greater activity limitation, more depressive symptoms, lower educational attainment, and cognitive complaint were independently associated with risk of onset of self-care restriction at 3 years. However, only depressive symptoms were associated with persistence of self-care restriction, which might be explained by the lack of power in the statistical analysis due to smaller sample.

The combination of age, activity limitation, educational attainment, perceived financial strain, cognitive complaint, and depressive symptoms was able to predict the onset of self-care restriction at 3 years with good discriminative ability. However, these were not able to predict the risk of persistence of self-care at 3 years, although again this may be related to loss of power in this analysis. Joint-specific characteristics did not add to the performance of the parsimonious model in predicting the onset or persistence of restricted self-care at 3 years.

7.6 Discussion

7.6.1 Principal findings

Among adults aged 50 years and older with peripheral joint pain, those with more severe, chronic symptoms are at higher risk of onset of self-care restriction, and of that restriction persisting over time. However, these joint-specific characteristics did not provide any added value in predicting the future course of self-care restriction over and above age, educational attainment, perceived financial strain, cognitive complaint, activity limitation, and depressive symptoms. The predictive ability of these latter factors was still only moderate (c-index: 0.76 for onset, 0.69 for persistence).

7.6.2 Critical comparison against previous studies

Previous studies into older adults with osteoarthritis reported strong links between pain, psychological factors and disability (Machado et al., 2008; Ay and Evcik, 2008; Cook et al., 2007; Ferreira and Sherman 2007; Gignac et al., 2006; Donald and Foy, 2004; Reid et al., 2003:a-b; Cardol et al., 2002). A study conducted using 226 community-dwelling adults aged 70 years and over in New Haven, Connecticut, USA, aimed to determine the relationship between psychological factors and the occurrence of disabling musculoskeletal pain in older people using restricted activity as a disability indicator. This study found that depressive symptoms were associated with greater disability in older adults due to joint pain experienced, and identified the presence of depressive symptoms as a key factor associated with the occurrence of disabling musculoskeletal pain in community-

dwelling older people (Reid et al., 2003:b). Reid and colleagues also suggested that the adherence to treatment and rehabilitative recommendations may be lower in older people with musculoskeletal pain and depression than those without depression, which may partially explain the risk for pain-related disability (Reid et al., 2003: b). Although the definitions of pain and restriction used in Reid and colleagues' study is different to this thesis, both studies point to the strong relationship between pain, depression and restricted activity. In the NorStOP sample, those with severe and chronic symptoms were also at a higher risk of self-care disability, but the inclusion of these symptoms in predictive models of self-care restriction did not provide any added value. The odds of reporting the onset and persistence of self-care restriction in those with joint pain at baseline were still twice as high in those with depression than in those without, after the inclusion of joint specific characteristics in the predictive models. This may be due to high correlations between the depressive symptoms and severe/chronic joint pain, as strong associations with these variables were also supported by previous studies (Cook et al., 2007; Donald and Foy, 2004; Reid et al., 2003:b).

Another study that emphasised the importance of the inclusion of psychological factors when measuring the relationship between pain and disability is the Longitudinal Study of Joint Pain conducted by Donald and Foy (2004). As reported in the systematic review (Chapter 2), Donald and Foy (2004) described the natural history of joint pain in a general practice sample of adults aged 75 years and over in the UK. Study results suggested that joint pain was associated with a threefold increase in the likelihood of dependency for ADL (i.e. dressing dependency and

personal hygiene) and psychological distress. This study concluded that the frequency of joint pain fluctuates over time, and is strongly linked to psychological factors. This study also highlighted that, even though the joint destruction from arthritis would be permanent once developed, the severity and frequency of joint pain may be intermittent and that the severity of joint pain can be influenced by psychological factors (Donald and Foy, 2004). Psychological factors such as depression and cognitive impairment were key factors associated with self-care restriction in this study, and adjusting the associations between these factors and self-care restriction for severe and chronic pain did not alter these relationships. Given the results of the previous studies done by Donald and Foy (2004) and others, these results may suggest that those with long lasting severe pain may be more depressed than those who do not experience such symptoms, which then may result in a negative appraisal of their needs for self-care being met, as and when wanted. For example, an individual with chronic severe pain may experience activity limitations due to pain, as a result, become depressed, and may not be motivated to carry out the personal care activities such as washing and dressing, and caring for body parts up to their normal standard, thus perceive themselves as being restricted in self-care.

Other studies also support strong links between depression and disability. A prospective cohort study of older adults conducted by Yang Yang and George (2005) suggested that both onset and persistence of functional disability are significantly associated with increased depressive symptoms over time; recovery on the other hand is a marker of decreased depressive symptoms. As it was

observed in both Chapter 6 and 7, a substantial number of adults with restricted self-care at baseline had recovered at the time of the 3 year follow-up study. Given the previous studies of self-care disability this was an unusual finding. According to these studies, self-care disability was one of the last disabilities experienced by older people, and a marker of becoming dependent on others, thus such recovery in 3 years was unexpected. However, restriction in self-care was measured from the person's perception of their self-care needs being met 'as and when wanted' in this study, therefore the recovery did not mean that the limitations were no longer there, but it meant that the person did not perceive themselves as restricted in self-care anymore as their needs were being met as and when they had wanted. This 'changeable nature' of person-perceived participation restriction may be partially explained by the healthier cohort at 3 years, as participants had reported better physical and mental health and less depression compared with those lost to follow-up at 3 years. Thus, the back-transitions in those with person-perceived restricted self-care may be due to improved psychological factors, and / or change in the environmental factors (e.g. receipt of help and assistance or use of aids for self-care activities).

7.6.3 Limitations

The sample used in this study was 77% of the general population sample used in Chapter 6. Thus, limitations discussed in the previous chapter with regards to selective loss to follow-up, and generalisability of the findings also apply to the study conducted in this chapter.

The definition of joint pain used in this study was self-reporting of joint pain. As the results have shown that more severe pain is associated with a higher risk of onset and persistence of self-care restriction at 3 years, current estimates for the risk of onset and persistence might be lower than for samples with radiographic osteoarthritis. However, this does not necessarily mean that the patterns of associations would be different for those with radiographic osteoarthritis.

7.7 Conclusions

Among older adults with peripheral joint pain, those with more chronic, severe pain are at increased risk of developing self-care restriction and of this persisting. However, this appears to be due to the relationship between pain and other socio-demographic and health factors, rather than being purely the result of the symptoms of joint specific characteristics. These findings indicate that self-care restriction in those with joint pain are due to a number of reasons and may be explained by complex interactions between biopsychological factors.

Having found that restriction in self-care is multifactorial, the next chapter examines the role of environmental factors on self-care in older adults with joint pain.

Table 7.5 Summary of key findings

- This chapter investigated the course of self-care restriction in older people with joint pain, building on the findings reported in the previous chapter. The analyses examined the associations between the risk of onset and persistence of self-care restriction and key factors independently associated with restricted self-care in older people at baseline, and test the predictive ability of the parsimonious model to determine whether joint specific characteristics make an additional contribution to the prediction of future self-care restriction.

- The onset and persistence of self-care restriction at three years in people with joint pain was 7.5% (95% CI: 6.6, 8.6) and 39.7% (CI: 34.2, 45.4) respectively.

- Chronic joint pain, severe pain and stiffness were associated with onset and persistence of self-care restriction at 3 years (i.e. for onset, severe vs. non-severe pain: crude OR 3.0 (2.1, 4.0), chronic vs. non-chronic pain (<3 months): 1.9 (1.3, 2.8), severe vs. non-severe stiffness: 2.7 (1.9, 3.7); for persistence, 2.0 (1.0, 3.8); 1.4 (1.0, 2.8); 1.7 (1.0, 2.8) respectively).

- For all joint pain factors, adjustment for the factors associated with self-care restriction in the general population attenuated all associations. Being aged 80 years and over, lower educational attainment, higher levels of activity limitation, depression and cognitive impairment were independently associated with onset (Aged ≥80 vs. 50-59: Adj. OR 2.1 (1.1, 4.1), lower vs. higher educational attainment: 1.5 (1.0, 2.4), highest (≤35) vs. lowest activity limitation (70.1-100) 3.4 (1.9, 6.1), definite (11+) vs. non cases of depression (0-7): 2.3 (1.0, 4.0), high levels of cognitive impairment vs. no cognitive impairment: 1.9 (1.2, 3.1).

- Only depression was associated with persistence of self-care restriction (adj. OR 2.4 (1.1, 5.4)) after adjustment for all other covariates. However, this might be explained by the lack of power in the statistical analysis due to smaller sample.

- Perceived self-care restriction, as assessed by the KAP, changes over time. Older adults with chronic and severe peripheral joint pain have an increased risk of developing self-care restriction and of this persisting. In a multivariable model these joint-specific characteristics were found not to be independent predictors, suggesting that, in the absence of significant bias or confounding, the effect of joint pain on self-care restriction may be through its effects on activity limitation, depression, and cognitive complaint.

- These analyses confirm that restriction in self-care is determined by multiple factors. Therefore the next chapter considers the role environmental factors play in the relationship between self-care and joint pain.

Chapter 8

The concordance between activities and participation and the impact of environmental factors on self-care

8.1 Introduction

Throughout this thesis, self-care restriction in community-dwelling older adults is measured using an aggregated self-care item from the Keele Assessment of Participation (KAP) (Wilkie, 2005). Response to this item involves aggregation of participation in a number of tasks, where individuals interact with their environment to look after themselves "as and when they want"; this includes personal care tasks such as washing, toileting, dressing, feeding and maintaining health. Some of these specific tasks have been referred to as basic activities of daily living (ADL) (Naik et al., 2004; Gignac et al., 2000; Gill et al., 1998) and traditionally have been measured in epidemiological studies with reference to *difficulty* (e.g. none, some, a lot, unable) and *dependence* (requiring help from another person). This is in contrast to the measurement of person-perceived self-care restriction by the KAP which measures performance rather than capacity and whether ones' needs were met "as and when they have wanted". Within this concept of self-care, it is therefore plausible for an individual to have difficulty with a task or even to depend on others for its completion, but still to feel as though their self-care needs have been met "as and when they have wanted" (i.e. they have limited capacity (activity limitation) but they continue to participate). Throughout this thesis, similarities and differences between person-perceived self-care restriction and task-specific

activity limitation have been discussed, but the level of agreement between these two constructs has not been examined empirically.

The ICF model encourages consideration of the impact of social and environmental factors on all components of functioning and restriction, and it is important to take these factors into account when examining the occurrence and determinants of self-care restriction. Contextual factors - both personal and environmental - may help to explain the difference in the occurrence of task specific activity limitation and self-care restriction. Although some contextual factors were included in the analyses described in the previous chapters (for example occupational class, educational attainment, structural aspects of social networks, perceived adequacy of income), these are classified as “personal” factors in the ICF and are not specific to the domain of self-care. Environmental factors particular to self-care were not measured in the baseline survey or at three year follow-up. However, data on environmental factors that link specifically to self-care were collected in the 6-year follow-up study and allow examination of their role on restriction.

This chapter investigates the level of agreement between the measures of task-specific activity limitation and person-perceived self-care restriction, and studies the impact that environmental factors have on this relationship in order to gain a better understanding of the differences between self-care restriction measured by KAP, and self-care disability measured using traditional ADL measures.

8.2 Aims and Objectives

The overall aims of this chapter are to establish the level of agreement between measures of task-specific activity limitation and person-perceived self-care restriction, and the impact environmental factors have on this relationship. The specific objectives of this study are:

i. To compare the frequency and age and gender distribution of task-specific activity limitations, multiple activity limitation, and relative severity of each limitation in relation to frequency and age and gender distribution of person perceived self-care restriction
ii. To estimate the level of agreement between estimates of person-perceived self-care restriction and task-specific activity limitation
iii. To determine and compare the risk profiles of person-perceived self-care restriction and task-specific activity limitations
iv. To determine whether environmental factors moderate the relationship between restricted self-care and task-specific activity limitation
v. To investigate the associations between task-specific activity limitation and person-perceived participation restriction by the need for, and use of, environmental facilitators
vi. To examine the socio-demographic, health and joint specific characteristics of the study sample to elucidate the wider factors associated with the need for, and use of, environmental facilitators in older adults with joint pain

8.3 Methods

8.3.1 Dataset

This chapter used data collected through the Health Survey Questionnaire of the NorStOP project at 6-year follow-up. This constrained the analysis to cross-sectional data from surviving respondents of the NorStOP cohort at 6 years. However, the content of the Health Survey Questionnaire at 6-year follow-up had been supplemented by a series of detailed questions on activity limitation on individual self-care tasks, as well as information on use of key environmental facilitators for self-care, notably personal help and assistance and aids and adaptations. The eligible sample were adults aged 50 years and over, reporting joint pain at 6 years follow-up, who responded to the KAP self-care item (person-perceived self-care restriction), and to at least one of the task-specific activities items (washing and bathing, dressing, caring for body parts, eating and drinking and toileting).

8.3.2 Outcome

There were two outcomes of this study, (i) self-care restriction at 6 years; which was measured using the KAP self-care item (restricted in self-care/ not restricted in self-care) and (ii) task-specific activity limitation; which was measured by a single item asking participants "*Does your health now limit you in these activities*?, If so, how much" the answer options were 'Yes, limited a lot / Yes, limited a little / No, not limited at all.' For the purpose of the selected analyses, this item was either used as it is, or dichotomised by categorising those who were limited a little

and limited a lot into the “limited” category and those who were not limited at all into the “not limited” category.

8.3.3 Covariates

The ICF framework was used to categorise variables (Table 8.1).

Environmental factors

In the NorStOP 6-year follow-up questionnaire, environmental factors were measured under the sections of ‘help and assistance’ and ‘aids and appliances’ as summarised below:

Help and Assistance (*Support and relationships*)

The perceived need for, and actual receipt of help and assistance were measured for each of the following task-specific activities: washing and bathing; looking after your skin, teeth, hair and nails; putting on and taking off clothes; eating and drinking and using a toilet. Participants were asked “*During the past 4 weeks have you had help from anyone else, such as family (including your suppose), friends, a health professional (e.g. nurse, occupational therapist, physiotherapist) or someone from social services (e.g. home help, care worker), to do the following activities?* Response options were ‘No I did not need any help / No, but I have needed help / Yes, I have had help from family or friends / Yes, I have had help from a health professional or from social services’ (Table 8.1).

Aids and adaptations (*Products and technology for personal use in daily living*)

The use of aids and adaptations to help with selected task-specific activities was measured by asking the participants "*During the past 4 weeks have you used any of the following aids and appliances to help with your daily activities*?" Examples were; aids to help you wash and dress / aids to help you with cooking or eating / raised chair or bed / special stool / raised toilet seat / hand rails in your bathroom / bath seat / shower seat and modified bath or shower' (Table 8.1). Response options were yes/no.

Demographic, socioeconomic and health factors

Other covariates used in the analysis to describe the characteristics of those who used environmental facilitators were chosen according to their level of association with restricted self-care (i.e. those variables from the parsimonious model), and to summarise the physical and mental health status (SF-12) of the participants (see Chapter 4 for details for these measures) (Table 8.2).

Table 8.1 Key variables on self-care restriction, task-specific self-care activity limitation, and environmental facilitators/barriers and their mapping to ICF

Concept	Domain/subdomain	Questionnaire item	Response options
Participation restriction	d5 Self-care	*'During the past 4 weeks, my self-care needs (examples are washing, toileting, dressing, feeding, maintaining health) have been met, **as and when I have wanted**'* ***NB**. This item was dichotomised as restricted/ not restricted (see chapter 5 for methods)*	*All the time* *Most of the time* *Some of the time* *A little of the time* *None of the time*
Activity limitation	d510 Washing oneself d520 Caring for body parts d530 Toileting d540 Dressing d550 Eating / d560 Drinking	*'Does your health now limit you in these activities? If so, how much?'* - Washing and bathing - Looking after your skin, teeth, hair and nails - Using a toilet - Putting on and taking off clothes - Eating and drinking	*Yes, limited a lot* *Yes, limited a little* *No, not limited at all*
Environmental factors	e3 Support and relationships / e575 General social support services, systems and policies / e580 Health services, systems and policies	*During the past 4 weeks have you had help from anyone else, such as family (including your spouse), friends, a health professional (e.g. a nurse, occupational therapist, and physiotherapist) or someone from social services (e.g. home help, care worker) to do the following activities?* - Washing and bathing - Looking after your skin, teeth, hair and nails - Using a toilet - Putting on and taking off clothes - Eating and drinking	*No, I didn't need help* *No, but I have needed help* *Yes, I have had help from family or friends* *Yes, I have had help from a health professional or from social services*
Environmental factors	e115 Products and technology for personal use in daily living / e155 Design, construction and building products and technology of buildings for private use	*'During the past 4 weeks have you used any of the following aids and appliances to help with your daily activities?'* - Aids to help you wash and dress - Aids to help you with cooking or eating - Raised chair or bed/special stool - Hand-rails in your bathroom/bath seat/shower seat - Modified bath or shower	*Yes* *No*

Table 8.2 Other covariates used in this chapter

Construct	Measure	Scoring	Reference
Demographic	Age	Years	
	Gender	Male, Female	
Socioeconomic	Educational attainment	Yes/ No	
	Perceived adequacy of income	Comfortable Little difficulty Be careful Strain	(Thomas, 1999)
Health Factors			
Depression	HADS: Depression	0-21 (Mean: SD) +	(Zigmond & Snaith,1983)
Cognition and alertness	Functional Limitations Profile – Cognitive and Alertness behaviour subscale	No impairment Low levels High levels	(Bergner et al.1981)
Joint pain	No of peripheral joint pain	0-4	
Joint specific characteristics	Hand pain intensity Hip pain intensity Knee pain intensity Foot pain intensity	0-10*	(Von Korff et al.1992)
Physical health Mental health	SF-12 PH** SF-12 MH++	0-100 0-100	(Ware et al. 1998)

+ 0 indicate no depression and 21 indicate severe depression
* 0 indicates no pain 10 indicate pain as bad as could be
** Medical Outcomes Study Short-Form 12 for physical health
++Medical Outcomes Study Short-Form 12 for mental health

8.3.4 Level of agreement between activities and participation

In previous chapters, the prevalence estimates of person-perceived self-care restriction were compared to reported estimates of task-specific activity limitation in the wider literature to discuss the implications of the study findings. Through these comparisons it was noted that similar prevalence estimates can be obtained from activity and participation measures, even though they differ conceptually. Therefore, in this analysis, this overlap is examined empirically to establish whether these are two distinct concepts in measuring self-care disability in older people.

The 'agreement' between measures of activities and participation were long debated in the previous literature and a few studies attempted to empirically distinguish between the two concepts (Badley, 2008; Whiteneck, 2006; Schuntermann 2005; Barral, 2004; Jette et al., 2003; Nordenfelt, 2003; Simeonsson et al. 2003). Together, using different methodologies, these studies provided conceptual and empirical arguments as to why activities and participation were two distinct concepts; emphasising how everyday tasks involve physical activity, and participation required individuals to interact with complex biopsychosocial factors. However, this thesis is not just another conceptual/empirical argument into differentiating between activities and participation. This thesis provides empirical support that self-care should be considered as a form of participation, and occurs as a result of complex interactions with other personal and environmental factors in the context of an

individual's life. It also suggests that participation restriction should be more appropriately measured against an individual's own standards (i.e. person-perceived "needs have met as and when I have wanted"), and not against the population norms, which may significantly vary across different socio-demographic and economic groups.

When evaluating a diagnostic test we assume that participants can ultimately be categorised as cases or non-cases. This differentiation is made by a standard test that calculates the sensitivity, specificity, and positive and negative predictive values to ascertain whether the test identifies those with or without the disease accurately (Lang and Secic, 1997). If at all possible, the diagnostic test should yield, 100% sensitive and 100% specific for the disease in question and should be applied to all participants in the study. The test should identify all cases of the disease that are of significance, but should not identify any cases that are of no significance. However, such a perfect reference standard probably does not exist. Therefore, defining the reference standard usually involves a degree of compromise. The reference standard used in this study was person-perceived self-care restriction. The analysis examines whether this captures task-specific activity limitation by task (e.g. washing and bathing limitation) and count (one or more limitations, two or more limitations), with the aim of establishing whether what the KAP measures differs to limitation in specific self-care tasks.

Introducing bias through the application of diagnostic tools may result in inflated estimates, which produce over-optimistic results within sensitivity and specificity analyses. In order to avoid bias it should be ensured that the test is evaluated in a cohort of participants presenting with suspected disease, and that the test is compared to an independent reference standard (Knottnerus et al., 2002).

It is recommended that, to estimate the potential role of chance in diagnostic tools, results should be reported with 95% confidence intervals (Porta, 2008). It is also understood that the prevalence of the disease is just as important as the larger sample size to provide more precise estimates. This is due to the fact that in diseases where the expected prevalence is low, there will be fewer people with the disease to estimate sensitivity, even though precise estimates of specificity can still be obtained (Porta, 2008).

8.3.5 Statistical Analysis

Main hypothesis tested

This thesis puts forward the hypothesis that participation restriction in self-care is not the same as task-specific activity limitation in self-care. Measuring self-care disability from the perspective of person-perceived participation restriction provides estimates of the prevalence, distribution and associated factors that contrast with those obtained from more traditional self-care disability measures. To test this hypothesis, analyses were undertaken in this chapter to address specific objectives set out below.

Objective 1: To compare person-perceived self-care restriction and task-specific activity limitation by age and gender

This analysis aimed to summarise the prevalence of person-perceived participation restriction and task-specific activity limitation in self-care to identify similarities and differences in the occurrence and pattern of self-care disability measured by these two different constructs.

Descriptive Analysis

The relative frequency and age and gender distribution of task specific activity limitation (e.g. washing oneself, dressing oneself), multiple activity limitation (e.g. one or more, two or more…), and relative severities (limited and limited a lot) of each limitation were cross-tabulated against the relative frequency and age and gender distribution of person-perceived self-care restriction. This was conducted using frequencies and percentages to observe differences in occurrence in terms of prevalence, difficulty threshold and pattern of distribution. Due to small numbers available for analysis, differences in groups were not tested for statistical significance.

Objective 2: To determine the level of agreement between measures of task specific activity limitation and self-care restriction

The results of the analysis undertaken to meet the first objective may provide some evidence on the possible differences in the measurement of participation restriction and task-specific activity limitation in self-care. However, additional

analysis is required to estimate the level of agreement between these two measures, as the same prevalence estimates can be obtained from two measures even if they describe completely different people. Thus, to understand how strongly person-perceived participation restriction in self-care is related to the number, severity, and type of task-specific activity limitation, it is necessary to look at individuals.

Statistical Analysis

The agreement between the two measurement constructs (KAP self-care item and task-specific self-care restriction) was tested by cross-tabulating those with task-specific activity limitation and person-perceived self-care restriction. Sensitivity and specificity analyses were then conducted as below, stratified by individual limitations (e.g. washing oneself, dressing oneself), and count of task-specific activity limitation (e.g. limitation in one or more, two or more activities) for two different cut-off points; (i) limited: those who answered as *limited a little* + *limited a lot*) and (ii) limited a lot: those who responded as *limited a lot.*

Sensitivity and specificity of the KAP measure was tested as below;

	Task-specific activity limitation	
Self-care restriction measured by KAP	limited	not limited
restricted	**a**	**b**
not restricted	**c**	**d**

a= true positive (individuals with task-specific activity limitation detected by the test as having person-perceived self-care restriction)

b= false positive (individuals with no task-specific activity limitation detected by the test as having person-perceived self-care restriction)

c= false negative (individuals with task-specific activity limitation detected by the test as not having person-perceived self-care restriction)

d= true negative (individuals with no task-specific activity limitation detected by the test as not having person-perceived self-care restriction)

Sensitivity = a/ a+c

True positive/ true positive + false negative

Specificity = d/ b+d

True negative/ false positive + true negative

Predictive value of a positive test result (PPV) = a/ a+b

True positive/ true positive + false positive

Predictive value of a negative test result (NPV) = d/ c+d

True negative/ false negative + true negative

Percentage agreement is (a+d) / (a+b+c+d) * 100

Objective 3: To identify the risk profiles of person-perceived self-care restriction and task-specific activity limitation

Following the estimation of the level of agreement between the two constructs (objective 2), this part of the analysis aims to establish how different the risk factors are for person-perceived participation restriction and task-specific activity

limitation in self-care, and to determine whether environmental factors moderate the relationship between these two constructs.

Statistical analysis

Cross-sectional associations were examined for person-perceived self-care restriction and for each factor in the parsimonious model (plus gender). Crude associations were adjusted for age and gender using multivariable logistic regression (column (a)). This analysis was repeated using task-specific activity limitation (limited in one or more task-specific activity) as the dependent variable (column (b)) to allow comparisons. Following these analysis, associations between person-perceived restricted self-care (a) and parsimonious model variables were adjusted using multivariable logistic regression; first for task-specific activity limitations (b) (as activity limitation in the parsimonious model was previously measured using PF-10 – a conceptually different tool to task-specific activity limitation in self-care as it actually measures 'physical limitation'), secondly for the environmental factors (c), and finally both for task-specific activity limitation and the environmental factors (receipt of help and assistance and/or use of aids and adaptations) to examine factors moderating this relationship.

Objective 4: To determine if environmental factors moderate the relationship between task specific limitation and self-care restriction

First of all, associations between task specific activity limitation, person-perceived self-care restriction and environmental factors were assessed. Then, to

understand what determines the need for, and the use of, environmental facilitators, such as aids and assistance, the analyses aimed to identify factors associated with the use of environmental facilitators in those with task-specific activity limitation.

Statistical analysis

Associations between those who are limited/restricted in self-care

Cross-tabulation was used to examine the associations (using percentages) between task specific activity limitation and person perceived self-care restriction. This was performed, first overall and then separately for: (a) those with no expressed need for assistance; unmet need in assistance (expressed need but non-receipt of help); and those who are in receipt of help (expressed need and receipt of help from friends and family / health professionals / social services), and (b) those who use aids/assistance and those who do not.

Socio-demographic, health and joint-specific characteristics

The socio-demographic, health and joint-specific characteristics of those who are limited in task-specific activities (e.g. limited in washing oneself, dressing) were cross-tabulated with help and assistance status. Frequencies and percentages to were used to allow comparisons between different groups. Differences between the groups were tested using *chi-squared* test for non-parametric variables and the *independent samples t-test* for parametric variables, and expressed as p-values.

8.4 Results

8.4.1 Comparison of person-perceived self-care restriction and task-specific activity limitation by age and gender

Of those responders with joint pain at 6 years follow-up (n=2313), 2282 (99%) had completed KAP self-care and task-specific activity limitation items; of those 58% were female and the mean age was 69 (SD: 8.9). Overall, 208 (9%) had reported person-perceived self-care restriction, and 65% of those were female with a mean age of 73 (SD: 9.1). When stratified by gender, the prevalence of restricted self-care appeared to be higher in women than men (10% cf 8%). This remained the same across the age groups, increasing with age, with the exception of the 60-69 age group category, where the gender distribution was more equal. Men reported slightly higher restriction in self-care than women (Age groups 50-59 (8% cf 4%); 60-69 (5% cf 6%); 70-79 (14% cf 9%); 80+ (20% cf 15%)).

ADL limitations, by count

Of 2282 responders with joint pain, 730 (32%) had task-specific activity limitation in one or more self-care activities, and 167 of those had reported severe limitations. Overall, the prevalence of task-specific activity limitation was slightly higher in women (33% cf 30%), and more women reported severe limitations (8% cf 6%). The difference between genders in reporting task-specific activity limitation narrowed with increasing number of limitations (e.g. any two or more; three or more limitations…), as well as the severity of these limitations. However the smaller numbers of participants in these groups may have affected the prevalence

estimates. When the prevalence of task-specific activity limitation was stratified by age groups and gender, similar patterns to person-perceived self-care restriction were observed. The prevalence of task-specific activity limitation increased with increasing age and was higher in women, with the exception of the 60-69 age group, where limitations were higher in men, although women reported higher rates of severe limitation (Table 8.3).

ADL limitations, by each ADL

In those with joint pain at 6 years, 605 (27%) had reported limitation in washing; 524 (23%) had reported limitation in dressing; 378 (17%) had reported limitation in caring for body parts; 135 (6%) had reported limitation in eating and drinking and 182 (8%) had reported limitation in toileting. Washing limitation was higher in women (28% cf 25%), and they reported more severe limitations (7% cf 4%), but there were no differences in between genders for other ADL limitations. Again, women appeared to experience more severe limitations in caring for body parts than men, whilst men reported more severe limitations in toileting (1% cf 2%).

Similar to the person-perceived self-care restriction and task-specific activity limitation by count, limitations in each task-specific task increased with age, and were higher in women in the 80 years and older age group (Table 8.3b and Figure 8.1).

Table 8.3 Comparative occurrence and distribution by age and gender of self-care restriction and self-care activity limitation

		All ages n=2282		50-59 n=322		60-69 n=949		70-79 n=722		80+ n=289	
	n	Female 1331 (58)	Male 951 (42)	Female 186 (58)	Male 136 (42)	Female 557 (59)	Male 392 (41)	Female 407 (56)	Male 315 (44)	Female 181 (63)	Male 108 (37)
Person-perceived participation restriction n %											
Self-care restriction	208	136 (10)	72 (8)	15 (8)	5 (4)	28 (5)	24 (6)	56 (14)	27 (9)	37 (20)	16 (15)
Activity limitation by count n %											
any 1+more limited	730	442 (33)	288 (30)	44 (24)	32 (24)	119 (21)	102 (26)	158 (38)	102 (32)	121 (63)	52 (46)
limited a lot	167	113 (8)	54 (6)	9 (5)	5 (4)	27 (5)	16 (4)	41 (10)	23 (7)	36 (19)	10 (9)
any 2+more											
limited	500	292 (25)	208 (24)	30 (17)	21 (17)	78 (15)	77 (21)	104 (29)	72 (25)	80 (53)	38 (39)
limited a lot	71	43 (3)	28 (3)	5 (3)	3 (2)	11 (2)	8 (2)	14 (4)	12 (4)	13 (8)	5 (5)
any 3+more											
limited	336	198 (18)	138 (17)	18 (11)	17 (14)	54 (11)	48 (14)	68 (21)	50 (19)	58 (45)	23 (28)
limited a lot	38	22 (2)	16 (2)	3 (3)	2 (2)	4 (1)	3 (1)	8 (2)	6 (2)	7 (4)	5 (5)
any 4+more											
limited	175	94 (9)	81 (11)	10 (7)	9 (8)	31 (7)	29 (9)	29 (10)	29 (12)	24 (26)	14 (19)
limited a lot	24	10 (1)	14 (2)	1 (1)	2 (2)	2 (0.4)	3 (1)	3 (1)	5 (2)	4 (3)	4 (4)
all 5											
limited	83	46 (5)	37 (5)	7 (5)	5 (5)	12 (3)	13 (4)	14 (5)	3 (6)	13 (16)	6 (9)
limited a lot	11	5 (0.4)	6 (1)	1 (1)	2 (2)	2 (0.4)	1 (0.3)	1 (0.3)	2 (1)	1 (1)	1 (1)

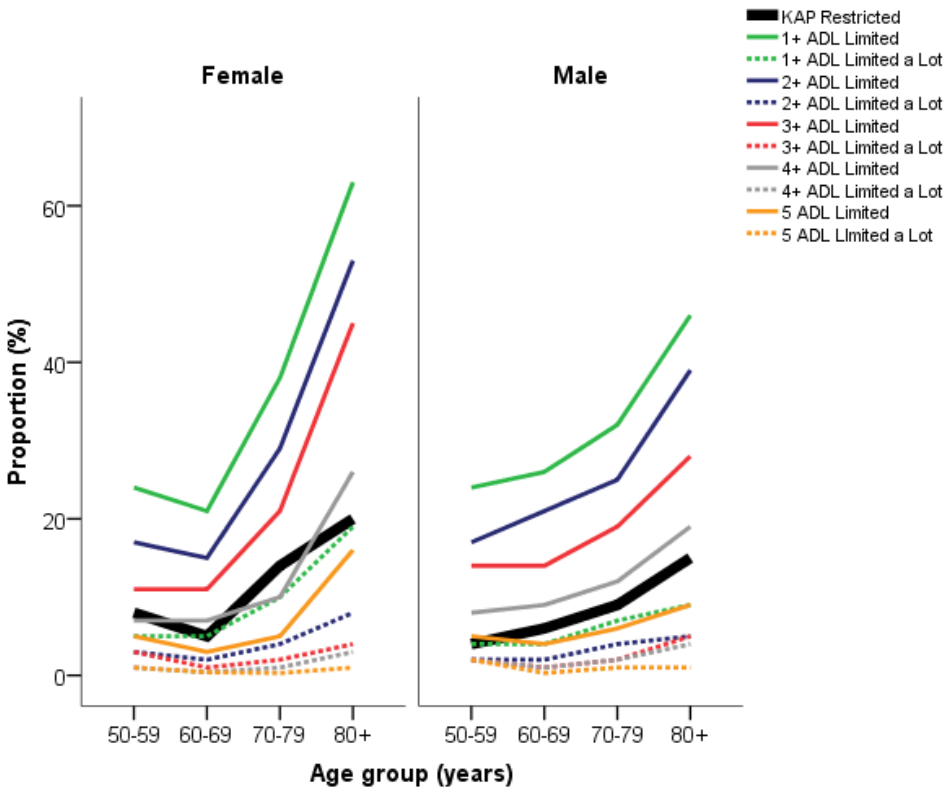
limited: represents those who are limited a little + limited a lot
limited a lot: only represents those who are limited a lot
columns do not add due to missing data

Table 8.3b Comparative occurrence and distribution by age and gender of self-care restriction and self-care activity limitation

	All ages n=2282			50-59 n=322		60-69 n=949		70-79 n=722		80+ n=289	
	Total n=	Female 1331 (58)	Male 951 (42)	Female 186 (58)	Male 136 (42)	Female 557 (59)	Male 392 (41)	Female 407 (56)	Male 315 (44)	Female 181 (63)	Male 108 (37)
Person-perceived participation restriction n %											
Self-care restriction	208	136 (10)	72 (8)	15 (8)	5 (4)	28 (5)	24 (6)	56 (14)	27 (9)	37 (20)	16 (15)
Activity limitation by task n %											
Washing											
limited	605	373 (28)	232 (25)	32 (17)	24 (18)	94 (17)	79 (20)	134 (33)	86 (28)	113 (61)	43 (38)
limited a lot	133	94 (7)	39 (4)	7 (4)	3 (2)	22 (4)	14 (4)	34 (8)	15 (5)	31 (17)	7 (6)
Dressing											
limited	524	305 (23)	219 (23)	34 (18)	27 (20)	93 (17)	84 (22)	106 (26)	73 (23)	72 (39)	35 (32)
limited a lot	72	40 (3)	32 (3)	5 (3)	3 (2)	7 (1)	7 (2)	15 (4)	14 (5)	13 (7)	8 (7)
Caring for body parts											
limited	378	219 (17)	159 (17)	19 (10)	15 (11)	58 (11)	54 (14)	76 (19)	57 (18)	66 (36)	33 (30)
limited a lot	60	37 (3)	23 (2)	5 (3)	3 (2)	9 (2)	6 (2)	12 (3)	10 (3)	11 (6)	4 (4)
Eating and drinking											
limited	135	74 (6)	61 (6)	9 (5)	9 (7)	21 (4)	20 (5)	26 (6)	23 (7)	18 (10)	9 (8)
limited a lot	19	9 (1)	10 (1)	1 (1)	3 (2)	4 (1)	1 (0.3)	2 (1)	4 (1)	2 (1)	2 (2)
Toileting											
limited	182	101 (8)	81 (9)	15 (8)	9 (7)	28 (5)	32 (8)	31 (7)	27 (9)	27 (15)	13 (12)
limited a lot	27	13 (1)	14 (2)	1 (1)	2 (2)	4 (1)	3 (1)	4 (1)	5 (2)	4 (2)	4 (4)

limited: represents those who are limited a little + limited a lot
limited a lot: only represents those who are limited a lot
columns do not add due to missing data

Figure 8.1 Comparison of age-related trends in prevalence of person-perceived self-care restriction (KAP restriction – solid bold black line) and number and severity of ADL limitations



Summary of comparisons for Figure 8.1

- *Both person-perceived self-care restriction measured by KAP and count of ADL limitations shows a general increase in prevalence with age and higher prevalence in females than males*
- *The KAP appears to show an age-related increase in prevalence that is not as steep as for ADL limitation, particularly for females*
- *In both males and females, the prevalence estimates from KAP appear similar to those reporting limitation on any 4 or more ADLs or a lot of limitation in at least one ADL. Therefore, KAP prevalence estimates may be most comparable with ADL definitions requiring either, a high threshold of limitation in any one activity or some limitation across multiple activities (Fig 8.1).*

8.4.2 Self-care disability in the individual: examining the level of agreement between the constructs of activity and participation

Sensitivity

Sensitivity answers the question "if the responder has the disease, how likely is it to have a positive test?" (Lang and Secic 1997). In this analysis the sensitivity of the KAP self-care measure was first tested in those with a number of task-specific activity limitations, and then in those with domain specific activity limitations to measure the level of agreement between the two constructs.

The sensitivity of the KAP self-care item increased with the increase in number of activity limitations (e.g. any two or more, any three or more) in those who were limited in task-specific activities (defined as limited a little + limited a lot). For those who were limited in any one or more task-specific activity, only 23% (95% CI 19.7, 25.8) had reported restricted self-care. However, of those who were limited in all five activities, 56% (CI 45.3, 66.6) also reported restriction in self-care. The level of agreement between participation and activities followed a different pattern for those who were 'limited a lot' in a number of activities. It was observed that in this group the restriction in self-care did not increase with the number of task-specific limitations. Instead, in those with severe limitation in any one or more activities, 39% (CI 31.9, 46.7) also reported restriction in self-care and in those with severe limitations in any two or more activity limitations nearly half (49% CI 37.8, 60.8) reported restriction. However, the wide confidence intervals suggested a greater variability in reporting self-care restrictions for those with a number of severe limitations (Table 8.4).

When the KAP self-care item was tested in those with specific activity limitations (e.g. in those with washing oneself limitation), it was more sensitive in detecting those with severe limitations in washing, dressing and caring for body parts. For example, one in two who were limited a lot in dressing also reported self-care restriction, whereas only 28% (CI 24.4, 32.1) of those who were 'limited' were also restricted in self-care. However, this gap was not as big in those with eating and drinking and toileting limitations. 48% (CI 39.4, 56.2) of those with eating and drinking limitations were also reporting self-care restriction as opposed to 32% (CI 15.4, 54.0) of those who were severely limited in eating and drinking. Also, 43% (CI 36.1, 50.6) of those who were limited in toileting were also restricted in self-care, and the proportion of those who were severely limited in toileting and restricted in self-care followed similar patterns (41% CI 24.5, 59.3) (Table 8.4).

Specificity

Specificity is the probability that a person without the disease will be correctly identified as not having the disease by the test (Porta, 2008). In this study this is interpreted as the probability of a person without the task-specific activity limitation to be correctly identified as 'not-restricted' in self-care by the KAP self-care item.

When the specificity of the KAP self-care item was tested on those with number of activity limitations, the specificity rates amongst *limited* or *limited a lot,* stratified by number of limitations, did not differ due to the definition of 'not limited' being the same for all different cut-offs. The specificity test showed that 97% (for *limited*

group; CI 96.0, 97.0) cf 93% (for *limited a lot group*; CI 92.0, 94.2) of those who reported *no limitations* in any one or more activity had also reported *no restriction* in self-care.

The specificity rates of the KAP self-care item remained satisfactory in those with task-specific activity limitations. The specificity rates were 91% and above for those who were limited and limited a lot in dressing, caring for body parts, eating and drinking and toileting limitations (e.g. specificity for dressing limitation; 96% of those who were *not limited* in dressing were also *not restricted* in self-care). In those with a 'washing oneself' limitation, the KAP self-care item had slightly lower rate of specificity; 77% (for *limited group*; CI 70.4, 81.7) of those who were *not limited* in washing oneself were also *not restricted* in self-care as opposed to 93% (for *limited a lot group*; CI 91.5, 93.7).

Positive predictive value (PPV)

The positive predictive value is the probability that a person with a positive test result is a true positive, or in other words, that they do have the disease (Porta, 2008). However, in this study, this analysis was conducted to examine the level of agreement between the measurement of activity and participation. Therefore, the PPV corresponds to the proportion who report limitation in one or more task-specific activity limitation and report self-care restriction.

As the number of activity limitations increased, the PPV decreased from 77% in those with one or more activity limitations (in limited group) (95% CI 71.3, 82.6), to

49% in those with all five activity limitations (CI 38.9, 59.0). The PPV were even lower in those who were *limited a lot*, and also decreased with increasing number of limitations. For example, 31% (CI 24.9, 37.3) of those who were restricted in self-care were also limited a lot in one or more activities, and 3% (CI 1.1, 6.7) were limited a lot in all five task-specific activities.

Highest PPV was attained in those with washing limitation for both who were limited, and limited a lot (in limited; 76% CI 69.6, 81.2 cf in limited a lot; 25% CI 19.3, 30.9). The PPV values were generally higher in those who were *limited* in task-specific activity limitations compared to those who were *limited a lot*. For example, 69% (CI 62.7, 75.1) of those who were restricted in self-care were also limited in dressing oneself, compared to 17% (CI 12.4, 22.5) who were limited a lot.

Negative predictive value (NPV)

The negative predictive value is defined as the probability that a person with negative test result is a true negative (Porta, 2008). Thus, in this study this means, of people reporting no self-care restriction, the proportion who reports no limitation in any task-specific activity in self-care.

73% (95% CI 71.5, 75.3) of those who reported no self-care restriction were also not limited in one or more task-specific activities, and the NPV values increased for those who were *limited* in any four or more activities (NPV: 94% CI 93.2, 95.4). For those who were *limited a lot*, NPV values varied between 95% (CI 64.1, 96.0)

for those who were limited in any one or more activities to 99% (CI 98.8, 99.6) for those who were limited in any four or more activities.

When stratified by each task, NPVs were again higher in those who were *limited a lot,* compared to those who were *limited*. 79% (CI 77.1, 80.6) of those who reported no self-care restriction were also not limited in washing oneself in the *limited* group, as opposed to 96% (CI 95.2, 96.9) in those who were *limited a lot*.

Table 8.4 Level of agreement between person-perceived self-care restriction and task-specific activity limitation

	% (95%CI)			
	Sn	**Sp**	**PPV**	**NPV**
Activity limitation by count				
any one or more				
limited	23 (19.7, 25.8)	97 (96.0, 97.0)	77 (71.3, 82.6)	73 (71.5, 75.3)
limited a lot	39 (31.9, 46.7)	93 (92.0, 94.2)	31 (24.9, 37.3)	95 (64.1, 96.0)
any two or more				
limited	29 (25.5, 33.6)	97 (96.0, 97.0)	75 (68.7, 80.9)	82 (79.8, 83.3)
limited a lot	49 (37.8, 60.8)	93 (92.0, 94.2)	19 (14.0, 25.0)	98 (97.6, 98.7)
any three or more				
limited	37 (32.1, 42.5)	97 (96.0, 97.0)	72 (64.8, 78.3)	88 (86.5, 89.6)
limited a lot	46 (31.0, 61.6)	93 (92.0, 94.2)	11 (6.7, 16.3)	99 (98.5, 99.3)
any four or more				
limited	47 (39.7, 54.5)	97 (96.0, 97.0)	63 (54.3, 70.9)	94 (93.2, 95.4)
limited a lot	42 (24.5, 61.2)	93 (92.0, 94.2)	7 (3.6, 11.5)	99 (98.8, 99.6)
all five activities				
limited	56 (45.3, 66.6)	97 (96.0, 97.0)	49 (38.9, 59.0)	98 (96.9, 98.4)
limited a lot	36 (15.2, 64.6)	93 (92.0, 94.2)	3 (1.1, 6.7)	97 (99.3, 99.8)
Activity limitation by task				
Washing oneself				
limited	20 (17.3, 24.0)	77 (70.4, 81.7)	76 (69.6, 81.2)	79 (77.1, 80.6)
limited a lot	39 (31.3, 47.8)	93 (91.5, 93.7)	25 (19.3, 30.9)	96 (95.2, 96.9)
Dressing oneself				
limited	28 (24.4, 32.1)	96 (95.3, 97.1)	69 (62.7, 75.1)	82 (80.2, 83.5)
limited a lot	50 (38.6, 61.4)	92 (90.8, 93.1)	17 (12.4, 22.5)	98 (97.6, 98.8)
Caring for body parts limited	30 (25.7, 35.0)	95 (93.9, 95.9)	54 (47.1, 60.6)	86 (86.0, 88.9)
limited a lot	44 (32.2, 56.7)	92 (90.6, 92.9)	13 (8.8, 18.0)	98 (97.7, 98.8)
Eating and drinking				
limited	48 (39.4, 56.2)	93 (92.2, 94.4)	31 (25.1, 37.7)	97 (95.8, 97.3)
limited a lot	32 (15.4, 54.0)	91 (89.9, 92.3)	3 (1.4, 6.3)	99 (98.9, 99.6)
Toileting				
limited	43 (36.1, 50.6)	94 (92.7, 94.8)	37 (30.9, 44.1)	95 (94.1, 96.0)
limited a lot	41 (24.5, 59.3)	91 (90.1, 92.4)	5 (3.0, 9.4)	99 (98.7, 99.5)

Sn Sensitivity; Sp Specificity; PPV Positive predictive value; NPV Negative predictive value (in each case person-perceived participation restriction is the 'reference standard') % 95% CI: Percentage with 95 percent confidence interval

8.4.3 The risk profile of person-perceived self-care restriction and task-specific activity limitation

Self-care restriction was associated with all of the variables in the parsimonious model. The strongest associations were with high levels of depression (Adj. OR 11.9; 95% CI 8.0, 17.9), perceived financial strain (8.2; CI 3.6, 18.8), and high levels of cognitive impairment (4.9; CI 3.3, 7.2) (Table 8.5; column (a)).

To compare the risk profiles, associations between limitation in one or more task-specific activities and the parsimonious model were examined. Similar to the analysis conducted using person-perceived self-care restriction as the dependent variable, age (for those aged 70 years and older), depression, cognitive impairment, perceived adequacy of income and not having adult qualifications were all associated with task-specific activity limitation, before and after adjusting for the parsimonious model in the multivariable analysis. Again, the highest associations were with those who had definite cases of depression (Adj. ORs 10.1; CI 6.8, 15.0), who found their income a 'strain' (9.1; CI 5.2, 15.7), and for those with high levels of cognitive impairment (5.6; CI 4.4, 7.1). Gender was not associated with task-specific activity limitation once adjusted for the parsimonious model (Table 8.5; column (b)).

In addition to adjustment for the parsimonious factors, associations were further adjusted for: (i) task-specific activity limitation in any one or more activities, (ii) aids and assistance and (iii) both in the multivariable analysis. Adjustment for activity limitation led to attenuation of the point estimates; female gender, cognitive

impairment and not having adult qualifications were no longer associated with restricted self-care (Table 8.5; column (a:b)). When the model was adjusted for ‘aids and help and assistance’, age, as well as gender, cognitive impairment and not having adult qualifications also dropped out of the model (Table 8.5; column (a:c)). Adjusting the model for both task-specific activity limitation and ‘aids and help and assistance’ meant that only depression and the ‘being careful’ category of the perceived adequacy of income remained in the parsimonious model of factors associated with restriction in self-care in those with joint pain at 6 years.

Table 8.5 Comparison of risk profiles of person-perceived self-care restriction and task-specific activity limitation

overall n= 2282		(a) Dependent variable: person-perceived self-care restriction++		(b) Dependent variable: task-specific activity limitation*		(a) adjusted for:		
						(b)	(c)	(b) + (c)
OR (95%CI) →		Crude	Adj. OR ┼	Crude OR	Adj. OR┼	Adj. OR┼	Adj. OR┼	Adj. OR┼
Age groups	56-59	1	1	1	1	1	1	1
	60-69	0.9 (0.5, 1.5)	0.9 (0.5, 1.5)	1.0 (0.7, 1.3)	1.0 (0.7, 1.3)	1.1 (0.3, 2.2)	1.1 (0.6, 2.3)	1.1 (0.5, 2.1)
	70-79	2.0 (1.2, 3.3)	2.0 (1.2, 3.3)	1.8 (1.3, 2.4)	1.8 (1.3, 2.4)	1.8 (1.0, 3.6)	1.7 (0.8, 3.3)	1.6 (0.8, 3.1)
	80+	3.4 (2.0, 5.8)	3.3 (1.9, 5.7)	4.3 (3.0, 6.1)	4.3 (3.1, 6.1)	2.2 (1.0, 4.6)	1.8 (0.8, 3.7)	1.6 (0.8, 3.5)
Gender	Male	1	1	1	1	1	1	1
	Female	1.4 (1.0, 1.9)	1.4 (1.0, 1.9)	1.1 (1.0, 1.4)	1.1 (0.9, 1.3)	1.4 (0.9, 2.0)	1.2 (0.8, 1.8)	1.2 (0.8, 1.8)
Depression (HAD)	Non cases	1	1	1	1	1	1	1
	Borderline cases	3.9 (2.7, 5.8)	3.8 (2.6, 5.6)	5.4 (4.1, 7.1)	5.5 (4.1, 7.3)	2.1 (1.3, 3.4)	2.4 (1.5, 3.9)	2.1 (1.3, 3.4)
	Definite cases	11.6 (7.8, 17.1)	11.9 (8.0, 17.9)	9.5 (6.5, 14.0)	10.1 (6.8, 15.0)	5.2 (3.1, 8.6)	5.3 (3.1, 9.1)	4.6 (2.7, 7.9)
Cognitive complaint								
	No cognitive complaint	1	1	1	1	1	1	1
	Low levels	2.7 (1.7, 4.2)	2.5 (1.6, 4.0)	2.7 (2.1, 3.5)	2.6 (2.0, 3.4)	1.4 (0.8, 2.3)	1.3 (0.7, 2.2)	1.2 (0.7, 2.1)
	High levels	5.4 (3.7, 7.9)	4.9 (3.3, 7.2)	5.9 (4.7, 7.4)	5.6 (4.4, 7.1)	1.4 (0.8, 2.2)	1.2 (0.7, 2.1)	1.1 (0.7, 1.9)
Perceived adequacy of income	Comfortable	1	1	1	1	1	1	1
	Little difficulty	1.7 (0.9, 3.2)	1.7 (0.9, 3.2)	1.5 (1.1, 2.1)	1.5 (1.1, 2.2)	1.7 (0.7, 3.7)	1.6 (0.7, 3.8)	1.7 (0.9, 3.8)
	Be careful	3.3 (1.8, 6.1)	3.4 (1.8, 6.3)	2.8 (2.0, 3.8)	3.0 (2.2, 4.2)	2.3 (1.0, 5.2)	2.2 (1.0, 5.0)	2.2 (1.0, 4.9)
	Strain	5.8 (2.6, 13.1)	8.2 (3.6, 18.8)	6.4 (3.8, 10.8)	9.1 (5.2, 15.7)	3.2 (1.2, 9.1)	2.8 (1.0, 8.2)	2.7 (0.9, 7.8)
Higher educational attainment	Yes	1	1	1	1	1	1	1
	No	2.2 (1.6, 3.1)	1.8 (1.3, 2.5)	1.7 (1.4, 2.1)	1.4 (1.2, 1.7)	1.4 (0.9, 2.1)	1.3 (0.9, 2.0)	1.3 (0.9, 2.0)

++ Measured by KAP self-care item * Defined as limited on at least one activity from washing, dressing, caring for body parts, eating/drinking and toileting; ** Defined as those who use an aid and/ help and assistance in any of the self-care tasks; ┼OR adjusted for age and gender

8.4.4 Use of environmental facilitators

Associations between ADL limitation and perceived self-care restriction

Of 730 people who were limited in one or more activities of daily living relating to self-care, 161 (22%) reported that their self-care needs were not met “as and when I wanted” (i.e. restricted self-care). Of 1552 people who were not limited in any self-care activities, 3% had reported self-care restriction (Table 8.6).

For those who were limited in at least one or more task-specific activities, restriction was greater for those who needed and received help (29%). However, 19% of those who needed help and did not receive it (unmet need) had also reported self-care restriction. In those who were not limited in any task-specific self-care activity, self-care restriction was greater in those who needed help but did not receive it (8%), compared to those who received help (5%), and those who did not need help (2%) (Table 8.6b).

Self-care restriction was greater in those who used aids and appliances, for both those who reported limitations and those who reported no limitations in task-specific self-care activities (limited: 26%; not limited: 8%), when compared to those who did not use aids and appliances (limited: 10%; not limited: 2%) (Table 8.6c).

Table 8.6 Cross-sectional association between restricted self-care and task-specific activity limitation in at least one self-care activity or more

N%		Restricted self-care+		
		Restricted	Not restricted	
ADL++ limitations	Limited in 1+ ADL	161	569	730
	Not limited	47	1505	1552
		208	2074	2282

+ Measured by KAP self-care item
++ Defined as limited on at least one activity from washing, dressing, caring for body parts, eating/drinking and toileting

Table 8.6b Associations between restricted self-care and task-specific activity limitation; stratified by help and assistance status

(i) Help & assistance = No need

N%		Restricted self-care		
		Restricted	Not restricted	
ADL limitations	Limited in 1+ ADL	5 (4)	99	114
	Not limited	27 (2)	1186	1213
		32	1285	1327

(ii) Help & assistance = Need help but do not receive it

N%		Restricted self-care		
		Restricted	Not restricted	
ADL limitations	Limited in 1+ ADL	32 (19)	137	169
	Not limited	8 (8)	91	99
		40	228	268

(iii) Help & assistance = Needs and receives help

N%		Restricted self-care		
		Restricted	Not restricted	
ADL limitations	Limited in 1+ ADL	123 (29)	300	423
	Not limited	10(5)	185	195
		133	485	618

Table 8.6c Associations between restricted self-care and task-specific activity limitation; stratified by use of aids and appliances

(i) Do not use aids & appliances

N%		Restricted self-care		
		Restricted	Not restricted	
ADL limitations	Limited in 1+ ADL	22 (2)	1218	1240
	Not limited	16 (10)	141	157
		38	1359	1397

(ii) Uses aids & appliances

N%		Restricted self-care		
		Restricted	Not restricted	
ADL limitations	Limited in 1+ ADL	23 (8)	259	282
	Not limited	141 (26)	399	540
		164	658	822

Socio-demographic, health and joint-specific characteristics

The next stage was to examine the socio-demographic and health characteristics of those with joint pain at 6 years, for each of the five task-specific activity limitations individually. The need and receipt of help for washing and bathing, dressing, caring for body parts, eating and drinking, and toileting was considered separately at each domain. Although the need for, and receipt of, help for each activity limitation varied, there was no notable difference across the 'help and assistance' status of people with these limitations. This might be due to the high correlation in occurrence of these limitations in people with joint pain. It was observed that there was a significant overlap between the limitations in these task-specific activities; 73% of those with washing oneself limitation also reported limitations in dressing, and 56% reported limitations in caring for oneself. Likewise,

of those who were limited in eating and drinking, 87% were limited in washing and dressing, 79% were limited in caring for body parts and 67% were limited in toileting. Thus, for the purpose of this analysis (i.e. providing descriptive characteristics of those who use environmental facilitators), and to avoid the repetitive reporting of results relating to each one of the task-specific activity limitations, only the characteristics of those who were limited in *washing oneself* is reported in this chapter.

The mean age of participants who were limited in washing oneself ranged from 72 (SD: 8.8) in those who did not need help, 73 (SD: 9.3) for those with unmet need in help, and 73 (SD: 10.1) in those who received help. There were no significant differences across the help status ($p=0.202$). The group of those who needed help had a significantly higher proportion of females (unmet need: 70%; needed and received help: 67%) than the group who did not need help (55%) ($p\leq0.005$). 24% of those who were restricted in self-care and limited in washing oneself did not report the need for help and assistance, but 46% who were restricted in self-care did require and received help, although 30% had unmet needs ($p\leq0.001$). There was also a significant difference between the amount of limitation reported and the help status of the participants. Of those who 'did not need help' 91% were limited a little. However, 75% of those with unmet needs in help and 58% of those who received help were also limited a little in washing oneself ($p\leq0.001$).

There was no statistical difference in different groups in terms of their perceived adequacy of income ($p=0.066$). However, those with adult qualifications needed

and used less help (not needed help; 34%, those with unmet needs; 23%, those in receipt of help; 25%) when compared to those without adults qualifications (p=0.049) (Table 8.7).

Table 8.7 Socio-demographic characteristics of those who report limitation in washing oneself; and their help and assistance status

Overall n=588▲	Not needed help n=309	Unmet need n=104	Received help┼ n=175	P value
Age (years): Mean (SD††)	71.9 (8.8)	73.2 (9.3)	73.2 (10.1)	p=0.202
Female (n %)	170 (55)	73 (70)	118 (67)	p≤0.005
Restricted self-care (n %)	35 (24)	45 (30)	68 (46)	p≤0.001
Limited a lot (n %)	27 (9)	26 (25)	73 (42)	p≤0.001
Perceived Adequacy of income (n %)				
Comfortable	29 (10)	7 (7)	11 (7)	
Little difficulty	108 (38)	26 (26)	54 (33)	
Be careful	124 (43)	59 (60)	89 (55)	
Strain	27 (1)	7 (7)	9 (5)	p=0.066
Higher Educational attainment (n %)				
NO	204 (66)	77 (77)	128 (75)	p=0.049

▲ Columns do not add to 588 due to missing data in covariates
┼ Help received from family and/ friends + health professionals and/ or social services

Health characteristics

Significant differences occurred in most health indicators. Those who required help and assistance (those with unmet needs and those who received help) had higher depression scores than those who reported no need for help (Unmet need: 7.9 (3.9); Needed and received help: 8.0 (3.9) cf Not needed help: 6.5 (3.4)) ($p \leq 0.001$). Those who required help also had higher levels of cognitive impairment than those who did not need help ($p=0.019$).

There were also significant differences in physical and mental health scores across the help and assistance categories. Those who did not need help had higher physical and mental health scores compared to those who required help ($p \leq 0.001$). Those with unmet needs reported better physical health than those who were in receipt of help, and by contrast, those who received help and assistance reported worse mental health than those who needed help, but their needs were unmet (Table 8.8).

Table 8.8 Health characteristics of those who report limitation in washing oneself; and their help and assistance status

	Not needed help	Unmet need n (%)	Received help┼ n (%)	P value
HAD+ depression score 0-21:				
Mean (SD) ††	6.5 (3.4)	7.9 (3.9)	8.0 (3.9)	p≤0.001
Cognitive Alertness (n %)				
No impairment	87 (32)	18 (19)	28 (18)	
Low levels	63 (23)	21 (23)	41 (27)	
High levels	125 (45)	53 (58)	83 (55)	p=0.019
*SF-12 Physical health 0-100:				
Mean (SD) ††	29.2 (7.4)	27.5 (5.7)	25.7 (5.9)	p≤0.001
*SF-12 Mental health 0-100:				
Mean (SD) ††	43.6 (11.4)	38.6 (10.3)	40.1 (11.0)	p≤0.001

┼ Help received from family and/ friends + health professionals and/ or social services
†† Standard deviation; * Medical Outcomes Study Short-Form 12; + Hospital Anxiety and Depression.

Joint specific characteristics

Those who received help reported higher hand pain intensity than those who did not need help and those who had unmet needs (p≤0.001). Hip pain intensity did not differ significantly by the need for, or receipt of help and assistance. Those with unmet needs in help reported the highest knee pain intensity (M=6.5 SD: 3.1) and this group were significantly different to those with unmet needs and no need for help (p≤0.001). In those with foot pain, those who received help had the most intense pain (p≤0.001). There was no significant difference across the help status of those with a number of peripheral joint pains (Table 8.9).

Table 8.9 Joint specific characteristics of those who report limitation in washing oneself; and their help and assistance status

	Not needed help	Unmet need n (%)	Received help┼ n (%)	P value
Hand pain intensity Mean (SD) ††	3.6 (3.1)	4.5 (3.3)	4.9 (3.4)	p≤0.001
Hip pain intensity Mean (SD) ††	4.1 (3.5)	4.2 (3.8)	4.7 (3.7)	p=0.239
Knee pain intensity Mean (SD) ††	5.0 (3.4)	6.5 (3.1)	5.9 (3.5)	p≤0.001
Foot pain intensity Mean (SD) ††	4.0 (3.4)	4.8 (3.4)	5.4 (3.6)	p≤0.001
No. of peripheral joint pain (n %)				
1	38 (13)	4 (4)	18 (11)	
2	65 (22)	27 (27)	31 (18)	
3	88 (29)	26 (26)	43 (25)	
4	109 (36)	44 (43)	76 (46)	p=0.102

┼ Help received from family and/ friends + health professionals and/ or social services
†† Standard deviation

8.5 Summary of results

Among a community sample of older adults with joint pain, person-perceived self-care restriction, as measured by the KAP tool, showed broadly similar age-related trends and prevalence as limitation across four or more self-care tasks or severe limitation in at least one self-care task. The prevalence of limitation in one or more activities of self-care was much higher than for self-care restriction (32% cf 9%).

Very few individuals who reported no limitation in self-care tasks felt that their self-care needs were not met “as and when I have wanted” (i.e. participation

restriction). However, one in five individuals reporting participation restriction reported no limitation in any of the five self-care ADLs. Conversely, only 47% of individuals reporting limitation in four or more self-care tasks reported participation restriction.

While the pattern of associations with socio-demographic and health-related variables was broadly similar for KAP and individual ADL items, there were several notable exceptions. Reporting participation restriction on the KAP appeared more likely to be associated with female gender, higher levels of depression and greater perceived inadequacy of income.

Lastly, it was shown that 28% of individuals in this sample of symptomatic older adults received help or assistance for self-care tasks, while a further 12% expressed an unmet need for such help. Joint pain intensity, cognitive function, general health, severity of limitation, and self-care restriction were generally worse among those receiving or expressing a need for help and assistance for self-care, as well as among those using aids and adaptations.

8.6 Discussion

8.6.1 Principal findings

The prevalence of person-perceived self-care restriction was much lower than the prevalence of task-specific activity limitation, but the patterns of occurrence in terms of age and gender distribution in older adults with joint pain was very similar.

This could be explained by the strong associations found in the previous chapters between self-care restriction and activity limitation, and from a simple analysis which suggested that activity limitation mediates the relationship between joint pain and self-care restriction (Chapter 5).

The level of agreement between the constructs of activity and participation was tested using a method designed to measure the diagnostic accuracy. Ultimately, this approach was taken to test the hypothesis that the KAP self-care item was not just an aggregated measure of self-care tasks. The convergent validity of the KAP was previously tested against other measures of participation (Wilkie et al., 2005) and it was reported that KAP had high levels of agreement with items from the Reintegration to Normal Living Index (RNL) (Wood-Dauphinee et al., 1988), and the Impact of Participation and Autonomy (IPA) (Cardol et al., 2001); two different tools that included items of participation restriction within their constructs. In this study, the diagnostic accuracy test was related to the measurement of agreement between the limitation in self-care tasks and restriction in self-care, rather than confirming the construct validity of the KAP. As expected, the sensitivity of the KAP measure increased with the increasing activity limitations, and the measure was more sensitive in detecting those with severe limitations. This finding strengthens the previous findings of strong associations between activity limitation and self-care restriction. As the number of limitations increase in task-specific activities, such as washing and dressing, and these limitations become severe, the risk of reporting self-care restriction also increases. Nevertheless, the sensitivity of KAP self-care item did not exceed 56% (limited in all five activities), suggesting

that even in those adults with multiple limitations in self-care tasks, restriction in self-care occurred in one in two people; hence the measure was not overly sensitive (e.g. it did not highlight all those with severe/multiple limitations as those with self-care restrictions, and was unable to differentiate between the two concepts). The relatively high proportion of specificity rates suggested that restriction in self-care did not occur without limitation in self-care tasks. However, the measure was less specific for those with the 'washing oneself' limitation. Again, this might suggest that those with no limitation in washing oneself might be restricted in self-care due to severe limitation in other self-care tasks, such as dressing and/or caring for body parts. The level of agreement between the constructs of person-perceived self-care restriction and task-specific activity limitation suggests there is discordance, and that measures of activity limitation yield different results to that of *person-perceived* participation restriction in self-care. That factors such as depression and perceived adequacy of income remained in the parsimonious model of factors associated with restricted self-care, after adjusting for task-specific limitations and environmental factors, suggests that these factors may impact the appraisal of needs in self-care being met as and when wanted. These further explain the changeable state of self-care restrictions in older people with joint pain as reported in Chapter 7.

The risk profiles of those with person-perceived self-care restriction and task-specific activity limitation were similar. The parsimonious model variables had similar levels of associations, with both task-specific activity limitation and self-care restriction in the univariable and multivariable analyses. This may be due to high

levels of correlation between the two constructs, as discussed earlier. When the associations between the parsimonious model of key factors associated with restricted self-care and person-perceived self-care restriction at 6 years (column (a) Table 8.5) was further adjusted for task-specific activity limitation (column (b) Table 8.5), associations with these factors were weakened and became statistically insignificant for gender, cognitive impairment and educational attainment. This could be explained by a high correlation between activity limitations and participation restriction in self-care, but could also be interpreted as evidence that activity limitation mediates the relationship between key factors associated with self-care participation, as suggested in chapter 5. Further adjustment of this relationship for aids and assistance (column (c) Table 8.5) resulted in eliminating age from the model also, removing the previously strong association between increasing age and self-care restriction. This suggests that the older people are, the more likely they are to receive aids and assistance, and despite this they are still restricted. Adjusting the model for both the task-specific activity limitation and 'aids and assistance' (column (b) + (c)) (Table 8.5) resulted in the borderline and definite cases of depression, and 'being careful' category of the 'perceived adequacy of income', remaining in the parsimonious model of factors associated with restricted self-care at 6 years. Perceived financial strain was also independently associated with restricted self-care at the baseline cross-sectional analysis and was an important predictor in estimating the onset of self-care restriction at 3 years. It was discussed in great length in previous chapters that responders with poorer backgrounds and depression may generally be less satisfied with their quality of life (Moore et al., 2005) (Chapter 5 & 7). Further more

that depression is associated with a disruption of normal emotional experience that can result in a negative bias. This means that the participant has a tendency to appraise both forthcoming and past events negatively (Henry et al., 2010). What the current analyses establish is that this may be particularly likely to happen to KAP responses compared to conventional ADL items.

Two percent of those who were restricted in self-care were not limited in any self-care activities, and neither expressed a need for help, nor used aids or adaptations. There may be a number of explanations for this discordance. One explanation for this may be the measurement error within the KAP self-care item, which may have resulted in the misclassification of those who are not restricted in self-care as restricted. The five task-specific activity limitations measured in this study may have not comprehensively captured all of the individual self-care tasks. Limitation in the non-measured tasks could lead to the report of not participating "as and when they want". As the concept of self-care that the KAP measures is person-perceived participation, people who do not define themselves as limited in task-specific activities could still perceive themselves as being restricted in self-care. This may be due to other factors such as depression, cognitive impairment and low socio-economic income affecting the appraisal of their situation.

The analysis of the dependence on task-specific activities demonstrated that there were no significant differences with age and help status, but women needed more help and assistance for washing. The poor physical health reported by female

responders compared to those of males could explain the increased dependency in washing (PCS mean score 28.5 cf 29.4 p=0.028).

One in three people with restricted self-care and who expressed a need for help had unmet needs. The majority of those with unmet needs in self-care were those who were limited a little, whereas nearly half of those who received help were severely limited in washing oneself. This may suggest that people experience limitation in self-care tasks over a certain period of time and only get help when their limitations and/or health worsen. Those who received help and assistance were more depressed compared to those who did not need help or had unmet needs in help. This could be due to becoming dependent on others, or again as a result of negative appraisal, as those who received help also had the poorest physical and mental health compared to those who did not need help, and those with unmet needs. Again, there were significant differences between help status for washing limitation and hand, knee and foot pain. Those who received help reported more intense pain in the hand and hip joints. However, for those with knee pain, those who needed, but did not receive help (unmet need), reported higher pain intensity than others. Due to the study design it was not possible to determine the direction of this association; thus it is unknown whether the severity of joint pain in those who receive help is due to restricted activity or whether they receive help due to the severity of pain and its disabling effects.

To summarise, those who received help were older, predominantly female, with severe limitations in washing, had higher levels of cognitive impairment, and worse

physical health than those who did not receive help and assistance. It was not possible to analyse the reasons why those who were in receipt of help and assistance were still restricted in self-care with the available data in this study. One explanation might be that once the individual's health deteriorates, even if their self-care needs have been met by means of help and assistance, they may still see themselves as *dependent* on others/services as the help may not be available/accessible to them '*as and when they have wanted it'*, which results in perceiving themselves as 'restricted in self-care'.

8.6.2 Previous studies of activities and participation

There are no other studies known to the author which have looked at the 'agreement' between measures of activities and participation in a population sample using a diagnostic accuracy test at the time this thesis written. However, there have been considerable debates regarding the conceptual differences concerning the development of ICF, and empirical attempts to distinguish between activities and participation.

In 2003, Jette and colleagues suggested that distinct activity and participation dimensions of the ICF could be identified using physical functioning items drawn from the Late Life Function and Disability Instrument (Late Life FDI) to test. Items in the Late Life FDI are similar to ones found in ICF Chapter 4 Mobility, Chapter 5 Self-care and Chapter 6 Domestic Life (Jette et al., 2003, p:146). This was a cross-sectional analysis of a sample of 150 community-dwelling adults aged 60 years and older living in Boston, Massachusetts, USA. The survey encompassed a

wide range of physical actions, daily activities and tasks outlined in the ICF manual, such as changing and maintaining body positions; carrying, moving and handling objects; mobility and travel; and ADLs. Similarly to the NorStOP 6 years cross-sectional study, responders had a mean age of 76 years, were predominately white (84%), and female (77%). The hypothesis of the existence of a single unified physical functioning domain underlying the 48 survey items was rejected in the initial factor analysis. The variance in the sample was explained by 3-factor solution that best fit the data, and these were “Mobility Activity” (perceived difficulty in performing vigorous physical actions such as walking a mile or getting up from the floor), “Daily Activities” (physical actions involved in basic and instrumental activities of daily life), and “Social Participation” (complex behaviours such as going out to public places and working at a volunteer job). This study concluded that contrary to qualifications and concerns noted within the ICF Handbook concerning physical functioning, differentiating between Activities and Participation on the basis of their domain content could be accomplished empirically (Jette et al., 2003, p:146). Although this study considered ‘social participation’ as opposed to ‘participating in self-care’, which is comparatively one form of participation that involves interaction with the environment, it highlighted the differences between the two constructs, and emphasised that participation required more complex behaviours than the physical actions involved in conducting daily activities. The results provide empirical support for self-care being multifactorial, determined by biopsychosocial factors and can be considered as one form of participation.

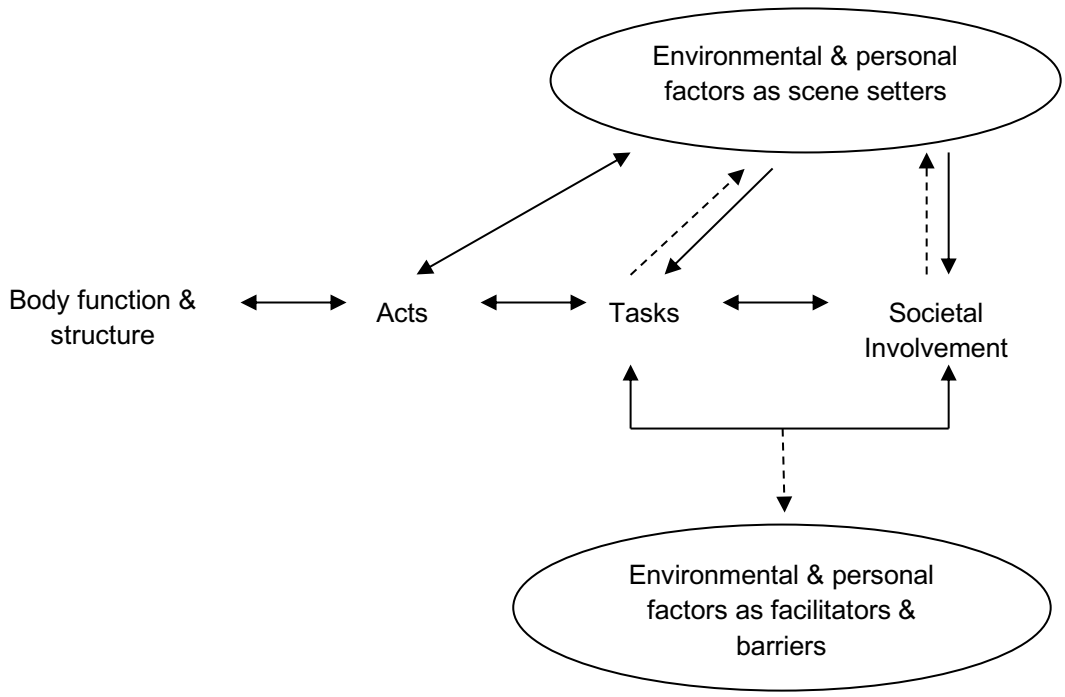
Schuntermann (2005) argued that the concept of activity is only intuitively introduced in the ICF and not theoretically founded. One theory, which is likened by Schuntermann to the activity concept of the ICF, is the action theory of Nordenfelt (Nordenfelt, 2003). This theory suggests that an *action* is what people actually do (i.e. performance) in their environment, and there are three preconditions for an action; (i) the individual must have the *capacity* to perform the action, (ii) they must objectively have the *opportunity* to transform their capacity into the respective action, (iii) and they must have the *will* to perform the action. Schuntermann suggests that the concept of activity is introduced without these internal factors, and describes this as a clear deficiency in the ICF (Schuntermann, 2005). However, one way to defend the ICF's approach to defining activity as simply "*the execution of a task or action by an individual"* (WHO, 2001), would be to highlight that the ICF uses activity to define these tasks and take these internal/external factors into account under *participation* to allow the breakdown, hence thorough analysis of such restrictions is taking place. Thus, the ICF considers difficulty in executing actions at an individual (activity limitation) and a societal level (participation restriction). Consequently, three preconditions suggested in this theory, which underpin the action, fit with the findings of this thesis. For example, those with pain and impairment have a reduced capacity to perform *activities*, and the use of environmental facilitators may create the *opportunity* to transform the intrinsic capacity into a respective action by enabling those with limitations to self-care. Again, Nordenfelt's theory suggests that the *will* to perform the action is also important, thus the strong association between depression and self-care restriction may be due to lack of motivation, such as

individuals not having the will to perform these self-care tasks, or seek out 'help and assistance' as and when they need it. Hence, Nordenfelt's approach brings further support for the argument that self-care is a form of participation, and restrictions in self-care cannot be determined by assessing difficulty threshold and dependency in performing these personal tasks only.

Further attempts were made by Badley (2008) to enhance the conceptual clarity of the activity and participation components of the ICF, by dividing activities and participation into three domains. These were defined as (i) acts (general things that a person can do independent of context or purpose), (ii) tasks (purposeful things that people do in daily life in a specific context), and (iii) societal involvement (individual in the context of societally defined and acknowledged areas of human endeavour). Badley suggested that there are reciprocal relationships between contextual factors acting as scene-setters, contextual factors acting as facilitators or barriers, societal involvement, tasks, and acts (Figure 8.2 and Table 8.10). However, Badley's attempt to improve the conceptual clarity of the ICF resulted in introducing further complexity in the use of terms when the original aim of the ICF was to simplify terms, allowing flexibility for researchers / health professionals / policy makers and stake holders to adapt the ICF concepts for their own purpose". Proposed clarification of the ICF's activities and participation domain in Badley's paper (2008) would not have necessarily allowed the study of person-perceived self-care restriction as the author defines the societal involvement as *"The individual in the context of societally defined and acknowledged areas of human endeavour"*, thus depicting participation from a

societal norm point of view, rather than person-perceived restriction. Furthermore, it suggests that tasks are not defined culturally. However, it could be argued that a practicing Muslim might need to wash using only the left hand when toileting, thus experience activity limitation in caring for body parts due to an impairment on one hand, whereas others would have made the use of right hand. Therefore, Badley's proposed model further complicates the classification of the simple concepts offered by ICF.

Figure 8.2 The disability model illustrating relationship between contextual factors as scene-setters, contextual factors as facilitators and barriers, societal involvement, tasks, and acts



Source: Badley, 2008

Table 8.10 Distinguishing the components of functioning disability

Distinguishing characteristic	Body structures and functions	Activity and participation		
		Acts	**Tasks**	**Societal involvement**
Relates to	Body systems and parts	General things that a person can do independent of context or purpose.	The purposeful things people do in daily life in a specific context	Defined by the social role
Exhibited by	Involvement of 1 or more body systems	Synchrony of functioning/ perhaps with other actions	Comprises synchronized acts or other (sub) tasks	The individual as a player in socially/culturally influenced areas of life
Origin of problems	Where >1 system involved, failure of any one can result in impairment	A problem in a contributing system need not result in a problem as there may be leeway	A difficulty need not result in a problem because of personal and environmental factors	May be trade-off between opportunities and personal preferences in choice of area
Individual effects cognitive	No cognitive component	Cognitive contribution (but often habitual or automatic processing)	Cognitive component	On-going appraisal and evaluation of the wider environment
volitional	Minimal voluntary control	Voluntary (and volitional)	Purposive, usually with a specific objective	Depends external factors /personal preference
Contextual scene-setters	No, except where integral to functioning	Context implied by what is done	Defines the nature of the tasks and how they are accomplished	Physical, cultural and social setting
Cultural variation	Does not vary by culture	Does not vary by culture	Nature and accomplishment dependent on setting	Only at conceptual level
Involvement of others for acquisition	No	Generally acquired with maturation: practice or skill may contribute	Acquired through informal or formal learning	Acquired through informal or formal processes
for performance	No	No	Incidental	Integral
Contextual facilitators or barriers	No, only if integral to structure or function	Can modify somewhat	Can modify manner and extent of accomplishment	May affect choices and degree of involvement

Source: Adapted from Badley, 2008

In a more recent study, Pollard and colleagues (2011) explored the relationships between ICF constructs of impairment, activity limitation and participation restriction in people with osteoarthritis (OA) prior to joint replacement. These authors highlighted that only a few studies have empirically explored the relationships between the constructs in the ICF model by condition (e.g. OA). The study sample was a geographical cohort of patients with osteoarthritis from the Tayside Joint Replacement (TJR) cohort who were about to undergo hip or knee joint replacement surgery at Hospital in Scotland (n=413). Participants completed measures of impairment, activity and participation prior to the surgery at home. Confirmatory factor analysis was used to test the three factors measurement model, and structural equation modelling (SEM) was used to explore the impairment, activity and participation pathways in the ICF model (Pollard at al., 2011). The study concluded that significant ICF pathways for OA prior to joint replacement were found to be between impairment and activity, and between activity and participation, but not between impairment and participation, suggesting that activity might fully mediate the relationship between impairment and participation. Although the sample used in this study was those with severe osteoarthritis requiring surgery, as opposed to those with joint pain in the general population, the findings were similar to those reported in this thesis.

Using similar methods to Pollard et al (2011) to derive instruments, Machado and colleagues (2008) also tested a model which hypothesized that the relationship between physical symptoms and later participation restrictions among older adults with osteoarthritis is mediated by activity limitations and depressive symptoms. This was a longitudinal study of 184 community-dwelling older adults aged 55

years and over, residing in the Greater Toronto area of Ontario, Canada. Thirteen items on activity limitations and participation restrictions were derived from a set of questions about difficulty with activities of everyday life. Respondents were asked to think about performing the activity "*without any help from another person or from a special gadget or piece of equipment*." Responses were rated on a 4-point Likert scale (where 0= no difficulty, 1= some difficulty, 2= a lot of difficulty, and 3= not able to do the activity). The study reported that physical symptoms, depressive symptoms, activity limitations, and participation restrictions were significantly correlated with one another. Physical symptoms were correlated with depressive symptoms, activity limitations and participation restrictions, and depressive symptoms were correlated with activity limitations and participation restrictions. The highest correlation occurred between activity limitations and participation restrictions (Machado et al., 2008). The findings of this study are also comparable to the study reported in this chapter in terms of highlighting the importance of taking both activity limitations and depressive symptoms into account as consequences of osteoarthritis/joint pain when establishing a pathway to the understanding of the association between impairment and an individual's participation.

In summary, previous studies provide empirical support that activities and participation are two distinct concepts; activities refer to the level of the individual and an individual's capacity and participation requires the individual to interact within the context of their environment and a multitude of other factors. The results in this analysis suggest that self-care is a complex concept determined by various

socio-demographic, health and environmental factors and that self-care is more than an individual's capacity in specific activities related to personal tasks.

8.6.3 Limitations

Although a generous population sample of 2282 responders was included in the 6 years cross-sectional analysis, responders were only the mere 29% of the NorStOP baseline study sample; in which the prevalence and factors associated with restricted self-care in the general population was established in Chapter 5. Responders at 6 years were younger, predominantly women and had better physical and mental health as well as improved socioeconomic status compared to those who were lost at follow-up (Chapter 4). As self-care restriction is associated with increasing age, poor health and lower socio-economic status, the study attrition may have biased the results, thus resulted in an underestimation of the frequencies of limitation, dependency, use of aids and adaptations and associations with restricted self-care.

At 6 years, some variables were measured at different time periods than others. Limitations in selected self-care activities (e.g. washing and bathing, dressing, caring for body parts) were measured at the present time (Does your health now limit you in these activities); environmental facilitators such as the receipt of help and assistance were measured during the past month (During the past 4 weeks have you had help from anyone else to do the following activities?); depression (HADS scale) was measured in the past week (How you have been feeling in the past week?); cognitive alertness was measured in the present time; presence of joint pain was measured in the last year; and joint pain intensity was measured in

the last 6 months. Different time periods may have under or overestimated the associations found.

The environmental facilitators studied in this chapter were only measured in the 6 years follow-up. Thus, it was not possible to test the cross-sectional associations with restricted self-care longitudinally to establish the direction of these associations, and whether environmental facilitators were associated with the onset and persistence of self-care restriction in older people with joint pain or not. There were also limitations to the cross-sectional associations developed. The study sample was a healthy cohort of older people compared to baseline and 3 years, which means those with severe self-care limitations / restrictions were already lost to the study. Also, the study sample was further reduced due to limited numbers of people having specific limitations in task-specific activities, such as washing and bathing, as the use of environmental facilitators such as 'help and assistance' and 'aids and adaptations' had to be measured against these specific limitations (e.g. receiving help for washing and bathing/ using modified bath or shower). Due to small numbers in each category, those who were in receipt of help and assistance from family or friends and/or health professionals or social services were collapsed into one category (i.e. needed and received help and assistance), which meant that it was not possible to analyse whether there were any differences in these groups.

8.7 Conclusions

This study provided empirical evidence to support the assumption that task-specific activity limitation and person-perceived participation restriction in self-care, measured by the KAP, are two distinct outcomes. However, these two concepts are highly correlated and thus have similar associations with known risk factors such as age, gender, depression, physical limitation, cognitive impairment, perceived adequacy of income and lower educational attainment. To an extent, the relationship between self-care restriction and known risk factors is moderated by environmental facilitators. However, the receipt of help and assistance was not sufficient for those with depression and inadequate incomes to report that their self-care needs were met 'as and when they have wanted.'

Among older adults with joint pain and difficulties in self-care tasks, there is a high level of expressed need for personal help and assistance and considerable proportion of these needs are unmet. The receipt of 'help and assistance' and use of 'aids and appliances' contributes to having their self-care needs met 'as and when they want', but is still insufficient in many cases. Additional provision of personal assistance may reduce self-care restriction. However, further investigation into the reasons for person-perceived self-care restriction is required to explain why it occurs when the need for personal help is met.

Table 8.11 Summary of key findings

- This chapter investigated the level of agreement between the measures of task-specific activity limitation and person-perceived self-care restriction, and studied the impact that environmental factors have on this relationship. The rationale behind this was to gain a better understanding of the differences between self-care restriction measured by KAP, and self-care disability measured using traditional ADL measures.

- Both self-care restriction measured by KAP and count of ADL limitations increased in prevalence with age. The prevalence was higher in women.

- The prevalence of self-care restriction measured by KAP was most similar with the prevalence of ADL where there was a higher threshold of limitation in any one or more activity, or some limitation across multiple activities.

- There was discordance between self-care restriction measured by the KAP, and task-specific activity limitation, suggesting these are different constructs.

- The pattern of associations with socio-demographic and health related factors was broadly similar for self-care restriction measured by KAP and individual ADL items. However, participation restriction in self-care measured by KAP was more likely to be associated with female gender, higher levels of depression and greater inadequacy of income.

- Amongst this sample of symptomatic older adults there was a high level of need for personal help and assistance, and self-care restriction was greater in those who needed help but did not receive it.

- Self-care restriction was also greater in those who used aids and appliances, compared to those who did not.

- Joint pain intensity, cognitive function, general health, severity of limitation and self-care restriction was generally worse among those receiving or expressing a need for help and assistance for self-care, as well as among those using aids and appliances.

Chapter 9
Summary and discussion

9.1 Introduction

The impetus for this research came from the need to prepare health and social care for the increasing number of older adults in the United Kingdom who may suffer from health conditions and disability. The number of older adults is expected to increase further over the next two decades, and with this there will be more older people with musculoskeletal conditions. Musculoskeletal conditions have been linked to increased dependency in self-care activities, which is associated with future morbidity and mortality in community-dwelling older adults. However, it is unknown whether self-care restriction is an inevitable consequence of joint pain or whether people with joint pain report more restriction in self-care than those without. This chapter presents a brief review of the principal findings in this thesis, critical discussion of key issues and reflection of the implications for future research and clinical practice.

9.2 Summary of key findings

A wide range of terms have been used to describe self-care disability which has tended to focus on the individual's capacity, with no consideration of the role of social and environmental factors. Differences in definitions of self-care disability have made comparison across studies difficult. Following a systematic review, the links between joint pain and self-care disability were still unclear and the determinants of self-care restrictions in older adults with joint pain were unknown.

The ICF was proposed as a framework that could provide a standard language to facilitate the understanding of health and its consequences (WHO, 2003). It provided a conceptual framework to define self-care restrictions in older people and investigate factors associated with restriction using a biopsychosocial model. In addition, self-care restriction was measured using a person-perceived approach in which individuals judge whether their self-care needs are met “as and when I have wanted”. The estimated prevalence of self-care restriction in adults aged 50 years and over in the general population was 11.5% (95% Confidence Interval (CI) 10.8; 12.2). Restrictions increased with age and were higher in women (% difference with 95% CI: 2.3 % 0.8, 2.7). Key factors associated with self-care restriction were identified as age, activity limitation, depression, cognitive impairment, perceived inadequacy of income and not having adult qualifications. Those with joint pain were more likely to report self-care restriction than those who did not have joint pain. Much of this relationship may be explained by other factors; for example, a simple mediation analysis indicated that activity limitation may be on the causal pathway between pain and self-care restriction, in line with the proposed conceptual model of the ICF. Of those who were free of self-care restriction at baseline, 6.6% (CI 5.9; 7.5) reported the onset of self-care restriction at 3 years. The risk of reporting onset of self-care restriction increased with age, and in those who reported lower socio-economic background, worse physical and mental health at baseline. Of those who were restricted in self-care at baseline, 38.9% (CI 33.7; 44.3) reported persistence at 3 years. The risk of reporting persistent self-care restriction was higher in men and in those who reported poor physical health and perceived financial strain at baseline. Peripheral joint pain, particularly multiple joint pains at baseline increased the risk of the onset of self-

care restriction 3 years later. Looking at older adults with joint pain, those who reported severe pain, stiffness and chronic pain (lasting >3 months) at baseline were at a higher risk of reporting both the onset and persistence of self-care restriction at 3 years. Key factors identified at baseline were also predictors of the onset of self-care restrictions in older people with joint pain at 3 years, but only depression at baseline predicted the persistence of self-care restriction.

The level of discordance in the measurements of activities and participation in self-care confirmed that these were two distinct constructs. There was a high level of expressed need for personal help and assistance among older adults with joint pain and difficulties in self-care tasks. Considerable proportions of these needs were unmet. The receipt of help and assistance and use of aids and appliances contributed to having their self-care needs met 'as and when they want' to an extent, but remained insufficient in many cases.

To conclude, self-care restriction is common in community-dwelling older people and strongly associated with joint pain. The relationship between joint pain and self-care restriction is linked by other health, socio-demographic and environmental factors. Self-care restriction measured by KAP is a changeable state, with the majority of people with self-care restrictions reporting 'back transitions' 3 years later (Table 9.1).

Table 9.1 Key findings from the thesis

- Self-care restriction occurs in one in ten community-dwelling older adults in the general population
- Self-care restriction increases with age and is more common in women
- Key factors associated with restricted self-care in older people in the general population are age, activity limitation, depression, cognitive impairment, inadequacy of income and not having adult qualifications.
- Joint pain is strongly associated with restricted self-care in community-dwelling older people, but the relationship is not independent from other factors
- One in twenty community-dwelling adults aged 50 years and over is at risk of reporting the onset of restricted self-care 3 years later. Onset is associated with increasing age, poor physical and mental health, multiple joint pains and low socio-economic status.
- 39% of older adults in the general population report persistent self-care restriction, which is higher in men, and is associated with poor physical health, and financial strain.
- Six out of ten adults with person-perceived self-care restriction report recovery 3 years later.
- In older adults with joint pain, severity, stiffness and pain duration are associated with both the risk of onset and persistence of self-care restriction.
- In older adults with joint pain the key factors associated with restricted self-care at baseline (i.e. age, activity limitation, depression, cognitive impairment, inadequacy of income, lower educational attainment) are also predictive of the onset of self-care restriction at 3 years. However, only baseline depression is associated with persistent self-care restriction.
- The level of discordance between person-perceived self-care restriction and task-specific activity limitation suggests these constructs measure different concepts. KAP self-care measure is able to distinguish between participation restriction in self-care, and task-specific activity limitation in self-care activities in those with joint pain.
- Amongst older adults with joint pain and difficulties in self-care tasks, there is a high level of expressed need for personal help and assistance and considerable proportion of these needs are unmet.
- The receipt of help and assistance and use of aids and appliances contributes to having a person's self-care needs met 'as and when they want' to an extent, but remains insufficient in many cases.

9.3 General discussion

This section discusses the key decisions taken in this thesis and potential issues with the conceptual arguments, the systematic review, and the suitability of the use of NorStOP for secondary analysis along with the interpretation of certain findings.

9.3.1 The systematic review

The systematic review aimed to identify the existing studies of self-care restriction and joint pain in the literature and was conducted at the beginning of this PhD project in 2009. In order to identify keywords, an eliminatory literature review was carried out to find alternative descriptions to terms such as 'self-care' and 'restriction'. Two issues arose from using this approach. First of all, 'self-care' was a widely used term in the literature for various concepts such as that of personal activities of daily living (ADL). Thus, in addition to the studies of limitation in ADL, the search yielded studies of self-maintenance/management (e.g. taking your medication, looking after your garden, taking exercise, seeing your friends and staying at work, taking control of your life and how to avoid being ill) as well as psychosocial studies of self-care of one's wellbeing through the use of mediums such as psychological therapy and meditation. This meant that most studies generated using these terms were not relevant to this systematic review. The large array of terms used to define self-care showed the need to use a common language to allow comparison across studies.

Although there were a number of studies which considered limitation and dependency in individual items of self-care (e.g. bathing) in community-dwelling older people, these studies were not included in the review if there were no references made to links with musculoskeletal conditions. Nevertheless, these studies were a good source for identifying potential determinants of self-care restrictions in older people in the general population, and were used to draw comparisons with the results of the analyses when possible.

The systematic review was conducted using 11 bibliographic databases from the time of their inception to 2009. However, this search did not cover grey literature (i.e. research either unpublished or has been published in non-commercial form, such as government or organisational reports), or contact any experts with regards to unpublished studies or thesis. There could potentially be relevant working papers, government reports or policy statements issued that were unknown to the author at the time.

New research on self-care

Stineman and colleagues (2012) published a paper on staging activity limitation and participation restriction in elderly community-dwelling persons, according to difficulties in self-care and domestic life functioning. This study aimed to describe the conceptual foundation and development of activity limitation, and participation restriction staging system for community-dwelling older adults aged 70 years or older, according to the severity and types of self-care and domestic life limitations experienced. Combined stages defined 29 patterns of activity limitations

expressing the individual's potential for participating in life situations pertinent to self-care and independent community life. This study concluded that ADL and IADL stages can serve to distinguish between groups of people according to both the severity and the types of limitations experienced (Stineman et al., 2012). Similar to the traditional measurement of self-care, this study examined task-specific activities such as bathing and dressing, and included 'walking' as one of these ADL. Despite references to ICF domains and qualifiers, the definition of participation restriction and the rationale behind the choice of personal and environmental factors included in the analysis were not clearly defined. Thus, although this study builds up on the existing literature of ADL hierarchy, by providing new evidence on how to stage these activities and combine with IADL to distinguish between groups of people with limitations, the study makes no reference to the determinants of self-care, other than briefly reporting on associations between ADL stage, and other 'person and environment' related factors.

A small scale study conducted by Josephine (2010) in Australia, described activity limitations and participation restrictions in a sample of older patients (n=57) from an acute health setting. This study identified any differences in activity limitations and participation restrictions between patient sub-groups within the sample, using Functional Independence Measure (FIM™) (Uniform Data System for Medical Rehabilitation, 1999) and the Personal Care Participation Assessment and Resource Tool (PC-PART) (Vertesi et al., 2000). The mean age of the participants were 80.3 (SD: 7.5) and 60% were female. Of 57 patients, 16 (28%) reported

mobility impairment, 21 (37%) reported frailty, and 20 (35%) reported cognitive impairment. The percentages for those reporting task-specific activity limitations in personal care, and requiring assisted supervision were: 81% in dressing; 78% in toileting; 83% in bathing; 39% in eating; and 60% in grooming. Overall, 65% of mobility impairment group and 95% of the cognitive impairment group had participation restrictions in hygiene, clothing and mobility domains. The FIM™ and PC-PART reflected distinct activity limitations and participation restrictions of participants with different medical conditions. This study recommended the use of both measures of activity and participation to enable an accurate assessment of the older patient's overall functioning at home (Josephine, 2010). This study had a small sample size and the sample was derived from a hospital site, which could potentially have resulted in the increased estimates of activity limitations and participation restriction. Also the mean age of the participants was 80; an age where these restrictions are expected to be present at an even higher rate. Unfortunately the published data on this study was limited and it was not possible to contact the author as the detailed source of this study was not available through the common search engines. Nevertheless, this study considered participation restriction in personal care activities akin to the definition of self-care in this thesis, and highlighted the importance of making the conceptual distinction between measuring activity limitation and participation restriction in assessing function in older people, supporting the findings of this thesis.

Meanwhile some studies reported 'self-neglect' which is broadly defined as the inability to perform essential self-care tasks threatening a person's health and

safety. Although this concept is somewhat closer to self-management behaviour, it also covers issues with personal hygiene (e.g. washing and bathing, dressing, grooming) thus the findings could be used to compare and contrast with the findings of this thesis. According to Papaioannou et al. (2012) the exact prevalence of self-neglect in community-based older adults is unknown. Papaioannou and colleagues (2012) suggest that cognitive impairment is the most important predisposing factor of self-neglect, alongside a number of other factors such as psychiatric diseases, pre-morbid personality, alcohol abuse, poor physical ability, lack of social support and a low socioeconomic situation. The risk factors mentioned in this overview are similar to the key factors associated with restricted self-care in older people in the general population in this thesis (i.e. age, activity limitation, depression, cognitive impairment, inadequacy of income and not having adult qualifications).

Dong et al., (2012) estimated the prevalence of self-neglect across gender, race, and socioeconomic status in older people. This study showed that black older adults had a significantly higher prevalence of self-neglect than white older adults. The prevalence of self-neglect was higher in those with less than high school education, and for those with an annual income of less than $15,000. It was not possible to determine differences across races using the NorStOP data, due to its homogeneity, thus comparisons cannot be made for these findings. However, the results of this study have shown associations between self-neglect and socio-economic factors that are very similar to the determinants of self-care restrictions in community-dwelling older people in the NorStOP sample. Therefore, the author

suggests that it is plausible that, conceptually, there may be associations between self-care restrictions and self-neglect in older people. However, specifically designed studies need to examine the concordance between these concepts before any conclusions can be drawn from the similarities in risk factors.

Summary of the studies of self-care

The systematic review of the literature identified three epidemiological studies of which two studies explored the relationship between limitation in self-care activities and joint pain, and one study considered the determinants of self-care restriction in community-dwelling older adults with joint pain. However, even in this small sample, there was variation in how these studies defined self-care, disability and joint pain. Therefore, although these studies indicated some links between joint pain and limitations in self-care activities, and pointed at the determinants of self-care disability in older people with joint pain, it was not possible to draw empirical evidence to support these links due to methodological issues which were discussed in detail in chapter 2. The results of the systematic review indicated the need for clear and consistent definitions of self-care and the need for empirical studies to investigate the extent and determinants of self-care restriction. The current research into self-care remains sporadic in terms of the concepts and definitions used to define self-care disability. This thesis is an important addition to the self-care and disability literature, by highlighting the ICF as a model that allows a common approach and helps the understanding of the occurrence, course, and determinants of self-care disability in older people with joint pain.

9.3.2 The concept of person-perceived self-care restriction

Most health measurement instruments do not differentiate between participation restriction and activity limitation (Wilkie et al., 2005 & 2004; Weigl et al., 2003; Fransen et al., 2002). Self-care involves the interaction between an individual and their environment. This is inherently different than the task-specific activity limitation in self-care (e.g. limitation in bathing), which measures individual's capacity to execute a task regardless of the context of the individual's situation or environmental surroundings. The WHO defines participation restriction as performance-based and context dependent, and promotes the assessment of participation restriction against an accepted population standard, that refers to what is expected for someone of the same age, gender and culture (WHO, 2001). The participation in self-care in this thesis was measured using one item from the Keele Assessment of Participation (KAP) tool that was developed to specifically measure participation restriction in population surveys (Wilkie et al., 2005). The conceptual model of participation restriction in KAP advocates that *"the experience of participation restriction is specific to each person due to the variability of roles and influencing factors; thus judgement on the occurrence of participation restriction is best perceived by the individual who experiences it*" (Wilkie et al., 2005: p.1890). Thus, the KAP does not measure participation restriction by describing the deviation from an established normative standard. Person-perceived self-care restriction measures whether the individual's needs in self-care are being met 'as and when wanted'. Therefore, the KAP measures participation restriction as perceived by the individual.

The estimated prevalence of person-perceived self-care restriction in community-dwelling older people at baseline was significantly lower than the published prevalence estimates of ADL limitations as discussed in Chapter 5. This was also true for the onset and persistence of self-care restriction at 3 years. Persistence estimates suggested that 60% of those with self-care restriction at baseline recover at 3 years. Considering that self-care disability increases with age, such a higher rate of recovery might suggest that self-care measured by KAP is an unstable state, with evidence of a substantial majority of people with self-care restriction at one point in time reporting a 'back-transition' 3 years later. Thus, the limitation of this subjective approach to participation restriction lies in the perceptual biases. This may explain the strong associations with other self-reported health and socio-demographic factors, such as depression and financial strain. A perceptual appraisal of one factor may influence the similar appraisal of another factor. The perception of a situation can be the cause of a negative psychological reaction, rather than the situation itself. To explain further, the perceived restriction may be part of a wider negative appraisal of themselves and their situation (Pincus and Morley, 2001). This can result in the underestimation of the potential determinants of self-care, and importance of such perception to actual behaviour cannot be assumed (Wilkie, 2005). Nevertheless, every measure has its limitations and subjective responses should not be considered inaccurate due to subjective factors impacting the person's appraisal of a situation.

When the levels of concordance between the task-specific activity limitation and person-perceived participation restriction were examined, analysis provided

empirical evidence to show that these are two distinct health outcomes. Nevertheless these two concepts are highly correlated, and thus have similar risk profiles. This raises the question of what the estimates of participation restriction tell us that is different from the estimates of activity limitation. Looking at these concepts at a population level, traditional methods of measuring capacity and performance in personal ADL only provide estimates of limitation and dependency; thus still refers to those who self-care with the help of environmental facilitators as disabled. This contradicts the modern understanding of disablement, which supports the measurement of actual disability (a person's ability to carry out tasks with environmental facilitators) as disability is not a personal characteristic, but is instead a gap between personal capability and environmental demand (Verbrugge, 1994). For example, the difference between the intrinsic and actual disability is not made in the Stanford Health Assessment Questionnaire (HAQ) Disability Scale (Fries et al., 1980), which is commonly used in epidemiological studies as a measure of function and disability. In this scale, higher scores indicate a greater disability. The use of environmental facilitators such as 'help and assistance' and 'aids and assistance' results in a higher score in HAQ, suggesting even those who are enabled to perform through the use of these facilitators are disabled.

The broad measure of self-care restriction provided by the KAP self-care item may be inadequate for use in studies where the outcomes require more detailed information on the nature of self-care restriction (i.e. restriction in washing and bathing or toileting specifically) for clinical or rehabilitation purposes. The dichotomous version of the KAP self-care measure does not provide information

on the levels of participation, or give any information as to whether the participation restriction occurs with or without the use of environmental facilitators. However, this is because the KAP was designed to be a crude measure of participation restriction, with the aim of being a short and easy to complete questionnaire that can be used in population surveys. There are various tools available to measure task-specific activity limitations in the literature, as discussed in previous chapters, and these tools may provide clinicians and researchers with more details on specific limitations than the KAP self-care item could offer.

9.3.3 The use of ICF as a framework

The ICF framework was used in this study as a guide to define self-care, and examine the associations with health conditions, impairments, activity limitation and the impact of environmental factors in this relationship. One of the reasons behind the use of ICF as a framework in this thesis was its capacity to provide a standard method for collating and communicating health information. The ICF framework was mainly used to provide a definition of self-care restriction (hence eliminating the ambiguity of self-care) and to organise the potential determinants of self-care restriction in the community-dwelling older adults in this thesis. As discussed in the earlier chapters, problems with the definition of self-care are evident both in the current literature and policies and legislations governing services for people with health conditions. Thus, attempts to define the extent and determinants of self-care restrictions have been hindered by the absence of common language to describe health status of people with chronic conditions such as osteoarthritis. The ICF has the potential to standardise the information on

participation and osteoarthritis as a widely accepted model. It was employed in this study to provide clear guidance on methods of administering data.

The ICF framework was helpful for organising variables under different components (i.e. impairment, activities, participation and contextual factors), despite the previous criticisms made in the literature about the lack of distinction between activities and participation (Badley 2008, Imrie, 2004; Jette et al., 2003; Fougeyrollas and Beauregard, 2001). These criticisms were discussed in the previous chapter (Chapter 8).

Is there a way forward?

Although the use of the ICF as a framework in this thesis was an attempt to clearly define self-care restriction in older adults using a common language, it is evident from the new studies that the use of the ICF is still limited amongst studies of self-care disability in older adults. Criticisms of the ICF's definitions of activities and participation may be one explanation for why disability researchers are not increasingly using the ICF as a framework to inform their studies. However, the use of ADL scales to describe disability in self-care tasks is common amongst the studies of community-dwelling older people. There is a need for a culture shift in self-care disability research. It needs to change from the measure of 'disability', which only considers the individual's intrinsic capacity and dependency on others, to a measure of 'self-care' on a societal level, where interactions between the person, their health outcome, and environmental factors are considered thoroughly.

9.3.4 The use of the NorStOP dataset

NorStOP provided a practical and cost-effective alternative to primary data collection and access to a large dataset allowed investigation of self-care restrictions and joint pain in older adults. The data contained information on self-care, physical functioning, joint pain, and other important demographic, health, and socio-economic factors that were necessary to address the main objectives of this thesis. Problems associated with secondary analysis of population health data usually relate to issues such as the difficulty in locating the required data, incongruity of primary and secondary research objectives, and ensuring the data quality (Bibbs, 2007). As this thesis was undertaken in the Arthritis Research UK Primary Care Centre at Keele University, where the KAP measure was developed and the NorStOP was designed, there were no difficulties in locating the required data. As capturing joint pain, participation restriction, and associated factors in the general population of older adults were amongst the primary objectives of NorStOP, there were no issues with regards to secondary research objectives meeting the primary objectives (i.e. investigating links between joint pain and self-care restriction). The statistical analyses of the NorStOP dataset was approached in the same manner as that for the primary analysis; the data was organised and cleaned, and the quality of the data for each variable was examined by the author.

There was attrition in the NorStOP cohorts at 3 and 6-year follow-up which resulted in a healthier cohort compared to those at baseline. Responders compared to those lost at follow-up at 3 years were younger, and had better physical and mental health, better physical functioning, less depression and lower

levels of cognitive impairment. There were also more people with adult qualifications, and fewer people who found their income inadequate. Similarly, responders at 6 years follow-up were healthier than that lost-at-follow-up for each variable, and those with adult qualifications and reporting adequate income were significantly higher. In comparison to the national population of England, the NorStOP population had a higher proportion of females, and those aged 60 to 69 were over represented in the sample. However, this was more likely to be related to the slightly different population structure of the NorStOP, in terms of age and socio-economic status compared to the national population, rather than entirely due to the response bias. The NorStOP sample was derived from a population sample in the North Staffordshire region, which is one of the 10 most deprived areas in England (Indices of Deprivation, 2010). Using a population that is high in females and individuals from lower socio-economic backgrounds may have biased the results, as this can result in reports of higher levels of ill health (DoH, 2003).

Ideally, a secondary analysis of a national, or even an international dataset would have provided more generalisable results for this PhD. The generalisability of the results is an important aspect of epidemiological research, particularly when aiming to establish the commonality, and determinants of a certain health outcome, such as 'self-care restriction in community-dwelling older people' as in this thesis. Nevertheless, there was not a database available nationally or internationally that included necessary measures, such as measuring self-care as a form of participation, as defined by ICF framework at the time this study was undertaken. This thesis measured self-care at a domain level, using a novel

person-perceived participation restriction measure, which was only available through the use of NorStOP dataset. Also, the time and financial constraints of this full-time PhD would not allow conducting a primary study to include all the necessary measures in a new population study of older adults in the community and a longitudinal follow-up of this population to observe changes in their self-care status.

9.4 Implications

9.4.1 Implications for practice (health and social care)

This study provided an estimate of the frequency, risk of onset, persistence, and factors associated with self-care restriction in community dwelling older adults in the general population, with a particular focus on those with joint pain. As the population is ageing both in the UK and other developed countries, the number of adults with osteoarthritis is expected to rise (Verzjil et al., 2003). A better understanding of self-care restriction and its determinants is important to (i) identify the need to reduce the burden, (ii) aid the development of preventative strategies in health and social care, and (iii) identify the potential for social and clinical interventions to help those with presenting self-care restrictions.

This study identified that one in ten adults aged 50 years and over in the general population experience restriction in self-care, and those who are older, depressed, cognitively impaired, don't have adult qualifications and have inadequate incomes, are at increased risk of reporting self-care restriction. The sheer number of older adults means that there is a need to manage this form of disability. Interventions

targeted at these specific groups of older adults may help to prevent and/or reduce the restriction in self-care, which may result in decreased use of health and social care services and hospital admissions in the longer term.

The results suggest that the association between joint pain and self-care restrictions is through activity limitation. Thus, there is a need for the use of effective strategies to prevent/reduce activity limitation in community-dwelling older adults. The research evidence suggests that regular physical activity in middle-aged and older adults reduces the risk of functional limitations and disability in older age (Paterson and Warburton, 2010). It is recommended that older adults should reduce sedentary behaviour, carry out muscle-strengthening activities similar to resistance exercises which use the major muscle groups, and involve themselves in a moderate-intensity aerobic physical activity for a minimum of 30 minutes on five days each week, or vigorous-intensity aerobic activity for a minimum of 20 minutes on three days each week to promote and maintain their health (Nelson et al., 2007). Thus, early identification of older people with joint pain and activity limitations in primary care and provision of patient education may help to improve functional capabilities in this population group. Furthermore, utilisation of needs assessments in older people with joint pain to identify needs for assistance in ADL could help in provision of appropriate rehabilitative solutions. This may be through personal assistance and / or aids and adaptations to manage activity limitation in older adults before self-care restrictions occurred. Unfortunately it was not possible to examine the influence of environmental facilitators on participation restriction in self-care in this study longitudinally as the

data for help and assistance and aids and adaptations were only collected at 6 years follow-up study.

Depression was also identified as strongly associated with restricted self-care, and as a predictor of its onset and persistence over 3 years. Strong associations were also observed between depression and task-specific activity limitation in older adults with joint pain. Previous research also reports links between joint pain and depression (Yang and George, 2005; Donald and Foy, 2004). Depression in later life (≥65 years) is associated with disability and poorer outcomes from physical illness (Manthorpe and Lliffe, 2010). Evidence suggests that chronic pain and social isolation are risk factors for depression in older people (Rodda et al., 2011). Studies of depression in older people put forward that psychological interventions and antidepressants provide an effective solution for the treatment of depression in older people (Chew-Graham et al., 2011). An earlier study found that in a population of older adults with arthritis and comorbid depression, benefits of improved depression go further than reduced depressive symptoms, and result in decreased pain and improved functional status and quality of life (Lin et al., 2003). Despite the availability of effective interventions, it may be problematic to identify the older people presenting with depressive symptoms in the community. Most people with mild mental health problems such as depression are managed in primary care (Age Concern, 2006). However older people can present with non-specific symptoms such as malaise, tiredness or insomnia which may go undiagnosed (Rabins, 1996). Furthermore, the symptoms of depression may be put down to ‘just getting older’ (Burroughs et al., 2006). Therefore, it is important

that primary care practitioners identify older people presenting with depression when consulted for joint pain and functional limitations to support people with depression. Interventions to increase social participation, physical activity, and provision of psychological support may help to overcome depression, which may result in increased participation in self-care.

Socio-economic factors such as not having adult qualifications and inadequacy of income was also amongst the key factors associated with restricted self-care. Socio-economic status, whether assessed by income, education, or occupation, is linked to a wide range of health problems, including arthritis (Pamuk et al., 1998). Education is identified as a key to health inequality, thus, policies encouraging more years of schooling and supporting early childhood education, may have health benefits in later life (Adler and Newman, 2002). While the association between income and health is stronger in those with lower incomes, income effects persist above the poverty level. This reflects a relative status for those in the upper side of the distribution, and may be more linked to absolute deprivation for those who are at the lower end of this distribution (Backlund et al., 1999). There is growing evidence to suggest inequalities in both the distribution of health (i.e. health outcomes) and access to healthcare both internationally and in the UK (WHO, 2007). It is suggested that some health care services may not be available to certain population groups, or clinicians may have different tendencies to offer/not offer treatment to patients from different population groups, even where they have identical needs (National Audit Office, 2010; Woods et al., 2005; Goddard and Smith, 2001). Inadequacy of income was strongly associated with

restricted self-care in this study, even after adjusting for environmental facilitators. One explanation of this might be that the provision of help and assistance was inadequately distributed for those with poorer backgrounds due to the aforementioned reasons. Therefore, increasing the availability of the support from the health and social care services for those with lower socio-economic backgrounds may result in better health outcomes and thus help to increase participation in self-care.

Preliminary analysis, conducted using NorStOP 6 years cross-sectional dataset, highlighted 588 adults as having 'washing limitation'. This showed that amongst older adults with joint pain and difficulties in self-care tasks, there was a high level of expressed need for personal help/assistance which, when received, is provided largely by informal networks of friends and family rather than formal health or social care (Greenhill et al., 2011). Although it did not emerge as one of the key factors associated with restricted self-care in the multivariable analysis, social networks were significantly associated with restricted self-care even after adjusting for age and gender (adj. OR: 2.7; 95% CI 1.9, 2.8). The high levels of missing data (7.7%) in Berkman and Syme Social Network Index variable may also have influenced the significance level of these associations. Implications of this finding might be that those who are older and socially isolated would be more vulnerable, as they could not depend on the support provided by family and friends. Thus, support provided by health care and/or social services should prioritise those individuals with less social support available to them.

As discussed in the introductory chapter, occupational therapists (OT) are best placed for the holistic assessment of individuals with functional problems to develop an effective intervention plan. The main goal of the OT is to help people with activity limitations to further their skill and function, or at least maintain their current ability and prevent the deterioration of their quality of life (Turner et al., 2002). Hypothetically, the older adults that present to primary care for joint pain/osteoarthritis could be screened for early signs of task-specific activity limitation in self-care care tasks (e.g. limitations in washing and bathing, toileting…) and other health factors such as depression and cognitive impairment to identify those at risk of developing restricted self-care. Those who present with the early signs of poor outcome in these measures could be referred to the community OTs to conduct needs assessments. Following a holistic assessment, OTs could provide the support and patient education required for those with pain and fatigue, and prescribe help and assistance and/or aids and adaptations needed to enable these people to overcome their limitations, thus self-care as and when they have wanted. This could help the community-dwelling older people with joint pain to cope with pain and limitations and become more independent. Consequently this would reduce primary care consultations and burden on social and health care provision within the NHS. According to the statutory legislation, local authorities in the UK provide equipment and minor works for vulnerable and disabled people (Department of Health (DoH), 2005). Prior to 2003, most local authorities used a locally developed eligibility criteria for their service. However, this method was criticised for not providing equal opportunities. Therefore in April 2003 the first national eligibility framework for adult services, namely ‘Fair Access

to Care Services (FACS)' (DoH, 2002), was put in place. This involved the assessment of an individual's autonomy, health and/or safety, daily activities and ability to maintain meaningful participation in family or community life (Sackley and Lett, 2007). However, it is suggested that this service has not been implemented widely, and local authority budgets continue to determine the level of provision, with some authorities choosing not to fund specific services and equipment (Sackley and Lett, 2007). Thus, access to available OT services may be an issue for community-dwelling older adults with joint pain, depending on the provision of these services in the local area they live. Implementation of FACS nationally may help to ensure a fair distribution of these services and reduce the self-care disability in older people living in the community.

9.3.2 Implications for research

The cohort suffered from response bias at the 3 and 6 years follow-up. Therefore, the analyses concerning the onset and persistence of restricted self-care and factors predicting restricted self-care in those with joint pain were conducted on a healthier cohort than those at baseline, which were representative of the general population. This might have resulted in the underestimation of the onset and persistence of self-care restriction in older people in the general population. Multiple imputation (MI) technique was used to attempt to understand and control this possible bias by examining whether the estimates based on partial and complete datasets had differed; the results of the MI analysis showed that the onset and persistence estimates of self-care restriction were not vastly different

than the estimates obtained using the original data. However, as discussed earlier in Chapter 6, the application of MI is not simple, and the approach to imputation taken in this study may not be less biased than the complete case analysis. Therefore, while participant attrition is inevitable in longitudinal studies where people are followed-up over long periods, future longitudinal studies of self-care based on a sample of older adults representative of the general population at follow-ups would increase the generalisability of the findings .

The use of a person-perceived measure of participation restriction in self-care was a novel approach for this thesis. The prevalence estimates of self-care disability were much lower compared to the previous studies' estimates which were acquired through the measure of limitation and/or dependency in self-care items. This could be due to one of two reasons. First of all, participation in self-care is a complex phenomenon which includes the interaction of biopsychosocial factors; thus people with limitation/dependency in self-care may still be 'not restricted in self-care' if their needs are met by environmental facilitators such as help and assistance or aids and adaptations. Secondly, person-perceived self-care restriction may be affected by the context they find themselves in, which may affect the judgement of their needs in self-care being met 'as and when I have wanted'. For example, an individual with depression may appraise their situation differently than a highly motivated individual just as restricted. Therefore, further studies are required to corroborate or refute the findings from this study. Further testing of the KAP self-care measure in other populations would also allow comparisons of the results and validation of what this tool really measures. The

concept of person-perceived participation restriction should also be evaluated by qualitative and quantitative studies to establish its appropriateness in use of population surveys. Further quantitative studies are also required to investigate factors mediating the relationship between joint paint and self-care restriction to build on the findings of this thesis.

Prior to this study the links between self-care restriction and joint pain in the general population of older adults were unknown, and the determinants of self-care restrictions in older people with joint pain were unclear. This study established factors that are potentially modifiable and amenable to interventions to enhance self-care in older adults, providing a basis for future studies to investigate the potential for interventions to enhance self-care in older adults with joint pain.

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Appendix 1: Baseline Health Questionnaire

Appendix 2: Health Questionnaire 3 years Follow-up

Appendix 3: Health Questionnaire 6 years Follow-up

Appendix 4: Baseline Regional Pains Questionnaire

Appendix 5: Regional Pains Questionnaire 3 years Follow-up

Appendix 6: Regional Pains Questionnaire 6 years Follow-up

Appendix 7: QUIPS-LBP Tool

Appendix 8: Published conference abstracts