# THE IMPACT ON HEALTH-RELATED QUALITY OF LIFE OF CAREGIVING WITHIN THE HOUSEHOLD FOR PEOPLE WITH ARTHRITIS

A thesis submitted for the degree of Master of Philosophy

by

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# Abstract

Approximately 10% of people in England and Wales provide care to a family member or a friend. Such care helps people stay in their own homes and saves costs to the NHS and social care systems, but is not without physical and mental effects to the caregivers. This thesis considers the effect on health-related quality of life (HRQOL) of providing care to people with arthritis and investigates the association between (1) time spent caregiving and caregiver HRQOL and (2) the HRQOL of the person with arthritis and caregiver HRQOL. First, a systematic review of the existing literature was undertaken. Second, data pairs from Understanding Society for people with arthritis and their caregivers were used in a regression analysis of the association between time spent caring, caregiver SF-6D values and SF-6D values of the person with arthritis. The analysis suggests that lower caregiver SF-6D values are associated with lower patient SF-6D values, increased time spent caregiving and the presence of caregiver external conflicts (issues with finances, leisure and relationships) and internal conflicts (lack of optimism, usefulness and presence of stress). An interaction is identified between the SF-6D values of the person with arthritis and the presence of caregiver external conflicts. In the absence of external conflicts as the SF-6D values of the person with arthritis increase so do caregiver SF-6D values. In the presence of external conflicts the association between SF-6D values in the person with arthritis and the caregiver is flat. The association identified in this thesis uses measures that could be formally included in economic evaluations such as those used by the National Institute for Health and Care Excellence (NICE). Policy and research relating to household caregiving should account for the effects on caregiver HRQOL that arise from increased time spent caring and caregiver external conflicts.

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## Abbreviations

ACR: American college of rheumatology
ADL: Activities of daily living
AIC: Akaike information criterion
ALSA: Australian Longitudinal Study of Ageing
AMED: Allied and Complementary Medicine Database
ANOVA: Analysis of variance
ASSIA: Applied Social Sciences Index and Abstracts
BHPS: British Household Panel Survey
BIC: Bayesian information criterion
BSRBR: British Society of Rheumatology Biologics Register
CES-D: Center for Epidemiologic Studies Depression Scale
CDC: Center for Disease Control
CINAHL: Cumulative Index to Nursing and Allied Health Literature
DARE: Database of Abstracts of Reviews of Effects
DMARD: Disease modifying anti rheumatic drug
EED: Economic evaluation database
ELSA: English Longitudinal Study of Ageing
EMBASE: Excerpta Medica dataBASE
EPIQ: Effective Practice, Informatics & Quality Improvement
ERAS: Early Rheumatoid arthritis study
ERAN: Early rheumatoid arthritis network
ESDS: Economic and Social Data Service
GLS: General Lifestyle Survey
GP: General practice
GPPS: General Practice Patient Survey
GHQ: General health questionnaire
HADS: Hospital Anxiety and Depression Scale
HAQ: Health assessment questionnaire
HILDA: Household, Income and Labour Dynamics in Australia

HODAR: Health Outcomes Data Repository

HRQOL: Health-related quality of life

HRS: Health and Retirement Study

HTA: Health Technology Assessment

ICPSR: Interuniversity Consortium for Political and Social Research

ITT: Intention to treat

LEAP: Leeds Early Arthritis Project

MCS: Mental component summary

MEPS: Medical Expenditure Panel Survey

MHQ: Mental health questionnaire

mnths: months

NHP: Nottingham Health Profile

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

NOAR: Norfolk arthritis register

OA: Osteoarthritis

OLS: Ordinary least squares regression

ONS: Office for national statistics

PCS: Physical component summary

PGA: Physician global assessment

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PSA /PsA: Psoriatic arthritis

PSID: Panel Study of Income Dynamics

PSS: Personal Social Services

PTM: Primary therapist model

QALY: Quality adjusted life year

RA: Rheumatoid arthritis

RADAI: Rheumatoid Arthritis Disease Activity Index

RAND-36: Research and Development 36-Item Short Form Health Survey

RCT: Randomised controlled trial

RESET: Ramsey Regression Equation Specification Error Test

SD: Standard deviation

SF-12: 12-Item Short Form Health Survey

SHARE: Survey of Health, Ageing and Retirement in Europe

TNF: Tumour necrosis factor

TTM: Traditional treatment model

UK: United Kingdom

US: Understanding Society

USA: United States

VAS: Visual analogue scale

VIF: Variance inflation factor

WEMWS: Warwick Edinburgh Mental Wellbeing Scale

wk: week

YEAR: Yorkshire Early Arthritis Register

yr: year

# 1 Introduction

The broad aim of this thesis is to consider the effects of providing care to people with arthritis on the person providing care and to gain an understanding of the association between time spent caregiving and caregiver health-related quality of life (HRQOL) and the HRQOL of the person with arthritis and that of the person providing care.

The thesis does not consider care provided by professionals as part of health or social care. Rather, it considers the help and support provided by family and friends to people who would otherwise not be able to manage. This type of care has been referred to in the literature as unpaid care, informal care, family caregiving or caregiving within the household. Approximately 10% of people in England and Wales provide such care (1) and this care is important for enabling people to remain in their homes and out of hospitals and social care institutions. However, caregiving is not without effects to the caregiver, their family and wider society because of changes in role and in time allocation.

This thesis rests on an assumption that the effects to caregivers of providing care should be included in economic evaluation. This assumption is consistent with the specific context of the thesis, that is, decision-making about reimbursement of health technologies in England and in particular technology appraisals. Within England, health technologies are evaluated by the National Institute for Health and Care Excellence (NICE) using health economic evaluation. NICE defines a reference case to guide its economic evaluation which specifies that direct health effects to patients, and where relevant their caregivers, can be taken into account (2). The health effects should be specified as quality adjusted life years (QALYs) and in preference, HRQOL should be measured using EQ-5D and valued using a representative sample of the UK population. These health effects should be incorporated into a cost-utility analysis using all relevant NHS and Personal Social Services (PSS) costs. Recommendations about reimbursement of a health technology takes into account cost per QALY thresholds, whereby treatments with a most plausible cost per QALY of less than £20,000 are likely to be recommended by NICE and treatments with a most plausible cost per QALY above £20,000 are likely to be recommended by NICE only with the presence of other factors (for example certainty in the analysis, innovative nature of the treatment and capture of HRQOL in the analysis).

The contribution of caregivers and the importance of including caregiver effects in economic evaluations is recognised (3), and could be included in cost-effectiveness analyses through quantification of either the effect or cost of providing care (4,5). However few economic evaluations submitted to NICE technology appraisals include caregiver effects.  which in part may be explained by an absence of data.

The population studied in this thesis are the caregivers of people with arthritis. Arthritis provides a good example to study caregiver effects. First, arthritis is a common condition and so impacts on a significant proportion of the population. The most common type of arthritis is osteoarthritis with an estimated total prevalence of knee and hip osteoarthritis of 18.20% and 10.92% respectively (6). Other types of arthritis are inflammatory arthritis such as rheumatoid arthritis and psoriatic arthritis. Second, the effect of the disease is not cognitive, so outcome measures collected directly from the patient can be used. Third, for inflammatory arthritis such as rheumatoid arthritis there are a variety of high-cost disease-modifying drugs available that are frequently subject to economic evaluation. Access to these drugs is often restricted based on the outcomes of economic evaluation, but the effects on caregivers, although recognised, are not frequently incorporated into evaluations.

This thesis is split into 6 further chapters: chapters 2 to 7. Chapter 2 provides background information on caregiving, how caregiving has been defined and measured and the effects of caregiving on the caregiver, their family and society. The final part of chapter 2 reviews theories of caregiving and presents the theoretical framework that will underline the thesis: Stress Process Theory and Pearlin's model of factors influencing caregiver outcomes. Chapter 3 presents the findings of a systematic review of the existing literature on effects on caregivers of caregiving for people with arthritis. The systematic review explores the variables that have been found to be associated with caregiver outcomes in the population of caregivers of people with arthritis and contextualises these within Pearlin's model of factors influencing caregiver outcomes. Having reviewed the existing literature chapter 4 describes the methodology for completing the secondary dataset analysis. It describes the research questions, the available datasets for completing an analysis of the association between patient HRQOL and caregiver HRQOL, the approach to regression analysis and the model to be tested in the analysis. Chapter 4 also describes the dataset chosen: the Understanding Society dataset, and provides a rationale for its use. Chapter 5 describes the sample of patients with arthritis and their caregivers in Understanding Society and presents bivariate analyses for the variables to be used in the analysis. Chapter 6 presents the development of the regression model used to explore the relationship between time spent caregiving, patient HRQOL and caregiver HRQOL. It also includes a series of sensitivity analyses considering the consistency of the effects observed across different caregiver groups. The discussion of the thesis including a statement of the findings, strengths and weaknesses of the research, and contextualisation of the findings within existing literature is then presented in chapter 7.

The overriding purpose of this thesis is to inform decision-making by developing a model of the association between patient HRQOL and caregiver HRQOL and quantifying that association. The methods and principles used in this thesis are generalisable to other disease areas and datasets.

# 2 Caregiving

## 2.1 Introduction

This chapter introduces the central concept for this thesis, that is care provided by family members, friends or neighbours and sometimes referred to as informal care, unpaid care, family caregiving or caregiving within the household. This section describes caregiving in England and Wales and considers some of the issues associated with studying caregiving. The chapter goes on to consider the effects of caregiving on the caregiver, their family and to society as well as the moderators of these effects. It then examines existing theories of caregiving and how the moderating effects reviewed in the chapter can be considered within existing theoretical frameworks. This chapter is the foundation for the development of a model of the association between patient HRQOL and caregiver HRQOL.

## 2.2 Caregiving

Approximately 10% of people provide care in England and Wales. People aged 50-64 are most frequently caregivers followed by people aged 39-49 and those aged 65 and over (1). A majority of caregivers are female (57%) (1). The majority of caregivers care for a family member: a parent (33%), a spouse or partner (26%), a child (13%), or another family member (18%). However, 9% care for a friend or neighbour (7).

The proportion of people providing care who are co-resident varies across studies between approximately a third (8) and a half (7). Caregivers providing care within the household are most likely to be looking after their partner (51%) or a child (22%), while those caring for someone living elsewhere are most likely to be caring for a parent (48%) or a friend or neighbour (18%) (7). The majority of people receiving care have a physical disability (62%), while 22% have both physical and mental disabilities, and 11% mental disability (7).

The majority of caregivers provide care for less than 20 hours a week (1,7) and are often also economically active. However, there is a minority of caregivers (25% in the 2011 census (1)) who are both economically active and provide more than 20 hours of care a week. The most common type of care provided is practical help such as preparing meals and doing the laundry (82%), followed by keeping an eye on the person being cared for (76%) and keeping the person company and taking them out (66%). Approximately half reported helping with paperwork or dealing with services and benefits, while approximately a third reported helping with personal care, physical help and giving medicines (7).

The number of people requiring care is predicted to increase as the population ages and more people live with chronic conditions. The number of people in England aged 65 and over is projected to grow from 7.8 million in 1996 to 12.4 million in 2031 (9). As the population ages the number of dependent elderly people living at home and requiring care is projected to rise by 63 per cent from 1.7 million in 1996 to 2.8 million in 2031 (9).

## 2.3 Identifying caregivers

The Carers Trust describe a caregiver as follows:

*A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.* (10)

Research commissioned by the Department of Health identified that 62% of people interviewed did not really think of themselves as a caregiver despite completing tasks that could be considered to be care tasks (11). People may see care as something expected or done anyway as part of a caring relationship, rather than as an additional role that has been acquired. Half of caregivers report providing care because it was expected of them, though a similar proportion indicated that they were willing or wanted to help out (7).

As people may not identify themselves as caregivers, surveys tend to ask whether the respondent provides help or support for other people, rather than whether they are a caregiver. Therefore a caregiver is defined on the basis of the nature of the role being performed rather than on self-identification as a caregiver. However, the methods by which caregivers are identified and recruited are poorly reported in many studies (12,13).

The care relationship is often conceptualised as unidirectional, that is, a person provides care to a person who receives care (14). However, caregivers may care for more than one person and people receiving care may do so from more than one person. In the survey of carers in households (7), the majority of people (83%) provided care to a single person. However, only a minority of people considered themselves to be the sole carer (37%) and other people surveyed described a scenario where there was joint care (that is, multiple people providing care to one person). The care relationship may also be one of reciprocal care where people provide care for each other. Spouses may support the other in certain tasks and *vice versa*, or dependent adult children may provide care to their parents while also receiving care from their parents. People providing care may themselves receive care either from the recipient of the care or from other sources.

## 2.4 Defining and measuring care

Care is individual to the person receiving care, and to the person providing care. No single definition of what constitutes care exists. In the English longitudinal study of aging (ELSA) (15) care is defined as support in activities (e.g. personal care tasks) or instrumental activities (e.g. domestic care tasks) of daily living (16). In the survey of carers in households (17) it is defined more broadly and also includes provision of companionship and ‘keeping an eye’ on someone. Differing definitions of care will identify different groups of people as ‘caregivers’ and provide different measurements of the amount of care provided.

Caregiving can be completed at the same time as other activities. A caregiver may shop for the care recipient at the same time as they shop for themselves, they may watch television or prepare a meal while they keep someone company, or they may sleep but be available in case they are needed in the night. This means that care can be difficult to measure accurately, and results will differ depending on how care is defined and whether primary (e.g. where the task has the caregiver’s sole attention) and secondary (e.g. where a task is completed alongside other activities) care activities are included.

The provision of care is not static, for some caregivers the amount of care provided may increase over time as the care recipient’s health worsens, in other cases it may decrease as health gets better. For care recipients with relapsing and remitting conditions care may be required intermittently or the amount of care required may fluctuate. Therefore measures of the amount of care may differ depending on the stage and duration of the health condition.

Care may not always be considered positive or helpful by the recipient, and there can be a difference in the amount of care required, in the amount of care that is perceived to be required and in the amount of care provided. Therefore when measuring care it is important to take account of who the measurement is taken from. Even among different family members there may be differences in perceived problems and perceived care required (18). Perceptions about the provision and receipt of care therefore depend on whether the question is asked of the person providing care, or of the person receiving care.

## 2.5 Effects on the individual

The outcomes of caregiving are often reported in terms of the negative effects or ‘burden’ on health and wellbeing, reduction in leisure time and financial costs in terms of reduced employment. However, caregiving can also be associated with positive benefits which are less widely reported (19,20).

### 2.5.1 Health and wellbeing

Physical health problems reported by caregivers include fatigue and sleep problems, physical strain, exacerbation of existing health conditions, development of new health conditions and eating problems such as loss of appetite (7). Emotional problems are also widely reported including anxiety, depression, mood, uncertainty and helplessness (7,21). Schultz and Beech (22), in a widely reported study of caregiving, found that older spousal caregivers who perceive greater emotional or mental strain have a higher likelihood of mortality than people not providing care. However, other studies using population samples have reported that caregiving, though associated with worse mental health, is associated with a decreased risk of mortality (23–25). In the 2011 census people providing more care reported worse health. The proportion of people providing less than 20 hours of care a week and reporting their health as very good or good was 69%, compared with 18% of those providing over 50 hours a week. Among those providing 50 hours of care a week or more, 46% reported bad or very bad health compared with 37% of those providing care for less than 20 hours a week (1). A multivariate analysis of 2001 census data also found caregiving associated with increased reporting of poor health (26). Smith, reporting outcomes from the adult psychiatric morbidity survey, found that there was worse mental health among caregivers compared to non-caregivers, but no difference in physical health (27).

### 2.5.2 Employment and financial costs

Over half of people in England and Wales providing care are economically active and these people have to balance the provision of care with participation in the labour force. Fast and colleagues reviewed literature considering the economic costs of caregiving (28–32).

The time required to provide care means that people may find that they have to give up work in order to provide care. In Understanding Society (33) approximately 40% of caregivers of working age were prevented from working either totally or partially. Alternatively for those not already in employment, starting work may not be possible because of caregiving responsibilities (28). This can cause financial strain through reduced available income, savings and pensions. Among caregivers who continue to work, absences may increase because of the need to provide care, leading to reduced productivity. Career progression may also be limited by restrictions created by the caregiving role and caregivers may choose to take early retirement to enable care provision. The economic impact of caregiving differs between countries (34). Research from the UK suggests that providing care is associated with receiving lower wages (35,36) and the effect of caregiving on employment may be greatest for people providing care within the same household (37,38).

Caregiving is associated with unpaid labour including the time spent providing care, time spent acting on behalf of the person receiving care, time spent travelling to and from the person receiving care and time spent keeping an eye on the person receiving care. These reduce the amount of time a caregiver is able to spend in paid work and in other activities. In the UK, benefits such as the carer's allowance, attendance allowance or disability living allowance may act to reduce some of the financial impact of providing care. Caregiving is also associated with expenses such as residential care, community services, transportation to appointments, supplies (for example food or medication) and adaptations to the home. Carers UK suggest that almost a third of caregivers (30%) find themselves with a reduction in £20,000 or more per year in their household income as a result of caring (39). Therefore caregivers can be financially worse off as a result of providing care.

### 2.5.3 Leisure and social participation

Caregiving can impact on the ability to take part in social or leisure activities. This may be because caregivers feel that they have to be there in case they are required, or the time required to provide care means there is no time for other activities, or the energy required to provide care means that the caregiver doesn't have the energy for leisure or social activities. In the survey of carers in households, 42% of people reported that providing care had affected their personal relationships, social life and leisure, most commonly because of reduced time (69%) or fatigue (32%), and only 1% indicated that caring had had a positive effect on their personal relationships, social life or leisure (7). This is significant because multiple roles and being able to combine multiple roles may be protective for some people providing care, supporting positive outcomes from care (40).

### 2.5.4 Identity and role

Becoming a caregiver can mean acquiring and taking on new roles and responsibilities, affecting a person's identify and sense of who they are. These roles may be new roles specific to caregiving, but can also be roles not related to caregiving that were previously performed by the other person, but which now must be completed by the caregiver. In some instances such changes may be positive and in others negative. For example, positive benefits are described in the review of the literature by Funk et al (12) to include pride, esteem and mastery of a new role. Further, Brouwer (41) suggests that caregivers may derive utility (described as "process utility") from being the person in the role of caregiver versus having that care being provided by someone else.

Caregiving can change the nature of the caregiver's relationship with the person cared for and the caregiver's role within the family (42). In a review of qualitative literature on caring for people who have had a stroke, Greenwood and Mackenzie (43) describe the changes in relationships, how being a caregiver may mean that they no longer feel like a partner, relationships may be less of a partnership and the person cared for may become more like a friend than a husband or family member. However, positive gains are also noted; the changing relationship may bring with it a greater depth and togetherness, or a re-evaluation of priorities which have a positive effect on wellbeing.

## 2.6 Wider effects of caregiving

The wider effects of caregiving can include the positive impact on keeping people out of hospitals and social care institutions with benefits to society and to the NHS and social services, as well as the potentially negative impact that caregiving may have on the labour market (44,45), and the effect of caregiving on employers and the family.

### 2.6.1 Society

The provision of care by family members and friends may substitute for care provided by formal services (46) and can help support people to stay in their own homes and be part of their local community. The availability and provision of unpaid care therefore can reduce costs to the health system and social care system (47,48). The amount of savings to the health and social care systems is not small. For example, Paraponaris (48) valued the annual cost of care provided by family and friends in France at 6.6 billion euros. In the UK, the importance of the role of caregivers was recognised in 2008 in a cross departmental strategy “*Carers at the heart of 21st-century families and communities*” (49) subsequently updated in 2010 as “*Recognised, valued and supported: Next steps for the Carers Strategy*” (50) and in 2014 as “*Carers Strategy: Second National Action Plan 2014 – 2016*” (51). These documents outline a long-term vision in which recognition and value are given to the role that carers play in enabling families and communities. Policies to support caregivers include access to formal services such as assessments by social services, monetary benefits, equalities legislation and policies to facilitate flexible working.

Although, caregivers help support people to remain at home, the theoretical concern is that if a person is providing care, they may be unable to, or choose not to be part of the workforce, thereby affecting the amount of workforce available, and government employment policies. High-intensity caregiving has been found to be related to full-time retirement (44), and for women, to being outside of the labour market and working part-time (52,53). Van Houtven (53) calculated that the provision of care was associated among female caregivers with an average reduction in working hours of 3 hours per week, rising to 10 hours a week for those providing care intensively. Considering the overall impact on society, Jacobs et al (52) calculated that, from a Canadian perspective, people providing fewer hours of care (less than 5 hours a week) provided a net benefit to the government of approximately 4.4 billion dollars, while people providing more than 5 hours of care a week provided a net cost to the government of 641 million dollars. The main driver of the costs was the reduction in the likelihood of being part of the workforce and the effect that this has on tax revenues. In Britain, Pickard (46) using 2010 data, estimates that 315,000 caregivers left employment and that the costs to the government of caregivers giving up work is 1.3 billion pounds comprised of 300 million paid in carer's allowance and 1 billion in foregone taxes from lost earnings.

### 2.6.2 Employers

For employers of caregivers there can be a number of costs. Direct costs include those associated with replacing staff (e.g. recruitment costs, training costs), costs associated with absences such as temporary staff costs, and costs associated with caregiver sickness and stress-related illness. Indirect costs include costs associated with lost productivity, the loss of organisational knowledge and the effect of staff absences and resignations on other staff and clients. Further 'discretionary' costs may also be accrued from supporting flexible working practices and providing a work environment designed to reduce the likelihood of accruing direct and indirect costs (31). The total cost to employers can be significant: the MetLife study (54) reports that the cost to employers of all caregivers in full-time employment was $2110 per employee or $33.6 billion in total.

### 2.6.3 Family

Caregiving can be associated with a disruption to the family, in terms of the effects on the family arising from the illness of the person receiving care, and the effects on the family arising from caregiving. Both contribute to the concept of family burden (55).

Other family members or people within the caregiver's or care recipient's social network may find themselves taking on new roles or responsibilities. These may be related directly to caregiving e.g. providing some caregiving themselves, or indirectly e.g. performing roles that the caregiver can no longer provide such as picking up children from school, or preparing meals. Other family members may also have to manage with less attention and physical or emotional support from the caregiver than previously received, which may be particularly problematic where caregivers have dependent children. Family members may also have to share the burden of financial worries that can be associated with providing care.

## 2.7 Moderating factors

The outcomes of caregiving are varied, that is, two caregivers providing a similar role may not be affected by it in the same way. A range of factors have been identified that moderate the effects of providing care.

### 2.7.1 Socio-demographic factors

Socio-demographic factors can relate to either the characteristics of the person receiving care e.g. the influence of the care recipient's age on caregiver outcomes, or of the caregiver e.g. the influence of caregiver age on caregiver outcomes. In meta-analyses of older caregivers, Pinquart and Sorenson (56) identified that female caregivers experienced more burden, depression and provided support for a greater number of care tasks than male caregivers. Stajdhurar (13) report that this is also observed in population studies, but note exceptions (citing Grov et al. (57) and Scott (58)). Pinquart and Sorenson (59) also report differences in effect depending on race and ethnicity with African American caregivers experiencing less depression than white non-Hispanic caregivers, and Hispanic and Asian American caregivers experiencing more depression than white non-Hispanic caregivers. Younger caregivers and caregivers to younger patients may also experience more negative outcomes than older caregivers (13), though again this is not consistently reported (60).

The availability of income may provide opportunity to purchase care. However, although availability of income is generally associated with positive wellbeing (61), among caregivers a relationship between income, education level or socioeconomic status and outcomes has not been consistently observed (13). One reason for the lack of a consistent relationship may be that the decision to provide care, or to provide greater amounts of care is motivated by a number of factors, only one of which is the caregiver's preferences, with the preferences of the care recipient and what is expected also playing a role in decisions to provide care.

The location of care may also affect caregiver outcomes. For example, caregivers providing care in urban locations may have more access to formal support such as transportation and medical services as well as informal resources such as support networks of family and friends. However, again no consistent relationship has been reported (62). This may be because of differing definitions of what constitutes an urban and rural environment.

### 2.7.2 The caregiving relationship

The relationship between the caregiver and recipient can also affect caregiver outcomes. Hirst (63) identified greater levels of distress among spousal caregivers compared to non-caregivers, but not for non-spousal caregivers compared to non-caregivers. Pinquart and Sorenson (64) also found greater levels of depression and lower levels of wellbeing among spousal caregivers than adult-child caregivers.

Caregiver outcomes may also be influenced by the extent to which the caregiver and care recipient are able to get on, or their emotional closeness; people who like each other and enjoy spending time with each other may be less prone to negative outcomes than people providing and receiving care who do not get on. Fauth et al. (65) report that emotional closeness is associated with less depression, but that over time, being emotionally close to the care recipient is associated with greater levels of depression. Al-Janabi et al. (66) identifies getting on with the person being cared for as a factor valued by caregivers.

### 2.7.3 Care needs and demands

The disease characteristics of the care recipient can affect caregiver outcomes. The severity of the condition can affect the amount of care required, which in turn can affect the ability of the caregiver to combine caregiving with other activities. Increasing caregiver demands have been reported to lead to increases in depression while reducing caregiver demands lead to reduced depressive symptoms (67). Patient diagnosis while not found to be associated with caregiver outcomes (68) can affect the type of disability (e.g. cognitive, sensory, mental, physical), which can affect the care required (69).

Disease trajectory and the place in the course of illness where caregiving is occurring is important to consider when investigating the impact of caregiving. A person’s care requirements and the way in which the caregiver feels about these are unlikely to be static because of the adaptation process that can occur, including both patient psycho-social adaptation and functional adaptation in terms of managing disability.

Care tasks include a range of activities such as self-care, shopping, advocating and surveillance. Care tasks differ in their ability to be combined with other jobs that a caregiver might have to do (70), to be done at different times of the day and therefore to fit in with the caregiver’s existing lifestyle (71), and the extent to which they change the relationship between the caregiver and care recipient. For example intimate tasks such as self-care may be more distressing than other activities such as shopping or cooking. Therefore the nature of care tasks required has the potential to influence caregiver outcomes.

### 2.7.4 Caregiver health and wellbeing

The caregiver’s health and wellbeing also affects other caregiver health and wellbeing outcomes. For example, caregivers who themselves have an illness or condition may find completing care tasks more challenging or physically wearing than people who are in good health. Caregivers who are restricted in the support they can provide may also have guilt at being unable to provide the full range of support required by the care recipient.

### 2.7.5 Environment

Caregivers perform a number of roles alongside caregiving. These roles interact with the caregiving role and can influence how the caregiver feels about caregiving. The effect of caregiving on employment, finances and the family were reviewed in section 2.6 as part of the effects of caregiving, but these factors can also moderate the effects of caregiving. Religious commitments and leisure commitments (for example clubs and societies attended) may also interact with the caregiving. Environmental factors may be protective as they provide the opportunity for the caregiver to maintain multiple roles within the family and society (40). However, their presence can also have a negative effect because the time and effort required for the different activities starts to compete with the caregiving role (72,73).

### 2.7.6 Self-concept

A caregiver’s perceived sense of identity and self-concept can be important moderating factors of caregiver outcomes. Schulz (74) found that caregivers who perceived a lack of choice in becoming a caregiver had greater emotional stress, physical strain and negative health impact. Further, higher levels of caregiver esteem, mastery and self-efficacy are associated with a beneficial effect on caregivers (75–77). However, becoming a caregiver may increase or decrease these feelings depending on the caregiver’s sense of self, that is, for some people becoming a caregiver may increase their sense of self-efficacy while for others it may decrease it. Further, as with other factors affecting caregiver outcomes, their relationship with caregiver outcomes may be subject to change over time. For example, caregivers may undergo a period of adjustment and adaptation whereby the caregiver becomes more used to the caregiving role. Godwin (78) reports a decreasing effect on HRQOL over time among caregivers of people who had had a stroke. Alternatively, as the caregiver takes on more caregiving responsibilities, their sense of self-efficacy may reduce, as they have to provide support with more tasks with which they are unfamiliar.

### 2.7.7 Resources

Both patients and caregivers have access to external resources that can help support them. These can be informal (e.g. social networks of friends and family) or they can be formal (e.g. healthcare facilities, social services). Both formal and informal support may be valued by caregivers (66), and access to such resources may improve caregiver outcomes by providing caregivers with a break, enabling them to share the caregiving responsibility, or to manage the role of caregiving more effectively. However, not all caregivers want to or know how to access formal resources such as respite (79), and studies of information and support interventions for caregivers tend to show mixed outcomes (80). Formal support services may only be available to caregivers under most strain, and therefore access to formal resources may be associated with worse caregiver outcomes. Likewise, informal support sources, while having the potential to ease caregiver strain, also require that the caregiver maintain their social network which takes time and energy that the caregiver may not have.

As well as external resources such as support networks and health care services, caregivers also have internal resources that they draw on such as coping and control strategies. Spirituality or religiosity can provide a protective effect against negative caregiver outcomes (81,82). Hodge and Sun (81) identified that religiosity was associated with positive feelings about caregiving, but that social support was not. Coping and control mechanisms are other internal resources that caregivers may draw on, and can be protective (77) and valued by caregivers (66).

## 2.8 Theories of caregiving

A number of theories have sought to explain the role of the different factors leading to variation in caregiver outcomes.

A person who becomes a caregiver experiences a change in roles and responsibilities as well as illness of a loved one. These changes are frequently long-term changes, may be unpredicted and can occur out of the expected order of the life course. Stress process theory considers how factors come together to create stress (83). It has frequently been used to frame the experience of caregiving and explain variation in impacts of providing care (73,84–90). It is not specific to caregiving and has been used in a variety of areas, for example patient experience of and adaptation to illness (91–93).

A conceptual model of caregiver outcomes developed by Pearlin (94) from Stress Process Theory has formed the theoretical basis for a number of studies of caregiving (73,86,95–99).

Pearlin’s model has 4 components: (1) background and context, (2) stressors, (3) mediators of the stressors and (4) the outcomes of the caregiver. The model provides a basis for considering how the various factors described in the preceding sections interact to determine the outcomes of caregiving (Figure 1).

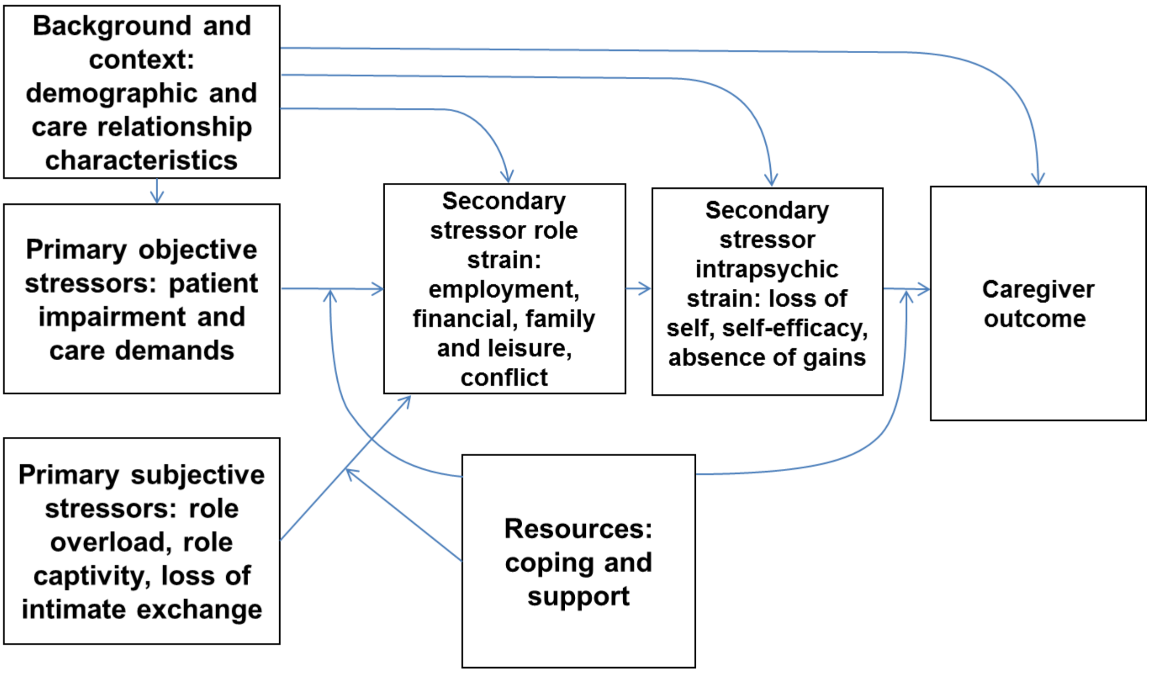
Primary stressors arise directly from caregiving and can be objective or subjective. Primary objective stressors are the care demands and characteristics of the impairment of the care recipient such as cognitive difficulties, behavioural difficulties and functional difficulties.

Subjective primary stressors include the perceived ability of the caregiver to cope with the tasks and responsibilities associated with being a caregiver (role overload), the desire to be in the caregiving role, as opposed to an alternative role (role captivity), and the change in relationship status between the caregiver and care recipient (loss of intimate exchange).

Secondary stressors are not directly associated with the caregiving role, but may arise as a result of caregiving and can be external or internal. External secondary stressors are described as role strain and include social, economic, and personal aspects of the caregiver’s life that are separate to caregiving. Secondary stressors include family conflict, employment conflict (for example work strain, work reduction, unemployment), financial conflict (for example increased expenses, financial strain) and restriction of social life. Internal secondary stressors described as intrapsychic strains are associated with the concept of ‘self’. The first of these factors is perceived loss of self. The second factor is perceived self-efficacy. The third of element is perceived positive gains. Secondary stressors are not caused directly by caregiving, but are consequences of caregiving.

Figure 1 shows the relationship between the different factors. Secondary stressors arise from primary stressors. Secondary stressors can be a source of negative outcomes in their own right, and also moderate the effects of the primary stressors creating negative caregiver outcomes. The outcomes and stressors are also moderated by available resources such as social network and health and social care services and caregiving context including patient and caregiver demographic factors and the caregiving relationship.

**Figure 1: Pearlin’s model of caregiver outcomes**



Note: Figure adapted from Aneshensel 1995; Pearlin et al. 1990; Family Caregiver Alliance 2006 (73,94,100).

Alternative models exist to frame and explain the caregiver experience. For example, lifespan theory of control (101) is used by Nieboer (67) in a study of a mixed population of caregivers focussing specifically on the disruption of caregiving to life activities. Cameron, in a study of caregiving in advanced cancer (102), draws on Nijboer's model of family caregiving (88) derived from stress process theory and also draws on Devins' illness intrusiveness model (103) and Stephens, in a study of caregiving in people with arthritis (104), draws on Caplan's person-environment fit theory (105). Other theories when applied to caregiving tend not to be as well described or as frequently used as Stress Process Theory. Further, theories (for example Nieboer) may be used to describe the influence of a specific factor on caregiving outcomes rather than as a general model of caregiving outcomes. Finally all theories applied to caregiving tend to emphasise the complexity of the caregiving experience and the important role that environmental and psychological factors play in defining the caregiving experience. Therefore, while alternative theories have been applied to caregiving research, none of these provide a more compelling alternative to the use of Stress Process Theory and Pearlin's model.

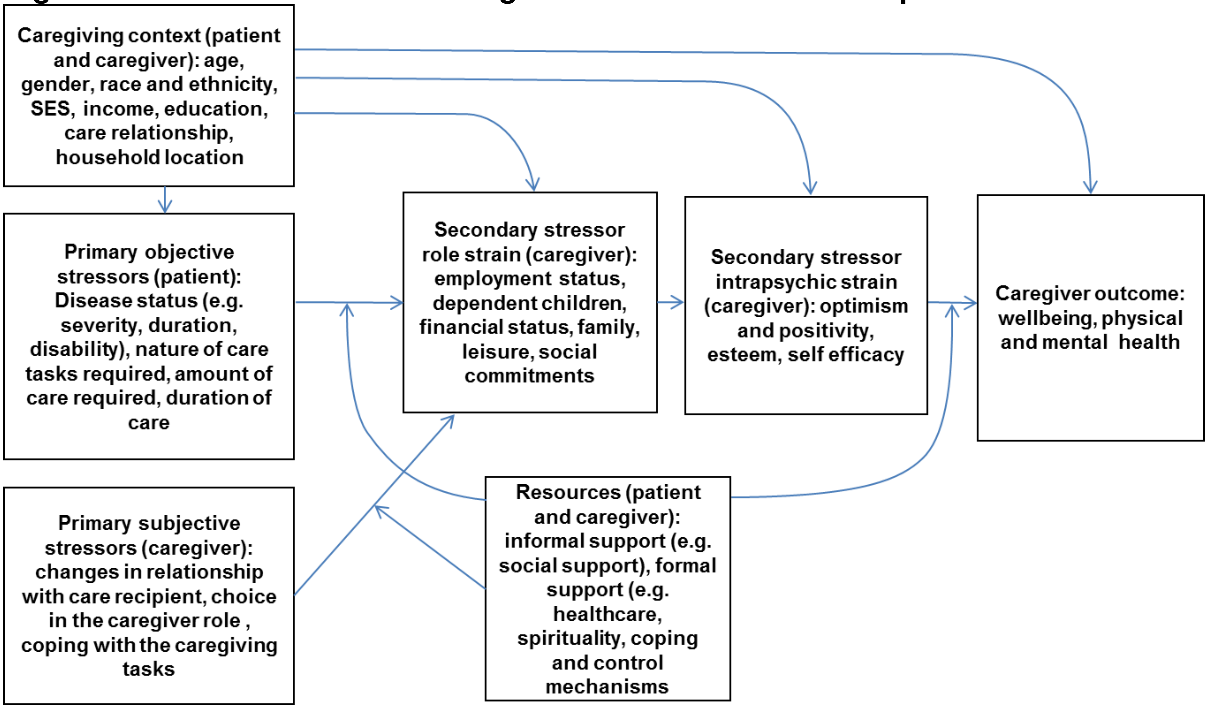
## 2.9 Summary

A significant proportion of the population within the UK provides care to a family member, neighbour or friend. This proportion is expected to increase over time as the population ages. Caregiving has an important policy focus recognising the centrality of caregivers in providing patient care and the role they play in ensuring people can remain in their homes for as long as possible. Although caregiving can be associated with positive outcomes, it can also have negative outcomes that can be physical, psychological and financial.

A person who provides care has to balance this with other activities such as their employment, leisure and social activities, and other family care, as well as with psychological factors such as their perceived identity and self-concept. People vary in the extent to which providing care is valued positively and in their ability to adapt to the changes associated with providing care. When care does not affect valued activities or self-concept or people have the resources to enable them to balance the caregiving role e.g. through the purchase of additional care, or to share the care role with other family members and friends, the provision of care in itself may not be valued negatively. However, where caregiving creates a conflict with other activities or with self-concept, this can lead to negative outcomes.

Pearlin’s model of caregiver outcomes has been widely used in caregiving research. It provides a foundation for developing a model of the association between patient and caregiver outcomes. Taking the moderating factors identified in this introduction and placing them within Pearlin’s model (figure 2) provides the foundation for starting to consider the factors that may be important to take into account when examining the association between patient HRQOL and caregiver HRQOL and how these factors may interact to produce caregiver outcomes.

**Figure 2: Pearlin’s model of caregiver outcomes with exemplars**



# 3 Systematic review

## 3.1 Introduction

Having considered caregiving more generally and identified a conceptual foundation for examining caregiver outcomes, this chapter specifically considers the existing literature about caregiving in adults with chronic arthritis. The systematic review further informs the development of the framework of variables hypothesised to influence the outcomes of caregivers that is the basis of the secondary data analysis in subsequent chapters. The start of this chapter describes the aims of the systematic review and the methods of identifying studies. It then describes the studies identified before summarising them based on their study type. The chapter includes a cross-study synthesis that shows the factors associated with caregiver outcomes identified in the existing literature and applies them to the model of caregiver outcomes outlined in chapter 2.

## 3.2 Aims and objectives

The overall objective of the systematic review is to identify existing research evidence relating to outcomes to caregivers of caregiving for adults with chronic arthritis.

Inclusion in the review was not limited by study type. Initially research questions were developed for each of the types of studies that informed the objective of the review:

- For studies of interventions: what is the effect of interventions on caregivers or on care-related outcomes (for example hours of care received as reported by the patient)?
- For non-intervention studies investigating associations between variables: what patient and caregiver factors influence the outcomes of caregivers or care-related outcomes?
- For qualitative studies: what do patients and/or caregivers perceive to be factors that influence the caregiving role?

Syntheses by study type were then brought together in a cross-study synthesis that identified the outcomes of caring for adults with chronic arthritis and the factors associated with these outcomes.

## 3.3 Methods of the systematic review

### 3.3.1 Criteria for including studies in the review

***Population: Care recipients***

To enable data analysis and interpretation the review was restricted to adults with chronic arthritis. In studies including people with multiple conditions the data for adults with arthritis had to be presented separately from the data for people with other conditions.

***Population: Caregivers***

The people providing care had to be identified by the primary research authors as caregivers or as providing assistance/help/support in activities of daily living or another task. The people providing care had to be working in a non-professional capacity.

Studies that did not include caregivers were included if they measured a care-related outcome (such as the number of hours of care provided from the perspective of the patient, or caregiver burden from the perspective of a spouse or family member).

***Outcomes***

Quantitative studies needed to report either the effect of an intervention on an outcome collected from a caregiver or related to the provision of care, or an association between a variable and an outcome of the caregiver or related to the provision of care. Qualitative studies needed to investigate the experience of providing care. To enable data analysis the care-related outcomes needed to be presented and analysed separately from other outcomes (for example in cost of illness studies). Because the review was primarily interested in factors affecting caregiver subjective health, psychological status and strain, studies were excluded if the *only* outcome collected from the carer was (1) their perspective or knowledge of patients' disease, symptomatology and level of functioning; (2) their perceptions of services; (3) a biochemical measure e.g. hormone levels.

***Interventions***

No restrictions were placed on the type of intervention that could be considered relevant for the review.

***Study type***

Studies had to be primary research but no limits were placed on study design. Reviews, systematic reviews and economic evaluations were searched for relevant references to primary studies. Due to resource constraints only studies reported in English were included.

The inclusion criteria were articulated as the exclusion criteria in Figure 3.

**Figure 3: Exclusion criteria for systematic review**

1. Study does not include people with chronic arthritis
2. Study includes only children with chronic arthritis
3. Data for adults with chronic arthritis is not presented separately from that of other conditions
4. Study does not include a sample of caregivers or a care-related outcome
5. Study includes a caregiver but no outcome from the caregiver or related to the provision of care is collected
6. The outcome from the caregiver is only (1) perspective or knowledge of patients' disease, symptomatology and level of functioning, or (2) perceptions of services, or (3) a biochemical outcome
7. For studies investigating an association the caregiver or care-related outcome is not the dependent variable or the analyses are only descriptive. Qualitative studies do not report on the caregiver experience
8. Care-related outcomes are not presented separately from other outcomes
9. Study is not primary research
10. Study is not English language

### 3.3.2 Search methods (electronic searches, searching other sources)

Studies were identified by searches of electronic databases, scrutinising bibliographies and citation lists of relevant studies for further relevant studies, and searches of the publication lists of authors of relevant studies. In addition, the *Journal of Rheumatology*, *Arthritis Research and Care* and *Arthritis and Rheumatism* were hand-searched for the last 5 years.

Electronic searches were completed in December 2011 for MEDLINE and Medline-In process, EMBASE; PsycINFO; AMED; CINAHL Plus; Social Policy and Practice; Health Management Information Consortium; ASSIA; Sociological Abstracts; Social Services Abstracts; Cochrane database of systematic reviews; Cochrane central register of controlled trials; DARE; HTA and NHS EED. No date restrictions were placed on the searches.

For each search free text and MESH descriptors relating to informal care were combined using the Boolean operator OR. The same process was undertaken for terms relating to arthritis. Having created the two sets of terms these were combined using the Boolean operator AND. Searches were individualised for the different databases (appendix 1).

### 3.3.3 Selection of studies

The results of the electronic database searches were managed in ProQuest Reference Works software. Initially, the titles and abstracts of the studies identified by the literature search were reviewed by the first author against the inclusion and exclusion criteria. Studies were screened hierarchically and criteria applied according to Figure 3. Studies where there were insufficient data in the title and abstract to assign an exclusion code were checked to first identify whether they met the criteria for primary research and English language before being ordered as full text articles. Full text articles retrieved were screened against the inclusion criteria hierarchically by the first author and a second researcher independently. Differences of opinion were resolved between the first author and second researcher through discussion until agreement was reached.

At the stage of screening titles and abstracts, citations were most frequently excluded because they didn't include adults with arthritis (exclusion criteria 1 and 2), didn't include caregivers (exclusion criteria 4) or were not primary research e.g. a review or article presenting opinion (exclusion criteria 9). At the stage of screening full text articles, the most common reasons for exclusion were that the study didn't include caregivers (exclusion criteria 4) or the outcomes related to caregiving were not the dependent variable in the analysis (exclusion criteria 7). A high number of studies were excluded because caregivers were not included. This arose because searches were designed to be sensitive rather than specific and therefore they identified studies of relationships between patients with arthritis and a range of people in a variety of situations e.g. patients and health professionals, patients and family or friends and patients and employers. The high number of exclusions also arose because the sample did not have arthritis, searches included terms for musculoskeletal conditions that include diseases broader than arthritis e.g. osteoporosis, fractures.

### 3.3.4 Data extraction and critical appraisal

Data were extracted from the papers by the first author using data extraction tables (appendix 2) and critically appraised (appendix 3) using EPIQ tools (106).

The following data were extracted from the studies:

- Study background: including study design, aims, theoretical framework, source of funding, country of completion, date of completion and linked publications
- Study intervention (where relevant) including description of the intervention and comparison and timing of assessments, number of groups and duration of follow up
- Study sampling and allocation: description of the sampling frame, methods of randomisation, allocation and blinding, unit of allocation, planned sample size, methods of identifying people from the sampling frame and methods of contacting possible participants and recruitment of identified participants

- Study participants: number of participants (total and per group), inclusion and exclusion criteria, description of the sample at baseline, definition of a caregiver.
- Data collection methods: including how data were collected, who collected the data, setting of data collection, outcomes collected from patients, outcomes collected from caregivers, information given about tests for the reliability and validity of data collection methods and measures
- Analysis methods: including methods of analysis, unit of analysis, tests of reliability and validity of data analysis, loss to follow up, number of withdrawals and reasons for withdrawal.
- Results: including whether results are reported for each of the given aims and descriptive and analytical data for patient outcomes and caregiver outcomes

The systematic review did not exclude studies based on study design and therefore studies included a range of designs e.g. intervention and non-intervention studies, longitudinal and cross-sectional studies and quantitative and qualitative studies. To support the critical appraisal process a search of the literature was undertaken to identify potential critical appraisal tools and assess the appropriateness of using these in a review with multiple study designs. The EPIQ critically appraised topics (CATs) checklists were chosen because different checklists were available for use with a range of study designs including intervention studies, cross sectional and cohort studies and qualitative studies. Each checklist is tailored for use with a particular study design, however, the approach taken to critical appraisal across the checklists is complementary, which helps ensure that studies are handled consistently in the data extraction, critical appraisal and synthesis processes. The CATs checklists were developed by the University of Auckland and are part of the Graphic Appraisal Tool for Epidemiology (GATE) approach to critical appraisal (106). The checklists for quantitative studies include elements assessing both the internal and external validity of studies, as well as precision of the results. The checklists are completed by carrying out an assessment of each individual element, these assessments are then used to complete a summary assessment of internal validity, external validity and precision, before finally completing an overall assessment of quality.  Each checklist includes a free text notes section with sub-questions to guide the process of appraising each individual element.

### 3.3.5 Study synthesis

Different study types were synthesised separately before being brought together in a single framework. The synthesis was guided by Pearlin's model of caregiver outcomes (73,107) using the categories and definitions shown in Table 1.

#### *Synthesis of intervention studies*

The studies of interventions were initially grouped based on the type of intervention: (1) pharmaceutical interventions (2) surgical interventions (3) psychological interventions (4) service delivery interventions. Patients and care-related / caregiver outcomes were then summarised based on the four groups. To enable synthesis with the other study types the focus of the intervention and the outcomes were then categorised into Pearlin's model of caregiver outcomes.

#### *Synthesis of studies of association*

For the studies that analysed their data using regression, the dependent and explanatory variables for each analysis were categorised using Pearlin's model of caregiver outcomes. The studies were synthesised by initially grouping them based on the categorisation of the dependent variable and then within these groups, the explanatory variables were then grouped. To illustrate, firstly analyses measuring a primary objective stressor as their dependent variable were grouped. The explanatory variables in these analyses were then grouped according to whether they measured an aspect of caregiving context, primary objective stressors, primary subjective stressors etc.

#### *Synthesis of data from other study types*

The studies of association that analysed their data descriptively by disease severity category were summarised narratively. The quotes from qualitative studies were data-extracted and categorised according to Pearlin's model of caregiver outcomes.

#### *Cross-study synthesis*

The cross-study synthesis takes each of the categories in Pearlin's model of caregiver outcomes and describes the evidence for the role they play in influencing care-related outcomes or caregiver outcomes. The data from the qualitative study are used to illustrate and contrast findings from the other study types.

**Table 1: Definitions used to categorise studies in the study synthesis**

| Component in model of caregiver outcomes | Definition used for categorisation |
|---|---|

| | |
|---|---|
| **Caregiving background and context** | Patient and caregiver demographic variables<br>Objective characteristics of the caregiving relationship |
| **Primary objective stressors** | Patient clinical and disease characteristics<br>Care provided |
| **Primary subjective stressors** | Measures of subjective burden, strain and stress from caregiving |
| **Resources** | Formal health and social services<br>Caregiver and patient social and/or spiritual support provided by partner and/or wider social network<br>Caregiver and patient perceived control of the environment |
| **Secondary stressors: role strain** | Caregiver family conflict<br>Caregiver employment or financial conflict<br>Caregiver time conflicts<br>Caregiver interpersonal conflict<br>Caregiver leisure conflict |
| **Secondary stressors: intrapsychic strain** | Caregiver self-efficacy and competence<br>Caregiver positivity and optimism |
| **Caregiver outcomes** | Caregiver wellbeing and life satisfaction<br>Caregiver mental or physical health status |

## 3.4 Description of the identified studies

Electronic searches identified 4265 citations. Of the 4265 citations, 1355 citations were duplicates resulting in 2910 unique citations. The inclusion and exclusion criteria were applied to the 2910 unique citations resulting in the exclusion of 2768 citations. Full text articles were sought for the remaining 142 citations.

Of the 142 papers to be obtained, four were US theses and unobtainable within the resource constraints of this systematic review. Therefore 138 papers were obtained and screened. Screening of full texts resulted in the exclusion of a further 100 papers. One additional citation identified in the searches related to a paper that was only available in abstract form and included insufficient detail to screen against the exclusion criteria. No contact details were available for the author of the abstract to clarify further aspects of the study. This study was therefore marked unobtainable. Screening of full texts resulted in the inclusion of 37 (89,90,104,108–141) papers reporting 23 unique studies.

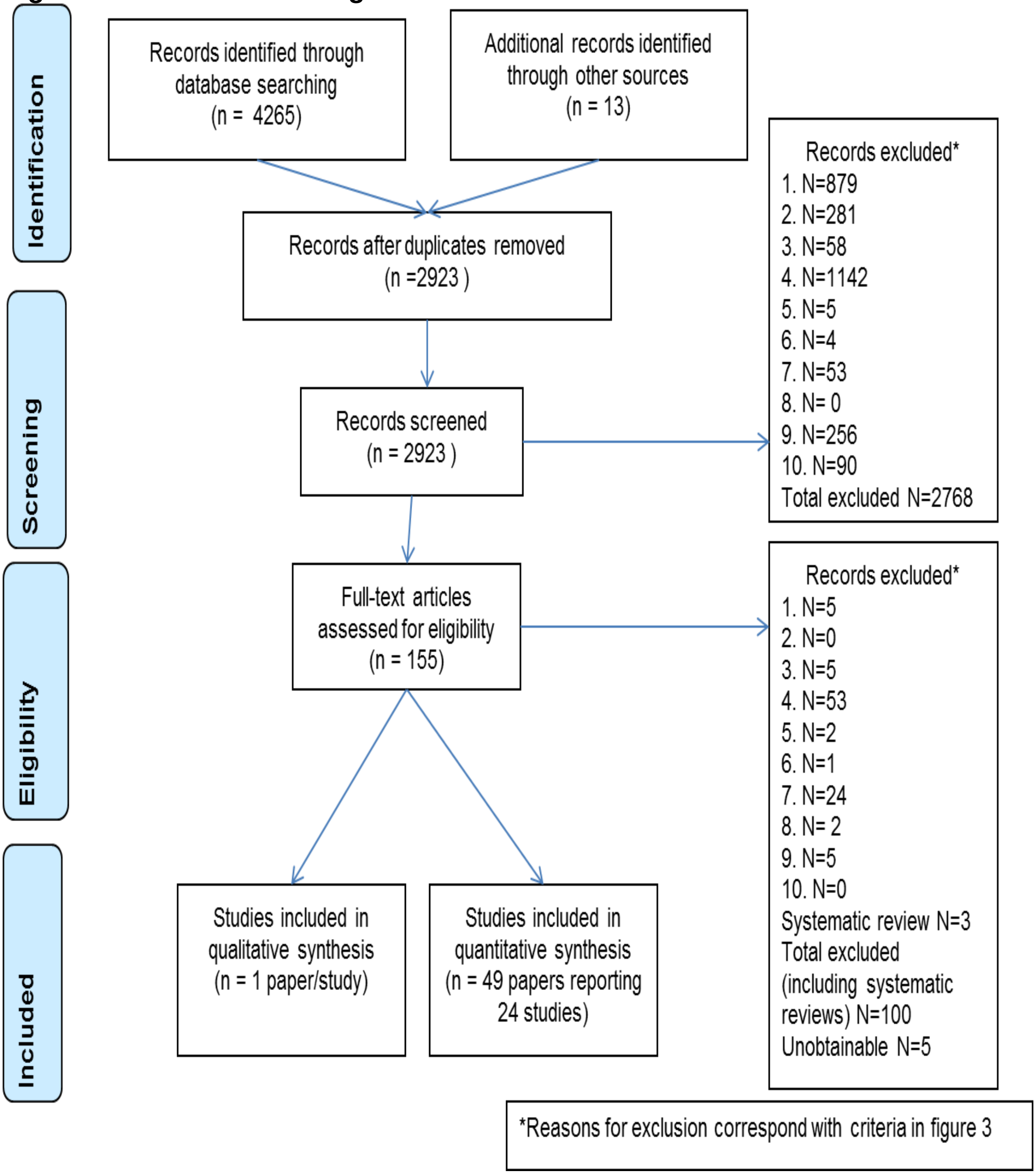
Hand searching and citation screening identified a further 13 papers (142–154) of which 2 were unrelated to the studies already identified in the electronic database searches. In total 50 papers meeting the inclusion criteria were identified. These reported 25 unique studies, of which 23 were identified through electronic searching, 1 through hand searching and 1 through citation screening (see PRISMA flow chart in Figure 4 (155)).

### 3.4.1 Characteristics of the identified studies

Of the 25 included studies 24 were quantitative and one was qualitative (131). Of the quantitative studies 11 were intervention studies. Five of these were randomised controlled trials (RCTs) of which two were evaluations of pharmaceutical interventions (114,116), two were evaluations of psychological interventions (123,125) and one was an evaluation of service delivery (121). There were two experimental studies without randomisation (both of these studies were single-group before-and-after studies and were evaluations of pharmaceutical interventions (118,142)). Finally there were four studies that evaluated existing clinical practice (of which three were single-group before-and-after studies, and one used an historical control). Three of these were evaluations of surgical joint replacement (108,111,127) and one was an evaluation of service delivery (137). The other 13 quantitative studies were studies of association. In 11 of these the analysis was based on correlation or regression. The remaining two studies (119,120) were cost of illness studies and included analyses describing how the costs of informal care varied by categories of disease severity.

A roughly equal proportion of the 25 studies were carried out in North America and Europe (N=11 and N=10 respectively) and there was one study from South America (Brazil (112)). Three studies were carried out in the UK, of which two were evaluations of surgical joint replacement (111,127) and one was a study of association using regression analysis (145). The remaining three studies were multinational, and were all studies of pharmaceutical interventions (114,116,142).

Figure 4: PRISMA flow diagram



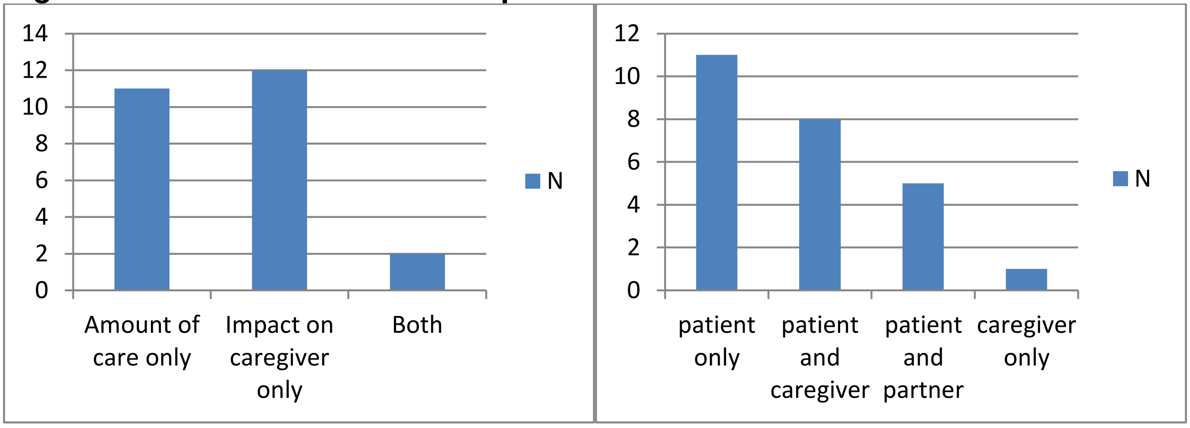
Thirteen studies measured outcomes at a single time point, sometimes asking participants to recall events retrospectively. Of the studies with a follow-up period, two measured care outcomes at up to three months (111,123), three measured them at 24 weeks (118,121,137), and six measured them at between six months and one year (104,108,114,116,125,127). The duration of follow-up in the final study was a mean 1.57 years and reported as a standardised six-month outcome (142).

Nine of the studies included a theoretical perspective guiding aspects of the data collection and analysis. These were more commonly the studies of associations using regression or correlation (6 out of 11 studies). The other three studies describing a theoretical perspective were intervention studies (111,121,123). In general the theoretical frameworks focussed on the factors relating to the individual and their environment that influence caregiving and how these interact to modify the impact of providing care. Three of the studies drew on general models of stress process or stress and coping (89,90,132) and Beckham and Burker (109) referenced a rheumatoid arthritis-specific model of coping and adaptation derived from Lazarus and Folkman (83). The other studies referenced alternative theories.

### 3.4.2 Description of the measurement of care

Eleven of the studies included only patients: these studies reported the amount of care received from the perspective of the patient. Eight studies (five studies of association and three intervention studies) included both patients and a person defined by the primary study author as a caregiver. Of these studies two (90,115) reported both the amount of care provided from the perspective of the caregiver and also a caregiver-completed measure of their health or mental health status. The other six studies included only a caregiver measure of health or wellbeing. Five studies (all studies of association) included patients and their partners and collected from the partner a measure of the partner's perception of caregiving burden or strain. The final study (the qualitative study) included only caregivers (Figure 5).

**Figure 5: Care outcome and sample in the studies**



Key: left = care outcome included in the study, right = sample enrolled in study (N=25 studies)

### 3.4.3 Description of the care provided

Thirteen studies included a measure of the amount of care being provided: eight were intervention studies and five were studies of association including the two cost of illness studies. In all studies except two the amount of care was patient-reported. Of these 13 studies, six reported the number of hours for which care was provided, five focused on the number of days taken off work by caregivers, and three included a count of the number of care tasks provided. Two studies included both hours of care and days off work providing care.

In the three studies that included a count of tasks with which help was provided, each reported a list of the activities that participants were asked to count as care. Other studies reported examples of what participants were told constituted a care activity, or referred to normal activities without providing further information. Of the studies that did include examples or lists of activities, these encompassed one or more of the following: activities of daily living (for example, help with: bathing, dressing, getting ready for bed, sitting/standing, toileting, walking, climbing stairs, taking medicines and foot care), supervision (further definitions not provided), transportation (for example, taking to doctor's appointments or visits) and household activities (for example shopping, preparing food, washing dishes, washing and ironing). Five studies included no definition about which tasks participants were asked to include as care tasks when measuring the amount of care received.

Four studies (90,112,115,131) reported care characteristics such as the duration of care, amount of care, or indicated whether professional support or other support from family and friends was received. In these four studies the duration of care ranged from an average 5.4 years to an average 11.4 years. The two studies (90,115) reporting longer durations of care (both average 11 years) had higher proportions of spousal caregivers than the two studies reporting shorter durations. The amount of care provided by the caregiver enrolled in the study was reported in only two studies. In one (90) the average number of hours of care per week was 33, and in the other (115) it was 26. Use of other support was recorded in three studies; the percentage of people receiving professional support in these three studies was 5%, 26% and 0% and receiving other support from family and friends 39%, 68% and 100%. The studies in which this information was recorded were carried out in Brazil (112), the Netherlands (115) and Puerto Rico (131) respectively. The caregivers in the study from Puerto Rico were specifically sampled so to enrol those who were not eligible for state support, and were specifically asked to name another person who provided help with care.

### 3.4.4 Description of the caregivers

Nine of the studies included a sample of participants identified by the primary study author as caregivers. Three of these studies were intervention studies (111,123,125), five were studies of association ((90,104,109,112,115) and one was qualitative (131). The definition used to identify caregivers was specified in four of the studies. In three of these studies the person was initially identified by the patient as their spouse or partner and then further screened against a criterion of whether the spouse helped with at least one activity of daily living and that the husband provided most assistance (one study), or helped with at least one daily activity (one study) or helped with at least one instrumental activity of daily living (one study) in order to identify them as providing care (104,123,125). In the other study the definition applied was “the person mainly responsible for looking after the patient during the course of the disease” (112). In a fifth study a definition of a caregiver was not provided, but it was stated that the interviews with the caregivers focused on issues around providing care for instrumental tasks (131). In all studies it was explicitly stated or implied (in the case of one study) that caregivers were identified by the patients following initial contact by the researchers with patients.

Of the nine studies that included a sample of people identified as caregivers, three included only caregiving spouses or partners (104,123,125), and a fourth included caregiving partners in some analyses of the dataset but also included non-partners in other analyses (115). Of the other five studies, in three the proportion of spousal caregivers was over 75%. In the other two studies (112,131), the proportion of spousal caregivers was smaller (24% and 0% respectively) and a greater proportion of care was completed by the children of the care recipient; one of these studies was completed in Brazil and the other was the qualitative study completed in Puerto Rico. The majority of caregivers in the studies were the spouses of the care recipients, therefore the majority of caregivers were co-residing with the care recipient. In the nine studies, eight reported 74% or more co-residence of caregivers and care recipients.

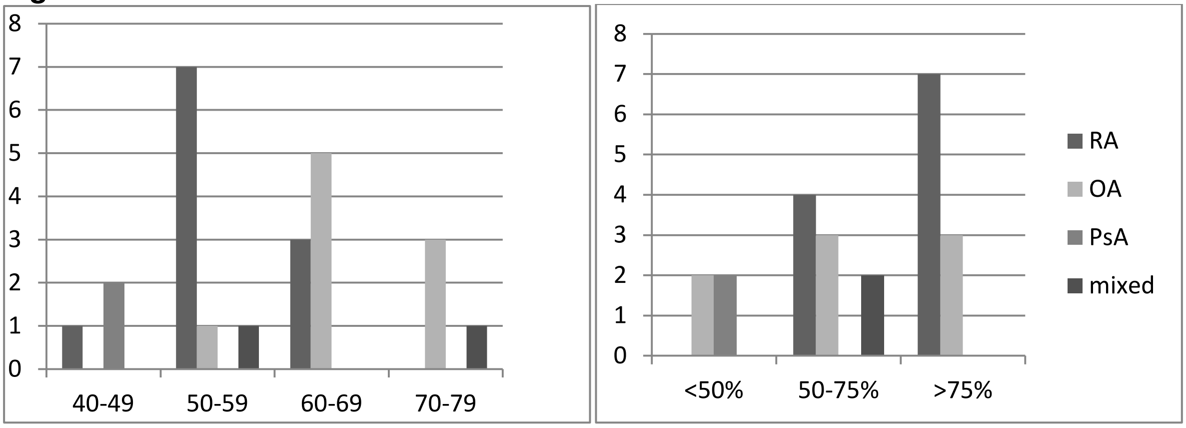
### 3.4.5 Description of the people receiving care

Eleven of the studies were completed in patients with rheumatoid arthritis and a further 10 were completed in patients with osteoarthritis. Two further studies (both intervention studies evaluating pharmaceutical interventions) were completed in patients with psoriatic arthritis. Two studies, including the qualitative study, included a mixed population of people with arthritis. In one this included polyinflammatory arthritis with the majority of patients having rheumatoid arthritis (63%). The other study included patients with rheumatoid arthritis, osteoarthritis or systemic lupus erythematosus.

In general the characteristics of the patients reflect known differences in the populations affected by the arthritis conditions. Patients with osteoarthritis tended to be older than patients with rheumatoid arthritis and with psoriatic arthritis, and studies including patients with rheumatoid arthritis tended to include a greater proportion of patients who were female than studies of osteoarthritis and psoriatic arthritis. Reflecting the spousal nature of many of the caregiver and care recipient relationships, the characteristics of the caregivers/partners enrolled in these studies tended to be similar (for example age), or a mirror (for example gender) to those of the care recipients (Figures 6 and 7).

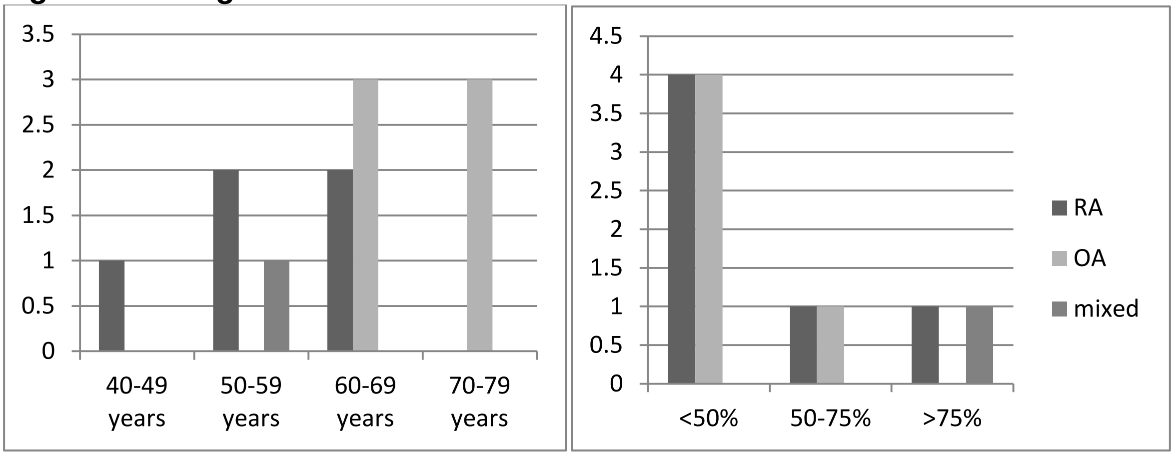
Average disease duration was reported in 16 studies, with 11 studies reporting average disease duration of over 10 years. Shorter disease durations were observed in the studies of pharmaceutical interventions than in the other studies. In general, studies including patients with osteoarthritis reported longer disease durations than the studies including patients with rheumatoid arthritis. Patient disease severity was reported using different measures across the studies, making comparisons across studies difficult.

**Figure 6: Patient characteristics in the studies**



Key: left = average patient age in the studies in years (N=24), right = proportion of patients who were female ( N=23 studies). In one study the age and gender of the participants was not reported; in a second study the gender of the participants was not reported.

**Figure 7: Caregiver characteristics in the studies**



Key: left = average caregiver/partner age in the studies in years (N=12 studies), right = proportion of caregivers/partners in the studies who were female (N=12 studies). Data on age and gender of caregivers/partners was not reported in two studies.

### 3.4.6 Description of study quality

Each of the studies was critically appraised to assess the weight of evidence that each study contributed to answering the question in this review. Half the studies were judged to provide low weight of evidence, nine of the studies judged to provide medium weight of evidence and three studies judged to provide high weight of evidence (Table 2).

**Table 2: Critical appraisal of the studies**

| | Quality of evidence | | | Total |
|---|---|---|---|---|
| **Study type** | **High** | **Medium** | **Low** | |
| Intervention | 1 | 4 | 6 | 11 |
| Association: Interval | 2 | 5 | 4 | 11 |
| Association: Categorical | 0 | 0 | 2 | 2 |
| Qualitative | 0 | 0 | 1 | 1 |
| **Total** | **3** | **9** | **13** | **25** |

## 3.5 Synthesis: Intervention studies

### 3.5.1 Pharmaceutical interventions

Four studies reported outcomes of pharmaceutical interventions. In each the intervention was a tumour necrosis factor (TNF) inhibitor, a type of biologic disease modifying anti-rheumatic drug (DMARD). Two studies were phase III RCTs to inform regulatory submission, one study was a single-arm open label extension enrolling people who had taken part in previous phase I-III trials, and one study was a single-arm phase IV study investigating efficacy in a community setting. Two studies were completed in patients with psoriatic arthritis (116,118) and two in patients with rheumatoid arthritis (114,142). None enrolled a sample of caregivers. One study was rated low quality because of the lack of detail in reporting of the care data (114).

In terms of patient outcomes, two studies (114,116) reported statistically significant improvements in the primary study endpoints. Kimball et al. (118) reported a 77% response rate measured by physician global assessment of psoriasis and Mittendorf et al. (142) reported maintenance of effect in patient outcomes between baseline and week 144. Of the care outcomes, Kavanaugh et al. (116) reported a statistically significant reduction in caregiver time off work ($p<0.05$). However, Genovese et al. (114) reported time lost from work by the caregiver as not being statistically significantly different from placebo at week 24. Of the single-arm studies, Kimball et al. (118) reported statistically significant reduction in the proportion of patients requiring care ($p<0.001$) and in the number of days off work per month ($p<0.001$). Mittendorf et al. (142) did not report statistical significance. The data showed a small reduction in mean hours of unpaid personal help in the six months prior to baseline and standardised to six months of treatment (Table 3).

**Table 3: Outcomes from the pharmaceutical intervention studies**

| **Study** | **N** | **Carer** | **Patient outcome*<br>(follow up)** | **Care outcome<br>(follow up)** |
|---|---|---|---|---|
| ***Study quality high*** | | | | |
| Kavanaugh et al (116,148)<br>PSA | 405 | No | ***ACR 20 (wk 14)***<br>9% placebo<br>48% golimumab (p<0.001) | ***Mean days off work (wk 24)***<br>1.1 (SD 4.0) placebo<br>0.2 (SD 1.0) golimumab (p<0.05)<br>Reduced to 0.03 (SD 0.03) in the golimumab arm at week 52 |
| ***Study quality medium*** | | | | |
| Kimball et al.(118)<br>PSA | 1122 | No | ***PGA psoriasis (wk 24)***<br>77% responders<br>(95% CI: 74.64-79.55) | ***Proportion requiring care (wk24)***<br>8.2% baseline<br>2.7% 24 weeks (p<0.001)<br>***Mean days off work (wk 24)***<br>0.99 baseline<br>0.03 24 weeks (p<0.001) |
| Mittendorf et al. (142)<br>RA | 505 | No | ***Mean pain (VAS)***<br>33.52 (SD 24.79) baseline<br>29.87 (SD 24.23) wk144<br>***Mean morning stiffness (minutes)***<br>45.99 (SD 89.65) baseline<br>24.53 (SD 56.11) wk144 | ***Mean hours of care***<br>119.18 (SD 389.27) 6 months prior to baseline<br>91.32 (SD 270.43) per 6 months (sig NR) |
| ***Study quality low*** | | | | |
| Genovese et al. (114)<br>RA | 444 | No | ***ACR 20 (wk 14)***<br>33.1% placebo<br>55.1% golimumab (p<0.001)<br>***Mean HAQ change (wk 24)***<br>-0.13 placebo<br>-0.38 golimumab (p<0.001) | ***Mean days off work (wk 24)***<br>Values not presented, reported as not significant |

*Primary outcome where stated

### 3.5.2 Surgical interventions

Three studies reported outcomes for surgical interventions. In two of these studies the intervention was total hip replacement (108,111) and in the third the intervention was knee or hip replacement (127). The size of the samples in the studies varied from 23 to 229, and follow up varied from three months to one year. All the studies were completed in patients with osteoarthritis. One of the studies recruited a sample of caregivers into the study (111): this study enrolled 23 patient and caregiver pairs. All three studies were case series evaluating the outcomes of a consecutive sample of patients who were assigned to undergo primary joint replacement. All studies were evaluated as having low study quality on the basis of the likelihood of bias.

The patient outcomes in these studies included general health status, pain, functional ability and anxiety. All differences were statistically significant with the exception of one study (127) which reported no statistically significant difference for Center for Epidemiologic Studies

Depression Scale (CES-D) depression nine months after surgery. In the same study outcomes for anxiety, pain and functional activity were all associated with a statistically significant improvement following joint replacement. Outcomes for care were less consistent across the studies. Chow (111) did not identify a statistically significant reduction in strain among caregivers (p=0.06) and Orbell et al. (127) presented contradictory results for the care outcomes: although the number of tasks with which help was received from friends and family was associated with a statistically significant reduction 9 months after joint replacement (p<0.01), the amount of hours of help received was associated with a statistically significant increase after joint replacement (p<0.01). Bachrach-Lindstrom et al. (108) reported a statistically significant reduction in the proportion of people requiring help at 1 year after surgical intervention (p<0.001) (Table 4).

**Table 4: Outcomes from the surgical intervention studies**

| **Study** | **N** | **Carer** | **Patient outcome (follow up)** | **Care outcome (follow up)** |
|---|---|---|---|---|
| ***Study quality low*** | | | | |
| Chow (111)<br>OA | 23 | Yes | ***Mean NHP (3mnths)***<br>20.9 (SD 7) pre surgery<br>9.9 (SD 7) post surgery (p<0.001) | ***Mean caregiver strain (3mnths)***<br>13 (SD 11.4) pre surgery<br>10 (SD 11.3) post surgery (p<0.06) |
| Orbell et al. (127)<br>OA | 72 | No | ***Mean CES-D (9mnths)***<br>9.4 (SD 6.58) pre surgery<br>7.53 (SD 6.73) post surgery (p<NS)<br>***Mean HADS (9mnths)***<br>9.29 (SD 4.93) pre surgery<br>7.76 (SD 4.65) post surgery (p<0.01)<br>***Mean functional activities (9months)***<br>18.25 (SD 8.14) pre surgery<br>26.35 (SD 4.71) post surgery (p<0.01) | ***Mean number of tasks (9mnths)***<br>2.1 (SD 2.67) pre surgery<br>1.07 (SD 1.20) post surgery (p<0.01)<br>***Mean hours of care (9mnths)***<br>2.42 (SD 7.0) pre surgery<br>7.08 (SD 15.13) post surgery (p<0.01) |
| Bachrach-Lindstrom et al. (108)<br>OA | 229 | No | ***Mean NHP (1yr)***<br>Men<br>33 pre surgery<br>3 post surgery (p<0.001)<br>Women<br>36 pre surgery<br>7 post surgery (p<0.001) | ***Proportion requiring care (1yr)***<br>58% before surgery<br>11% after surgery (p<0.001) |

### 3.5.3 Psychological interventions

Two studies reported the outcomes of psychological interventions (123,125). In both studies the intervention was designed to improve arthritis self-management, and in one group patients received the intervention alone and in the other group patients and their caregiving spouse received the intervention together. Martire et al. (125) also included a usual care group in which people received their OA medications and treatment from their rheumatologist, but did not participate in any self-management interventions or receive any surgical interventions. The sample size in one study was 24 (123) and in the other 242 (125), with the smaller study designed as a pilot for the larger study. Both studies enrolled patients and their caregiving spouses and in the larger study the patients enrolled were all female. Both studies were RCTs but methods of randomisation were not described. Both studies were evaluated as having medium quality.

In terms of patient outcomes, Martire (123) reported that patients in the couple intervention group experienced a greater increase in self-efficacy over time than patients in the patient intervention group (p<0.01: group × time effect). Other outcomes of pain, disability and depression were not statistically significant. In Martire et al. (125) for the intention-to-treat (ITT) analysis no statistically significant differences were found for WOMAC total score, pain score and physical function score, nor for arthritis self-efficacy score, pain score and physical function score. In terms of care outcomes, ITT analyses in both studies did not find statistically significant differences for caregiver stress, depression, or for caregiving mastery, or for outcomes related to patient-reported support e.g. satisfaction with spousal assistance, emotional support and insensitive responses (Table 5).

**Table 5: Outcomes from the psychological intervention studies**

| **Study** | **N** | **Carer** | **Patient outcome (ITT)** | **Care outcome (ITT)** |
|---|---|---|---|---|
| ***Study quality medium*** | | | | |
| Martire et al. (123)<br>OA | 24 | Yes | ***Mean HAQ****<br>PE: 12.30 (SD 3.03)<br>CE: 9.32 (SD 6.92) (NS)<br>***Mean CES D***<br>PE: 18.61 (SD 13.38)<br>CE: 9.67 (SD 7.45) (NS)<br>***Mean arthritis self-efficacy***<br>PE: 60.73 (SD 18.82)<br>CE: 86.66 (SD 14.10) (p=0.01) | ***Mean caregiving stress****<br>PE: 1.17 (SD 0.31)<br>CE: 1.13 (SD 0.46) (NS)<br>***Mean caregiving mastery***<br>PE: 14.55 (SD 2.11)<br>CE: 14.15 (SD 2.44) (NS)<br>***Mean CES-D***<br>PE: 5.45 (SD 5.39)<br>CE: 6.38 (SD 9.06) (NS) |
| Martire et al. (125)<br>OA | 242 | Yes | ***Mean WOMAC total*****<br>PE: 33.49 (SD 1.57)<br>CE: 34.47 (SD 1.50)<br>UC: 37.73 (SD 2.03) (NS)<br>***Mean arthritis self-efficacy total score***<br>PE: 78.43 (SD 1.87)<br>CE: 80.02 (SD 1.78)<br>UC: 73.52 (SD 2.40) (NS) | ***Mean Perceived stress*****<br>PE: 12.51 (SD 0.74)<br>CE: 12.37 (SD 0.71)<br>UC: 14.41 (SD 0.94) (NS)<br>***Mean CES-D***<br>PE: 5.27 (SD 0.59)<br>CE: 5.22 (SD 0.57)<br>UC: 5.95 (SD 0.75) (NS)<br>***Mean caregiver mastery***<br>PE: 43.82 (SD 0.74)<br>CE: 44.81 (SD 0.71)<br>UC: 42.39 (SD 0.95) (NS)<br>***Mean critical attitudes***<br>PE: 6.38 (SD 0.25)<br>CE: 6.52 (SD 0.24)<br>UC: 6.81 (SD 0.32) (NS) |

* all patient and caregiver outcomes taken within 2 weeks after 6 week intervention programme
**6 months after 6 week intervention programme

### 3.5.4 Service delivery interventions

Two studies compared different methods of service delivery. Van der Sluis et al. (137) evaluated the effect of including a nurse practitioner in a multi-disciplinary team to support the other members of the multi-disciplinary team and provide a central point for coordinating care. An historical control was used in this study including patients who received treatment before the nurse practitioner became a team member, no further details of the control are given. Li et al. (121) was an RCT that investigated two different service delivery methods. The primary therapist model (PTM) included a single primary therapist who was able to provide physical and occupational therapy, the traditional treatment method (TTM) involved maintaining the disciplinary division with patients being referred to another professional where needed. Neither study included a sample of carers. The sample sizes in the studies were 144 and 147. Both studies were evaluated as being of low quality. For the RCT this was primarily based on the limited reporting of care outcomes and low treatment completion rates.

In Li et al. (121) the primary end point (clinical responder criteria) was statistically significant favouring the primary therapist model. Of the secondary outcomes knowledge outcomes at 6 months favoured the primary therapist group, while coping self-efficacy favoured the traditional treatment group. Other patient outcomes including HAQ, pain, RADAI and self efficacy were not statistically significantly different. Van der Sluis et al. (137) reported no statistically significant difference for patient outcomes between groups. For care outcomes, no statistically significant differences were reported (Table 6).

**Table 6: Outcomes from the service delivery intervention studies**

| **Study** | **N** | **Carer** | **Patient outcome** | **Care outcome** |
|---|---|---|---|---|
| ***Study quality Low*** | | | | |
| Li et al. (121)<br>RA | 144 | No | ***Clinical response rate (6mnths)***<br>44.4% PTM<br>18.8% TTM (p<0.004) | ***Proportion with caregiver time loss at 6 months***<br>27% PTM<br>16% TTM (p=NR)<br>***Mean costs of caregiver time loss (6mnths)***<br>$321 Canadian PTM<br>$295 Canadian TTM (p=0.93) |
| Van der Sluis et al. (137)<br>Mixed | 147 | No | ***Mean patient satisfaction (6mnths)***<br>4.1 (SD 0.6) Intervention<br>3.9 (SD 0.7) Control (p=0.275)<br>***Mean MHQ (6mnths)***<br>52.0 (SD 17.8) Intervention<br>48.8 (SD 18.5) Control (p=0.337) | ***Mean costs of caregiver time loss post intervention***<br>Euros 309 (SD 735) Intervention<br>Euros 626 (SD 889) Control<br>Controlling for differences pre treatment NS between groups. (p=NR) |

### 3.5.5 Summary of intervention studies

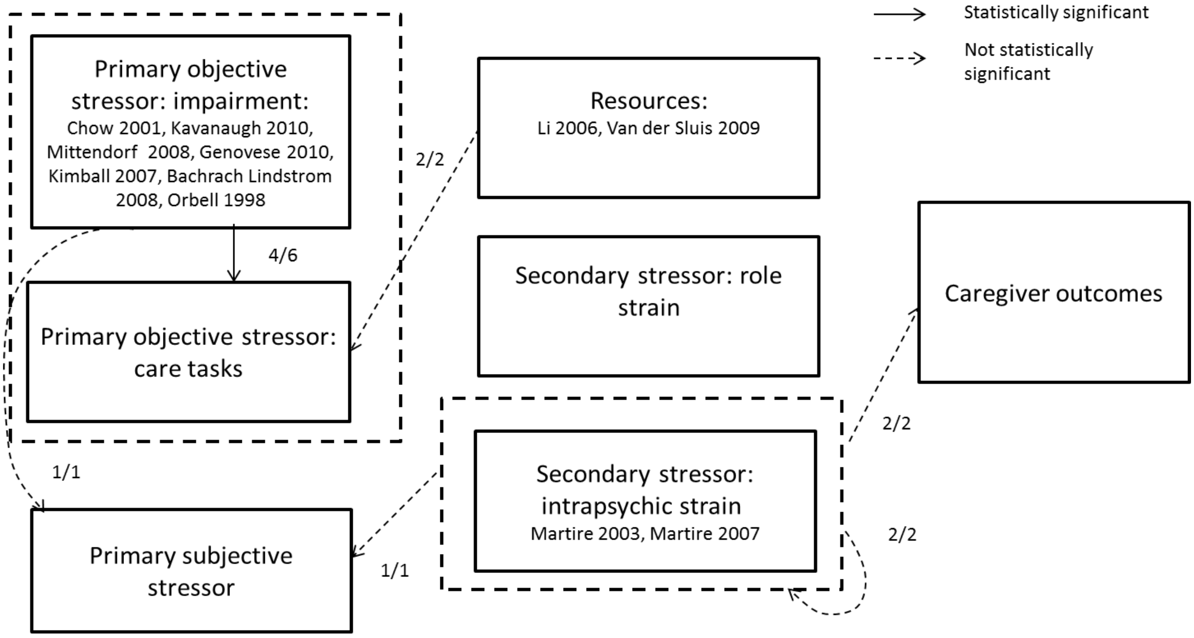
In general the study quality was poor with six of the eleven studies being graded as low quality and only one study being graded as high quality (116). The care outcomes in these studies were often poorly reported both in terms of describing the measure used to collect the data and the reporting of the outcome data obtained.

The majority of intervention studies that aimed to improve patient impairment such as pharmaceutical or surgical interventions showed a beneficial effect on care outcomes in terms of time off work, proportion requiring care, or number of tasks for which help is required. Only one study (111) measured the effect of improving patient impairment on caregiver burden. This showed an improvement in perceived caregiver burden but this did not reach statistical significance.

Interventions that were designed to improve arthritis self-management (123,125) showed little impact from including caregivers even though caregivers reported finding the sessions useful. These studies also demonstrated limited change in patient outcomes. Interventions that were designed to provide a more focused service delivery through having a single therapy contact (121,137) showed no statistically significant differences in care outcomes and also limited improvements in patient outcomes. However, the quality of these studies means this result should be interpreted with caution.

In order to synthesise the data with the other study designs in this systematic review, the interventions were arranged based on the aims and focus of the study intervention into the categories described in Pearlin's framework. Figure 8 shows the categorisation of the intervention studies with arrows showing the outcomes collected and the direction of effect.

**Figure 8: Summary of the outcomes of the intervention studies**



*Pearlin's framework also includes factors associated with caregiving context. This has been removed from the figure as it was not addressed in the studies.

## 3.6 Synthesis: studies of association using regression

Twelve studies were identified that analysed their data using regression or correlation to investigate the factors influencing a caregiver outcome or outcome relating to care. For one study a separate cross-sectional analysis was completed as part of an intervention study (125). The synthesis is based on the outcomes from regression, therefore two studies only reporting correlations without any regression (128,129) were excluded from the synthesis.

Seven of the studies considered a population of patients with rheumatoid arthritis and the remainder included patients with osteoarthritis. Six of the studies included patients and their caregivers and in two this was specified as a caregiving spouse or partner. In five of the studies patients and their partners were enrolled, and a measure of caregiver burden collected from the partner. In the final study only patients were enrolled. The analyses in all but one of the studies (104) were cross-sectional. The sample sizes in the studies ranged from 32 patient and partner pairs to 349 patients. Four of the studies were judged for the purposes of this review to provide low quality evidence (including the two correlations studies), six studies medium quality evidence and two studies high quality evidence.

The ten studies included in the synthesis of regression analyses reported a total of 38 analyses. These analyses were categorised for synthesis according to their dependent variable within Pearlin's framework (Table 7). The synthesis focuses on the 18 analyses where the dependent variable is categorised as a primary objective stressor or a caregiver outcome.

**Table 7: Categorisation of the dependent variables**

| **Dependent variable** | **Weight of evidence** | | | **Total** |
|---|---|---|---|---|
| | **High** | **Medium** | **Low** | |
| Caregiving context | 0 | 0 | 0 | 0 |
| **Primary objective stressor** | **1** | **0** | **1** | **2** |
| Primary subjective stressor | 3 | 3 | 1 | 7 |
| Resources | 0 | 0 | 0 | 0 |
| Secondary stressors: role strain | 3 | 4 | 0 | 7 |
| Secondary stressors: intrapsychic strain | 2 | 2 | 2 | 6 |
| **Caregiver outcome** | **4** | **12** | **0** | **16** |
| Total number of analyses | 13 | 21 | 4 | 38 |

### 3.6.1 Analyses in which the dependent outcome is a primary objective stressor

Two studies reporting two analyses included as the dependent variable a measure of the amount of care. In one study (145) this was specified as hours of care reported by the patient and in the other (90) as number of tasks completed from the perspective of the caregiver. Both studies were cross-sectional, with one of the studies (90) including patients with rheumatoid arthritis and their caregivers and one (145) including patients with arthrosis of the knee. The quality of one of the studies was considered to be high (90), and one low (145). These ratings were based on the description of the samples and the range of the explanatory variables considered.

#### *The explanatory variable is caregiving context*

Riemsma et al. (90) reported that people with RA who were younger received help with a greater number of care tasks than those who were older. In addition caregivers who were male provided help with a greater number of care tasks than those who were female.

#### *The explanatory variable is a primary objective stressor*

Patient disease duration and comorbidities were not identified as influencing the number of care tasks with which help was provided. Patient function was found in both studies to be associated with the amount of care provided. Riemsma et al. (90) reported that people with RA and increased physical difficulties received help from caregivers with a greater number of care tasks. Dixon et al. (145) included the EQ-5D domains and levels in the regression analysis and found that patients with arthrosis of the knee having some self-care difficulties versus no self-care difficulties reported receiving more days of care. In addition patients having severe problems with usual activities versus no problems with usual activities also reported receiving more days of care.

***The explanatory variable is a primary subjective stressor***

Caregiver burden was measured in Riemsma et al. (90), but was not identified as being associated with the amount of care tasks provided.

***The explanatory variable is a caregiver outcome***

Caregiver general health status was measured using the RAND-36 by Riemsma et al. (90), but was not identified as being associated with the amount of care tasks provided.

***The explanatory variable is a resource***

Riemsma et al. (90) measured patient perceived support from their social network, a measure of the caregiver's social network and patient marital status. Only patient marital status was included in the regression analysis, with married patients receiving help from caregivers with a greater number of tasks than those who were not married.

Riemsma et al. (90) measured patient's perceived loneliness (using a visual analogue scale) and perceived problematic support from their social network. Neither was found to be associated with the amount of tasks with which help was received. Riemsma et al. (90) also measured patient perceived ability to manage their RA and get help if required. The study identified an association between patients considering themselves less able to manage their RA and the patient receiving more help with care tasks.

***The explanatory variable is a secondary stressor: role strain and intrapsychic strain***

The study by Riemsma et al. (90) measured caregiver perceived self efficacy in completing household tasks and activities of daily living. These were not identified as being associated with the amount of care tasks provided.

### 3.6.2 Analyses in which the dependent outcome is a caregiver outcome

Five studies included a dependent variable categorised as a caregiver outcome (89,90,104,132,139). Each study was categorised as measuring mental health. Stephens et al. (104) also included four analyses that used as the dependent variable a measure of life satisfaction. In four of the studies the patient group was rheumatoid arthritis and in the fifth study it was osteoarthritis (104). Two of the studies enrolled patients and their caregivers (90,104); in Stephens et al. (104) the caregiver was specified as a caregiving husband. In the other three studies partners of patients were included and a measure of caregiver burden measured. Stephens et al. (104) was longitudinal; the other analyses were all cross-sectional. The study quality was assessed as being high in one study (90) and medium in the others.

### *The explanatory variable is caregiving context*

Of the patient variables measured (age, gender, education and urbanisation of residence) Walsh et al. (139) found that older patients had partners with worse mental health outcomes. This finding was not replicated in either Riemsma et al. (90) or Strating et al. (132). Of the caregiver variables (age, gender, income and education) only caregiver gender was identified as being associated with caregiver mental health. Strating et al. (132) reported that female caregivers had more depression and anxiety than male caregivers. This finding was not replicated in the study by Riemsma et al. (90). In terms of caregiving relationship characteristics Riemsma et al. (90) reported that caregivers who were partners of the person they cared for had poorer mental health than caregivers who were not. The analyses by Stephens et al. (104) included income and age as control variables in their analyses, but did not report the coefficients.

### *The explanatory variable is a primary objective stressor*

Each of the studies included a variable relating to the patient's clinical characteristics, but only Riemsma et al. (90) also included a measure of care tasks.

In terms of patient disease characteristics, Riemsma et al. (90) reported that patients with higher levels of fatigue had caregivers who had greater levels of mental health problems. However, this was not replicated in the study by Walsh et al. (139). Considering patient pain, Stephens et al. (104) found no direct relationship between pain and husband depression. However, the study reported that when wives experienced more severe pain and had higher levels of pain disclosure at the start of the study, husbands were more depressed at study follow-up. The analyses of life satisfaction from the same study reported that husbands of women who had high levels of pain and who showed higher levels of pain behaviour had husbands who had less life satisfaction than those whose wives had high levels of pain but expressed low levels of pain behaviour.

In terms of care tasks Riemsma et al. (90), although including the number of care tasks in their final regression model, did not find that the number of care tasks with which help was provided was significantly associated with caregiver mental health.

### *The explanatory variable is a primary subjective stressor*

Four studies included a measure of caregiver burden (89,90,132,139). Strating et al. (132) found that higher levels of perceived caregiver burden were associated with higher levels of partner depression and anxiety. The same study also found an interaction between patient disability and partner burden, whereby the effect of burden on the partner's depression and anxiety was higher if there was greater patient impairment. The association between caregiver burden and mental health was not replicated in the study by Riemsma et al. (90).

### *The explanatory variable is a caregiver outcome*

Three of the studies included a measure of caregiver health status in their analyses (90,104,139). In two of these studies caregiver physical function was found to be related to caregiver mental health (90,139): caregivers who had more difficulties with physical functioning had greater mental health difficulties. Caregiver physical function was also included as a control variable in the analyses of depression by Stephens et al. (104) but the coefficients were not reported in the paper. Walsh et al. (139) found that the general health status and vitality subscales of the SF-36 were not associated with partner depression.

In terms of mental health, Druley et al. (113) reported that caregivers with higher levels of depression at the start of the study had higher levels of depression at study follow-up. Likewise, in Stephens et al. (104) life satisfaction at the start of the study was included as a control variable in the regression analyses of life satisfaction at study follow-up.

### *The explanatory variable is a resource*

In terms of informal support, the studies included variables relating to the support provided by partners, families and the wider network. Support was measured both in terms of support provided to the caregiver and to the patient. Studies also included measures of patient and caregiver internal resources such as coping and vulnerability. None of the analyses included measures of formal resources such as healthcare services.

In terms of patient support from their partner, Walsh et al. (139) reported that patients who perceived less satisfaction with their marriages had husbands with greater levels of depression. However, this relationship was not found in the study by Strating et al. (132). Three studies (89,104,139) included measures of patient perceived social support received from their partners. None of these found social support from the partners to be a factor influencing caregiver mental health. The same result was found in the analyses by Stephens et al. of life satisfaction (104). However, Manne and Zautra (89) reported that patients who perceived their partners as providing more problematic social support had partners with higher levels of mental health difficulties.

In terms of patient support from their families and wider network, patients with more children in the area were found to have caregivers with better mental health status (90). Walsh et al. (139) measured patient perceived social support from their network, but unlike Riemsma et al. (90) this study found that patients who perceived less support from their wider network had caregivers with greater mental health problems. The statistical significance of the coefficient was not reported.

In terms of support to caregivers, no associations were reported for caregiver perceived support from their wider network and caregiver mental health.

Considering internal resources, Manne and Zautra (89) included assessments of patient's self-blame and coping. The analysis found that these factors were not associated with partner mental health. Riemsma et al. (90) measured patient self-efficacy but reported no association in regression analysis. Walsh et al. (139) reported an association between patients who perceived themselves to be a burden and their caregivers having higher levels of depression. However, the level of significance was not reported.

#### *The explanatory variable is a secondary stressor: role strain and intrapsychic strain*

Riemsma et al. (90) found that caregiver's perceived ability to complete household tasks was associated with caregiver mental health. Caregivers who perceived themselves to have greater competence at managing household tasks had lower levels of mental health difficulties. The study by Walsh et al. (139) suggested that caregivers who identified more stressors that caused them distress had more depression, but the level of significance was not reported. Manne and Zautra (89) also found that the partner's perception of their vulnerability and their perceived ability to cope were both related to psychological adjustment. Partners who considered themselves to be more vulnerable and less able to cope with these vulnerabilities had higher levels of mental health difficulties.

### *Summary of regression studies*

In general, the studies of regression show few consistent relationships. The dependent variables in the studies are limited in terms of the care variables considered and no studies used caregiver HRQOL as their dependent variable. The role that environmental factors (e.g. financial status, family status) play in caregiver outcomes has not been studied extensively in terms of its effect on caregiver outcomes, and variables related to internal stressors are mainly limited to measures of caregiver self-efficacy.

## 3.7 Synthesis: Cross sectional studies with a categorical analysis

Two studies were cost of illness studies (119,120). These studies aimed to capture the costs associated with disease and presented their analyses based on costs per category of disease severity with a separate category for informal care costs. One of the studies (119) measured the costs associated with osteoarthritis and one study (120) measured the costs associated with rheumatoid arthritis. In the case of the rheumatoid arthritis study, the age of the study means that the participants involved will not have had access to the biologic disease-modifying treatments or changes in clinical management involving earlier and more aggressive management, which could affect cost estimates. Both studies were completed in Italy and used cost data from that country. Each of the studies was graded as being of low quality on account of the limited generalisability to the UK context and limited description of the analyses. The studies use different disease severity measures and so cannot be combined.

### *Rheumatoid arthritis*

The study in patients with rheumatoid arthritis ((120); N=200) was carried out in Italy in 1998. Data for informal care was collected in terms of time off work (including working days lost, permanent reduction in hours and loss of working activities), and hours of informal care. Care tasks were direct care including cleaning and preparation of meals and supervision. Data were presented as costs in euros per American College of Rheumatology (ACR) functional class (the higher functional class the greater the disability of the patient). Caregiver’s time off work or loss of work was costed in terms of the average salary for the sector in which they were employed and informal care was costed at 6.4 euros an hour for care, and 3.3 euros an hours for supervision. In total 114 of the patients required informal care, with three quarters of the people in ACR functional class 3 and 4 requiring informal care. Forty-nine of these patients had more than one caregiver (totalling 62 other caregivers). The paper reports that the highest indirect costs came from the hours used for informal care with 98 of the 114 caregivers using their free time to do this. On average these people spent 5.5 hours providing care of which 2.5 was for care and 3 hours was for company and surveillance. Data from the paper are reported below; it is implied from the paper that these costs are average costs per patient per year (Table 8).

**Table 8: Outcomes in Leardini et al. 2002**

| | **ACR class 1 N=49** | **ACR class 2 N=53** | **ACR class 3 N=54** | **ACR class 4 N=44** |
|---|---|---|---|---|
| **Main caregiver** | | | | |
| *Loss of work* | | | | |
| N | 0 | 0 | 0 | 1 |
| Cost per patient | 0 | 0 | 0 | 2698.5 |
| *Working days lost* | | | | |
| N | 2 | 8 | 17 | 12 |
| Cost per patient | 88.3 | 149.2 | 1167.3 | 1033.0 |
| *Hours of informal care* | | | | |
| N | 7 | 24 | 31 | 36 |
| Cost per patient | 739.3 | 3457.4 | 5985.5 | 7159.0 |
| **Other caregivers** | | | | |
| *Hours of informal care* | | | | |
| N | 1 | 10 | 16 | 22 |

| | | | | |
|---|---|---|---|---|
| Cost per patient | 13.9 | 944.8 | 811.0 | 1514.7 |
| ACR I = completely capable to perform the usual activities of daily life (self care, vocational and avocational)<br>ACR II – capable of performing the usual self care and vocational activities but limited in avocational activities<br>ACR III – capable of performing the usual self care activities, but limited in vocational and avocational activities<br>ACR IV = limited in ability to perform self care, vocational and avocational activities.<br>Costs are in Euros study was completed in 1998 | | | | |

***Osteoarthritis***

The study by Leardini et al. ((119); N=254) was completed in Italy over a 12 month period between 2000 and 2001. Data on informal care were collected using the same definitions as in Leardini et al. (120). Data are presented in the papers as costs in euros based on Kellgren and Lawrence criteria (radiological presence of osteoarthritis). Data were costed using the average salary for the sector in which they were employed (daily costs varied between 88 euros for a farmer to 161 euros for a medical doctor). Hours of informal care were valued based on 6.20 euros for direct care and 3.46 euros for supervision. The average amount of care provided was 2.6 hours per day including 1.1 hours of direct care and 1.5 hours of supervision, and it is stated that the percentage of patients receiving care increased as Kellgren Lawrence criteria increased from 9% at grade 1 to 37% at grade 4 (Table 9).

**Table 9: Outcomes in Leardini et al. 2004**

| | **Kellgren Lawrence Grade** | | | |
|---|---|---|---|---|
| | **1**<br>**N=23** | **2**<br>**N=84** | **3**<br>**N=120** | **4**<br>**N=27** |
| Euro per patient cost per year | 144 | 501 | 887 | 1758 |
| Grade 1: doubtful narrowing of joint space and possible osteophytes<br>Grade 2: definite osteophytes and possible narrowing of joint space<br>Grade 3: moderate multiple osteophytes, definite narrowing of joint space, and some sclerosis and possible deformity of bone ends<br>Grade 4: large osteophytes, marked narrowing of joint space, severe sclerosis and definite deformity of bone ends<br>Costs are in Euros study was completed in 2000 | | | | |

***Summary***

Each of the studies was graded of low quality. The study in rheumatoid arthritis (120) suggests most clearly that as functional disability of a patient increases the costs of informal care also increase. Leardini et al. (119) suggests that as radiographic damage increases so do costs of informal care for patients with osteoarthritis. However disease categories are based on radiographic criteria rather than specifically functional status.

## 3.8 Synthesis of qualitative evidence

One study (131) contained qualitative data about the experience of providing informal care. This study used interviews of 30 female primary caregivers of adults aged 60 years or older with a diagnosis of arthritis. Twenty-seven of the participants were the daughters of the person they cared for and three were sisters of the person they cared for. Twenty-two of the care recipients were female and eight were male. Only six of the care recipients were married. The study was completed in households from neighbourhoods of the capital city of Puerto Rico classified as low-middle or middle-middle income. The interviews focussed on the instrumental tasks of caregiving and interview data were corroborated with visits to participants during the week. The study was rated as low quality for the purposes of this review because of the limited generalisability to the UK context. Because these data are from a single study they are not presented separately. Rather, these data are incorporated into the cross-study synthesis described below.

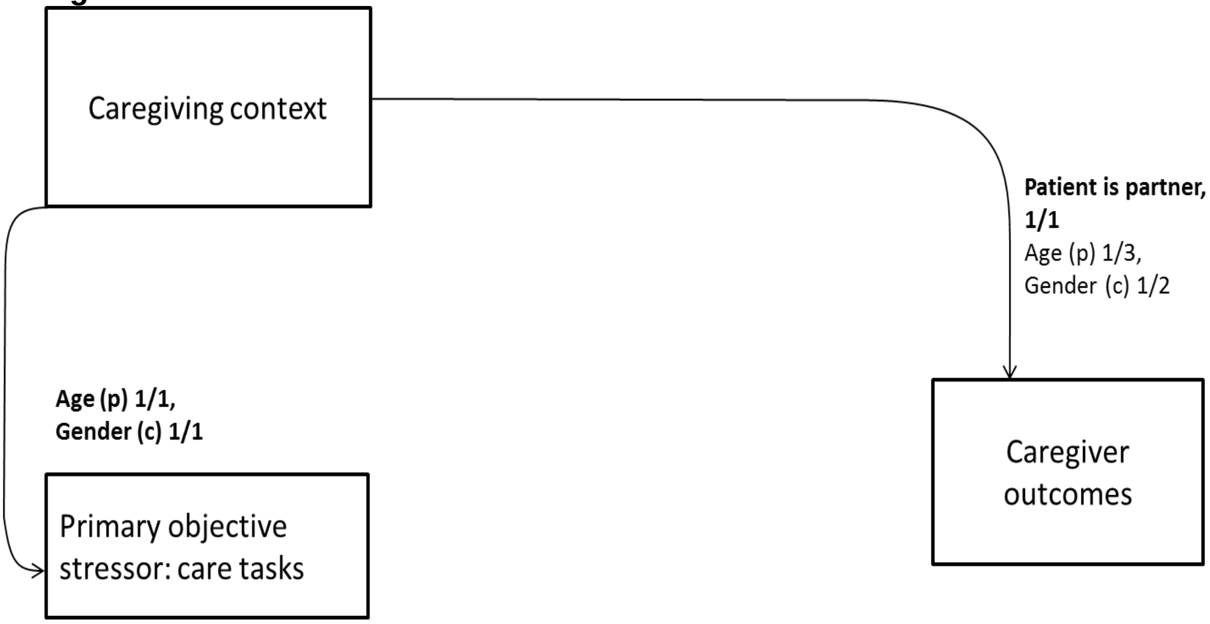
## 3.9 Cross-study synthesis

The cross-study synthesis brings together the data from the intervention studies, studies of association and the qualitative study, to consider the factors influencing caregiver outcomes and the provision of care.

### 3.9.1 Role of caregiving context

Evidence for the role of caregiving context comes from the studies of association and the qualitative study. Caregivers of younger patients and caregivers who were male were found to provide help with a greater number of tasks (high quality evidence). Caregivers of patients who were also their partners had worse mental health outcomes than non-partners (high quality evidence). Medium quality evidence suggested that caregivers of older patients and female caregivers may experience worse mental health outcomes than younger caregivers and male caregivers (figure 9).

Figure 9: Summary of the role of caregiving context on care tasks and caregiver outcomes



Key: Text in bold type comes from studies where one or more if graded as high quality evidence, (p) = measured from patients, (c) = measured from caregivers, *x*/*y* = statistically significant relationship reported in *x* out of *y* number of studies.

Factors relating to the caregiving context are described in the qualitative study mainly in relation to how the participants came to be caregivers rather than the effect that these factors had on care outcomes. Participants described being female and living closest to the person requiring care as reasons for becoming a caregiver. Birth order was also mentioned although in some instances the role of caregiver was associated with being the oldest daughter and sometimes the youngest.

Residential location was not identified in the quantitative evidence. However, in the qualitative evidence residential location was mentioned, with caregivers not co-residing highlighting how they often had to perform the tasks twice, once for their own families and once for the person for whom they provided care.

> *"I get very tired. I wish that I could have her at home with us but there isn't that much space at our house. I'm always rushing from one place to another: work, her apartment [frail mother's], and then my house. . . ." (p92)*

### 3.9.2 Role of primary objective stressors: patient impairment

Evidence for the role of patient health status comes from the intervention studies, the studies of association and the qualitative study. In the qualitative study perceptions of primary objective stressors were generally in terms of the characteristics of the care required rather than in relation to the impairment of the patient. However, a couple of participants reflected on the influence of patient impairment.

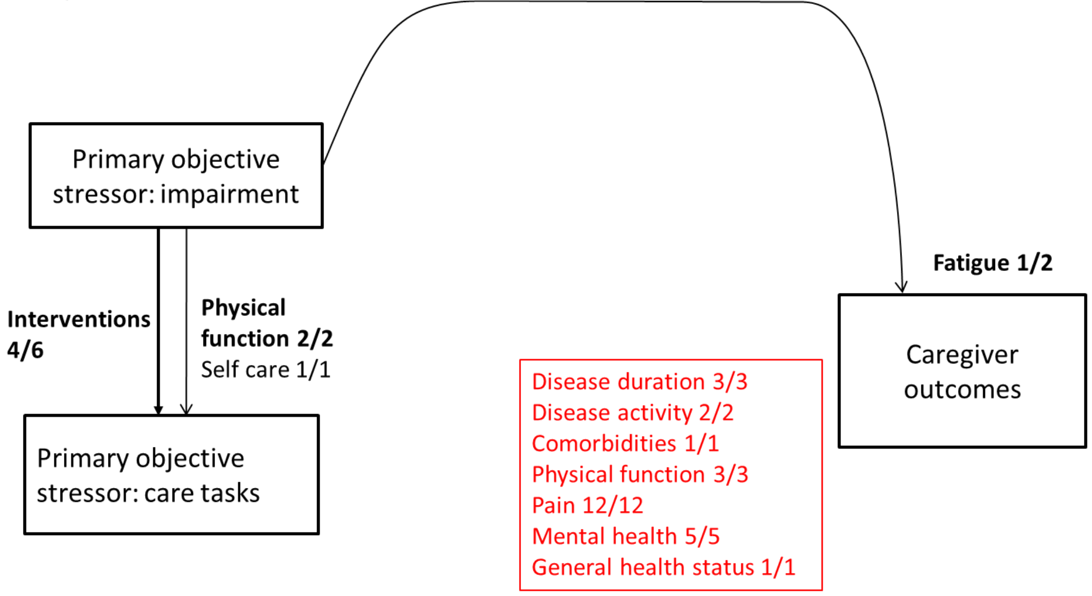
In general the intervention studies suggested that improving patient physical function and symptoms reduced the amount of care provided (high quality evidence). This was also supported by the studies of association (including the cost of illness studies) which showed that as patient physical function decreased amount of care or costs of care increased. This was also captured in the qualitative study.

> *"It is not so easy to look after her now that her condition requires so much attention, requires a lot of work". (p79)*

In regard to patient impairment the majority of analyses did not find this to be associated with caregiver outcomes (as shown by the analyses in the unconnected box in Figure 10), although the qualitative evidence did suggest a possible relationship.

> *"There are times when he is really feeling bad because he hurts more or can't do as much–or little–as he can by himself. . . . He gets very depressed and seeing him like that depresses me". (p91)*

**Figure 10: Summary of the role of patient impairment on care tasks and caregiver outcomes**



Key: Text in bold type comes from studies where one or more if graded as high quality evidence, *x*/*y* = statistically significant relationship reported in *x* out of *y* number of studies.

### 3.9.3 Role of primary objective stressor: care tasks

The evidence for the role of care tasks came from the studies of association and from the qualitative study. Overall the nature of care was less comprehensively described in the studies than factors such as the caregiving context and patient clinical characteristics.

Variables related to care tasks were not shown to be associated with caregiver outcomes (high quality evidence), but in this analysis the variable was restricted to number of care tasks without any exploration of the type of care required (figure 11).

In the qualitative study the nature of the tasks completed and the strain that these tasks took were explored. Questionnaires accompanying the interviews identified medical appointments, household cleaning and self-care activities as being the most stressful tasks.

> *“Bathing her is difficult too. I generally do it before going to bed and am exhausted by then. I don't do it earlier because when I arrive I am tired from work and like to rest for about an hour or so; depending on what I must do. . . . I get up at 5:20 in the morning and leave for work by 6:30 at the latest……Her bath takes about 20-30 minutes between bathing, drying and dressing her [mother has rheumatoid arthritis and can barely move her elbows and shoulders]. When I wash her hair it takes longer. She gets tired from all this. I can't rush her. . . . And all I want is to go to bed and collapse”. (p86)*

> *“I guess what I find more tiresome is that I don’t like to do the heavy cleaning in my own house and that I must do his on Saturday mornings when I would love to be at ease in my house.” (p87)*

In addition, participants highlighted the need to multitask, combining meal preparation both for their families and for the care recipient, and care tasks and supervision.

> *“In the afternoon I prepare the meals for the whole week; both ours and his. I prepare different meals for him because he is on a low sodium-low fat diet. Sometimes he sits in the kitchen with me and we talk.” (p83)*

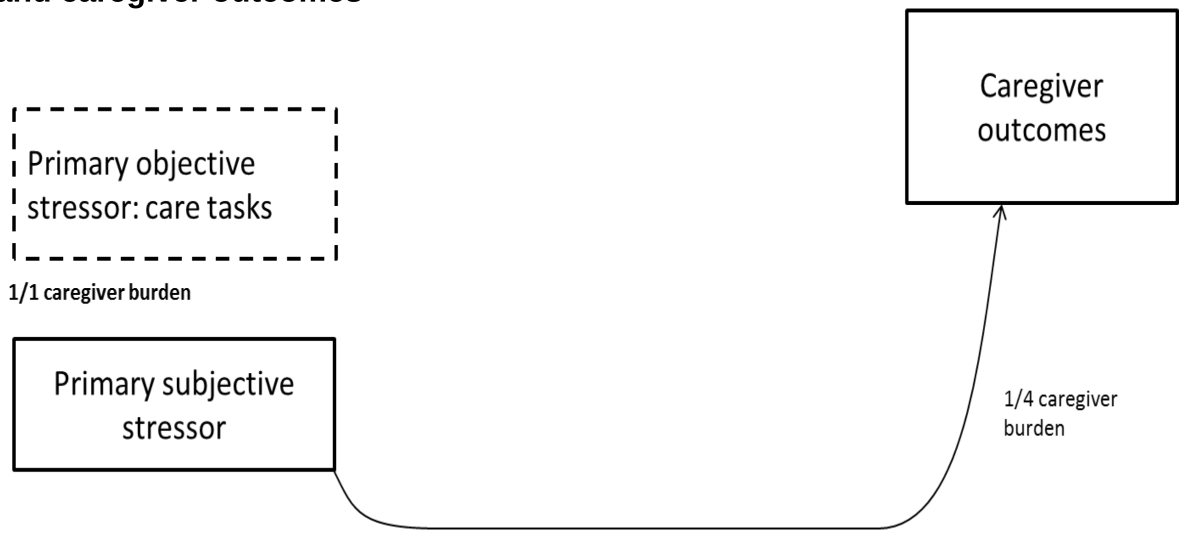
**Figure 11: Summary of the role of care tasks on caregiver outcomes**

Key: Text in bold type comes from studies where one or more if graded as high quality evidence, *x*/*y* = statistically significant relationship reported in *x* out of *y* number of studies.

### 3.9.4 Role of primary subjective stressors

Evidence for the role of primary subjective stressors came from the studies of associations and also from the qualitative study. The qualitative study provided a more in-depth consideration of the individual elements from Pearlin's framework that make up primary subjective stressors (role captivity, role overload and loss of intimate exchange). Caregiver burden was not shown to be related to number of care tasks with which help was provided (high quality evidence). Caregiver burden was measured in four of the studies that used as a dependent variable a mental health outcome. In one of these (medium quality evidence) a relationship was observed (figure 12).

**Figure 12: Summary of the role of primary subjective stressors on care tasks and caregiver outcomes**



Key: Text in bold type comes from studies where one or more if graded as high quality evidence, *x*/*y* = statistically significant relationship reported in *x* out of *y* number of studies.

In the qualitative study, participants mentioned the change in the nature of the relationship between the caregiver and care recipient.

> *"I could bathe him but he [Father] cried the first time I had to do it. He was desperate ["desesperado"] and yelling why God had allowed him to live to have his only daughter see him naked and bathe him like a baby! . . . Now my son and husband help. . . . But it was not easy to convince him [father]. He [father] always comments that he never expected to see the day when he would be treated like a child." (p80)*

Participants also mentioned perceptions of being captured by the role or overloaded by caregiving. A number of times, participants described rushing from one task to the next which was often related to the care recipient and caregiver not living in the same household.

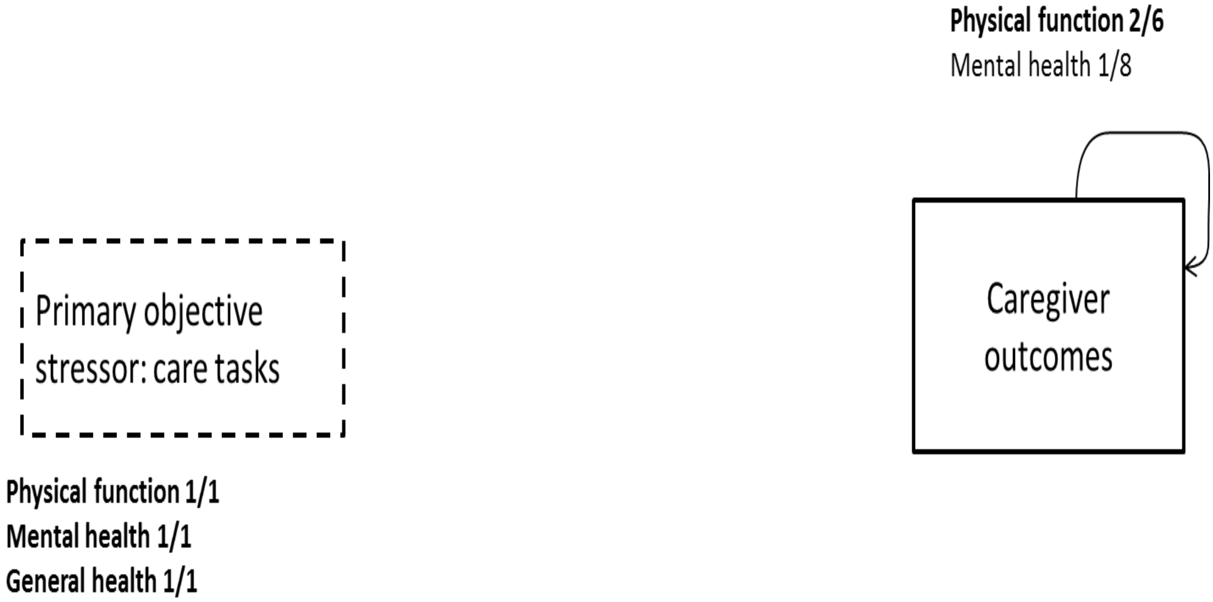
> *"I yearn for the day when I can sleep a Saturday until barely eight in the morning or just stay at home doing household chores without having to rush from one place to the other. . . . Or just lay in bed doing absolutely nothing or reading a "Vanidades" [Latin American female-oriented journal]!" (p92)*

> *"There are times when I resent being the one who has to take care of everything. But immediately I feel guilty and ashamed. How can I think that I am a good daughter and have these thoughts? She was a wonderful mother, completely devoted to us. . . . What kind of a daughter am I?" (p93)*
>
> *"He doesn't want me to leave and plays this guilt-trip on me. It works! . . . When I must leave because I have to go home to sleep, I feel really awful! I don't need that." (p91)*

### 3.9.5 Role of caregiver outcomes

Caregiver outcomes refer to the caregiver's health status and the role that this plays with respect to the provision of care and other caregiver outcomes such as mental health, wellbeing and life satisfaction. Evidence for the role of caregiver outcomes comes from the studies of association. One study (high quality evidence) suggested that caregiver health status was not associated with the number of care tasks for which help was provided (figure 13).

**Figure 13: Summary of the role of caregiver outcomes on care tasks and caregiver outcomes**



Key: Text in bold type comes from studies where one or more if graded as high quality evidence, *x*/*y* = statistically significant relationship reported in *x* out of *y* number of studies.

Caregiver clinical characteristics were identified as impacting on caregiver mental health outcomes. High quality evidence suggested that caregivers with less physical function had greater mental health difficulties. This was also observed in a study of medium quality evidence. One study of medium quality evidence identified that caregiver depression at time 2 was associated with their levels of depression six months earlier at time 1.

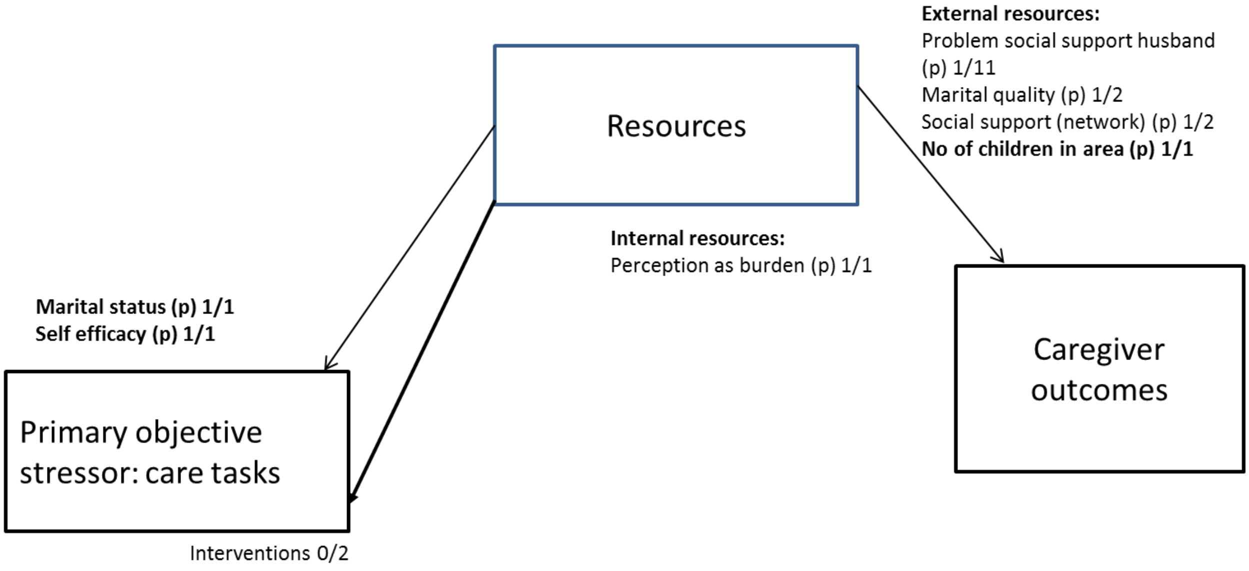
### 3.9.6 Role of resources

Evidence for the role of resources came from the studies of association, from two intervention studies that investigated different mechanisms for service delivery and from the qualitative study. The qualitative study focussed on the role of the family in supporting care.

The two intervention studies (low quality evidence) focused on changing service delivery to include a single point of contact. These studies did not show that this changed the amount of informal care provided. Formal care management was not included in the regression analyses of primary objective stressors or caregiver outcomes.

The availability of resources to the caregiver such as family and social support was not shown to be a statistically significant variable in the regression analyses. Where relationships were observed, these were resources available to the patient rather than resources available to the caregiver. Patients who perceived more marital or relationship problems with their husbands/caregivers had husbands/caregivers who reported worse mental health outcomes (all medium quality evidence). Patients who were married had caregivers who provided help with more tasks; patients who had children living in the area had caregivers who had fewer mental health difficulties (high quality evidence). One study suggested that patients who received more social support from their wider network had caregivers with fewer mental health difficulties (medium quality evidence), but this was not replicated in higher quality evidence. One study (medium quality evidence) considering internal resources suggested that patients who perceived themselves to be a greater burden on their partners had partners who had worse mental health (figure 14).

**Figure 14: Summary of the role of resources on care tasks and caregiver outcomes**



Key: Text in bold type comes from studies where one or more if graded as high quality evidence, (p) = measured from patients, (c) = measured from caregivers, *x*/*y* = statistically significant relationship reported in *x* out of *y* number of studies.

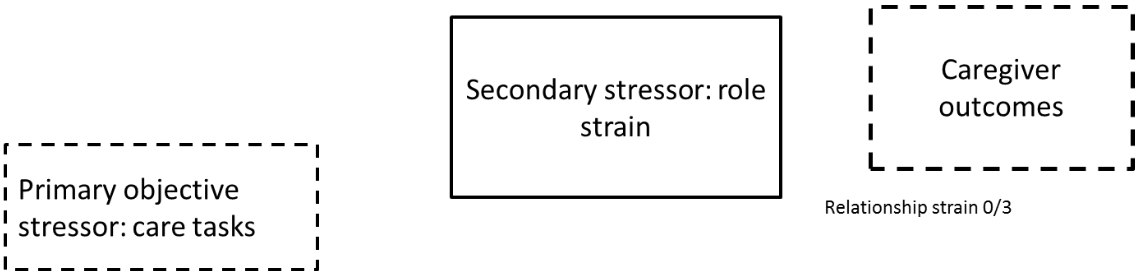
In the qualitative study, participants noted that although they were the primary carer other family members could provide support when required. Questionnaires accompanying the interviews indicated that in all cases the primary carer could identify a second person who provided support, although not all caregivers could identify more than one other person.

> *"My husband takes the children to school and I take her [mother] to the physician's office; it is near my school. We are there very early, like around 6:45. I take her inside the office and seat her. . .Then I leave for school. She calls my sister-in-law when the doctor is through with her, usually around 11:00-11:30 and my sister-in-law picks her up and brings her home." (p83)*

### 3.9.7 Role of secondary stressors: role strain

Evidence for the influence of role strain came from the studies of association and the qualitative study. There was an absence of evidence relating to role strain in relation to employment, finances and leisure or social commitments. The evidence available was from relationship strain but when measured from the caregiver this showed no statistically significant relationships with caregiver mental health (figure 15).

**Figure 15: Summary of the role of role strain on care tasks and caregiver outcomes**



Key: Text in bold type comes from studies where one or more if graded as high quality evidence, *x*/*y* = statistically significant relationship reported in *x* out of *y* number of studies.

In the quantitative study participants described stressors which made providing care harder. These tended to focus on tensions within the family about who provided care.

> *"My other two brothers do not live close-by and they come to visit them every other weekend so I can't depend on them for assistance with the bath . . . or anything else for that matter." (p80)*

They also related to tensions in how care is provided.

> *"She [sister who lives about 10 miles from her] knows that I do the best that I can. I have a husband who is driving me crazy with his adjustment to retirement and I must look after these two babies [grandchildren]. She dares to complain that I am not cleaning his house [elderly father's] the way I should! . . . I'm not a maid! I have many things to do! Why doesn't she go over every now and then and help? She stops by just to visit . . . My two brothers live in the United States and I can't depend on them. She is very much aware of that. . . . And even my two brothers sometimes dare to criticize from far away!*
> *What bothers me very much is that they complain about how I do certain things. Even my sister-in-law dares to criticize! They don't understand her [frail sister] like I do. . . . Besides, they don't have to deal with the situation every day and every single hour. . . . It is very easy to criticize when you don't have to face the situation day-after-day." (p90)*

The importance of schedules to help ensure that all tasks were completed was implicit in participants' comments. The impact of a disrupted schedule when something didn't go to plan was also described.

> *"At times, the physician does not come in until later than usual and I have to leave her alone at the office, pick up my youngest grandchild, go with my grandchild to the office, and pick her up. I get very anxious and she gets upset and the baby gets upset. At times I find myself incriminating her. It is not her fault and then I feel awful. It is not easy when she has a medical appointment because one never knows how long the wait will be at the physician's office. Many times there is something unexpected and I get tense." (p84)*

The difficulties of completing both work and care were noted, including the impact that this had in factors such as fatigue. Some participants noted the positive impact of being able to work flexibly, but for a number of participants activities such as taking the care recipient to a medical appointment required taking time off work either as vacation time, or as sick leave.

> *"My workday demands a lot; it is not that easy to do what I do. Then, everyday the same: work, her place, and mine. I am very tired in the evenings. . . . I must take half-a-day or the whole day off when I take her to her medical appointments. Not all my bosses are equally understanding. . . . When she underwent surgery I used my remaining vacation-time to stay in the hospital with her and throughout the rehabilitation period. I even had to ask for three extra days that were taken off from my sick leave." (p92)*

Financial issues were not discussed in detail by participants, but were noted in relation to their influence on family conflict and being unable because of financial difficulties to ease some of the strains of doing stressful tasks.

> *"My brother and sister who live in the United States do not help us on a regular basis and his Social Security check isn't a lot. It covers some basic things but not all. But my siblings don't seem to understand this." (p87)*

> *"I guess what stresses me the most is cleaning his apartment. The irony of it all is that I have a cleaning woman who comes in twice a week to my house to help me. But she charges a lot and we can't afford to have her another day." (p87)*

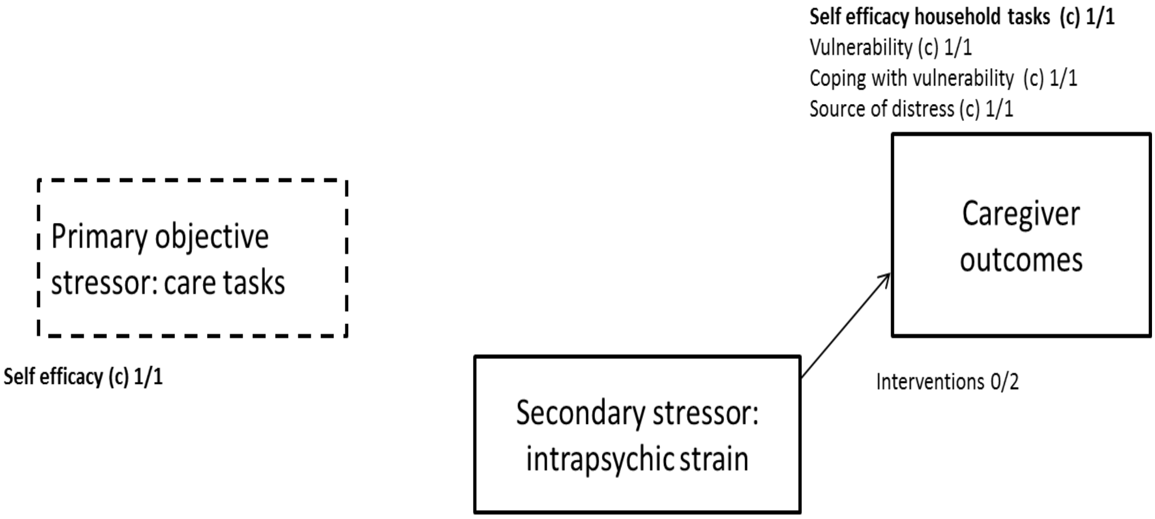
### 3.9.8 Role of secondary stressors: intrapsychic strain

Evidence for the role of intrapsychic strain came from the studies of association, from the qualitative study and the two intervention studies that investigated the impact of including both the patient and caregiver in an intervention for arthritis self-management. The intervention studies did not show that including the partner of the patient in a rheumatoid arthritis self-management intervention improved caregiver depression relative to an intervention that included only the patient or to usual care. The regression analyses suggested that caregivers' perceived ability to provide care was not associated with provision of care tasks. However, caregivers who perceived themselves to be more effective at completing household tasks had better mental health (high quality evidence). One study (medium quality evidence) suggested that partners who perceived themselves to be vulnerable and to have less coping ability to respond to vulnerable situations also had worse mental health (figure 16).

In the qualitative study one participant noted that the provision of opinions on how to provide care led to self-doubt about how best to provide care.

> *"Everybody has an opinion of their own as to how I should divide my time. I sometimes wonder if I'm the one who is incorrect and don't know how to handle the situation." (p93)*

**Figure 16: Summary of the role of intrapsychic strain on care tasks and caregiver outcomes**



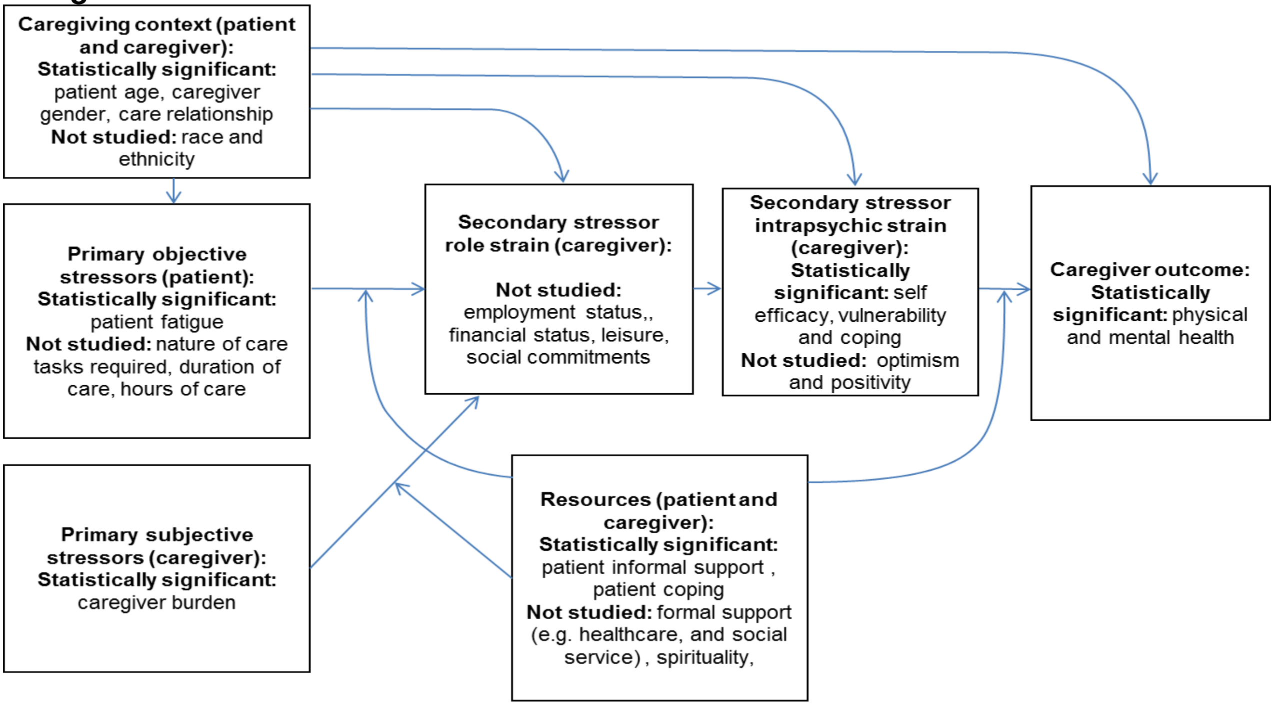
Key: Text in bold type comes from studies where one or more if graded as high quality evidence, (c) = measured from caregivers, *x*/*y* = statistically significant relationship reported in *x* out of *y* number of studies.

## 3.10 Summary

The systematic review identified 25 studies considering the outcomes of caregivers of adults with chronic arthritis. Twenty-four of the studies were quantitative and one was qualitative. Of the quantitative studies 11 were intervention studies.

Figure 17 shows the variables in which at least one study identified a statistically significant association or effect on caregiver outcomes within the framework presented in chapter 2.

**Figure 17: Pearlin's model of caregiver outcomes showing relationships with caregiver outcomes**



Overall the caregiver outcomes used as dependent variables in the studies in the review were limited to mental health and life satisfaction. None of the studies measured HRQOL. Studies incorporating time spent caregiving were also limited, with only one study using time as a dependent variable; other studies measured number of care tasks or days off work as a result of caregiving as a proxy for the amount of care. The review identifies a dearth of relevant evidence that measures outcomes relevant to NICE assessments. This provides support for further research and analysis such as that completed in subsequent chapters.

In terms of the association between patient health or care tasks and caregiver outcomes, few studies included in the review identified statistically significant associations between patient health and caregiver health outcomes. One study identified an association between patient fatigue and caregiver mental health. Fewer statistically significant relationships identified between patient health and caregiver outcomes were found than expected. This may possibly be explained by the moderating role that secondary stressors play in determining caregiver outcomes.

The other factors associated with the relationship between patient health and caregiver outcomes are shown to be inconsistent across the studies with no single variable being identified as being a key factor across all analyses. There are also important moderating factors that have not been studied in the existing literature, most notably the role of financial, employment and social conflict on caregiver outcomes. The systematic review supports the case for completing further research considering the role of patient health on caregiver health and including in the assessment a fuller range of possible moderating factors.

# 4 Methods of the secondary dataset analysis

## 4.1 Introduction

The previous chapter of the thesis reviewed the existing literature about the effects of caring for a person with arthritis on care outcomes. It found that no studies have considered the effects of caregiving on caregivers in terms of HRQOL and the role that environmental factors such as financial situation play in moderating these outcomes.

This next chapter considers the datasets available that can answer the research question. An appropriate dataset is identified, Understanding Society, and the chapter provides a rationale for the choice. The chapter describes the general characteristics and data collection methods of Understanding Society, before describing more specifically the measures of caregiving available. The arthritis sample in the dataset is subject to descriptive, univariate and multivariate analyses in chapter 5.

This chapter also describes the methods for the secondary dataset analysis and the data to be used. First it describes the research question, the measures used in the analysis and the approach to assessment of missing data. It then describes the approach to descriptive analysis before describing the approach to regression analysis. It outlines specific considerations when analysing the Understanding Society dataset such as clustering within households. It then describes the approach to analysing the interactions that may be expected from caregiving theory. Finally, it specifies the model that is then built in chapter 6.

## 4.2 Research question

The overarching research question for the secondary dataset analysis is:

- What is the relationship between the HRQOL of a person with arthritis and the HRQOL of their caregiver? What are the other factors that influence this relationship?

Based on stress process theory, the relationship between patient HRQOL and caregiver HRQOL may be indirect. Other factors, namely secondary stressors, may modify the relationship between patient HRQOL and caregiver HRQOL. Sociodemographic characteristics, available resources and other patient and caregiver health and wellbeing characteristics are considered as factors to control for.

A variety of measures exist for capturing caregiver quality of life (notably caregiver-specific measures such as the Adult Carer Quality of Life Questionnaire (156), Caregiver Experience Scale (66) and Carer Quality of Life (157)) and patient quality of life (such as disease specific measures). However, reflecting the context of the thesis the patient and caregiver measure of interest is preferably the EQ-5D or in the absence of EQ-5D and alternative measure of HRQOL that can be used to calculate a QALY.

## 4.3 Available datasets

Given the research question, the dataset for analysis requires the following measures:

- A measure of the presence of arthritis to identify patients with arthritis;
- A patient measure of measure of HRQOL that can be used to calculate a QALY;
- A caregiver measure of measure of HRQOL that can be used to calculate a QALY.

The measure of HRQOL should in ideally be EQ-5D or in the absence of EQ-5D a preference-based measure that can produce a utility value. Further, it must be possible to link the patient and the caregiver within the dataset to create a series of patient and caregiver pairs so as to model the association: to do this the person providing the care and receiving the care must be uniquely identified and linked.

A fourth measure is also considered an important variable for the analysis and to interpret the data:

- A measure of time spent caregiving.

From the perspective of NICE and decision-making in England, datasets including UK data are preferred to datasets from other countries where the above criteria are met.

**Table 10: Summary of UK datasets**

| Dataset | Disease | Patient HRQOL | Caregiver HRQOL | Link patient and caregiver | Time measure |
|---|---|---|---|---|---|
| **Disease specific** | | | | | |
| BSRBR (158) | X | X EQ-5D | - | - | - |
| NOAR (159) | X | | - | - | - |
| ERAS/ERAN (160) | X | | - | - | - |
| **Caregiver specific** | | | | | |
| Survey caregivers in households (17) | - | - | x | - | X |
| **Household and general population** | | | | | |
| ONS longitudinal study (161) | - | - | - | - | - |
| Understanding Society (33) | X | X SF-12 | X SF-12 | X | x |
| Health Survey England (162) | X | X EQ-5D | X EQ-5D | - | - |
| Family Resources | - | - | - | X | x |

| | | | | | |
|---|---|---|---|---|---|
| study (163) | | | | | |
| English Longitudinal Study of Ageing (15) | X | | - | X | x |
| GP National Patient Survey (164) | X | X EQ-5D | X EQ-5D | - | x |
| HODAR (144) | X | X EQ-5D | - | - | x |

Table 10 shows that in 2011 when the secondary dataset was identified there was no perfect dataset available. In the UK there are a number of disease-specific datasets such as the British Society of Rheumatology Biologics Register (BSRBR). These provide in-depth information about the patient’s disease status and patient sociodemographic information, but do not collect data from caregivers. In contrast caregiver surveys such as the Survey of Carers in Households collect in-depth data only from caregivers. General household surveys collect data from both patients and their caregivers within households, but these tend not to collect in-depth disease information or validated measures of HRQOL. In contrast the health surveys identified more often collect EQ-5D which would be the preferred measure for the analysis, and may ask questions about caregiving, but do not allow the link to be made between patients and caregivers. Of the surveys identified only Understanding Society collects all measures of interest in the analysis and enables a link to be made between patients and caregivers. While the measures collected in Understanding Society are associated with limitations in terms of collection of SF-12 rather than EQ-5D, no datasets identified from other countries provided a better option for analysis (appendix 4).

## 4.4 Description of Understanding Society

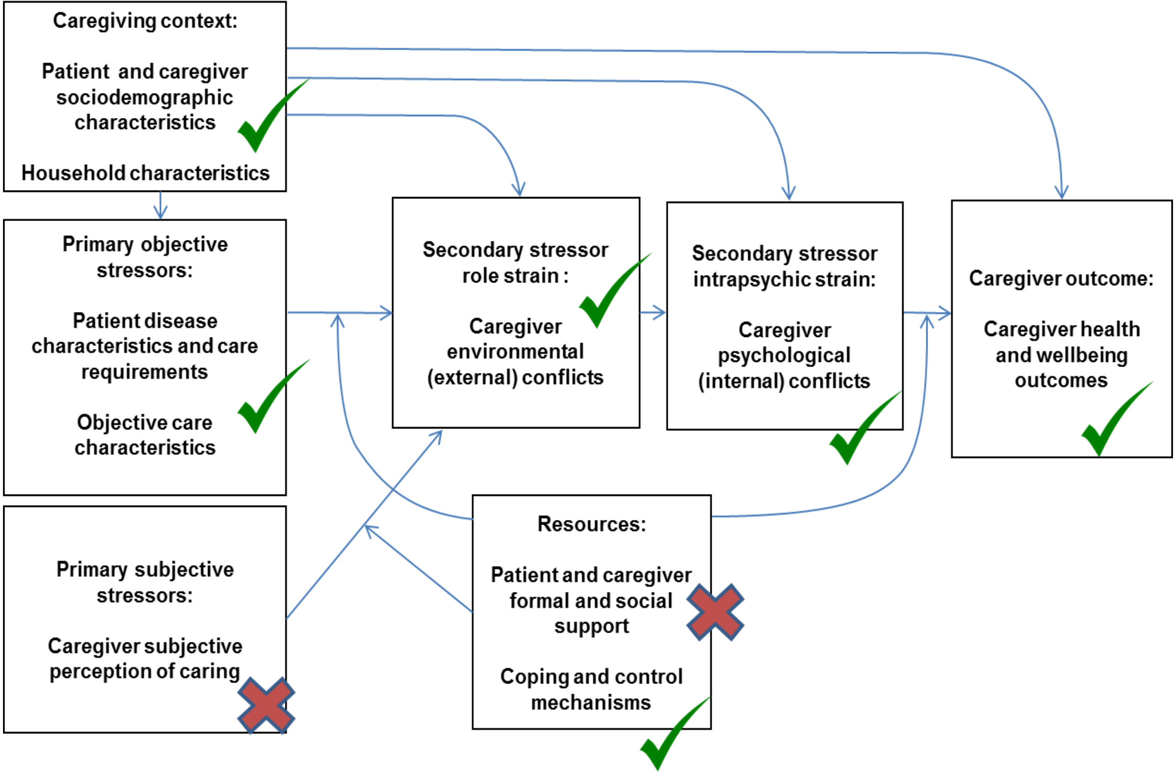
Understanding Society is a large longitudinal household panel study which collects data from individuals living in households across the UK (165). It is sampled to provide information that is representative of the population and builds on a previous survey, the British Household Panel Survey. Data are collected through a combination of interviews and self-completion questionnaires and households are followed up each year, allowing cross-sectional and longitudinal analysis. Topics covered in Understanding Society include family dynamics, household organisation, household income and welfare, and labour market participation as well as health, wellbeing, social participation and other behavioural measures.

The dataset used in the analysis and described in subsequent chapters is the first wave data (wave 1) collected in 2009. This was the only wave available at the time the secondary dataset analysis started. The wave 1 dataset includes a general population sample which is a stratified, clustered, equal-probability sample of residential addresses drawn from the whole of the UK. In wave 1 the general population sample data were collected from 26,089 households which include 43,674 individuals. The wave 1 dataset also includes an ethnic minority boost sample which was designed to provide data from adults who are Indian, Pakistani, Bangladeshi, Caribbean and African. The wave 1 ethnic minority boost sample includes 7,320 people from 4,080 households. Therefore the total wave 1 dataset comprises just over 50,000 people from 30,000 households.

In terms of general characteristics of wave 1, 45% of the dataset are male and 55% female; the mean age is 46 years with a standard deviation of 18. Forty-seven percent are living with their partner, 29% are single and never married and 6% are widowed. Half of the dataset is in paid employment and a quarter is retired. Twenty-one percent of the dataset report having a degree-level education while 18% have no educational qualifications. The mean monthly household income is £2990.393 (SD £4110.867), the mean number of children in a household 0.592 (SD 1) and 80% of households are in an urban location.

Not all measures are collected in each wave. For example, measures of social support were not collected in wave 1. Figure 18 shows the types of variables in Understanding Society mapped onto Pearlin's framework that are available for the analysis.

**Figure 18: Types of variables available in Understanding Society**



### 4.4.1 Measures of caregiving

As part of the interviewer-led questionnaire Understanding Society asks: “*is there anyone living with you who is sick, disabled or elderly whom you look after or give special help to (for example, a sick, disabled or elderly relative/husband/wife/friend etc)?*”. This question is then followed up with further questions about to whom care is provided within the household (with the person’s person number within the household recorded), the provision of care outside of the household and the number of people outside of the household to whom care is provided. Seven percent of the dataset provide care within the household and 10% provide care to someone outside of the household.

To collect data on time spent caregiving people are asked: “*now thinking about everyone who you look after or provide help for both those living with you and not living with you - in total, how many hours do you spend each week looking after or helping (him/her/them)?”.* Time spent caring is coded in uneven ordered categories: *0 - 4 hours per week / 5 - 9 hours per week / 10 - 19 hours per week / 20 - 34 hours per week / 35 - 49 hours per week / 50 - 99 hours per week / 100 or more hours per week / continuous care*. If the respondent indicates that the time spent caring varies, the interviewer probes whether it is normally under or over 20 hours a week. These responses are coded separately. This question identifies the total time spent caregiving within and outside of the household rather than the amount of time spent providing care to each person to whom care is provided. Six percent of the dataset report providing care for 0-4 hours a week and one percent for more than 100 hours a week.

The dataset does not include subjective caregiver perceptions of how they feel about caregiving nor does it collect data on the type of care being provided or the formal resources (such as health and social care services) that caregivers may draw on to support the caregiving role. Therefore the dataset includes measures of primary objective stressors but not primary subjective stressors nor formal resources.

The patients and their caregivers are not automatically linked in the dataset, but the unique identification of the patient and their caregiver means that researchers are able to make a link. Therefore it is possible to identify households who share care or who have a sole caregiver, caregivers who themselves receive care, caregivers who care for their partners and people in reciprocal care relationships. Due to the household nature of the survey only caregiver and patient pairs within a household can be studied.

### 4.4.2 Measure of patient arthritis

Information is gathered about the presence of different health conditions, one of which is arthritis. As part of the interview led questionnaire people are asked *"Has a doctor or other health professional ever told you that you have any of the conditions listed on this card?"* People are then presented with a list of different health conditions, one of which is arthritis. Follow-up questions then ask whether the person still has the health condition *"Do you still have arthritis?"* and the age of diagnosis "*What age were you when you were first told you had arthritis?"*. Thirteen percent of the dataset report having arthritis with a mean age of diagnosis of 48 (SD 16).

### 4.4.3 Caregiver and patient health-related quality of life

Understanding Society collects the SF-12 (166). The SF-12 is a short-form survey with 12 questions selected from the SF-36 Health Survey. It is a generic health survey which asks questions about physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role and mental health. The individual questions are used to calculate a summary score of physical and mental health. As part of the interview led questionnaire people are asked each of the questions in the SF-12. These questions are:

| | Question | Response |
|---|---|---|
| 1 | In general, would you say your health is... | Excellent / Very good/ Good/ Fair/ Poor |
| 2 | …moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf...Does<br>your health now limit you a lot, limit you a little or not limit you at all? | Yes, limited a lot / Yes, limited a little / No, not limited at all |
| 3 | Climbing several flights of stairs...does your health now limit you a lot, limit you a little, or not limit you at all? | Yes, limited a lot / Yes, limited a little / No, not limited at all |
| 4 | During the past 4 weeks, how much of the time have you accomplished less than you would like as a result of your physical health? | All of the time / Most of the time / Some of the time / A little of the time / None of the time |
| 5 | During the past 4 weeks, how much of the time were you limited in the kind of work or other regular daily activities you do as a result of your physical health? | All of the time / Most of the time / Some of the time / A little of the time / None of the time |
| 6 | During the past 4 weeks, how much of the time | All of the time / Most of the time / |

| | | |
|---|---|---|
| | have you accomplished less than you would like as a result of any emotional problems | Some of the time / A little of the time / None of the time |
| 7 | During the past 4 weeks, how much of the time did you work or other regular daily activities less carefully than usual as a result of any emotional problems, such as feeling depressed or anxious? | All of the time / Most of the time / Some of the time / A little of the time / None of the time |
| 8 | During the past 4 weeks, how much did pain interfere with your normal work including both work outside the home and housework? Did it interfere... | Not at all / A little bit / Moderately / Quite a bit / Extremely |
| 9 | How much of the time during the past 4 weeks have you felt calm and peaceful? | All of the time / Most of the time / Some of the time / A little of the time / None of the time |
| 10 | How much of the time during the past 4 weeks did you have a lot of energy? | All of the time / Most of the time / Some of the time / A little of the time / None of the time |
| 11 | How much of the time during the past 4 weeks have you felt downhearted and depressed? | All of the time / Most of the time / Some of the time / A little of the time / None of the time |
| 12 | During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities like visiting friends or relatives? | All of the time / Most of the time / Some of the time / A little of the time / None of the time |

The responses from the individual SF-12 questions are available as well as mean physical component summary (PCS) and mental component summary (MCS) scores derived from the individual questions. The mean PCS score for the dataset is 49 (SD 11) and mean MCS score is 50 (SD 10).

## 4.5 Conceptualisation of the research question

The research question for the secondary dataset analysis is conceptualised within Pearlin's model of caregiver outcomes and the variables in Understanding Society, as the following:

$y = f(x_1, x_2, x_3, x_4 \ldots x_i)$:

y = caregiver outcome

$x_1$ = primary objective stressor

$x_2$ = caregiving context

$x_3$ = secondary stressors: role strain external

$x_4$ = secondary stressors: intrapsychic strain internal

$x_5$ = resources

$x_6$ = other patient and caregiver health and wellbeing variables

where:

$x_2$ $x_5$ $x_6$ = control variables

$x_1$ = key explanatory variable

$x_3$ $x_4$ = moderators of the key explanatory variable

with a proposed interaction:

$x_1$ $x_3$ = interaction between primary objective stressor and secondary stressors: external

$x_1$ $x_4$ = interaction between primary objective stressor and secondary stressors: internal

## 4.6 The data

### 4.6.1 The dependent variable

The dependent variable is caregiver HRQOL. In Understanding Society this is measured using the SF-12 collected as part of the interviewer-led questionnaire. The SF-12 itself cannot be included in cost-utility economic evaluations. However, because the individual responses to the SF-12 questions are available, these can be used to calculate the SF-6D (167) using the questions from the SF-12 about: physical functioning, role participation (combined role-physical and role-emotional), social functioning, bodily pain, mental health, and vitality. The SF-6D provides a means of transforming the SF-12 into a preference-based single index measure, the SF-6D on a scale of 0 to 1 so that it can be used to obtain a quality adjusted life year for use in cost utility analysis.

### 4.6.2 The key explanatory variables

There are two key explanatory variables: (1) patient SF-6D and (2) time spent caregiving.

Patient SF-6D is derived from the patient SF-12 data collected in Understanding Society and is calculated using the same methods and on the same scale as caregiver SF-6D.

Time spent caregiving is obtained from the question about how much time the caregiver spends providing care. Because of the inclusion of the ‘varies’ categories the time spent caring variable does not have a strict categorical order; further, the categories for time spent caregiving are uneven with an uneven distribution of observations. In the base model time spent caring is specified as more or less than 35 hours of care a week. The specification of the variable as more or less than 35 hours a week is roughly equivalent to a full-time job and is used to define the threshold for receipt of the carer’s allowance.

### 4.6.3 Moderators of the key explanatory variables

The moderators of the key explanatory variables are the secondary stressors, that is the external conflicts and the internal conflicts not directly associated with caregiving that may arise from caregiving. The presence of external conflict in the analysis is defined as the presence of concerns with finances, leisure and/or unhappiness with partner.

In Understanding Society financial dissatisfaction is measured in 3 ways, as part of the interviewer-led questionnaire where participants are asked firstly, if they are living comfortably, just getting by or finding it hard to get by and secondly, how they expect this to change in the future, get easier, get harder or remain about the same. The third finance question is asked in the self-completion questionnaire where people are asked to judge satisfaction with their income on a seven-point Likert scale. The other types of external conflict are also measured as part of the self-completion questionnaire, again using a seven-point Likert scale to express happiness with their partner and satisfaction with leisure. Within the caregiving sample used in the analysis few caregivers express extreme negative views and the variables are specified as binary variables:

- Presence of financial concerns = caregiver currently finding it quite or very difficult to get by or believing that they will be worse off in the future, or are currently somewhat, mostly or completely dissatisfied with their income.
- Presence of leisure concerns = caregiver being somewhat, mostly or completely dissatisfied with their leisure.
- Presence of relationship unhappiness = if the caregiver has a partner being extremely, fairly or a little unhappy in their relationship.

Internal conflicts are defined as the absence of optimism for the future, whether the caregiver is feeling useful and/or whether the caregiver is feeling relaxed. The measures are taken from the Warwick Edinburgh Mental Wellbeing Scale (WEMWS) included in the self-completion questionnaire. Each question in the WEMWS is measured on a five-point Likert scale spanning none of the time to all of the time. As with the external conflict measures, few caregivers express extreme negative emotions and the variables are expressed as binary outcomes.

- Not feeling relaxed – feeling relaxed rarely or none of the time
- Not feeling optimistic about the future - feeling optimistic rarely or none of the time
- Not feeling useful - feeling useful rarely or none of the time

The base model includes the external and internal conflicts measures as two composite variables (presence of external conflicts and presence of internal conflicts), each defined as the presence or absence of dissatisfaction in one or more of the conflict areas.

Based on the literature, two other variables are included as possible external conflicts; presence of employment and presence of dependent children. The presence of children and presence of employment have been shown in some circumstances to be associated with a positive effect on caregivers e.g. through multiple roles or providing time spent away from caregiving, and a negative effect in others e.g. through reducing time available for caregiving or creating conflicts with caregiving tasks. Therefore these variables are considered separately in the model from the conflicts associated with ‘dissatisfaction’.

In Understanding Society both presence of employment and presence of dependent children are collected as part of the interviewer-led questionnaire. In the sample in the analysis very few of the caregivers have dependent children; the variable is tested both as a continuous variable including the number of dependent children, and as a binary variable, presence or absence of dependent children. The employment variable is dominated by caregivers who are either in employment or who are retired with few observations in other categories. Therefore employment is specified as a binary variable, working or not working, where working includes: in paid employment, self-employment, and students and people in government training schemes.

### 4.6.4 The control variables

Control variables are in 3 groups (1) caregiving context, (2) resources (3) other health and wellbeing measures.

The first group of variables is defined as caregiving context variables. These are patient and caregiver age, gender, race, education level and household characteristics: income and location (specified as rural or urban). Patient and caregiver age and household income are specified as continuous variables. Patient and caregiver gender, race and household location are specified as binary variables (male/female; white/other; urban/rural respectively). Patient and caregiver education is specified as a categorical variable with 6 levels from no educational qualification to degree level qualification. Variables used in the analysis are included in the form they occur in Understanding Society, with the exception of race where small numbers in non-white categories means the variable is specified as a binary white/other. All variables are collected as part of the interviewer-led questionnaire with the exception of household location which is derived by Understanding Society using the office for National Statistics Rural and Urban Classification of Output Areas and a definition of urban of the address falling within an urban settlement with a population of 10,000 or more. The definition of rural is those not classified as urban.

The second group of variables are resource variables. These are patient and caregiver spirituality measured by the extent to which religion makes a differences to their life, and a series of individual questions from the WEMWS about the extent to which the patient and the caregiver feel they are thinking clearly, dealing with their problems well, feeling close to others and able to make up their own mind. The question about religion is asked as part of the interviewer-led questionnaire and is categorical with participants indicating that religion makes no difference, a little, some or a great difference. The WEMWS is collected as part of the self-completion questionnaire. As with the internal conflict questions, each are measured on a five-point Likert scale spanning none of the time to all of the time. As with the conflicts variables there are small numbers of observations in the extreme negative ends of the scales, and these variables are specified as binary outcomes:

- Not dealing with problems well – dealing with problems well rarely or none of the time
- Not thinking clearly – thinking clearly rarely or none of the time
- Not close to others – feeling close to others rarely or none of the time
- Not able to make up own mind – able to make up own mind rarely or none of the time.

The third set of variables is other patient and caregiver health and wellbeing variables. These are duration of patient arthritis, patient General Health Questionnaire (GHQ) score and life satisfaction and caregiver GHQ score and life satisfaction. Duration of patient arthritis is a continuous variable, and calculated based on responses to the questions in the interviewer-led questionnaire about the age of the participant and age at diagnosis. Patient and caregiver GHQ is measured on an interval scale from 0-35. The GHQ (168) is a self-completed survey that can be used in the general population to screen for minor psychiatric disorders. It focusses on two areas, the ability to carry out normal functions, and the presence of new and distressing phenomena. Understanding Society uses the short-form GHQ consisting of 12 questions which provides a single overall score where high scores indicate increased mental distress. Life satisfaction is a categorical variable with 7 levels from completely dissatisfied to completely satisfied. Both the GHQ and life satisfaction measures are collected in the self-completion questionnaire. Descriptive analyses identified that a proportion of caregivers were caring for a patient with a better wellbeing score than they had. On this basis GHQ is explored in the analyses as the patient GHQ, the caregiver GHQ and the difference in GHQ scores between the patient and the caregiver.

Appendix 5 includes a summary of the variable questions, response categories, missing data and specification in the secondary dataset analysis.

## 4.7 Missing data

Missing data was assessed for each variable included in the analysis. Assessment of the data showed that the majority of missing data was from the self-completion questionnaires. For these data, statistical tests of association were used to assess potential reasons for missingness (that is missing completely at random, missing at random and missing not at random). The main analysis was conducted with only those cases with complete results. The assessment of missing data is presented in chapter 5

## 4.8 Descriptive analysis

For each of the variables means (standard deviations) and proportions were calculated as appropriate. Correlations, the chi-squared test, t-test, and ANOVA were used to compare the proportions and means. Correlations were used where there were two continuous outcomes, t-test where there was one continuous outcome and one binary outcome, ANOVA where there was one continuous outcome and a categorical outcome with more than two categories, and chi-squared test where there were two categorical outcomes. The results of the univariate and bivariate analyses are presented in chapter 5

## 4.9 Methods of regression analysis

### 4.9.1 Approach to regression analysis

The regression model was built in stages. In the first step the key explanatory variables (patient SF-6D and time spent caring) were regressed on the dependent variable (caregiver SF-6D). The possible effect-modifying variables (external conflicts, internal conflicts) as well as job status and presence of dependent children were then added.

Having built the model with the key explanatory variables and the effect modifiers, the control variables (sociodemographic variables, resources and other health and wellbeing factors) were added. Firstly the effect of the control variables on the key explanatory variables and the effect modifiers was explored. To do this, the variables were entered into the model in groups before building the final model. Sociodemographic variables were explored in three groups: (1) caregiver sociodemographic characteristics (2) patient sociodemographic characteristics and (3) household characteristics. Resource variables were explored in four groups: (1) caregiver religion (2) caregiver internal resources (3) patient religion and (4) patient internal resources. Other health and wellbeing measures were then explored in three groups: (1) patient health and wellbeing (2) caregiver health and wellbeing and (3) patient and caregiver wellbeing difference.

Having completed this further exploration, the model with the control variables was built. When deciding to include a control variable the following statistical outputs were taken into account:

- Statistical significance of the coefficient
- Effect of the variable on the Akaike information criterion (AIC) and Bayesian information criterion (BIC)
- Effect of the variable on the model specification statistics

Model specification error can occur when relevant variables are omitted or irrelevant variables are included. Model specification was tested using the Ramsey Regression Equation Specification Error Test (RESET) test (169) and the Linktest. The Linktest tests model specification by assessing whether there are additional statistically significant independent variables that could be fitted. The test creates two new variables (1) the variable of prediction and (2) the variable of squared prediction. The model is then refit using the two variables as predictors. The squared prediction variable should not be statistically significant if the model is correctly specified. The RESET test is similar to the Linktest and is a general test of model specification that identifies whether there may be nonlinearities that have been missed. Squared and cubed variables of the fitted values are calculated and the model refitted and tested against the hypothesis that the model has been correctly specified.

AIC (170) and BIC (171) are measures to support model selection. AIC and BIC estimate the quality of a model relative to other models, taking into account the goodness of the fit of the model and the complexity of the model. AIC and BIC aim to mitigate the risk of over fitting a model by penalising the addition of parameters and therefore supporting the choice of a model that fits well for the smallest set of parameters. For BIC the penalty for the addition of parameters is greater than for AIC. Smaller values of AIC and BIC are preferred over larger values. The AIC and BIC was calculated following each analysis to identify whether the values reduced from the previous version of the model.

Statistically significant ($p<0.05$) results for the model specification tests meant that the model was rejected, increases in both AIC and BIC also meant that the model was rejected. Models in which the AIC increased but the BIC reduced were not immediately rejected but were explored further to identify the combination of variables leading to the changes in AIC and BIC. Coefficients that were not statistically significant were examined to identify their effect on AIC and BIC. Where coefficients were not statistically significant but they reduced the AIC and BIC, these were retained in the model.

In addition to the statistical outputs, model results were assessed qualitatively against the expected relationship from the literature, consistency of the coefficients in different versions of the model and changes in other diagnostic tests.

### 4.9.2 Ordinary Least Squares regression

The SF-6D is on a scale of 0 - 1. Although the dependent variable in ordinary least squares regression should classically be continuous, in some situations data which are discrete can be treated as continuous for analysis purposes. Ordinary least squares regression is often used for data such as that obtained from the SF-6D and provides a starting point for the analyses of caregiver HRQOL to consider the goodness of the models before considering more complex types of regression.

Ordinary least squares (OLS) regression determines the best-fitting straight line as the line with the smallest sum of the squares. Each observation has a point in X and Y and a corresponding point on the fitted line. Ordinary least squares regression fits the line where the sum of the differences between the observed and fitted points is smallest.

For OLS the general model would be:

$Y = \beta_0 + \beta_1 X_1 + \beta_2 X_2 + \ldots .\, \beta_k X_k + E$

Where Y is the dependent variable, $\beta_0$ is the intercept (that is the value of Y when X =0), X is the explanatory variable(s), $\beta_1$ is the coefficient (that is, the amount of change in Y for each 1 unit change in X) and E is the residual (error component).

### 4.9.3 Interactions

Based on caregiving theory an interaction is proposed between patient HRQOL and time spent caregiving, and secondary stressors, that is, the presence in the caregiver's life of external conflicts and the internal conflicts. In the presence of internal and external conflicts the association between patient HRQOL, time spent caregiving and caregiver HRQOL is hypothesised to be different to a situation where internal and external conflicts are absent. Having built the basic model with the key explanatory variables, effect modifiers and control variables, sensitivity analyses are undertaken to explore different interactions to see whether these improve the fit of the model.

The model for ordinary least squares regression with an interaction is represented as:

$Y = B_0 + B_1 X_1 + B_2 X_2 + B_3 X_1 X_2 \ldots .\, B_k X_k + E$

The interactions considered are:

- Patient SF-6D × presence of external conflicts
- Patient SF-6D × presence of internal conflicts
- Time spent caring × presence of external conflicts
- Time spent caring × presence of internal conflicts.

### 4.9.4 Effect of the household

Within the dataset used in the analysis each caregiver provides care for one patient, but within a single household a patient may have more than one caregiver. The data are therefore clustered and some covariates vary at the level of the caregiver e.g. caregiver age, physical functioning, and time spent caring, while others vary at the level of the household e.g. income, patient health status, patient age etc.

Clustering within ordinary least squares regression is specified as

$Y = \beta_0 + \beta_{ij} X_{ij} + \beta_j X_j + \ldots .\, B_k X_k + b_j + e_{ij}$

where $\beta_0$ is the regression intercept; $x_{ij}$ represents the covariates that vary between caregivers; $x_j$ represents those covariates that vary only between households; b is the 'effect' of household j; and $e_{ij}$ is a caregiver-level residual.

The clustered nature of the data is explored in a sensitivity analysis that accounts for the effect of the household.

### 4.9.5 Alternative specification of time spent caring

An alternative specification for the variable time spent caregiving is considered in a sensitivity analysis to assess consistency of the effects. In the base model time spent caring is specified as more and less than 35 hours of care a week. In a sensitivity analysis an alternative specification of more and less than 20 hours a week is used. The analysis using 20 hours as the cut point allows for the inclusion of a greater number of observations because it can include all caregivers indicating that time spent caring varies. The differences in the observation counts between the two analyses are shown in Table 11.

**Table 11: categorisation of observations using different cut points of time spent caring**

| | <35 hours | =>35 hours | Missing | Total |
|---|---|---|---|---|
| <20 hours | 331 | 0 | 0 | 331 |
| =>20 hours | 57 | 196 | 105 | 358 |
| Missing | 0 | 0 | 6 | 6 |
| Total | 388 | 196 | 111 | |

### 4.9.6 Consistency across different caregiver groups

The Understanding Society dataset includes a heterogeneous group of caregivers. The consistency of the relationship between patient SF-6D, time spent caring and caregiver SF-6D is explored in sensitivity analyses for different groups of caregivers:

- Including only caregivers caring for their partners
- Excluding caregivers who share care with other people in the household
- Excluding caregivers who receive care from someone in the household
- Excluding caregivers caring for someone with a mental as well as a physical disability (e.g. the patient reports having a diagnosis of clinical depression as well as arthritis).

## 4.10 Regression diagnostics

As well as testing model specification a range of other regression diagnostics were used to assess the appropriateness of the model.

Observations that have extreme values for explanatory variables are points with high leverage. These can affect the outputs of the regression analysis. The overall impact of unusual and influential data was assessed by examining patterns of residuals to identify possible outliers as well as leverage plots (including stem and leaf plots of leverage and leverage versus residual squared plots). The specific impact of an observation on the regression coefficients was examined using DFBeta plots (that is, a plot that assesses how each coefficient is changed by deleting the observation) of the key explanatory variables and effect modifiers to identify whether any single or small groups of variables could be affecting the results. Sensitivity analyses were run removing possible outliers.

Normality of residuals was assessed by a series of plots including histograms and boxplots as well as kernel density plots, standardized normal probability plots and plots of the quantiles of a variable against the quantiles of a normal distribution.

The homogeneity of the variance of the residuals was assessed by plotting the residuals against the fitted values. Heteroskedasticity was tested using Cameron & Trivedi's decomposition of IM-test and the Breusch-Pagan / Cook-Weisberg test for heteroskedasticity.

Collinearity and multicollinearity between the explanatory variables was tested using the variance inflation factor (VIF) and tolerance (1/VIF). No specific cut-off value for acceptable VIF was applied, in all analyses VIF was less than 5 except for the interaction terms. All statistical analyses were undertaken using Stata version 11.

## 4.11 Specification of the full model

The full model is specified as:

Caregiver SF-6D = $\beta_0$ + $\beta_1$patient SF-6D + $\beta_2$ caregiver time spent caring + [$\beta_3$ caregiver age + $\beta_4$ caregiver gender + $\beta_5$ caregiver education + $\beta_6$ caregiver race] + [$\beta_7$ patient age + $\beta_8$ patient gender + $\beta_9$ patient education + $\beta_{10}$ patient race] +[$\beta_{11}$ household income + $\beta_{12}$ household location] + [$\beta_{13}$ caregiver dependent children + $\beta_{14}$caregiver employment] + [ $\beta_{15}$ caregiver external conflict] + [ $\beta_{16}$ caregiver internal conflict] + [$\beta_{17}$ caregiver spirituality + $\beta_{18}$ caregiver thinking clearly + $\beta_{19}$ caregiver dealing with problems + $\beta_{20}$ caregiver close to others + $\beta_{21}$ caregiver making up mind] + [$\beta_{22}$ patient spirituality + $\beta_{23}$ patient thinking clearly

$+ \beta_{24}$ patient dealing with problems $+ \beta_{25}$ patient close to others $+ \beta_{26}$ patient making up mind] + [$\beta_{27}$ patient duration of arthritis $+ \beta_{28}$ patient life satisfaction $+ \beta_{29}$ patient GHQ $+ \beta_{30}$ caregiver life satisfaction $+ \beta_{31}$ caregiver GHQ] $+ \beta_1 \beta_{15} + \beta_1 \beta_{16} + \beta_2 \beta_{15} + \beta_2 \beta_{16} + u$

It is hypothesised that the relationship between patient and caregiver SF-6D will be positive (i.e. as patient SF-6D increases, caregiver SF-6D also increases), the relationship between time spent caregiving and caregiver SF-6D will be negative (i.e. greater time spent providing care is associated with worse caregiver SF-6D). The relationship between caregiver SF-6D and the presence of internal conflicts and external conflicts will both be negative (i.e. the presence of conflicts will be associated with worse caregiver SF-6D). Further, in the presence of conflicts the relationship between patient SF-6D and caregiver SF-6D and time spent caregiving and caregiver SF-6D will be different. The presence of conflicts reduces the benefits to the caregiver of improved patient health status or in another way increases the negative outcomes to the caregiver associated with worsening patient health status.

## 4.12 Summary

The aim of the secondary dataset analysis is to identify the association between the HRQOL of a patient with arthritis and the HRQOL of their caregiver. The use of HRQOL measures such as the SF-6D can be criticised. For example, the SF-6D has recognised issues with capturing changes in some health states (172,173) and other measures such as caregiver-specific measures (66,157) may be more sensitive in picking up changes in caregiver quality of life. However, its use in this study is justified by the focus on NICE decision-making in England where there is a preference for the EQ-5D or in the absence of EQ-5D and alternative preference-based measure that can be used to calculate a QALY.

There are a number of potentially relevant UK datasets. However, only the Understanding Society dataset was identified as offering a measure of HRQOL, a measure of the presence of arthritis, a measure of the time spent caregiving and the ability to make the link between the patient and their caregiver. The Understanding Society dataset provides an opportunity to study caregiving within the household and the large sample size means that subgroup analyses are possible. A variety of measures collected in Understanding Society are relevant to an analysis of caregiving, but the general nature of it means that caregiver subjective measures about caregiving are not available and within Wave 1 information about external resources such as social support and health and social care utilisation are also not collected.

The key dependent variable for the analysis is caregiver SF-6D; the key explanatory variables are patient SF-6D and time spent caregiving. The analysis controls for patient and caregiver sociodemographic characteristics, household characteristics, resources and other patient and caregiver health and wellbeing variables. The model includes a series of possible moderators of caregiver SF-6D including external conflicts such as financial dissatisfaction, leisure dissatisfaction, dissatisfaction with partner, job status and presence of dependent children. It also includes internal conflicts, such as optimism for the future and extent to which the caregiver feels useful. The model specifies the interaction to be considered between patient SF-6D, time spent caregiving and caregiver SF-6D and accounts for the clustering effect within the household.

# 5 Descriptive and bivariate analyses of the arthritis sample

## 5.1 Introduction

This chapter presents the descriptive characteristics of the arthritis sample and bivariate analyses of the variables. Firstly, this chapter describes the arthritis sample to be used in the regression analyses. Secondly, this chapter presents the bivariate analyses of the variables described in chapter 4 which consider the relationship between the variables without controlling for other variables. The methods used reflect the mostly categorical or binary nature of the variables and include correlation, chi square, t tests and ANOVA. The bivariate analyses inform model development in chapter 6.

## 5.2 Description of the arthritis dataset

There are 50,994 people in 30,169 households in the wave 1 Understanding Society dataset. The first stage of obtaining the sample for analysis was to remove people living in households where no one had arthritis, this left approximately 10,000 people living in a household with someone with arthritis. Households of single people and households with no caregivers were removed from the dataset, leaving approximately 2,000 people living in a household where there was both a caregiver and a person with arthritis. The following were then removed from the dataset.

- Proxy respondents for whom there was insufficient data to classify as either a patient or as a caregiver (N=140)
- Caregivers providing care to more than 1 person (either within the household or both within and outside of the household), because the outcomes as measured in Understanding Society would confound the relationship between patient and caregiver (N=200)

Following removal of caregivers providing care to more than 1 person, the data were checked to ensure that this hadn’t created any households without a patient, a caregiver or had created a household of 1. This resulted in another 30 people being removed from the dataset. The caregivers were then matched to the person they were caring for, to identify households where there was a person providing care to someone with arthritis. People in households where there was no caregiver providing care to someone with arthritis, were removed (approximately 300 household members). Having identified the households where there was a caregiver of a person with arthritis, other people living in these households who were neither a patient nor a caregiver were removed (approximately 90 household members). This process left a sample of 695 caregivers providing care to 645 patients. One hundred caregivers were also patients receiving care within the household meaning that not all observations are unique. In total there were 1240 unique individuals.

## 5.3 Dependent variable: caregiver health-related quality of life

The mean PCS score and MCS score for the caregivers is 43.81 and 49.71, respectively. The mean SF-6D value is 0.73 (table 12).

**Table 12: Summary of caregiver SF-12 and SF-6D score**

| | Caregiver |
|---|---|
| Physical health status (PCS)<br>(Mean (SD) Range)<br>*4 missing values* | N=691<br>43.81 (SD 13.70)<br>Range 6.27-70.41 |
| Mental health status (MCS)<br>(Mean (SD) Range)<br>*4 missing values* | N=691<br>49.71 (SD 11.18)<br>Range 10.26-71.70 |
| SF-6D<br>(Mean (SD) Range)<br>*3 missing values* | N=692<br>0.73 (SD 0.16)<br>Range 0.35 – 1.00 |

The histogram of caregiver MCS, PCS and SF-6D values (figures 19 and 20) show the data are skewed with the distribution having a tail towards the lower end of the scale.

**Figure 19: Histogram of caregiver MCS and PCS scores**

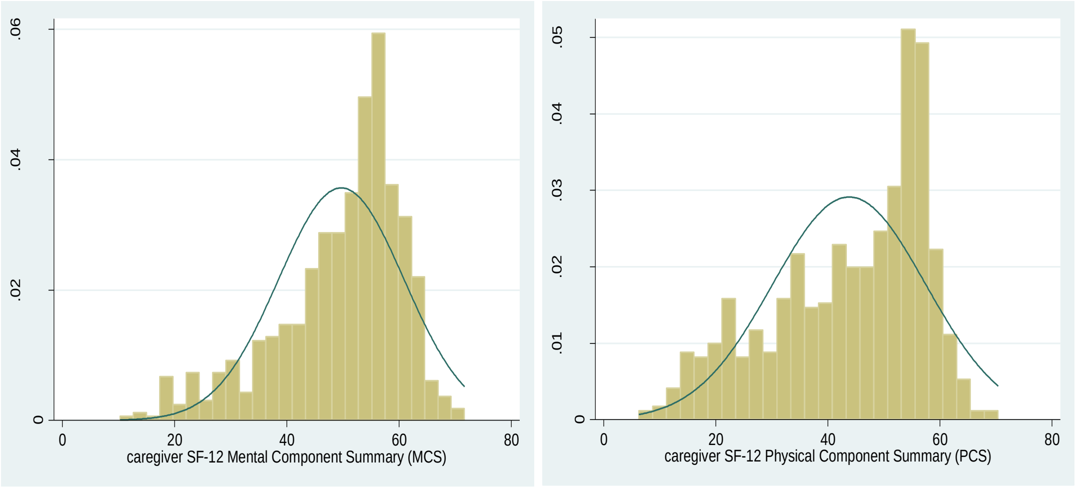
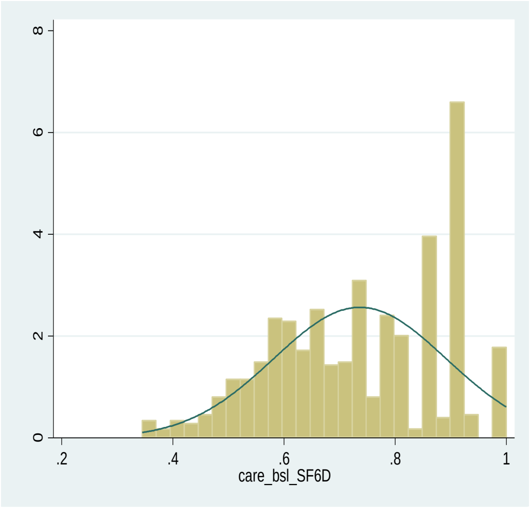


**Figure 20: Histogram of caregiver SF-6D values**



## 5.4 Description of key explanatory variables

### 5.4.1 Caregiver time spent caring

Just under 30% of the sample are providing care for more than 35 hours a week, the equivalent of a full-time job. One hundred and thirty-four of the caregivers report that the time spent caring 'varies' either more or less than 20 hours a week. Caregivers reporting that their time spent providing care varied were more likely to be female and the patients receiving care more likely to be male. The difference in caregiver gender approaches statistical significance (p=0.054). The differences between a caregiver reporting that the time spent caring varies and other caregiver variables are not statistically significant (table 13).

**Table 13: Summary of hours of care provided per week**

| | Caregiver (N=695) |
|---|---|
| Hours of care provided per week | N (%) |
| 0-4 | 101 (14.5%) |
| 5-9 | 103 (14.8%) |
| 10-19 | 98 (14.1%) |
| 20-34 | 57 (8.2%) |
| 35-49 | 40 (5.8%) |
| 50-99 | 32 (4.6%) |
| Over 100 | 124 (17.8%) |
| Varies under 20 | 29 (4.2%) |
| Varies more than 20 | 105 (15.1%) |
| Other | 3 (0.4%) |
| Don't know / refused | 3 (0.4%) |
| *6 values 'other, don't know and refused' counted as missing* | |

### 5.4.2 Patient health status

The mean PCS score and MCS score for the patients is 23.1 and 44.79 respectively. The mean SF-6D value is 0.54 (table 14).

**Table 14: Summary of patient SF-12 and SF-6D score**

| | Patient |
|---|---|
| Physical health status (PCS)<br>(Mean (SD) Range)<br>*5 missing values* | N=640<br>23.1 (SD 8.89)<br>Range 4.56-55.93 |
| Mental health status (MCS)<br>(Mean (SD) Range)<br>*5 missing values* | N=640<br>44.79 (SD 13.55)<br>Range 12.64-74.74 |
| SF-6D value<br>(Mean (SD) Range)<br>*2 missing values* | N=643<br>0.54 (SD 0.11)<br>Range 0.35-1.00 |

The distribution of PCS scores has a bulk of people in the lower scores, as might be expected from a population of people with arthritis, with a smaller proportion of people with higher scores. The MCS scores show a less skewed distribution. The SF-6D values show a pattern similar to that observed in the PCS scores (figures 21 and 22).

**Figure 21: Histogram of patient PCS and MCS score**

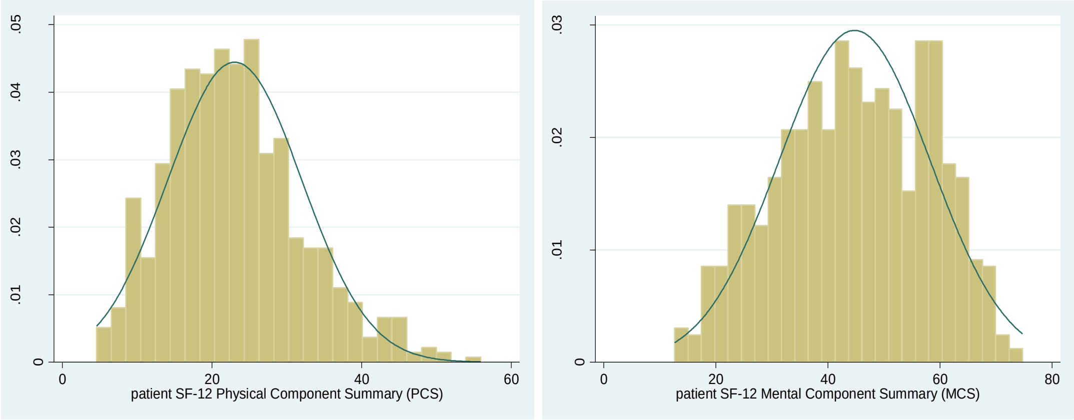
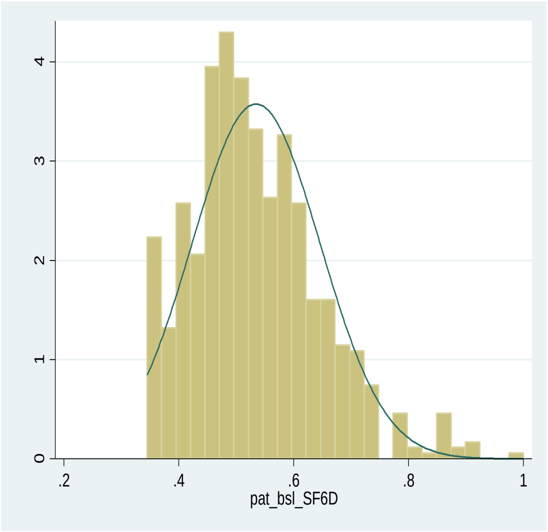


**Figure 22: Histogram of patient SF-6D values**



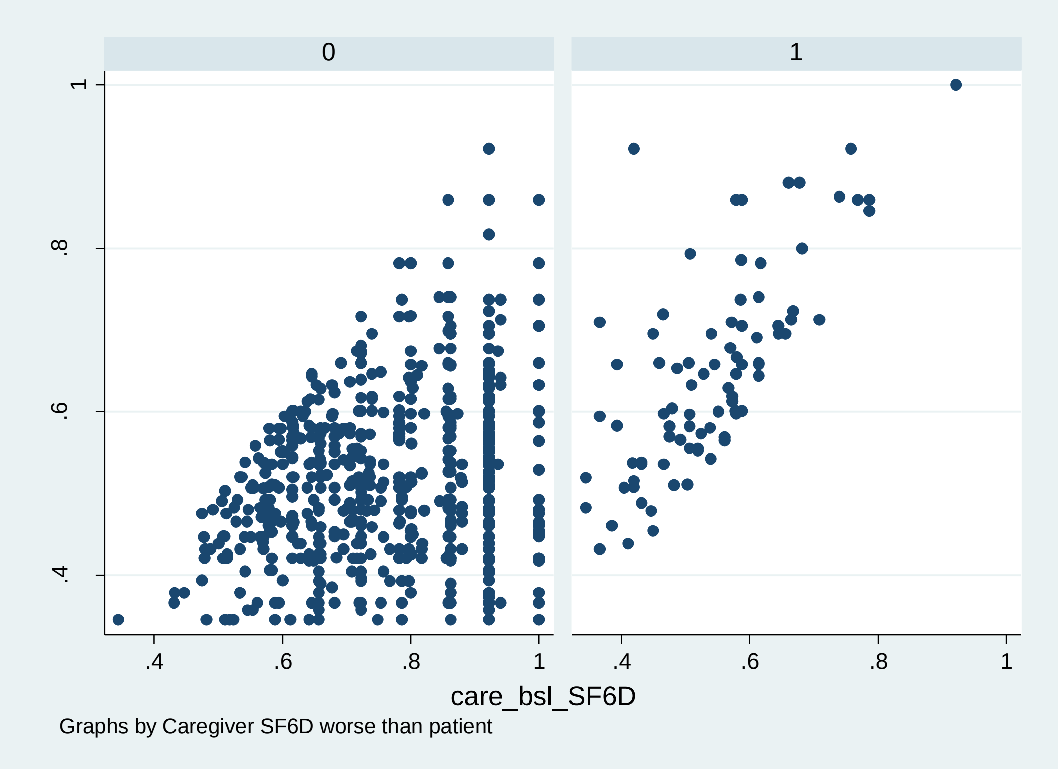
The majority of patients have worse SF-6D values than their caregiver (table 15), as would be expected. However, 86 (12% of those for whom there are data) patients are receiving care from someone with a worse SF-6D value than they have. The scatterplot (figure 23) shows that for the majority of caregivers their SF-6D value is either similar or better than that of the person they care for, but a small number have much worse SF-6D values than the person they care for. Of the caregivers with worse SF-6D values, 7 share care and 28 are in reciprocal care relationships. In terms of time spent caregiving, 39 provide care for less than 20 hours a week and 16 provide care for more than 100 hours a week. Fifty-nine patients have MCS scores that are better than the MCS score of their caregiver and 36 have PCS scores better than the caregiver.

**Table 15: Summary of patient and caregiver SF-6D difference**

| | |
|---|---|
| SF-6D difference<br>(Mean (SD) Range)<br>*4 missing values* | N=691<br>0.20 (SD 0.19)<br>Range -50 to 65 |

Note: A negative value in the range represents a caregiver with a worse SF-6D value than the person they care for and a positive value in the range a caregiver with a better SF-6D value than the person they care for.

**Figure 23: Scatterplot of differences in patient and caregiver SF-6D values**



Key: graph on the left shows values for caregivers with better SF-6D value than the person they care for; the graph on the right shows values for caregivers with a worse SF-6D value than the person they care for.

## 5.5 Description of conflicts

### 5.5.1 External conflicts

***Employment status (caregiver variable)***

A total of 202 caregivers have an external work commitment (for example are in self-employment, paid employment, or a government training scheme or are a full time student; table 16). Of these 202 caregivers, 29 report that caregiving limits the amount of work that they can do.

**Table 16: Summary of caregiver employment status**

| | Caregiver (N=695) |
|---|---|
| Employment status | N (%) |
| • Self-employed | 17 (2.5%) |
| • Paid employment | 156 (22.5%) |
| • Unemployed | 59 (8.5%) |
| • Retired | 315 (45.3%) |
| • Maternity leave | 2 (0.3%) |
| • Looking after family or home | 65 (9.4%) |

| | |
|---|---|
| - Full time student | 26 (3.7%) |
| - Long term sick/disabled | 37 (5.3%) |
| - Government training scheme | 3 (0.4%) |
| - Other | 15 (2.2%) |
| *15 values 'other' counted as missing* | |

***Dependent children (caregiver variable)***

Only 55 caregivers (8%) are recorded as having dependent children under 18. For these caregivers the number of dependent children ranges from 1 (in 29 cases) to 5 (in one case).

**Table 17: Summary of caregivers with dependent children**

| | Caregiver |
|---|---|
| Number of children under 18 responsible for<br>(Mean (SD) Range)<br>*0 missing values* | 0.13 (SD 0.52)<br>Range 0-5 |

***Perceived financial situation (caregiver variable)***

A total 329 (47%) caregivers are coded as having at least some financial concerns (coded as one or more of finding it difficult to get by, dissatisfaction with income or likely to be worse off in the future than they are now).

**Table 18: Summary of caregiver financial status**

| | Caregiver N (%) |
|---|---|
| Subjective current financial situation | (N=695) |
| - Living comfortably | 132 (19.0%) |
| - Doing alright | 187 (26.9%) |
| - Just about getting by | 268 (38.6%) |
| - Finding it quite difficult | 76 (10.9%) |
| - Finding it very difficult | 32 (4.6%) |
| *0 missing values* | |
| Subjective financial status future | (N=674) |
| - better off | 108 (16.0%) |
| - worse off than you are now | 142 (21.1%) |
| - or about the same? | 424 (62.9%) |
| *21 missing values* | |
| Satisfaction with income | (N=583) |
| - completely dissatisfied | 47 (8.1%) |
| - mostly dissatisfied | 52 (8.9%) |
| - somewhat dissatisfied | 99 (17.0%) |
| - neither satisfied or dissatisfied | 89 (15.3%) |
| - somewhat satisfied | 116 (19.9%) |
| - mostly satisfied | 141 (24.2%) |
| - completely satisfied | 39 (6.7%) |
| *112 missing values* | |

***Satisfaction with leisure (caregiver variable)***

A third of the caregivers indicated some dissatisfaction with their amount of leisure time (table 19).

**Table 19: Summary of caregiver leisure status**

| | Caregiver (N=581) |
|---|---|
| Satisfaction with leisure (Likert seven categories) | N(%) |
| • Completely dissatisfied | 22 (3.8%) |
| • Mostly dissatisfied | 44 (7.6%) |
| • Somewhat dissatisfied | 63 (10.8%) |
| • Neither satisfied not dissatisfied | 96 (16.5%) |
| • Somewhat satisfied | 112 (19.3%) |
| • Mostly satisfied | 147 (25.3%) |
| • Completely satisfied | 97 (16.7%) |
| *114 missing values* | |

***Relationship with partner (caregiver variable)***

Forty-two caregivers record some difficulties with the relationship with their partner, coded as reporting being extremely unhappy, fairly unhappy or a little unhappy with their relationship. In 39 of these cases the partner is the person being cared for by the caregiver (table 20).

**Table 20: Summary of caregiver relationship satisfaction**

| | Caregiver (N=604) |
|---|---|
| Satisfaction with relationship (partner) | N(%) |
| • Extremely unhappy | 10 (1.7%) |
| • Fairly unhappy | 13 (2.2%) |
| • A little unhappy | 19 (3.2%) |
| • Happy | 163 (27.0%) |
| • Very happy | 119 (19.7%) |
| • Extremely happy | 92 (15.2%) |
| • Perfect | 43 (7.1%) |
| • Inapplicable (no partner) | 145 (24.0%) |
| *91 missing values* | |

In total 383 caregivers (out of 620 with data; 62%) report a conflict with one or more of their relationship, leisure or finances. The number of conflicts present can be calculated for 563 caregivers (that is those with data for all 3 conflicts): 218 (39%) people report a single conflict, 101 (18%) report conflicts in two areas and 7 (1%) report conflicts in all three areas.

Of the 383 caregivers with an external conflict, 329 have financial concerns (86%), 129 have dissatisfaction with leisure (34%) and 42 of them express unhappiness with their partner (11%).

**Table 21: Summary of the presence of caregiver external conflicts**

| | Caregiver N (%) |
|---|---|
| Presence of external conflict (N=620) | |
| Yes | 383 (61.8%) |
| No | 237 (38.2%) |
| *75 missing values* | |
| Number of external conflict (N=563) | |
| 0 | 237 (42.1%) |
| 1 | 218 (38.7%) |
| 2 | 101 (17.9%) |
| 3 | 7 (1.2%) |
| *132 missing values* | |

### 5.5.2 Internal conflicts

Only a minority of caregivers rarely or never feel relaxed (approximately 15%) or useful (approximately 13%). A slightly larger minority rarely or never feel optimistic for the future (approximately 23%) (table 22).

**Table 22: Summary of caregiver optimism, relaxation and usefulness**

| | Caregiver N (%) |
|---|---|
| Feeling useful (N=583) | |
| • None of the time | 25 (4.3%) |
| • Rarely | 51 (8.8%) |
| • Some of the time | 237 (40.7%) |
| • Often | 202 (34.7%) |
| • All of the time | 68 (11.7%) |
| *112 missing values* | |
| Feeling relaxed (N=575) | N (%) |
| • None of the time | 22 (3.8%) |
| • Rarely | 74 (12.9%) |
| • Some of the time | 261 (45.4%) |
| • Often | 157 (27.3%) |
| • All of the time | 61 (10.6%) |
| *120 missing values* | |
| Feeling optimistic about the future (N=583) | N (%) |
| • None of the time | 33 (5.7%) |
| • Rarely | 102 (17.5%) |
| • Some of the time | 270 (46.3%) |
| • Often | 129 (22.1%) |
| • All of the time | 49 (8.4%) |
| *112 missing values* | |

In total 204 caregivers (out of 571 with data; 36%) report a conflict with one or more of their feeling useful, felling relaxed and feeling positive for the future. Of the 565 caregivers with data for all 3 conflicts 116 people report a single conflict, 63 report conflicts in two areas and 19 report conflicts in all three areas.

In the dataset there are 204 caregivers recorded as having internal conflicts (table 23): 76 (37%) of them have issues with the extent to which they feel useful, 96 (47%) of them do not feel relaxed and 135 (66%) do not feel optimism for the future. (These categories are not mutually exclusive as caregivers can have dissatisfaction in more than one area).

**Table 23: Summary of the presence of caregiver internal conflicts**

| | Caregiver |
|---|---|
| Presence of internal conflict (N=571) | N (%) |
| Yes | 204 (35.7%) |
| No | 367 (64.3%) |
| *124 missing values* | |
| Number of internal conflict (N=565) | |
| 0 | 367 (65.0%) |
| 1 | 116 (20.5%) |
| 2 | 63 (11.2%) |
| 3 | 19 (3.4%) |
| *130 missing values* | |

There are 560 caregivers for whom data are available for both the presence of internal and external conflicts. Of these, 25% record both internal and external conflicts, 31% record neither conflict, 34% record the presence of external conflicts only and 10% record the presence of internal conflicts only (table 24).

**Table 24: Caregiver presence of external and internal conflict**

| Internal conflicts | External conflicts | | |
|---|---|---|---|
| | present | absent | Total |
| Present | 142 (25.4%) | 55 (9.8%) | 197 |
| Absent | 188 (33.6%) | 175 (31.3%) | 363 |
| Total | 330 | 230 | 560 |

## 5.6 Description of control variables

### 5.6.1 Sociodemographic characteristics

***Age (patient and caregiver variable)***

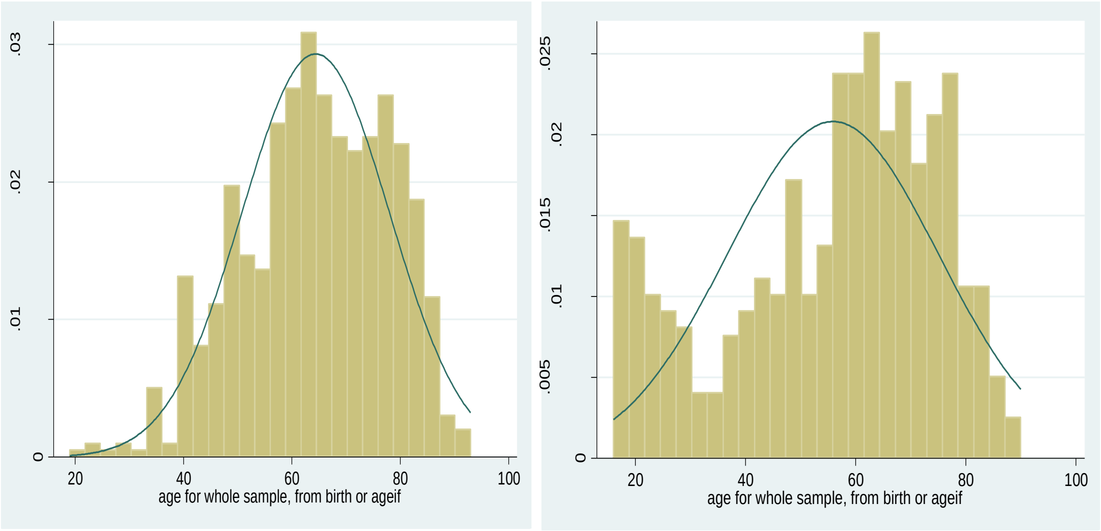
The mean age of the patient sample is 65 years and the mean age of the caregivers is approximately 10 years younger than this. The standard deviation for the caregivers is greater than for the patients but the age range is similar (table 25).

### Table 25: Summary of patient and caregiver age

| | Patient (N=645) | Caregiver (N=695) |
|---|---|---|
| Age (Mean (SD) Range)<br>*0 missing values* | 64.92 (SD 13.37)<br>Range 19-93 | 55.86 (SD 19.17)<br>Range 16-90 |

The distribution for patient age has a skew with a number of younger people receiving care. With the caregiver data the histogram shows that the distribution includes a group of younger caregivers and a group of older caregivers (figure 24).

### Figure 24: Histogram of patient and caregiver age



### *Gender (patient and caregiver variable)*

In terms of gender, more of the patients are female than male which generally corresponds with a greater proportion of females having arthritis. The caregivers in the dataset are approximately half female and half male, with slightly more males than females (table 26).

### Table 26: Summary of patient and caregiver gender

| | Patient (N=645) | Caregiver (N=695) |
|---|---|---|
| Gender (male/female)<br>*0 missing values* | 249 male (38.6%)<br>396 female (61.4%) | 358 male (51.5%)<br>337 female (48.5%) |

### *Race (patient and caregiver variable)*

There are relatively small counts of data and uneven numbers of observations in each category for patient and caregiver race. In the sample approximately 80% of patients and caregivers are coded as being white with UK family origin (table 27).

### Table 27: Summary of patient and caregiver race

| | Patient (N=645) | Caregiver (N=695) |
|---|---|---|
| Race | N (%) | N (%) |
| • White UK | 533 (82.6%) | 567 (81.6%) |

| | | |
|---|---|---|
| • White Irish | 13 (2.0%) | 13 (1.9%) |
| • White other | 10 (1.6%) | 11 (1.6%) |
| • Mixed white and black Caribbean | 0 | 5 (0.7%) |
| • Mixed white and Asian | 2 (0.3%) | 2 (0.3%) |
| • Mixed other | 0 | 1 (0.1%) |
| • Indian | 13 (2.0%) | 16 (2.3%) |
| • Pakistani | 29 (4.5%) | 35 (5.0%) |
| • Bangladeshi | 12 (1.9%) | 18 (2.6%) |
| • Chinese | 1 (0.2%) | 2 (0.3%) |
| • Asian other | 4 (0.6%) | 2 (0.3%) |
| • Caribbean | 12 (1.9%) | 11 (1.6%) |
| • African | 5 (0.8%) | 3 (0.4%) |
| • Black other | 1 (0.2%) | 0 |
| • Arabic | 1 (0.2%) | 2 (0.3%) |
| • Other | 8 (1.2%) | 6 (0.9%) |
| • Refused | 1 (0.2%) | 1 (0.1%) |
| *1 patient value and 1 caregiver value ‘refused’ counted as missing* | | |

***Educational level (patient and caregiver variable)***

The majority of patients in the dataset are recorded as not having any educational qualification. Just under a third of patients have an educational qualification of GCSE level (or equivalent) or higher. For the caregivers 52% have educational qualifications at GCSE level (or equivalent) or higher and 40% have no educational qualification (table 28).

**Table 28: Summary of patient and caregiver highest educational level**

| | Patient (N=645) | Caregiver (N=695) |
|---|---|---|
| Education (based on highest educational qualification) | | |
| | N (%) | N (%) |
| • Degree | 33 (5.1%) | 62 (8.9%) |
| • Other higher | 60 (9.3%) | 61 (8.8%) |
| • A level | 63 (9.8%) | 99 (14.2%) |
| • GCSE | 52 (8.1%) | 137 (19.7%) |
| • Other | 52 (8.1%) | 44 (6.3%) |
| • None | 384 (59.5%) | 291 (41.9%) |
| • Missing | 1 (0.2%) | 1 (0.1%) |
| *1 patient value and 1 caregiver value missing* | | |

### 5.6.2 Household characteristics

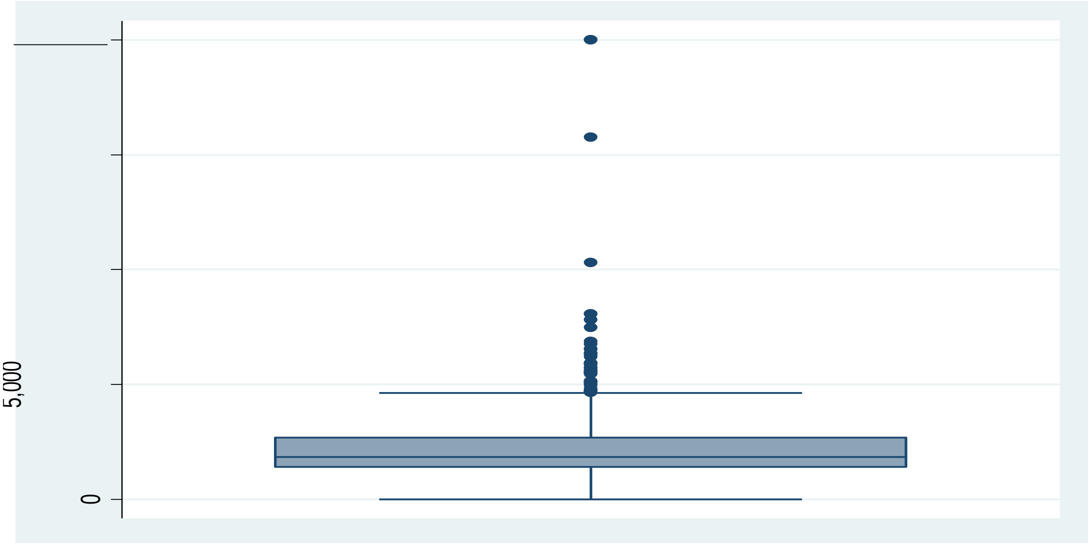
The range of household income reported is £0-20,000 per month with the mean being £2279 (table 29). The household income variable appears to be affected by a small number of outliers reporting very high income in the month before interview (box plot; figure 25)).

**Table 29: Summary of household income**

| | Households (N=645) |
|---|---|
| Gross household income in month before | Mean 2279 (SD 1729) |

| | |
|---|---|
| interview (Mean (SD) Range)<br>*No missing data* | Range 0 -20,000 |

**Figure 25: Box plot of household income in month before interview**



The majority of households in the dataset are recorded as being urban (81%) (Table 30).

**Table 30: Summary of household location**

| | Households (N=645)<br>N (%) |
|---|---|
| Household location (urban/rural)<br>*No missing data* | Urban 521 (80.8%)<br>Rural 124 (19.2%) |

### 5.6.3 Patient and caregiver resources

***Identification with religion (patient and caregiver variable)***

For the majority of both patients and caregivers in the sample religion makes a difference in their life. For approximately half of the patients and the caregivers it makes a great or some difference in their life. For just under a third of patients and just over a third of caregivers religion makes no difference in their life (table 31).

**Table 31: Summary of patient and caregiver Identification with religion**

| | Patient (N=645) | Caregiver (N=695) |
|---|---|---|
| Identification with religion | N (%) | N (%) |
| • Religion make a great difference | 186 (28.8%) | 164 (23.6%) |
| • Religion makes some difference | 146 (22.6%) | 156 (22.5%) |
| • Religion makes a little difference | 113 (17.5%) | 117 (16.8%) |
| • Religion makes no difference | 198 (30.7%) | 256 (36.8%) |
| • Don’t know / refused | 2 (0.3%) | 2 (0.3%) |
| *2 patient values and 2 caregiver values ‘don’t know / refused’ counted as missing* | | |

***Coping and control (patient and caregiver variable)***

As well as using external resources to help cope with challenges, people draw on internal resources. Approximately 16% of patients and 8% of caregivers report dealing with their problems well none of the time or rarely. The corresponding figures for patients thinking clearly, feeling close to others and being able to make up one's own mind are 12%, 9% and 8% respectively. For caregivers the figures are 7%, 7% and 3% (table 32).

**Table 32: Summary of patient and caregiver internal resources**

| | Patient | Caregiver |
|---|---|---|
| | (N=645) | (N=695) |
| Dealing with problems well | | |
| • None of the time | 42 (6.5%) | 13 (1.9%) |
| • Rarely | 64 (9.9%) | 46 (6.6%) |
| • Some of the time | 237 (36.7%) | 232 (33.4%) |
| • Often | 107 (16.6%) | 202 (29.1%) |
| • All of the time | 53 (8.2%) | 92 (13.2%) |
| • missing | 142 (22.0%) | 110 (15.8%) |
| Thinking clearly | | |
| • None of the time | 26 (4.0%) | 9 (1.29%) |
| • Rarely | 50 (7.8%) | 37 (5.32%) |
| • Some of the time | 196 (30.4%) | 158 (22.73%) |
| • Often | 142 (22.0%) | 255 (36.69%) |
| • All of the time | 88 (13.6%) | 124 (17.84%) |
| • missing | 143 (22.2%) | 112 (16.12%) |
| Close to other people | | |
| • None of the time | 13 (2.02%) | 14 (2.01%) |
| • Rarely | 48 (7.44%) | 36 (5.18%) |
| • Some of the time | 189 (29.30%) | 181 (26.04%) |
| • Often | 156 (24.19%) | 234 (33.67%) |
| • All of the time | 98 (15.19%) | 117 (16.83%) |
| • missing | 141 (21.86%) | 113 (16.26%) |
| Able to make up my own mind | | |
| • None of the time | 16 (2.48%) | 6 (0.86%) |
| • Rarely | 38 (5.89%) | 16 (2.30%) |
| • Some of the time | 140 (21.71%) | 115 (16.55%) |
| • Often | 144 (22.33%) | 229 (32.95%) |
| • All of the time | 170 (26.36%) | 224 (32.23%) |
| • missing | 137 (21.24%) | 105 (15.11%) |

### 5.6.4 Other patient and caregiver health and wellbeing measures

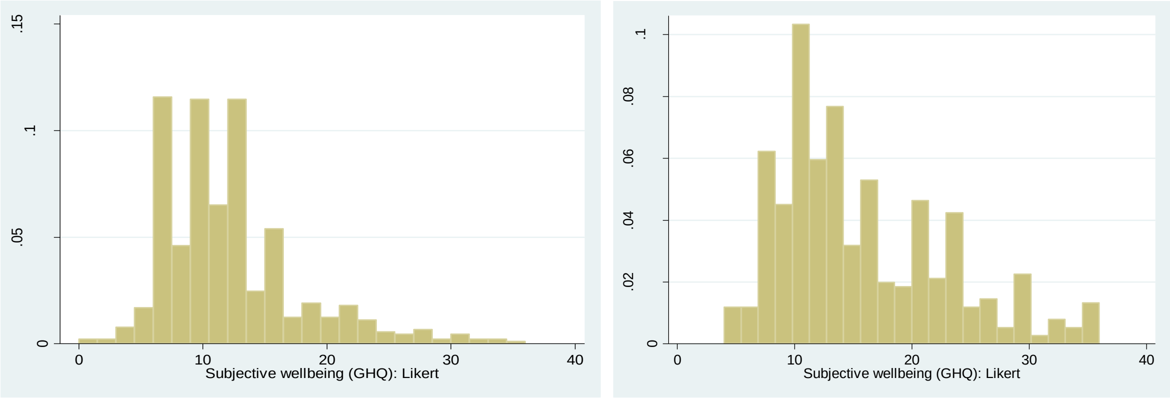
***Wellbeing (patient and caregiver variable)***

The mean GHQ score for caregivers is 11.90. Patients have higher GHQ scores (i.e. patients have worse levels of wellbeing) with a mean score of 15.69 (table 33, figure 26).

**Table 33: Summary of patient and caregiver GHQ scores**

| | Caregiver | Patient |
|---|---|---|
| GHQ (Mean (SD) Range)<br>*102 missing values caregiver*<br>*126 missing values patient* | N=593<br>11.90 (SD 5.61)<br>Range 0-36 | N=519<br>15.69 (SD 7.15)<br>Range 4-36 |

**Figure 26: Histogram and box plot of caregiver and patient GHQ**



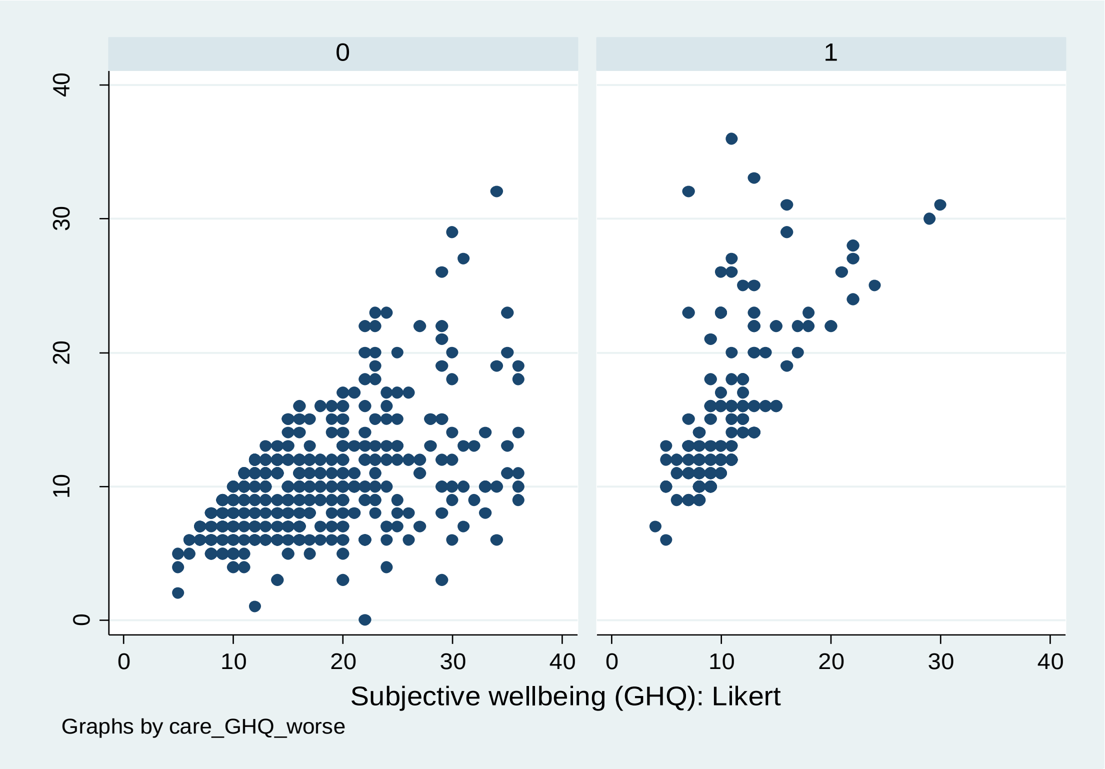
As with caregiver and patient SF-6D, analyses show that there is a group of caregivers caring for people with better wellbeing than they have. The scatter plot shows a similar pattern to SF-6D with a small number of caregivers having GHQ much worse than that of the person that they care for. On average caregivers have wellbeing scores 4 points better than the patient but the range of differences is large with the differences ranging from 28 points better to 24 points worse (table 34, figure 27).

**Table 34: Summary of patient and caregiver GHQ difference**

| | |
|---|---|
| GHQ difference (Mean (SD) Range) | N=530<br>-4.04 (SD 8)<br>Range 24 to -28 |

Note: A negative value in the range represents a caregiver with better wellbeing than the person they care for and a positive value in the range a caregiver with worse wellbeing than the person they care for.

**Figure 27: Scatterplot of patient and caregiver GHQ difference**



Key: the graph on the left shows values for caregivers with better GHQ score than the person they care for; the graph on the right shows values for caregivers with a worse GHQ score than the person they care for.

***Life satisfaction (patient and caregiver variable)***

Few of the caregivers report being mostly or completely dissatisfied with their life (approximately 6.5%). The majority of caregivers are mostly or somewhat satisfied with their life. A greater proportion of patients report being dissatisfied with their life than caregivers and fewer report being satisfied (table 35).

**Table 35: Summary of patient and caregiver life satisfaction**

| | Caregiver (N=586) | Patient (N=547) |
|---|---|---|
| Satisfaction with life (Likert seven categories) | N (%) | N (%) |
| • Completely dissatisfied | 14 (2.39%) | 53 (9.69%) |
| • Mostly dissatisfied | 24 (4.10%) | 39 (7.13%) |
| • Somewhat dissatisfied | 42 (7.17%) | 73 (13.35%) |
| • Neither satisfied not dissatisfied | 79 (13.48%) | 74 (13.53%) |
| • Somewhat satisfied | 114 (19.45%) | 88 (16.09%) |
| • Mostly satisfied | 222 (37.88%) | 164 (29.98%) |
| • Completely satisfied | 91 (15.53%) | 56 (10.24%) |
| *109 missing caregiver values 98 missing patient values* | | |

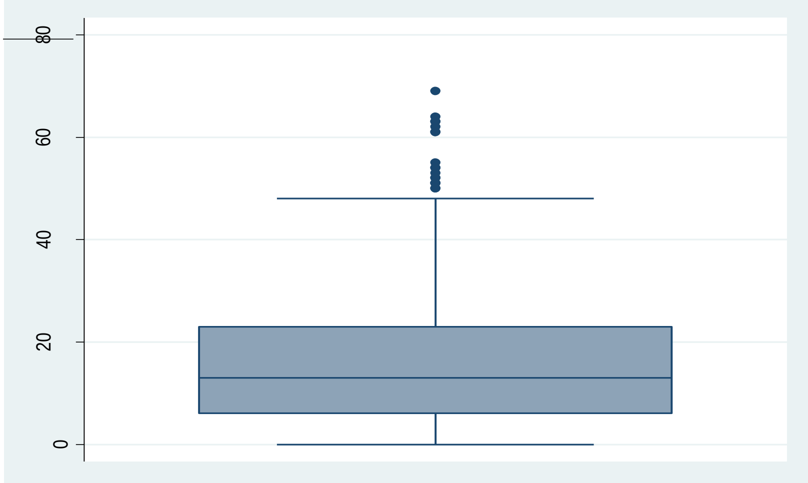
***Arthritis duration (patient variable)***

The duration of arthritis is available for 637 out of 645 patients. The mean duration is 16.2 years with a standard deviation of 12.9 years. Arthritis duration has a number of outliers with people having very long durations of arthritis of over approximately 50 years (table 36, figure 28).

**Table 36: Summary of patient arthritis duration**

| | Patient (N=637) |
|---|---|
| Arthritis duration (Mean (SD) Range)<br>*8 missing values* | 16.21 (SD 12.94)<br>Range 0-69 |

**Figure 28: Boxplot of patient arthritis duration**



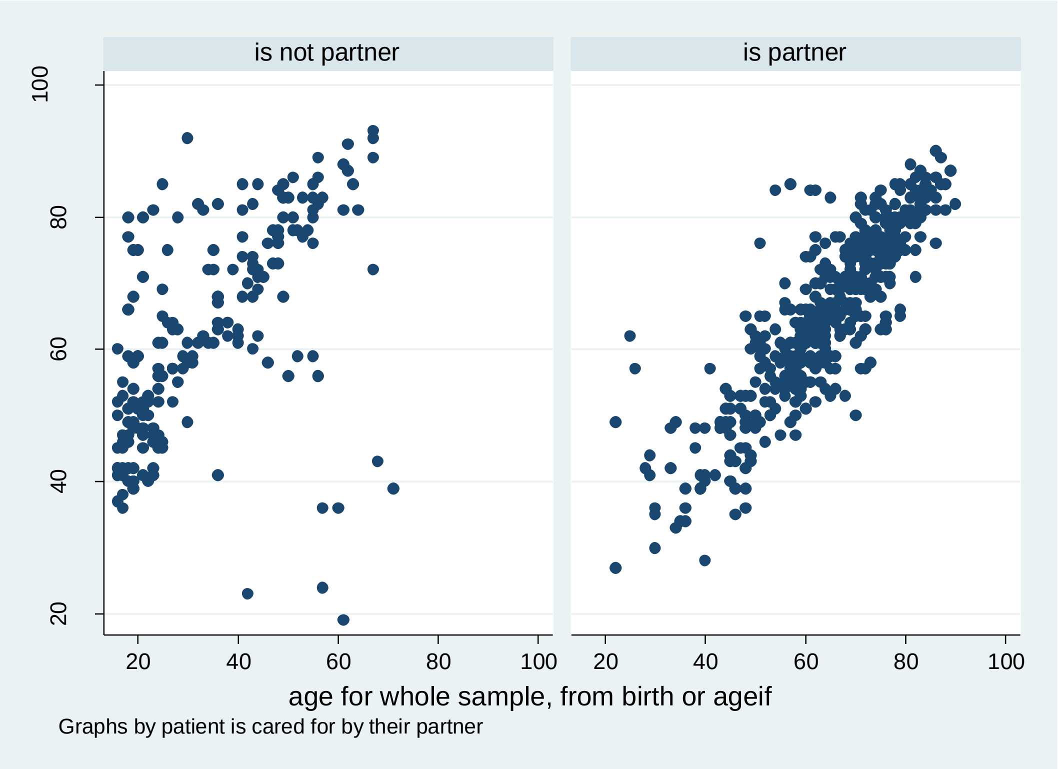
## 5.7 Caregiving subgroups

The majority of caregivers are providing care to their partners (72%) (table 37). A scatter plot for patient age against caregiver age (figure 29) shows two main groups of caregivers: caregivers providing care for someone roughly the same age who are also their partner, and caregivers providing care to someone older than them who is not their partner. There are a small number of observations who are caregivers providing care to someone younger than them who is not their partner.

**Table 37: Summary of caregivers caring for their partner**

| | Patients (N=645)<br>N (%) |
|---|---|
| Caregiving for partner (yes/no) | 499 (71.80%) |

### Figure 29: Scatter plot for patient age and caregiver age



Key: y axis is patient age, x axis is caregiver age in both scatter plots

Some caregivers provide care to someone within the household and also receive care from someone in the household. One hundred of the caregivers in the sample (14.3%) receive care as well as providing care (table 38). Fifty-eight of these caregivers are in reciprocal care arrangements, whereby they receive care from the person to who they provide care, and forty-two of the caregivers receive care from someone else.  Some caregivers in the dataset share care responsibilities with other members of the household: ninety-three (13%) of the caregivers in the sample share the caregiving role with another person in the household.

### Table 38: Summary of caregiver receiving and sharing care

| | Caregiver (N=695) N (%) |
|---|---|
| Both gives and receives care | 100 (14.3%) |
| Caregiver shares the caring role | 93 (13.38%) |

Arthritis is often comorbid with other conditions. The most common comorbid conditions among patients are high blood pressure, diabetes and asthma. Fifteen percent of caregivers are caring for someone with both clinical depression and arthritis (table 39).

### Table 39: Summary of patient's most common conditions

| Condition | Depression | High blood pressure | Diabetes | Angina | Asthma |
|---|---|---|---|---|---|
| N | 105 | 325 | 184 | 87 | 147 |

| | | | | | |
|---|---|---|---|---|---|
| % | (15%) | (47%) | (26%) | (13%) | (21%) |

## 5.8 Missing data

Table 40 shows the amount of missing data in the arthritis sample.

**Table 40: Summary of missing data**

| | Patient missing data | Caregiver missing data |
|---|---|---|
| SF-6D | 2 | 3 |
| Hours of care | - | 6 |
| Employment status | - | 0 (15 other) |
| Dependent children | - | 0 |
| Financial concerns | - | 77 |
| Leisure satisfaction | - | 114 |
| Relationship satisfaction | - | 91 |
| Feeling useful | - | 112 |
| Feeling relaxed | - | 120 |
| Optimistic for the future | - | 112 |
| Age | 0 | 0 |
| Gender | 0 | 0 |
| Race | 1 | 1 |
| Education | 1 | 1 |
| Household income | 0 | |
| Household location | 0 | |
| Arthritis duration | 9 | - |
| GHQ | 140 | 102 |
| Life satisfaction | 148 | 109 |
| Religion | 2 | 2 |
| Dealing with problems well | 142 | 110 |
| Thinking clearly | 143 | 112 |
| Close to others | 141 | 113 |
| Making up own mind | 137 | 105 |

The table 40 shows that the variables collected as part of the interviewer-led questionnaire are subject to very low levels of missingness. The measures collected as part of the self-completion questionnaire are associated with higher levels of missingness, and analysis of the data shows that the missingness occurs because caregivers and patients didn't complete the questionnaire, rather than because they completed the questionnaire but did not respond to a specific question in the questionnaire. There are two factors statistically associated with not completing the questionnaire. The first is race with non-white caregivers being less likely to complete the questionnaire (p<0.001). However, the association between caregiver race and caregiver SF-6D is not statistically significant (p=0.18). The second factor is caregiver SF-6D; caregivers with lower SF-6D are less likely to complete the questionnaire (p=0.005). It is concluded that the data are not missing completely at random. The completion of a complete case analysis in light of this is addressed in the discussion in chapter 7.

## 5.9 Bivariate analyses

This section reports the bivariate analyses of the dependent variable (that is caregiver SF-6D value) with each of the explanatory variables.

### 5.9.1 Caregiver SF-6D and key explanatory variables

Bivariate analyses show a statistically significant association between patient MCS scores and caregiver SF-6D values: increases in patient MCS scores are associated with increases in caregiver SF-6D values. The association for patient PCS scores with caregiver SF-6D values and patient SF-6D values with caregiver SF-6D values are not statistically significant. The association between time spent caregiving and caregiver SF-6D values is statistically significant. Caregivers spending less than 35 hours a week have higher SF-6D values than caregivers who spend more than 35 hours a week providing care (table 41).

**Table 41: Bivariate analyses of caregiver SF-6D and key explanatory variables**

| | Patient PCS score Mean (SD) | Patient MCS score Mean (SD) | Patient SF-6D value Mean (SD) | Time spent caring | |
|---|---|---|---|---|---|
| | | | | <35 | =>35 |
| N | 686 | 686 | 691 | 338 | 194 |
| Caregiver SF-6D value | -0.0688 | 0.1376 | 0.0621 | Mean =0.76 (SD 0.15) | Mean = 0.71 (SD 0.16) |
| p value | 0.0717 (correlation) | **0.0003 (correlation)** | 0.1031 (correlation) | **0.0004 ( t test)** | |

**Figure 30: Scatter plot of patient SF-6D and caregiver SF-6D**

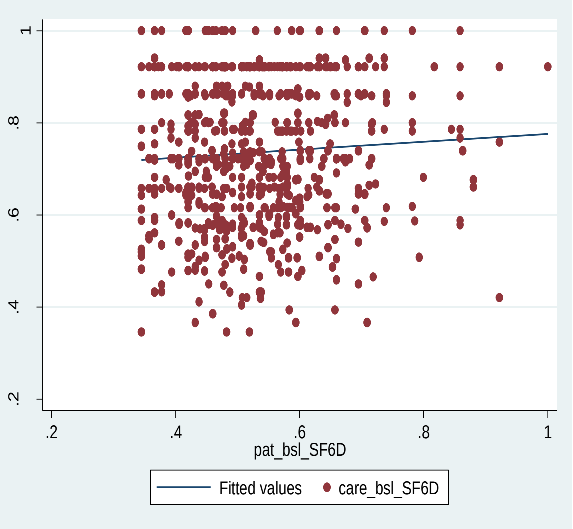


**Figure 31: Scatter plot of patient PCS and MCS and caregiver SF-6D**

Key: patient PCS score on left and patient MCS score on right

### 5.9.2 Caregiver SF-6D and caregiver external conflicts

Bivariate analyses show associations between caregiver SF-6D values and external conflicts. Relationships are statistically significant for financial conflicts, employment status and leisure dissatisfaction, as well as the composite binary variable of the presence or absence of external conflicts and the number of external conflicts counted from 0-3. The presence of dependent children is not statistically significant. Being in employment is associated with higher caregiver SF-6D values than the absence of employment. Conversely, the satisfaction variables show that the presence of concern or dissatisfaction is associated with lower caregiver SF-6D values (table 42).

**Table 42: Bivariate analyses of caregiver SF-6D and external conflicts**

| | Employment status | | Number dependent children | Dependent children | |
|---|---|---|---|---|---|
| | Yes | No | | No | Yes |
| N | 202 | 475 | 692 | 637 | 55 |
| Caregiver SF-6D values | Mean=0.79 (SD 0.13) | Mean=0.71 (SD 0.16) | 0.0308 | Mean=0.74 (SD 0.16) | Mean=0.75 (SD 0.14) |
| p value | **<0.0001 (t test)** | | 0.4189 (correlation) | 0.4649 (t test) | |

| | | Financial concerns | | Leisure dissatisfaction | | Conflicts with partner | | Presence of external strain | |
|---|---|---|---|---|---|---|---|---|---|
| | | Yes | No | Yes | No | Yes | No | Yes | No |
| | | 327 | 288 | 128 | 451 | 42 | 559 | 381 | 236 |
| Caregiver SF-6D values | Mean<br>SD | 0.72<br>0.15 | 0.76<br>0.15 | 0.70<br>0.16 | 0.76<br>0.15 | 0.70<br>0.16 | 0.74<br>0.15 | 0.72<br>0.15 | 0.77<br>0.15 |
| p value | | **0.0011 ( t test)** | | **0.0008 ( t test)** | | 0.0616 (t test) | | **0.0001 ( t test)** | |

### 5.9.3 Caregiver SF-6D and caregiver internal conflicts

As with caregiver external conflicts, caregiver internal conflicts show an association with caregiver SF-6D values. The internal strain variables all show a pattern where if the caregiver expresses positivity, this is associated with higher caregiver SF-6D values. All variables show a statistically significant relationship with caregiver SF-6D values (table 43).

**Table 43: Bivariate analyses of caregiver SF-6D and internal conflicts**

| | | Feeling useful | | Feeling relaxed | | Optimistic about future | | Presence of internal strain | |
|---|---|---|---|---|---|---|---|---|---|
| | | Yes | No | Yes | No | Yes | No | Yes | No |
| N | | 505 | 76 | 478 | 95 | 446 | 135 | 203 | 366 |
| Caregiver SF-6D values | Mean<br>SD | 0.76<br>0.15 | 0.65<br>0.15 | 0.76<br>0.15 | 0.65<br>0.14 | 0.76<br>0.15 | 0.70<br>0.16 | 0.69<br>0.15 | 0.78<br>0.14 |
| p value | | **<0.0001 (t test)** | | **<0.0001 (t test)** | | **0.0002 ( t test)** | | **<0.0001 ( t test)** | |

### 5.9.4 Caregiver SF-6D and control variables

***Sociodemographic variables***

In terms of patient characteristics there is a statistically significant association between gender and caregiver SF-6D values: being a female patient is associated with having a caregiver with a higher SF-6D value. There is also a statistically significant association between patient education level and caregiver SF-6D values, patients with no educational qualifications have caregivers with lower SF-6D values while patients with degree qualifications have caregivers with higher SF-6D values (table 44).

**Table 44: Bivariate analyses of caregiver SF-6D and patient sociodemographic variables**

| | Age | | | Gender | | Race | |
|---|---|---|---|---|---|---|---|
| | | | | Male | Female | White | Other |
| N | 692 | | | 260 | 432 | 588 | 103 |
| Caregiver SF-6D | -.0565 | Caregiver SF-6D values | Mean<br>SD | 0.72<br>0.16 | 0.75<br>0.15 | 0.74<br>0.16 | 0.71<br>0.15 |
| p value | 0.1375 (correlation) | | | **0.0271 ( t test)** | | 0.0865 ( t test) | |

| Education | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | Degree | Other higher | A level equivalent | GCSE equivalent | Other | None |
| N | | 36 | 67 | 68 | 54 | 53 | 413 |
| Caregiver SF-6D values | Mean<br>SD | 0.81<br>0.12 | 0.74<br>0.15 | 0.77<br>0.15 | 0.76<br>0.14 | 0.78<br>0.15 | 0.72<br>0.15 |
| p value | | **0.0004 (ANOVA)** | | | | | |

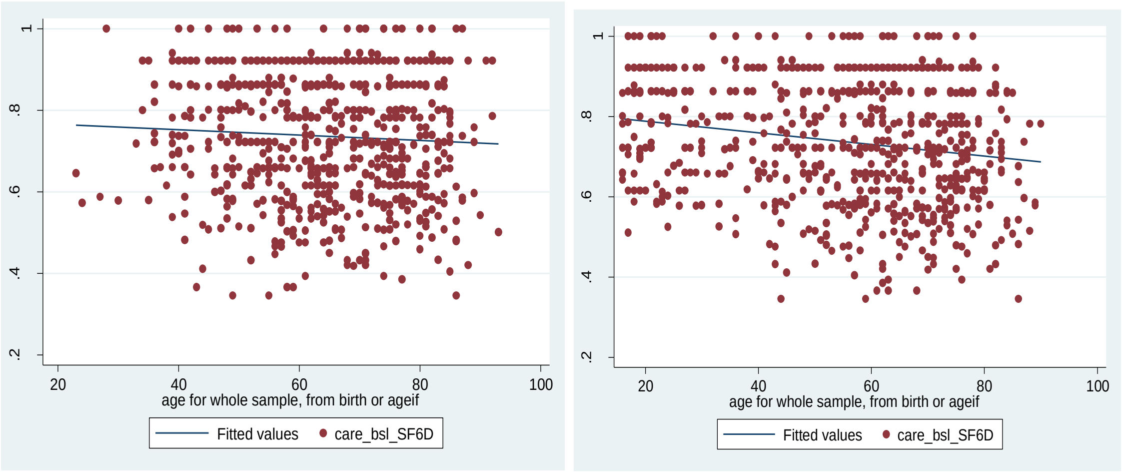
Caregiver characteristics suggest a statistically significant relationship between caregiver age and caregiver SF-6D values: lower caregiver SF-6D values are associated with increased caregiver age. The relationship between caregiver education level and caregiver SF-6D values is also statistically significant with lower caregiver educational levels being associated with lower SF-6D values (table 45).

**Table 45: Bivariate analyses of caregiver SF-6D and caregiver sociodemographic variables**

| | Age | | | Gender | | Race | |
|---|---|---|---|---|---|---|---|
| | | | | Male | Female | White | Other |
| N | 692 | | | 356 | 336 | 589 | 102 |
| Caregiver SF-6D | -.1789 | Caregiver SF-6D values | Mean<br>SD | 0.75<br>0.15 | 0.73<br>0.16 | 0.72<br>0.16 | 0.74<br>0.16 |
| p value | **<0.0001 (correlation)** | | | 0.0666 ( t test) | | 0.1768 ( t test) | |

| Education | | | | | | |
|---|---|---|---|---|---|---|
| | Degree | Other higher | A level equivalent | GCSE equivalent | Other | None |
| N | 61 | 59 | 99 | 137 | 44 | 291 |
| Mean<br>SD | 0.78<br>0.15 | 0.79<br>0.14 | 0.77<br>0.15 | 0.76<br>0.13 | 0.70<br>0.14 | 0.70<br>0.16 |
| p value | **<0.0001 (ANOVA)** | | | | | |

**Figure 32: Scatter plots of caregiver SF-6D and patient and caregiver age**



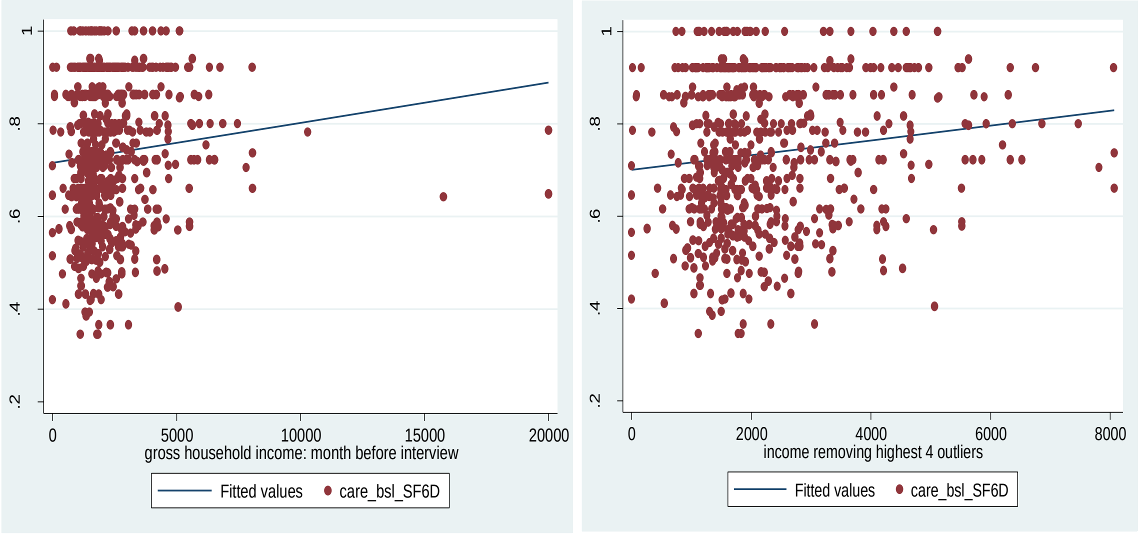
Key: patient age on left and caregiver age on right

In terms of household characteristics there is a positive correlation between household income and caregiver SF-6D values that is statistically significant: higher household income is associated with higher caregiver SF-6D values (table 47). The scatter plots show there are four extreme values with households reporting much higher than average income in the last month (figure 33).

**Table 46: Bivariate analyses of caregiver SF-6D and household characteristics**

| | Income | | | Household location | |
|---|---|---|---|---|---|
| | | | | Urban | Rural |
| N | 692 | | | 561 | 131 |
| Caregiver SF-6D | 0.0964 | Caregiver SF-6D values | Mean<br>SD | 0.73<br>0.16 | 0.75<br>0.14 |
| p value | **0.0112 (correlation)** | | | 0.2640 ( t test) | |

## Figure 33: Scatter plots of caregiver SF-6D against household income



Key: household income with extreme values on left without extreme values on right

### *Resource variables*

In terms of caregiver resources higher caregiver SF-6D values are associated with caregivers feeling that they are dealing with their problems well, thinking clearly, feeling close to others and being able to make up their own mind. All associations are statistically significant. The association between extent to which religion plays a role in the caregiver life and caregiver SF-6D values is also statistically significant. Caregivers who feel that religion plays no difference in their life have higher SF-6D values than caregivers who consider that religion plays a great difference in their life (table 47).

## Table 47: Bivariate analyses of caregiver SF-6D and caregiver resources

| | | Religion | | | |
|---|---|---|---|---|---|
| | | Great difference | Some difference | A little difference | No difference |
| | | 163 | 156 | 116 | 255 |
| Caregiver SF-6D values | Mean<br>SD | 0.70<br>0.15 | 0.75<br>0.16 | 0.73<br>0.15 | 0.76<br>0.15 |
| p value | | **0.0009 (ANOVA)** | | | |

| | | Dealing problems | | Thinking clearly | | Close to others | | Make up own mind | |
|---|---|---|---|---|---|---|---|---|---|
| | | Yes | No | Yes | No | Yes | No | Yes | No |
| N | | 293 | 290 | 378 | 203 | 350 | 230 | 452 | 136 |
| Caregiver SF-6D values | Mean<br>SD | 0.79<br>0.14 | 0.69<br>0.15 | 0.78<br>0.14 | 0.67<br>0.14 | 0.76<br>0.15 | 0.71<br>0.16 | 0.76<br>0.15 | 0.68<br>0.15 |
| p value | | **<0.0001** | | **<0.0001** | | **<0.0001** | | **<0.0001** | |

| | | | | | |
|---|---|---|---|---|---|
| | | **( t test)** | **( t test)** | **( t test)** | **( t test)** |

In terms of patient resources higher caregiver SF-6D values are associated with the patient feeling that they are dealing with their problems well, thinking clearly, feeling close to others and being able to make up their own mind. All associations are statistically significant. The extent to which religion plays a role in the patient’s life is not associated with caregiver SF-6D values (table 48).

### Table 48: Bivariate analyses of caregiver SF-6D and patient resources

| | | Religion | | | |
|---|---|---|---|---|---|
| | | Great difference | Some difference | A little difference | No difference |
| | | 205 | 157 | 114 | 214 |
| Caregiver SF-6D values | Mean<br>SD | 0.73<br>0.16 | 0.73<br>0.16 | 0.72<br>0.15 | 0.75<br>0.15 |
| p value | | 0.2071 (ANOVA) | | | |

| | | Dealing problems | | Thinking clearly | | Close to others | | Make up own mind | |
|---|---|---|---|---|---|---|---|---|---|
| | | Yes | No | Yes | No | Yes | No | Yes | No |
| N | | 172 | 367 | 246 | 292 | 273 | 267 | 335 | 209 |
| Caregiver SF-6D values | Mean<br>SD | 0.76<br>0.15 | 0.73<br>0.16 | 0.76<br>0.15 | 0.72<br>0.16 | 0.76<br>0.15 | 0.72<br>0.15 | 0.75<br>0.15 | 0.72<br>0.15 |
| p value | | **0.0133 ( t test)** | | **0.0014 ( t test)** | | **0.0003 ( t test)** | | **0.0061 ( t test)** | |

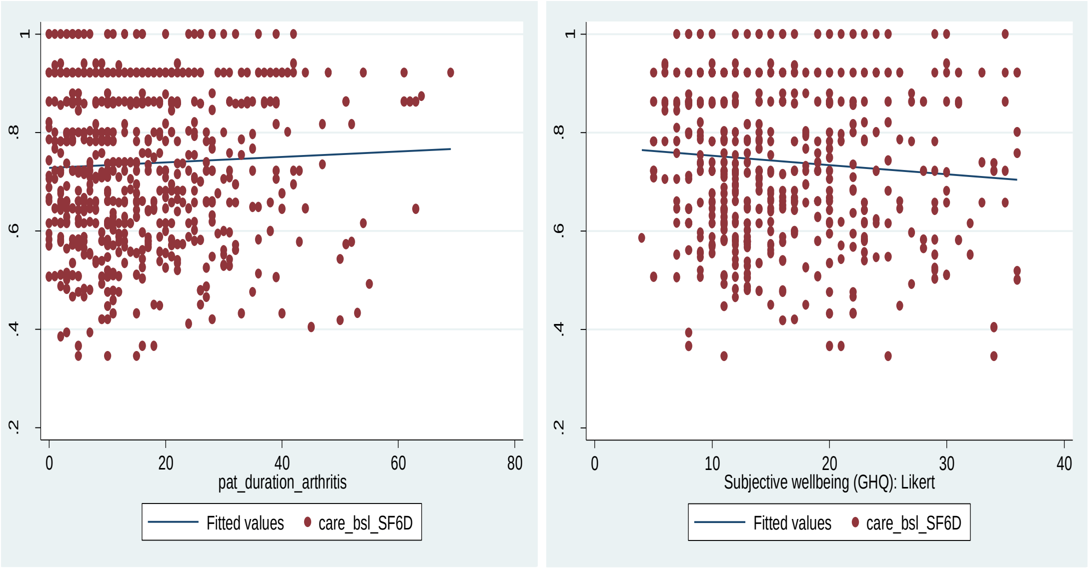
#### *Other patient and caregiver health and wellbeing control variables*

In terms of other patient health and wellbeing variables, statistically significant associations were observed between caregiver SF-6D values and patient GHQ scores but not with the duration of the patient’s arthritis. Higher caregiver SF-6D values are associated with better patient GHQ scores (table 49).

### Table 49: Bivariate analyses of caregiver SF-6D and patient arthritis duration and GHQ score

| | Patient | |
|---|---|---|
| | Arthritis duration | GHQ score |
| N | 683 | 552 |
| Caregiver SF-6D | 0.0466 | -0.0882 |
| p value | 0.2239 (correlation) | **0.0384 (correlation)** |

## Figure 34: Scatter plots of caregiver SF-6D and patient duration arthritis and GHQ score



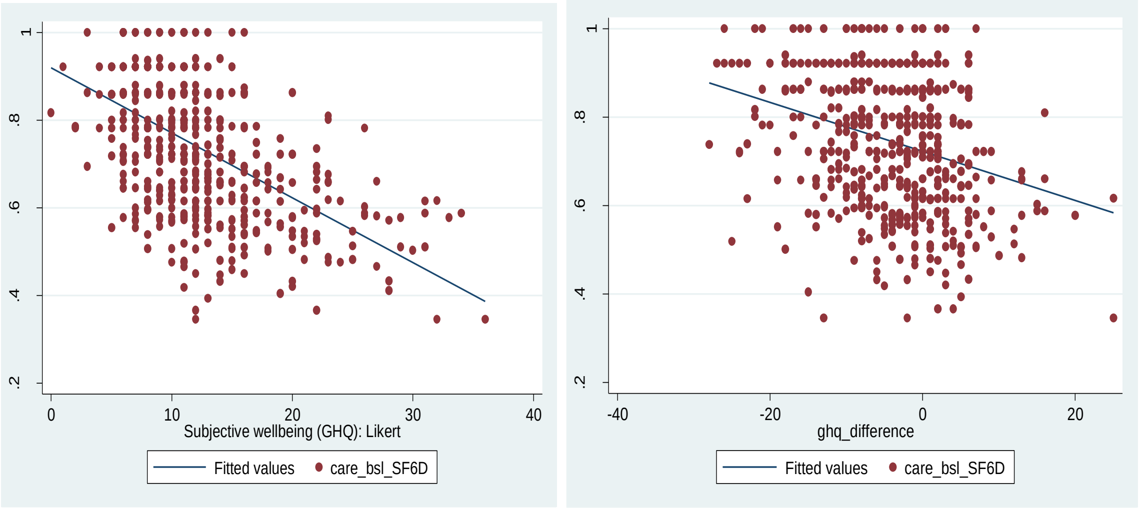
Key: patient duration of arthritis on left and patient GHQ score on right

As expected a statistically significant association is observed between caregiver SF-6D values and caregiver GHQ scores. Higher caregiver SF-6D values are associated with better GHQ scores. Analyses also show that there is a statistically significant association between caregiver SF-6D values and the difference in GHQ score between the patient and the caregiver. To illustrate this association, a better caregiver SF-6D value is associated with caring for someone with a worse GHQ score than themselves, whereas a worse caregiver SF-6D value is associated with the caregiver have a worse GHQ score than the person they are caring for (table 50, figure 35).

## Table 50: Bivariate analyses of caregiver SF-6D and caregiver GHQ score

| | Caregiver | |
|---|---|---|
| | GHQ score | GHQ difference |
| | 590 | 527 |
| Caregiver SF-6D | -0.5418 | -0.2891 |
| p value | **<0.0001 (correlation)** | **<0.0001 (correlation)** |

### Figure 35: Scatterplot of caregiver SF-6D and caregiver GHQ and GHQ difference



Key: Caregiver GHQ score on left and difference in GHQ score on right

As with GHQ score, there is a statistically significant association between life satisfaction of both patients and caregivers and caregiver SF-6D values. As expected the relationship between caregiver life satisfaction and caregiver SF-6D values is more consistent than that of patient life satisfaction and caregiver SF-6D values (table 51).

### Table 51: Bivariate analyses of caregiver SF-6D and patient and caregiver life satisfaction

| | Caregiver | | | Patient | | |
|---|---|---|---|---|---|---|
| Satisfaction with life | N=586 | | | N=547 | | |
| | N | Mean | SD | N | Mean | SD |
| • Completely dissatisfied | 14 | 0.67 | 0.10 | 53 | 0.75 | 0.17 |
| • Mostly dissatisfied | 23 | 0.67 | 0.20 | 39 | 0.72 | 0.14 |
| • Somewhat dissatisfied | 42 | 0.69 | 0.15 | 73 | 0.72 | 0.15 |
| • Neither satisfied not dissatisfied | 79 | 0.67 | 0.16 | 74 | 0.69 | 0.16 |
| • Somewhat satisfied | 113 | 0.72 | 0.15 | 87 | 0.73 | 0.17 |
| • Mostly satisfied | 222 | 0.77 | 0.14 | 163 | 0.77 | 0.15 |
| • Completely satisfied | 91 | 0.82 | 0.13 | 55 | 0.78 | 0.14 |
| p value | **<0.0001 (ANOVA)** | | | **0.0052 (ANOVA)** | | |

## 5.10 Caregiver subgroups

In terms of caregiving characteristics, caregiver SF-6D values are associated with caring for your partner, with caregivers sharing care and with caregivers receiving care (all associations statistically significant). Higher SF-6D values are associated with caregivers who share care than caregivers who are sole caregivers. Lower SF-6D values are associated with caregivers who also receive care than caregivers who do not receive care. The same association is observed for caregivers caring for their partners versus caregivers caring for someone who is not their partner. The difference in SF-6D values for a caregiver caring for a patient with depression and arthritis compared to caregiver caring for a patient without depression is not statistically significant (table 52).

**Table 52: Bivariate analyses of caregiver SF-6D and caregiver status**

| | | Is partner | | Shares care | | Receives care | | Comorbid depression | |
|---|---|---|---|---|---|---|---|---|---|
| | | Yes | No | Yes | No | Yes | No | Yes | No |
| N | | 497 | 195 | 93 | 599 | 99 | 593 | 105 | 587 |
| Caregiver SF-6D values | Mean<br>SD | .72<br>.16 | .78<br>.15 | .77<br>.14 | .73<br>.16 | .57<br>.12 | .76<br>.14 | 0.73<br>0.15 | 0.74<br>0.16 |
| p value | | **<0.0001 ( t test)** | | **0.0106 ( t test)** | | **<0.0001 ( t test)** | | 0.5239 (t test) | |

## 5.11 Summary

The sample from Understanding Society used in these analyses includes 645 patients with arthritis and 695 caregivers of these patients. The patient sample is defined by the presence of arthritis and reflects the expected characteristics of a sample with arthritis rather than the general population. The mean age of the sample is higher than for the Understanding Society dataset as a whole and the mean physical component summary score is lower than the mean for the Understanding Society dataset as a whole. For the caregivers the mean age is higher than in the Understanding Society dataset as a whole and therefore a smaller proportion of the arthritis sample than the whole dataset are in employment and have dependent children. Reflecting widely reported issues with caregiving a greater proportion of the caregivers in the sample than the Understanding Society dataset as a whole report having financial concerns, leisure concerns and psychological strains. Finally, compared to population samples of caregivers this sample contains a high proportion of male caregivers. This likely stems from some types of arthritis more often affecting women and a large proportion of this sample providing care for their partner.

Reflecting the real-life complexities of caregiving, the sample contains a proportion of people who are sharing the care of a single person and a proportion of people who are in reciprocal caregiving relationships. The sample also includes a group of caregivers with worse physical and mental health and wellbeing than the person they care for. In some cases these caregivers are receiving care themselves from either the person receiving care or another person within the household, but in some cases they are a sole caregiver within the household and not receiving further care from within the household.

The bivariate analyses support the choice of external conflicts variables. There is a statistically significant relationship between caregiver SF-6D values and caregiver employment status, financial concerns, leisure dissatisfaction and the composite variable presence of external conflicts. The direction of the association is as expected: higher caregiver SF-6D values are associated with being in employment, not having financial concerns, not having dissatisfaction with leisure, not having external conflicts and having a fewer number of external conflicts. In terms of internal conflicts, bivariate analyses show that all of the variables are associated with caregiver SF-6D values and all associations are statistically significant. The direction of the association is again as expected: higher caregiver SF-6D values are associated with the caregiver feeling useful, feeling relaxed, feeling optimistic about the future, and with absence of internal conflicts.

Sociodemographic variables show fewer relationships with caregiver SF-6D values. Statistically significant associations with caregiver SF-6D values are patient gender, patient education, caregiver age and caregiver education. Higher SF-6D values are associated with caregivers of female patients. Lower SF-6D values are associated with caregivers and patients with no educational qualifications. As expected, lower SF-6D values are associated with older caregivers. Household income is also associated with caregiver SF-6D values: lower caregiver SF-6D values are associated with lower household income.

Resource variables are also statistically significant in bivariate analyses. Higher caregiver SF-6D values are associated with caregivers and patients dealing well with their problems, thinking clearly, feeling close to others and being able to make up their own mind. Of the religion variables ANOVA suggested that there were statistically significant associations between caregiver SF-6D values and caregiver perception of religion making a difference in their lives.

Finally in terms of patient and caregiver health and wellbeing variables, as expected statistically significant associations are observed between caregiver SF-6D values and caregiver wellbeing: higher SF-6D values are associated with better wellbeing. The association between caregiver SF-6D values and patient wellbeing (measured as either GHQ score or life satisfaction) is also statistically significant: a higher level of wellbeing in patients is associated with higher caregiver SF-6D values. The difference in GHQ score between the patient and the caregiver is also associated with caregiver SF-6D values: two caregivers with the same GHQ score will have different SF-6D values depending on the GHQ scores of the patient they care for.

The bivariate analyses show a broad range of statistically significant relationships across the different categories of variables that are to be used in the regression analysis.

# 6 Regression analyses

## 6.1 Introduction

Having presented an overview of the arthritis sample and described the bivariate analyses, this chapter presents the multivariate analyses. The chapter starts with the model including only the key explanatory variables (patient SF-6D values and time spent caring). To this model the potential effect modifiers (internal and external conflicts) and control variables (sociodemographic variables, resource variables and other patient and caregiver health and wellbeing variables) are added. Having built the basic model, the chapter explores the inclusion of interaction terms, household effects, a different specification of time spent caring and the consistency of effect across different groups of caregivers: (1) sole caregivers, (2) caregivers who also receive care, (3) caregivers of their partners and (4) caregivers of patients with a diagnosis of both arthritis and clinical depression.

## 6.2 Model development

### 6.2.1 Models including patient SF-6D and time spent caring

The model including patient SF-6D as the only explanatory variable (Table 52, model *a*) shows a positive relationship between patient SF-6D and caregiver SF-6D values. The coefficient suggests that an increase in patient SF-6D of 0.20 is associated with an increase in caregiver SF-6D of 0.017. The coefficient is not statistically significant.

The addition of time spent caring to the model (Table 52, model *b(35)*) shows a statistically significant association between time spent caring and caregiver SF-6D values. Providing care for more than 35 hours per week is associated with a caregiver having an SF-6D 0.04 less than those providing care for less than 35 hours per week. In model *b(35)* the relationship between patient SF-6D and caregiver SF-6D values is positive as per model *a*, but the inclusion of time spent caring reduces the size of the coefficient: an increase in patient SF-6D of 0.20 is now associated with an increase in caregiver SF-6D of 0.004.

The reduction in caregiver SF-6D values associated with increased time spent caregiving and the positive association between patient SF-6D and caregiver SF-6D values is consistent with stress process theory (94,107) and the literature (174). The reduction in the size of the coefficient for patient SF-6D with the addition of time spent caregiving is perhaps larger than may be expected: the relationship between patient and caregiver SF-6D values is broadly flat, with only small changes in caregiver SF-6D values for increases in patient SF-6D values.

### 6.2.2 Addition of internal and external conflicts

To the model with time spent caring and patient SF-6D, the internal and external conflicts variables are added (Table 52; model *c(35)*).

The presence of internal conflicts and external conflicts are associated with reduced caregiver SF-6D values by 0.09 and 0.03 respectively, and the coefficients are statistically significant. This is the expected relationship given that the conflicts variables measure the presence of environmental or psychological strains which would negatively affect a person's quality of life. With the addition of internal and external conflicts to the model, the coefficient for time spent caring remains unchanged. The association between patient SF-6D and caregiver SF-6D values remains not statistically significant, but the sign of the coefficient changes; an increase in patient SF-6D of 0.20 is associated with a reduction in caregiver SF-6D of 0.007. The addition of internal and external conflicts reduces the AIC and BIC.

To the model with patient SF-6D, time spent caring and internal and external conflicts, job status is added (Table 53; model *d*(35)). The absence of a job is associated with a caregiver having an SF-6D 0.05 lower than that of a caregiver with a job. The coefficient is statistically significant and the AIC and BIC are reduced by the inclusion of this variable. The coefficient for job status is expected given that people with lower SF-6D values are less likely to be in employment and also consistent with theory, which suggests that having roles additional to the caregiving role can be positive for caregivers (40). The inclusion of job status reduces the size of the coefficient for time spent caring from -0.048 to -0.034 (remaining statistically significant). This is expected as job status and time spent caring are associated: caregivers who are not in employment are more likely to be providing greater hours of care.

The variable representing whether a caregiver has dependent children is added to the model with patient SF-6D, time spent caring, internal and external conflicts and job status (Table 53; models e(35), f(35)). The coefficient for the presence of dependent children suggests that the presence of dependent children is associated with an increase in caregiver SF-6D of 0.01 compared to an absence of dependent children. The coefficients are not statistically significant, specified either as presence or absence of children or as the number of children. The AIC and BIC between the two variables is very similar. The adjusted $R^2$ is slightly smaller with the variable for the presence of the dependent children. The other coefficients in the model are unchanged by the dependent children variables.

On this basis the variables representing the caregiver having dependent children are not included in the model and the model going forward is *d*(35) including: patient SF-6D, time spent caring, presence of internal conflicts, presence of external conflicts, and job status.

### Table 52: Model of Caregiver SF-6D and time spent caring with conflicts variables

| | ***a*** | | ***b(35)*** | | ***c(35)*** | |
|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | **With patient SF-6D** | | **With patient SF-6D and time spent caring** | | ***b(35)* + internal and external conflicts** | |
| | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring<br>Ref less than 35 hours | | | **-0.047** | **0.001** | **-0.048** | **0.001** |
| Patient SF-6D | 0.086 | 0.103 | 0.022 | 0.706 | -0.036 | 0.555 |
| Presence external conflict<br>Ref absent | | | | | **-0.032** | **0.023** |
| Presence internal conflict<br>Ref present | | | | | **0.086** | **0.000** |
| Constant | 0.690 | 0.000 | 0.746 | 0.000 | 0.750 | 0.000 |
| Number of obs | 691 | | 582 | | 465 | |
| Prob > F | 0.1031 | | 0.0019 | | 0.0000 | |
| R-squared | 0.0039 | | 0.0214 | | 0.1137 | |
| Adj R-squared | 0.0024 | | 0.0180 | | 0.1060 | |
| Root MSE | 0.15503 | | 0.15341 | | 0.14567 | |
| AIC | -613.2268 | | -527.4306 | | -466.9643 | |
| BIC | -604.1506 | | -514.3312 | | -446.2541 | |
| Hatsq | 0.58 | | 0.97 | | 0.49 | |
| Reset | 0.89 | | 0.52 | | 0.77 | |

**Table 53: Model with addition of dependent children and job status variables**

| | ***c(35)*** | | ***d(35)*** | | ***e(35)*** | | ***f(35)*** | |
|---|---|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | ***b(35)* + internal and external conflicts** | | ***c(35)*+ job status** | | ***d(35)* and presence dependent children** | | ***d(35)* and number dependent children** | |
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring Ref less than 35 hours | **-0.048** | **0.001** | **-0.034** | **0.028** | **-0.034** | **0.027** | **-0.034** | **0.028** |
| Patient SF-6D | -0.036 | 0.555 | -0.020 | 0.748 | -0.020 | 0.748 | -0.020 | 0.748 |
| Presence external conflict Ref absent | **-0.032** | **0.023** | **-0.036** | **0.012** | **-0.036** | **0.012** | **-0.036** | **0.012** |
| Presence internal conflict Ref present | **0.086** | **0.000** | **0.079** | **0.000** | **0.080** | **0.000** | **0.079** | **0.000** |
| Job status Ref presence of job | | | **-0.052** | **0.001** | **-0.052** | **0.001** | **-0.052** | **0.001** |
| Number of children | | | | | | | 0.001 | 0.966 |
| Presence of children Ref none | | | | | 0.009 | 0.768 | | |
| Constant | 0.750 | 0.000 | 0.779 | 0.000 | 0.778 | 0.000 | 0.779 | 0.000 |
| Number of obs | 465 | | 454 | | 454 | | 454 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R-squared | 0.1137 | | 0.1303 | | 0.1305 | | 0.1303 | |
| Adj R-squared | 0.1060 | | 0.1206 | | 0.1188 | | 0.1186 | |
| Root MSE | 0.14567 | | 0.14465 | | 0.1448 | | 0.14481 | |
| AIC | -466.9643 | | -461.2026 | | -459.2912 | | -459.2044 | |
| BIC | -446.2541 | | -436.494 | | -430.4645 | | -430.3777 | |
| Hatsq | 0.49 | | 0.69 | | 0.61 | | 0.68 | |
| Reset | 0.77 | | 0.79 | | 0.81 | | 0.79 | |

### 6.2.3 Exploration of control variables

#### ***Sociodemographic variables***

Ten patient and caregiver sociodemographic variables are considered for inclusion in the model as control variables: patient and caregiver age, gender, race and education level, plus household income and household location. The variables are entered into the model in three groups: caregiver demographics, patient demographics and household characteristics (models Table 54; *g*(35), *h*(35) and *i*(35)).

The variables showing statistically significant associations with caregiver SF-6D values are caregiver age, patient race, caregiver race, caregiver education level and patient education level. The coefficients show that lower caregiver SF-6D values are associated with older caregiver age, being a non-white caregiver or a caregiver of a non-white patient, and patients and caregivers having lower educational status. In terms of expected relationships, this is consistent with the finding that older people, non-white people and people with lower educational levels tend to have worse health status (168,169). For the variable highest educational qualification, only the coefficient for no educational qualifications versus degree qualification is statistically significant, and the contribution of the whole variable is not statistically significant.

The addition of demographic variables has little effect for the coefficients for time spent caring (the values vary from -0.03 to -0.033), external conflicts (the values vary from -0.032 to -0.038) or internal conflicts (the values vary from -0.075 to -0.08). The coefficient for patient SF-6D is never statistically significant and broadly reflects a flat relationship between patient SF-6D and caregiver SF-6D values. The coefficient for job status is sensitive to the addition of caregiver demographics because of the relationship between caregiver age and job status.

The addition of caregiver and patient demographic variables increases the AIC, but reduces the BIC; the addition of household variables (income and location) reduces both the AIC and BIC. The adjusted $R^2$ increases most with the addition of the caregiver demographics and gets smaller with the addition of the household variables.

## Table 54: Exploration of sociodemographic variables (35 hours)

| | ***d(35)*** | | ***g(35)*** | | ***h(35)*** | | ***i(35)*** | |
|---|---|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | ***c(35)* + job status** | | ***d(35)* + caregiver** | | ***d(35)* + patient** | | ***d(35)* + household** | |
| | | | **CAREGIVER** | | **PATIENT** | | **HOUSEHOLD** | |
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring<br>Ref less than 35 hours | **-0.034** | **0.028** | **-0.030** | **0.051** | **-0.032** | **0.040** | **-0.033** | **0.032** |
| Patient SF-6D | -0.020 | 0.748 | -0.004 | 0.952 | -0.041 | 0.519 | -0.023 | 0.718 |
| Presence external conflict<br>Ref absent | **-0.036** | **0.012** | **-0.038** | **0.007** | **-0.032** | **0.022** | **-0.035** | **0.013** |
| Presence internal conflict<br>Ref present | **0.079** | **0.000** | **0.075** | **0.000** | **0.079** | **0.000** | **0.080** | **0.000** |
| Job status<br>Ref presence of job | **-0.052** | **0.001** | -0.021 | 0.224 | **-0.060** | **0.000** | **-0.053** | **0.001** |
| Age | | | **-0.001** | **0.003** | -0.0002 | 0.645 | | |
| Gender Reference Male | | | -0.012 | 0.360 | 0.006 | 0.679 | | |
| Race Reference white | | | **-0.088** | **0.000** | **-0.078** | **0.000** | | |
| Education Ref degree level | | | - | | - | | | |
| Other higher | | | -0.001 | 0.978 | -0.053 | 0.142 | | |
| A level | | | -0.031 | 0.251 | -0.043 | 0.234 | | |
| GCSE | | | -0.015 | 0.566 | -0.059 | 0.124 | | |
| Other | | | -0.064 | 0.056 | -0.049 | 0.172 | | |
| None | | | **-0.053** | **0.032** | **-0.075** | **0.013** | | |
| Household location Ref urban | | | | | | | 0.007 | 0.677 |
| Household income | | | | | | | -4.99e-07 | 0.921 |
| Constant | 0.779 | 0.000 | 0.884 | 0.000 | 0.880 | 0.000 | 0.780 | 0.000 |
| Number of obs | 454 | | 452 | | 452 | | 454 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R-squared | 0.1303 | | 0.1922 | | 0.1744 | | 0.1307 | |
| Adj R-squared | 0.1206 | | 0.1682 | | 0.1499 | | 0.1170 | |
| Root MSE | 0.14465 | | 0.14026 | | 0.14234 | | 0.14494 | |
| AIC | -461.2026 | | -479.167 | | -465.8919 | | -457.3878 | |
| BIC | -436.494 | | -421.5755 | | -408.3003 | | -424.4431 | |
| Hatsq | 0.69 | | 0.72 | | 0.44 | | 0.71 | |
| Reset | 0.79 | | 0.62 | | 0.33 | | 0.86 | |

### ***Exploration of resource variables***

Resource variables are also considered as control variables. There are 10 variables considered for inclusion, patient and caregiver: making up mind, dealing with problems, thinking clearly, feeling close to others and the difference that religion makes in life. These variables are entered in the model in four groups: (1) patient resource variables and (2) caregiver resource variables and the extent to which religion makes a difference in (3) the patient's and (4) the caregiver's life (Table 55; models j(35), *k*(35), *l*(35), *m*(35)).

The coefficients for religion making a difference in the life of the caregiver are statistically significant (model *j*(35)). The association suggests that caregivers for whom religion makes a great difference in life have lower SF-6D values than caregivers for whom religion makes only some difference or less. In terms of patients the same relationship is seen but only the coefficient for a great difference versus no difference is statistically significant. The contribution of the variable as a whole is not statistically significant in the model. Including patient religion in the model (model *l*(35)) reduces both the AIC and BIC while including caregiver religion increases both the AIC and BIC. The negative relationship between religion and SF-6D values is perhaps unexpected because religiosity or spirituality is associated in the literature with positive wellbeing (61). However, in this sample this association may be explained by the fact that non-white people are more likely to consider that religion makes a great difference in their life (60% versus 17%) and there is an association between being non-white and having lower SF-6D values. The variables measuring religion make little difference to the coefficients for time spent caring, patient SF-6D, external conflicts and internal conflicts.

In terms of caregiver resources (model *k*(35)), the statistically significant coefficients are caregiver thinking clearly and dealing with problems well. The model suggests that caregivers who do not consider they are dealing with problems well or thinking clearly have lower SF-6D values than caregivers who do (0.05 and 0.07 respectively). This relationship is as expected because these variables are measuring aspects of mental distress which would be expected to also be captured in quality of life. The inclusion of these two variables affects the other coefficients in the model: the coefficients for internal conflicts and external conflicts become smaller (-0.016 versus -0.036 and 0.057 versus 0.079 respectively). The AIC and BIC increase with the inclusion of caregiver resources.

In terms of patient resources none of the coefficients are statistically significant (model *m*(35)). The inclusion of patient resources affects the coefficient for patient SF-6D with it becoming more strongly negative, as patient SF-6D values increase caregiver SF-6D values decrease. The inclusion of patient resource leads to a large reduction in AIC and BIC.

## Table 55: Exploration of resource variables (35 hours)

| | ***d(35)*** | | ***j(35)*** | | ***k(35)*** | | ***l(35)*** | | ***m(35)*** | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | ***c(35)*** **+ job status** | | ***d(35)*** **plus caregiver religion** | | ***d(35)*** **plus caregiver resources** | | ***d(35)*** **plus patient religion** | | ***d(35)*** **plus patient resources** | |
| | | | **SPECIFICATION CAREGIVER RESOURCE** | | | | **SPECIFICATION PATIENT RESOURCE** | | | |
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring<br>Ref less than 35 hours | **-0.034** | **0.028** | **-0.030** | **0.047** | **-0.045** | **0.003** | **-0.035** | **0.023** | **-0.029** | **0.091** |
| Patient SF-6D | -0.020 | 0.748 | -0.027 | 0.657 | -0.054 | 0.367 | -0.023 | 0.712 | -0.094 | 0.183 |
| Presence external conflict<br>Ref absent | **-0.036** | **0.012** | **-0.036** | **0.009** | -0.016 | 0.248 | **-0.034** | **0.017** | **-0.033** | **0.034** |
| Presence internal conflict<br>Ref present | **0.079** | **0.000** | **0.088** | **0.000** | **0.057** | **0.000** | **0.085** | **0.000** | **0.081** | **0.000** |
| Job status<br>Ref presence of job | **-0.052** | **0.001** | **-0.049** | **0.001** | **-0.054** | **0.000** | **-0.050** | **0.001** | **-0.058** | **0.000** |
| Able to make up mind<br>Reference no or rarely | | | | | 0.008 | 0.692 | | | 0.015 | 0.426 |
| Able to deal problems<br>Reference no or rarely | | | | | **0.054** | **0.001** | | | 0.005 | 0.825 |
| Thinking clearly<br>Reference no or rarely | | | | | **0.066** | **0.000** | | | 0.015 | 0.444 |
| Feeling close to others<br>Reference no or rarely | | | | | -0.003 | 0.851 | | | 0.021 | 0.201 |
| Religion | | | | | | | | | | |
| Ref a great difference | | | **-** | | | | - | | | |
| Some difference | | | **0.078** | **0.000** | | | 0.008 | 0.667 | | |
| A little difference | | | **0.055** | **0.011** | | | 0.010 | 0.644 | | |
| No difference | | | **0.087** | **0.000** | | | 0.**038** | **0.033** | | |
| Constant | 0.779 | 0.000 | 0.715 | 0.000 | 0.727 | 0.000 | 0.760 | 0.000 | 0.789 | 0.000 |
| Number of obs | 454 | | 452 | | 447 | | 452 | | 390 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R-squared | 0.1303 | | 0.1790 | | 0.2358 | | 0.1409 | | 0.1519 | |
| Adj R-squared | 0.1206 | | 0.1642 | | 0.2200 | | 0.1254 | | 0.1318 | |
| Root MSE | 0.14465 | | 0.14084 | | 0.13673 | | 0.14435 | | 0.1437 | |
| AIC | -461.2026 | | -480.3531 | | -500.4477 | | -458.0995 | | -396.5571 | |
| BIC | -436.494 | | -443.3299 | | -459.4221 | | -421.0763 | | -356.8956 | |
| Hatsq | 0.69 | | 0.26 | | 0.40 | | 0.36 | | 0.89 | |
| Reset | 0.79 | | 0.57 | | 0.54 | | 0.55 | | 0.92 | |

### *Exploration of other patient health and wellbeing variables*

There are six patient and caregiver health and wellbeing variables: patient duration of arthritis, patient and caregiver life satisfaction and GHQ scores and the difference between patient and caregiver GHQ scores. The variables are included in three groups: (1) patient health and wellbeing, (2) caregiver health and wellbeing and (3) the difference in patient and caregiver GHQ scores (Table 56; models *n*(35), *o*(35), *p*(35)).

The coefficients for patient health and wellbeing variables are not statistically significant (model *n*(35)). The coefficients for the other variables in the model remain unchanged with the addition of patient health and wellbeing variables. The AIC and BIC are reduced by the inclusion of the patient health and wellbeing variables. This is driven by the inclusion of patient GHQ and life satisfaction rather than the patient duration of arthritis variable.

The inclusion of caregiver health and wellbeing variables shows that the coefficient for caregiver GHQ is statistically significant (model *o*(35)). However, the model specification statistics show that the AIC and BIC have increased and the model is now mis-specified. The mis-specification arises from the inclusion of caregiver GHQ in the model. However, both variables contribute to increases in the AIC and BIC.

The coefficient for the difference in GHQ scores is statistically significant. This variable shows that a larger positive difference between caregiver wellbeing and patient wellbeing is associated with higher caregiver SF-6D values, while a larger negative difference between caregiver wellbeing and patient wellbeing is associated with lower caregiver SF-6D values. This variable has an effect on the coefficient for patient SF-6D with the sign of the coefficient becoming positive (as in the original specification of the model with patient SF-6D before the addition of internal and external conflicts). An increase in patient SF-6D of 0.20 is associated with an increase in caregiver SF-6D of 0.020, but the coefficient remains statistically non-significant. The other coefficients for time spent caring and external conflicts are unchanged and the internal conflicts variable becomes smaller (0.063 versus 0.079); all remain statistically significant. The AIC and BIC reduce with the inclusion of the difference in GHQ scores in the model.

## Table 56: Exploration of other patient and caregiver health and wellbeing variables (35 hours)

| | ***d(35)*** | | **n(35)** | | **o(35)** | | **p(35)** | |
|---|---|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | **c(35) + job status** | | ***d(35)* plus patient health and wellbeing** | | ***d(35)* plus caregiver health and wellbeing** | | ***d(35)* plus GHQ difference patient and caregiver** | |
| | | | PATIENT | | CAREGIVER | | | |
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring<br>Ref less than 35 hours | **-0.034** | **0.028** | **-0.041** | **0.017** | **-0.019** | **0.165** | **-0.037** | **0.022** |
| Patient SF-6D | -0.020 | 0.748 | -0.127 | 0.108 | -0.031 | 0.576 | 0.101 | 0.153 |
| Presence external conflict<br>Ref absent | **-0.036** | **0.012** | **-0.032** | **0.043** | **-0.0004** | **0.974** | **-0.036** | **0.012** |
| Presence internal conflict<br>Ref present | **0.079** | **0.000** | **0.069** | **0.000** | **0.029** | **0.032** | **0.063** | **0.000** |
| Job status<br>Ref presence of job | **-0.052** | **0.001** | **-0.052** | **0.002** | **-0.055** | **0.000** | **-0.046** | **0.004** |
| Duration of arthritis | | | 0.0004 | 0.524 | - | | | |
| Life satisfaction | | | | | | | | |
| Ref Completely dissatisfied | | | - | | - | | | |
| Mostly dissatisfied | | | -0.058 | 0.109 | 0.003 | 0.946 | | |
| Somewhat dissatisfied | | | -0.041 | 0.197 | 0.020 | 0.659 | | |
| Neither | | | -0.058 | 0.066 | -0.026 | 0.554 | | |
| Somewhat satisfied | | | -0.021 | 0.503 | 0.010 | 0.812 | | |
| Mostly satisfied | | | 0.012 | 0.696 | 0.025 | 0.564 | | |
| Completely satisfied | | | -0.003 | 0.931 | 0.052 | 0.252 | | |
| GHQ score | | | -0.001 | 0.688 | **-0.012** | **0.000** | | |
| GHQ score difference | | | | | | | **-0.005** | **0.000** |
| Constant | 0.779 | 0.000 | 0.870 | 0.000 | 0.921 | 0.000 | 0.702 | 0.000 |
| Number of obs | 454 | | 387 | | 441 | | 399 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R-squared | 0.1303 | | 0.1575 | | 0.3400 | | 0.1850 | |
| Adj R-squared | 0.1206 | | 0.1282 | | 0.3215 | | 0.1725 | |
| Root MSE | .14465 | | .14379 | | .12673 | | .14001 | |
| AIC | -461.2026 | | -389.0901 | | -557.6224 | | -429.6299 | |
| BIC | -436.494 | | -333.6722 | | -504.4648 | | -401.7072 | |
| Hatsq | 0.69 | | 0.22 | | 0.68 | | 0.27 | |
| Reset | 0.78 | | 0.22 | | **0.003** | | 0.59 | |

### 6.2.4 Addition of control variables

To the model with patient SF-6D, time sent caring, internal and external conflicts and job status (Table 57; model *d*(35)) the three types of control variables (socio-demographics, resources and other health and wellbeing) are added.

In the first instance the difference in GHQ scores is added because this is the only control variable that has a statistically significant coefficient and also reduces AIC and BIC (Table 57; model *q*(35)). When added to the model with the difference in GHQ scores, the other caregiver wellbeing variables result in increased AIC and BIC and model misspecification and are not included. Patient GHQ score and life satisfaction are not included in the model because of the correlation with patient SF-6D values and the difference in GHQ scores.

The socio-demographic variables are then considered. The exploratory analyses suggested that the socio-demographic variables tend to increase the AIC while reducing the BIC. The combination of demographic variables chosen as reducing the BIC the most for the smallest gain in AIC (a nine point increase in AIC for a reduction in BIC of 27) is: caregiver age, caregiver race, caregiver highest educational qualification and caregiver gender along with patient gender. Not all these coefficients are statistically significant, but they each reduce the BIC. The addition of these variables does not affect the other coefficients except for the coefficient for caregiver job status. The size of the coefficient for job status is reduced with inclusion of the caregiver age. The household variables, income and location, were not statistically significant when tested alone but did reduce the AIC and BIC. When considered with the other demographic variables, the AIC and BIC is no longer reduced by the addition of these variables and therefore these two variables are not included.

In terms of resource variables, the addition to the model of caregiver religion as well as caregiver race results in model misspecification. These variables are highly correlated, with non-white caregivers more likely than white caregivers to consider that religion makes a great difference in their lives (61% versus 17%). However, the combination of caregiver race and patient religion improves the AIC and BIC even though the coefficients for patient religion are not statistically significant (a reduction in AIC of 7 and reduction in BIC of 19). The inclusion of the other patient and caregiver resource variables increases the AIC and BIC when considered with the other control variables and these variables are not included in the model.

Therefore the model going forward includes patient SF-6D, time spent caring, internal conflicts, external conflicts and job status, as well as the control variables the difference in GHQ scores, caregiver age, gender, race, educational qualification, patient gender and the extent to which religion makes a difference in the patient's life. The diagnostic tests for this model are given in appendix 6.

In this model (Table 57; *s*(35)), the coefficients for the key explanatory variables and possible effect modifiers suggest that lower caregiver SF-6D values are associated with:

- lower patient SF-6D values (for an increase in patient SF-6D of 0.20 there is an 0.024 increase in caregiver SF-6D; p=0.09),
- greater than 35 hours spent caring per week (0.034 reduction; p=0.035),
- the presence of internal conflicts (0.06 reduction; p=0.000),
- the presence of external conflicts (0.036 reduction; p=0.013), and
- the absence of employment (0.015 reduction; p=0.416).

This is consistent with the hypotheses in section 4.11.

Of the control variables the statistically significant coefficients suggest that lower caregiver SF-6D values are associated with

- older caregiver age (0.001 reduction for each year of age; p=0.018),
- non-white caregivers (0.067 reduction; p=0.008), and
- caregiver having lower educational qualifications (0.052 reduction for someone with no educational qualification versus someone with a degree qualification; p=0.047).

In addition, the difference in GHQ scores shows that a larger positive difference between caregiver wellbeing and the patient's wellbeing is associated with higher caregiver SF-6D values, while a larger negative difference between caregiver wellbeing and the patient's wellbeing is associated with lower caregiver SF-6D values (p<0.0001).

## Table 57: Addition of the control variables

| | ***d(35)*** | | ***q(35)*** | | ***r(35)*** | | ***s(35)*** | |
|---|---|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | ***c(35)* + job status** | | ***e(35)* plus GHQ difference** | | ***q(35)* plus demographics** | | ***r(35)* plus resources** | |
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring<br>Ref less than 35 hours | **-0.034** | **0.028** | **-0.037** | **0.022** | **-0.034** | **0.033** | **-0.034** | **0.035** |
| Patient SF-6D | -0.012 | 0.748 | 0.101 | 0.153 | 0.123 | 0.087 | 0.122 | 0.090 |
| Presence external conflict Ref absent | **-0.036** | **0.012** | **-0.037** | **0.012** | **-0.038** | **0.010** | **-0.037** | **0.013** |
| Presence internal conflict Ref present | **0.079** | **0.000** | **0.063** | **0.000** | **0.058** | **0.000** | **0.060** | **0.000** |
| Job status Ref presence of job | **-0.052** | **0.001** | **-0.046** | **0.004** | -0.015 | 0.421 | -0.015 | 0.416 |
| GHQ difference | | | **-0.005** | **0.000** | **-0.005** | **0.000** | **-0.005** | **0.000** |
| Caregiver age | | | | | **-0.001** | **0.014** | **-0.001** | **0.018** |
| Caregiver race Ref white | | | | | **-0.068** | **0.006** | **-0.067** | **0.008** |
| Education Ref degree | | | | | | | - | |
| Other higher | | | | | -0.008 | 0.809 | -0.006 | 0.849 |
| A level | | | | | -0.027 | 0.331 | -0.024 | 0.396 |
| GCSE | | | | | -0.010 | 0.717 | -0.007 | 0.802 |
| Other | | | | | **-0.072** | **0.038** | -0.069 | 0.051 |
| None | | | | | **-0.055** | **0.032** | **-0.052** | **0.047** |
| Caregiver gender Ref male | | | | | -0.025 | 0.212 | -0.026 | 0.211 |
| Patient gender Ref male | | | | | -0.033 | 0.115 | -0.033 | 0.121 |
| Patient religion | | | | | | | | |
| Ref a great difference | | | | | | | - | |
| Some difference | | | | | | | -0.014 | 0.483 |
| A little difference | | | | | | | -0.003 | 0.892 |
| No difference | | | | | | | 0.007 | 0.712 |
| Constant | 0.779 | 0.000 | 0.702 | 0.000 | 0.815 | 0.000 | 0.812 | 0.000 |
| Number of obs | 454 | | 399 | | 397 | | 395 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R-squared | 0.1303 | | 0.1850 | | 0.2375 | | 0.2400 | |
| Adj R-squared | 0.1206 | | 0.1725 | | 0.2075 | | 0.2036 | |
| Root MSE | 0.14465 | | 0.14001 | | 0.13654 | | 0.13696 | |
| AIC | -461.2026 | | -429.6299 | | -438.664 | | -431.0911 | |
| BIC | -436.494 | | -401.7072 | | -374.921 | | -355.4923 | |
| Hatsq | 0.69 | | 0.23 | | 0.43 | | 0.31 | |
| Reset | 0.78 | | 0.59 | | 0.14 | | 0.23 | |

## 6.3 Addition of the interaction

### 6.3.1 Interaction patient SF-6D

The models including the interaction between internal and external conflicts and patient SF-6D are shown in Table 60. The interaction of patient SF-6D and external conflicts is statistically significant. The interaction of patient SF-6D and internal conflicts is not statistically significant. The models with the interaction for patient SF-6D and external conflicts have the highest adjusted $R^2$, but have slightly higher levels of AIC and BIC (5 and 2 points respectively) than the model without the interaction.

Table 58 shows the change in caregiver SF-6D values for an 0.20 change in patient SF-6D. The external conflicts interaction suggests that in the absence of external conflicts as patient SF-6D values increase so do caregiver SF-6D values. However, in the presence of external conflicts the association is flat: caregiver SF-6D values do not change in the presence of changes in patient SF-6D values. The interaction for internal conflicts shows no big differences in changes in caregiver SF-6D values depending on the presence or absence of internal conflicts.

**Table 58: summary of changes in conflicts by caregiver status (35 hours)**

| | No interaction | with patient SF-6D x external conflicts | with patient SF-6D x internal conflicts |
|---|---|---|---|
| N in analysis | 395 | 395 | 395 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with no conflicts | 0.024 | 0.065 | 0.0265 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with external conflicts only | 0.024 | -0.006 | 0.0265 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with internal conflicts only | 0.024 | 0.065 | 0.0215 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with both types of conflicts | 0.024 | -0.006 | 0.0215 |

### 6.3.2 Interaction time spent caring

The models including the interaction between internal and external conflicts and time spent caring are shown in Table 61. None of the interactions are statistically significant. The model with no interaction has the highest adjusted $R^2$ but the AIC and BIC are slightly smaller when the models with the interactions are considered.

Table 59 shows the change in caregiver SF-6D values for a movement to providing 35 hours of time spent caring with the different interactions. The interaction with time and internal conflicts suggests that moving to providing more than 35 hours of care per week is associated with larger reductions in caregiver SF-6D in caregivers who have internal conflicts. The interaction with external conflicts shows small differences in change in caregiver SF-6D values depending on the presence or absence of external conflicts.

**Table 59: summary of changes in conflicts by time (35 hours)**

| | No interaction | with time x external conflicts | with time x internal conflicts |
|---|---|---|---|
| N in analysis | 395 | 395 | 395 |
| Changes in caregiver SF-6D associated with caregiving more than 35 hours per week without conflicts | -0.034 | -0.038 | -0.026 |
| Changes in caregiver SF-6D associated with caregiving more than 35 hours per week with external conflicts only | -0.034 | -0.031 | -0.026 |
| Changes in caregiver SF-6D associated with caregiving more than 35 hours per week with internal conflicts only | -0.034 | -0.038 | -0.047 |
| Changes in caregiver SF-6D associated with caregiving more than 35 hours per week with both types of conflict | -0.034 | -0.031 | -0.047 |

**Table 60: Model development addition of the patient SF-6D interaction**

| | **s(35)** | | **s(35)** | | **s(35)** | |
|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | **No interaction** | | **Patient SF-6D x external conflicts** | | **Patient SF-6D x internal conflicts** | |
| | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring Ref less than 35 hours | **-0.034** | **0.035** | **-0.034** | **0.034** | **-0.034** | **0.036** |
| Patient SF-6D | 0.122 | 0.090 | **0.325** | **0.002** | 0.108 | 0.307 |
| Presence external conflict Ref absent | **-0.037** | **0.013** | **0.157** | **0.030** | **-0.037** | **0.013** |
| Presence internal conflict Ref present | **0.060** | **0.000** | **0.064** | **0.000** | 0.047 | 0.514 |
| SF-6D x external conflicts | | | **-0.354** | **0.006** | | |
| SF-6D x internal conflicts | | | | | 0.025 | 0.850 |
| Job status Ref present | -0.0147 | 0.416 | -0.013 | 0.457 | -0.015 | 0.409 |
| GHQ difference | **-0.005** | **0.000** | **-0.005** | **0.000** | **-0.005** | **0.000** |
| Caregiver age | **-0.001** | **0.018** | **-0.001** | **0.013** | **-0.001** | **0.018** |
| Caregiver race Ref white | **-0.067** | **0.008** | **-0.072** | **0.004** | **-0.067** | **0.008** |
| Education Ref degree | - | | - | | - | |
| Other higher | -0.006 | 0.849 | -0.017 | 0.608 | -0.006 | 0.853 |
| A level | -0.024 | 0.396 | -0.025 | 0.380 | -0.024 | 0.399 |
| GCSE | -0.007 | 0.802 | -0.010 | 0.706 | -0.007 | 0.808 |
| Other | -0.069 | 0.051 | **-0.069** | **0.050** | -0.069 | 0.052 |
| None | **-0.052** | **0.047** | **-0.057** | **0.028** | **-0.052** | **0.047** |
| Caregiver gender Ref male | -0.026 | 0.211 | -0.030 | 0.132 | -0.026 | 0.209 |
| Patient gender Ref male | -0.033 | 0.121 | -0.040 | 0.058 | -0.033 | 0.123 |
| Religion Ref a great difference | - | | - | | - | |
| Some difference | -0.014 | 0.483 | -0.015 | 0.471 | -0.014 | 0.492 |
| A little difference | -0.003 | 0.892 | -0.005 | 0.842 | -0.003 | 0.893 |
| No difference | 0.007 | 0.712 | 0.008 | 0.664 | 0.008 | 0.696 |
| Constant | 0.812 | 0.000 | 0.710 | 0.000 | 0.820 | 0.000 |
| Number of obs | 395 | | 395 | | 395 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | |
| R-squared | 0.2400 | | 0.2549 | | 0.2400 | |
| Adj R-squared | 0.2036 | | 0.2171 | | 0.2015 | |
| Root MSE | 0.13696 | | 0.13579 | | 0.13713 | |
| AIC | -431.0911 | | -436.9204 | | -429.129 | |
| BIC | -355.4923 | | -357.3427 | | -349.5512 | |
| Hatsq | 0.31 | | 0.34 | | 0.30 | |
| Reset | 0.23 | | 0.33 | | 0.23 | |

### Table 61: Model development addition of the time interaction

| **Caregiver SF-6D** | **No interaction** | | **Time spent caregiving x external conflicts** | | **Time spent caregiving x internal conflicts** | |
|---|---|---|---|---|---|---|
| | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring Ref less than 35 hours | **-0.034** | **0.035** | -0.038 | 0.110 | -0.047 | 0.066 |
| Patient SF-6D | 0.122 | 0.090 | 0.122 | 0.092 | 0.123 | 0.089 |
| Presence external conflict Ref absent | **-0.037** | **0.013** | **-0.039** | **0.026** | **-0.037** | **0.014** |
| Presence internal conflict Ref present | **0.060** | **0.000** | **0.061** | **0.000** | **0.054** | **0.002** |
| Time x external conflicts | | | 0.007 | 0.812 | | |
| Time x internal conflicts | | | | | 0.021 | 0.514 |
| Job status ref present | -0.015 | 0.416 | -0.015 | 0.410 | -0.015 | 0.411 |
| GHQ difference | **-0.005** | **0.000** | **-0.005** | **0.000** | **-0.005** | **0.000** |
| Caregiver age | **-0.001** | **0.018** | **-0.001** | **0.018** | **-0.001** | **0.017** |
| Caregiver race Ref white | **-0.067** | **0.008** | **-0.067** | **0.008** | **-0.067** | **0.008** |
| Education Ref degree | - | | - | | - | |
| Other higher | -0.006 | 0.849 | -0.006 | 0.853 | -0.006 | 0.846 |
| A level | -0.024 | 0.396 | -0.024 | 0.396 | -0.024 | 0.393 |
| GCSE | -0.007 | 0.802 | -0.007 | 0.797 | -0.006 | 0.817 |
| Other | -0.069 | 0.051 | -0.069 | 0.052 | -0.069 | 0.052 |
| None | **-0.052** | **0.047** | -0.052 | **0.047** | -0.052 | **0.049** |
| Caregiver gender Ref male | -0.026 | 0.211 | -0.025 | 0.216 | -0.027 | 0.194 |
| Patient gender Ref male | -0.033 | 0.121 | -0.033 | 0.120 | -0.034 | 0.110 |
| Religion Ref a great difference | - | | - | | - | |
| Some difference | -0.014 | 0.483 | -0.014 | 0.488 | -0.016 | 0.447 |
| A little difference | -0.003 | 0.892 | -0.003 | 0.893 | -0.003 | 0.899 |
| No difference | 0.007 | 0.712 | 0.007 | 0.715 | 0.007 | 0.729 |
| Constant | 0.812 | 0.000 | 0.813 | 0.000 | 0.818 | 0.000 |
| Number of obs | 395 | | 395 | | 395 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | |
| R-squared | 0.2400 | | 0.2401 | | 0.2408 | |
| Adj R-squared | 0.2036 | | 0.2016 | | 0.2024 | |
| Root MSE | 0.13696 | | 0.13713 | | 0.13706 | |
| AIC | -431.0911 | | -429.1508 | | -429.5411 | |
| BIC | -355.4923 | | -349.5731 | | -349.9634 | |
| Hatsq | 0.31 | | 0.27 | | 0.36 | |
| Reset | 0.23 | | 0.22 | | 0.22 | |

### 6.3.3 Interactions with patient SF-6D and time spent caregiving

The interaction between patient SF-6D and external conflicts and time spent caring and internal conflicts is explored in a single model and compared to the specification of the model with only the interaction with patient SF-6D and external conflicts. The model including interactions with both time spent caregiving and patient SF-6D is shown in Table 63. In both models only the interaction between patient SF-6D and external conflicts is statistically significant. Table 62 summarises the changes in caregiver SF-6D values for the different models. The relationship between patient SF-6D values and caregiver SF-6D values is consistent between models. In the absence of external conflicts an improvement in patient SF-6D of 0.20 is associated with an improvement in caregiver SF-6D of 0.065. In the presence of external conflicts the relationship becomes flat. The coefficients are statistically significant in both models. In terms of the interaction for time spent caregiving and internal conflicts. The interaction for time spent caring and internal conflicts suggests that in the presence of internal conflicts a move to providing more than 35 hours per week of care is associated with a greater reduction in caregiver SF-6D than the same move in the absence of internal conflicts. However, the coefficient is not statistically significant. The diagnostics for the 2 models are compared (Appendix 7 and 8).

**Table 62: Summary of changes in conflicts by time (35 hours)**

| | Patient SF-6D x external conflict | Patient SF-6D x external conflict and<br>Time x internal conflict |
|---|---|---|
| N in analysis | 395 | 395 |
| Changes in caregiver SF-6D associated with caregiving more than 35 hours per week with internal no conflicts | -0.034 | -0.028 |
| Changes in caregiver SF-6D associated with caregiving more than 35 hours per week with internal conflicts | -0.034 | -0.045 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with no external conflicts | 0.065 | 0.065 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with external conflicts | -0.006 | -0.005 |

**Table 63: Model development addition of the time and SF-6D interactions 35 hours**

| **Caregiver SF-6D** | **No interaction** | | **Patient SF-6D x external conflicts only** | | **Patient SF-6D x external conflicts Time spent caregiving x internal conflicts** | |
|---|---|---|---|---|---|---|
| | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring Ref < 35 hours | **-0.034** | **0.035** | **-0.034** | **0.034** | -0.045 | 0.080 |
| Patient SF-6D | 0.122 | 0.090 | **0.325** | **0.002** | **0.324** | **0.002** |
| External conflict Ref absent | **-0.037** | **0.013** | **0.157** | **0.030** | **0.156** | **0.032** |
| Internal conflict Ref present | **0.060** | **0.000** | **0.064** | **0.000** | **0.059** | **0.001** |
| SF-6D x external conflicts | | | **-0.354** | **0.006** | **-0.351** | **0.007** |
| Time x internal conflicts | | | | | 0.017 | 0.587 |
| Job status Ref present | -0.015 | 0.416 | -0.013 | 0.457 | -0.013 | 0.452 |
| GHQ difference | **-0.005** | **0.000** | **-0.005** | **0.000** | **-0.005** | **0.000** |
| Caregiver age | **-0.001** | **0.018** | **-0.001** | **0.013** | **-0.001** | **0.012** |
| Caregiver race Ref white | **-0.067** | **0.008** | **-0.072** | **0.004** | **-0.072** | **0.004** |
| Education Ref degree | - | | - | | - | |
| Other higher | -0.006 | 0.849 | -0.017 | 0.608 | -0.017 | 0.608 |
| A level | -0.024 | 0.396 | -0.025 | 0.380 | -0.025 | 0.377 |
| GCSE | -0.007 | 0.802 | -0.010 | 0.706 | -0.010 | 0.719 |
| Other | -0.069 | 0.051 | **-0.069** | **0.050** | **-0.069** | **0.050** |
| None | **-0.052** | **0.047** | **-0.057** | **0.028** | **-0.057** | **0.030** |
| Caregiver gender Ref male | -0.026 | 0.211 | -0.030 | 0.132 | -0.031 | 0.123 |
| Patient gender Ref male | -0.033 | 0.121 | -0.040 | 0.058 | -0.041 | 0.053 |
| Patient Religion | | | | | | |
| Ref a great difference | - | | - | | - | |
| Some difference | -0.014 | 0.483 | -0.015 | 0.471 | -0.016 | 0.442 |
| A little difference | -0.003 | 0.892 | -0.005 | 0.842 | -0.004 | 0.848 |
| No difference | 0.007 | 0.712 | 0.008 | 0.664 | 0.008 | 0.678 |
| Constant | 0.812 | 0.000 | 0.710 | 0.000 | 0.715 | 0.000 |
| Number of obs | 395 | | 395 | | 395 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | |
| R-squared | 0.2400 | | 0.2549 | | 0.2555 | |
| Adj R-squared | 0.2036 | | 0.2171 | | 0.2157 | |
| Root MSE | 0.13696 | | 0.13579 | | 0.13592 | |
| AIC | -431.0911 | | -436.9204 | | -435.2317 | |
| BIC | -355.4923 | | -357.3427 | | -351.6751 | |
| Hatsq | 0.31 | | 0.34 | | 0.32 | |
| Reset | 0.23 | | 0.33 | | 0.26 | |

## 6.4 Diagnostics

In general the diagnostics (appendix 7 and 8) for the models with the two different interactions are similar. All models show some kurtosis that is statistically significant.

The dfbeta plots for the key explanatory variables and interaction terms suggest that the influential coefficients appear to become more influential with the addition of the interaction with time spent caring. The leverage plots and dfbeta plots show that four points in particular warrant further exploration. The first is a female caring for their male partner. They live in a household of 4 adults but the female is the sole caregiver and she provides care for more than 100 hours a week. Her SF-6D score is 0.40 and that of her partner is 0.51. The second are two caregivers who share care. They both provide care for more than 100 hours a week. Their SF-6D scores are both 0.92 and that of the person they care for is 0.48. The third is a male being cared for by his female partner providing 35 to 49 hours of care a week. The caregiver is a sole caregiver and has an SF-6D score of 0.37 and the patient has an SF-6D score of 0.71. The fourth is a male patient being cared for by a female sole caregiver. The caregiver has an SF-6D of 0.59 and the patient has an SF-6D of 0.79. Three of the four outliers are for caregivers with lower SF-6D scores than the person they care for. The analysis and diagnostics removing these patient and caregiver pairs is shown in appendices 12 and 13.

Appendix 12 shows that the analyses removing the possible influential observations show little change in the coefficients. The statistical significance of the coefficients is unchanged: the interaction with caregiver SF-6D and external conflicts remains statistically significant, while the interaction with time spent caring and internal conflicts remains not statistically significant. The adjusted $R^2$ increases with the removal of the possible influential points, but the AIC and BIC also increase.

**Table 64: summary of changes in conflicts by time (35 hours)**

| | Patient SF-6D x external conflicts | | Patient SF-6D x external conflicts and Time x internal conflicts | |
|---|---|---|---|---|
| | Whole sample | Removing outliers | Whole sample | Removing outliers |
| N in analysis | 395 | 390 | 395 | 390 |
| Changes in caregiver SF-6D associated with caregiving more than 35 hours per week with no internal conflicts | -0.034 | -0.032 | -0.028 | -0.03 |
| Changes in caregiver SF-6D associated with caregiving more than 35 hours per week with internal conflicts | -0.034 | -0.032 | -0.045 | -0.037 |

| | | | | |
|---|---|---|---|---|
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with no external conflicts | 0.065 | 0.073 | 0.065 | 0.073 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with external conflicts | -0.006 | 0.0003 | -0.005 | 0.0005 |

Table 64 shows the summary of changes in caregiver SF-6D values with and without the potentially influential observations. The potentially influential observations are not unduly affecting the analyses. The relationship between patient SF-6D values and caregiver SF-6D values in the presence and absence of external conflicts is unchanged with the removal of the observations. However, the difference in the change in caregiver SF-6D values in the presence or absence of internal conflicts with the move to providing more than 35 hours of care becomes smaller. On this basis the interaction between time spent caregiving and internal conflicts does not go forward. Therefore the final model includes the key explanatory variables patient SF-6D, time spent caregiving, external conflicts, internal conflicts, job status, an interaction between patient SF-6D and external conflicts and the control variables caregiver age, gender, race, education level and patient gender, the difference in GHQ scores and the extent to which religion makes a difference in the patient's life.

## 6.5 Alternative specification of time spent caring

The development of the 20-hour model took place over the same stages as the 35-hour model and is shown in appendices 9, 10 and 11. In general the pattern of results is similar and the alternative specification provides support for the findings in the base model.

To compare the models without the interaction, the coefficients for the key explanatory variables and possible effect modifiers suggest that lower caregiver SF-6D values are associated with:

- lower patient SF-6D values (for an increase in patient SF-6D of 0.20 there is an 0.028 increase in caregiver SF-6D; p=0.034),
- greater than 20 hours spent caring per week (0.024 reduction; p=0.079),
- the presence of internal conflicts (0.06 reduction; p=0.000),
- the presence of external conflicts (0.034 reduction; p=0.011), and
- the absence of employment (0.028 reduction; p=0.094).

The main difference is that the coefficient for time spent caring is not statistically significant with the 20 hours per week cut point and the coefficient for patient SF-6D is statistically significant. The other coefficients and their statistical significance are similar.

The addition of the interaction shows a similar pattern as for the 35-hour model. Only the interaction for patient SF-6D and external conflicts is statistically significant. In the absence of external conflicts an increase in patient SF-6D of 0.20 is associated with an increase in caregiver SF-6D of 0.059; in the presence of external conflicts this is reduced to 0.008. This compares with 0.065 and -0.006 respectively for the 35 hour model.

## 6.6 Consistency across caregiver groups

The Understanding Society dataset includes a heterogeneous group of caregivers. The next set of analyses explores the consistency of the relationship between patient SF-6D values, time spent caring and caregiver SF-6D values for different groups of caregivers:

- Including only caregivers caring for their partners
- Excluding caregivers who share care with other people in the household
- Excluding caregivers who receive care from someone in the household
- Excluding caregivers caring for someone with a mental as well as a physical disability (that is, the care recipient reports having a diagnosis of clinical depression as well as arthritis).

The summary table (Table 65) shows that for the whole arthritis sample, providing care for more as opposed to less than 35 hours a week is associated with a reduction in caregiver SF-6D of 0.034. The values for the different groups of caregivers range from 0.031 to 0.042. The coefficients are statistically significant except for the coefficient for the analysis that excludes caregivers caring for someone with both arthritis and clinical depression.

Considering the association between patient SF-6D values and caregiver SF-6D values, the analysis for the whole arthritis dataset suggests that in the absence of external conflicts an improvement in patient SF-6D of 0.20 is associated with an increase in caregiver SF-6D of 0.065. For the different groups of caregivers the value ranges between 0.056 and 0.065. In the presence of external conflicts, caregiver SF-6D is flat: it is associated with very small increases or decreases in SF-6D for a gain in patient SF-6D of 0.20 and this is seen across the different caregiver groups. The interaction effect is statistically significant across each of the caregiver groups except for the analysis using only sole caregivers.

**Table 65: Summary of changes in caregiver SF-6D by caregiver status**

| | Whole sample | Caring for partner | Sole caregiver | Caregiver not receiving care | Patient with physical disability only |
|---|---|---|---|---|---|
| N in analysis | 395 | 290 | 338 | 341 | 333 |
| Changes in caregiver SF-6D associated with increased time spent caregiving | -0.034 | -0.04 | -0.042 | -0.036 | -0.031 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with no external conflicts | 0.065 | 0.062 | 0.056 | 0.058 | 0.062 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with external conflicts | -0.006 | -0.00005 | 0.008 | -0.009 | -0.003 |

## Table 66 Consistency across caregiving groups (35 hours)

| **Caregiver SF-6D** | **Whole sample** | | **Caring for partner** | | **Sole caregiver** | | **Does not receive care** | | **Physical only** | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring<br>Ref less than 35 hours | **-0.034** | **0.034** | **-0.040** | **0.028** | **-0.042** | **0.017** | **-0.036**<br>**0.025** | | **-0.031** | **0.083** |
| Patient SF-6D | **0.325** | **0.002** | **0.307** | **0.008** | **0.279** | **0.014** | **0.292** | **0.005** | **0.309** | **0.005** |
| External conflict Ref absent | **0.157** | **0.030** | 0.141 | 0.095 | 0.089 | 0.274 | **0.145** | **0.046** | 0.140 | 0.081 |
| Presence internal conflict Ref present | **0.064** | **0.000** | **0.073** | **0.000** | **0.067** | **0.000** | **0.060** | **0.000** | **0.066** | **0.000** |
| SF-6D x external conflicts | **-0.354** | **0.006** | **-0.308** | **0.042** | -0.237 | 0.102 | **-0.337** | **0.009** | **-0.324** | **0.021** |
| Job status | -0.013 | 0.457 | -0.024 | 0.312 | -0.021 | 0.309 | 0.009 | 0.616 | -0.011 | 0.579 |
| GHQ difference | **-0.005** | **0.000** | **-0.005** | **0.000** | **-0.005** | **0.000** | **-0.004** | **0.000** | **-0.005** | **0.000** |
| Caregiver age | **-0.001** | **0.013** | -0.0002 | 0.762 | -0.001 | 0.059 | **-0.001** | **0.018** | **-0.001** | **0.021** |
| Caregiver race Reference white | **-0.072** | **0.004** | -0.067 | 0.072 | -0.053 | 0.069 | **-0.082** | **0.001** | **-0.066** | **0.016** |
| Education Ref degree | - | | - | | - | | - | | - | |
| Other higher | -0.017 | 0.608 | -0.049 | 0.209 | -0.021 | 0.548 | -0.011 | 0.728 | -0.001 | 0.968 |
| A level | -0.025 | 0.380 | -0.057 | 0.117 | -0.019 | 0.552 | -0.033 | 0.225 | -0.029 | 0.332 |
| GCSE | -0.010 | 0.706 | -0.030 | 0.429 | -0.007 | 0.812 | -0.020 | 0.454 | -0.004 | 0.881 |
| Other | **-0.069** | **0.050** | **-0.093** | **0.022** | -0.074 | 0.058 | **-0.080** | **0.027** | -0.066 | 0.095 |
| None | **-0.057** | **0.028** | **-0.096** | **0.004** | **-0.065** | **0.023** | -0.040 | 0.121 | **-0.055** | **0.045** |
| Caregiver gender Ref male | -0.030 | 0.132 | 0.118 | 0.106 | -0.035 | 0.155 | -0.022 | 0.258 | -0.032 | 0.151 |
| Patient gender Ref male | -0.040 | 0.058 | 0.100 | 0.166 | -0.042 | 0.097 | -0.023 | 0.265 | -0.040 | 0.089 |
| Religion Ref a great difference | - | | - | | - | | - | | - | |
| Some difference | -0.015 | 0.471 | 0.001 | 0.967 | -0.013 | 0.552 | -0.011 | 0.605 | 0.003 | 0.891 |
| A little difference | -0.005 | 0.842 | 0.014 | 0.587 | 0.004 | 0.887 | -0.004 | 0.867 | 0.021 | 0.398 |
| No difference | 0.008 | 0.664 | 0.028 | 0.213 | 0.009 | 0.670 | 0.008 | 0.672 | 0.030 | 0.160 |
| Constant | 0.710 | 0.000 | 0.522 | 0.000 | 0.737 | 0.000 | 0.722 | 0.000 | 0.701 | 0.000 |
| Number of obs | 395 | | 290 | | 338 | | 341 | | 333 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R-squared | 0.2549 | | 0.2436 | | 0.2490 | | 0.2197 | | 0.2594 | |
| Adj R-squared | 0.2171 | | 0.1904 | | 0.2041 | | 0.1735 | | 0.2144 | |
| Root MSE | 0.13579 | | 0.13708 | | 0.13888 | | 0.12561 | | .13671 | |
| AIC | -436.9204 | | -310.3199 | | -355.9211 | | -427.7445 | | -360.9006 | |
| BIC | -357.3427 | | -236.9223 | | -279.4602 | | -351.1069 | | -284.7378 | |
| Hatsq | 0.34 | | 0.61 | | 0.41 | | 0.20 | | 0.18 | |
| Reset | 0.33 | | 0.85 | | 0.53 | | 0.30 | | 0.24 | |

### Effect of the household

The next set of analyses explores the effect of the household. Within Understanding Society some patients may have more than one caregiver within the household: therefore the data are clustered. For the analysis using time spent caring as 35 hours the number of patients is 395 and the number of households 359. The analyses including an effect of the household are shown in appendix 14.

The summary table (Table 67) shows that providing care for more as opposed to less than 35 hours a week is associated with a reduction in caregiver SF-6D of 0.034. Taking into account the effect of the household the figure is 0.036. Both are statistically significant.

Considering the association between patient SF-6D values and caregiver SF-6D values, the analysis using 35 hours (Table 67) for the whole dataset suggests that in the absence of external conflicts an improvement in patient SF-6D of 0.20 is associated with an increase in caregiver SF-6D of 0.065. Taking into account the effect of the household this figure is 0.061. In the presence of external conflicts, caregiver SF-6D is associated with a reduction of 0.006 for a gain in patient SF-6D of 0.20. This value is similar (0.008) in the analysis taking into account the effect of the household. In both analyses the main effect for patient SF-6D and presence of external conflicts, and the interaction effect, are statistically significant.

**Table 67: Summary of changes in caregiver SF-6D by caregiver status**

| | 35 hours | |
|---|---|---|
| | No effect household | Effect household |
| N in analysis | 395 | 395 |
| Changes in caregiver SF-6D associated with increased time spent caregiving | -0.034 | -0.036 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with no external conflicts | 0.065 | 0.061 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with external conflicts | -0.006 | -0.008 |

## 6.7 Summary

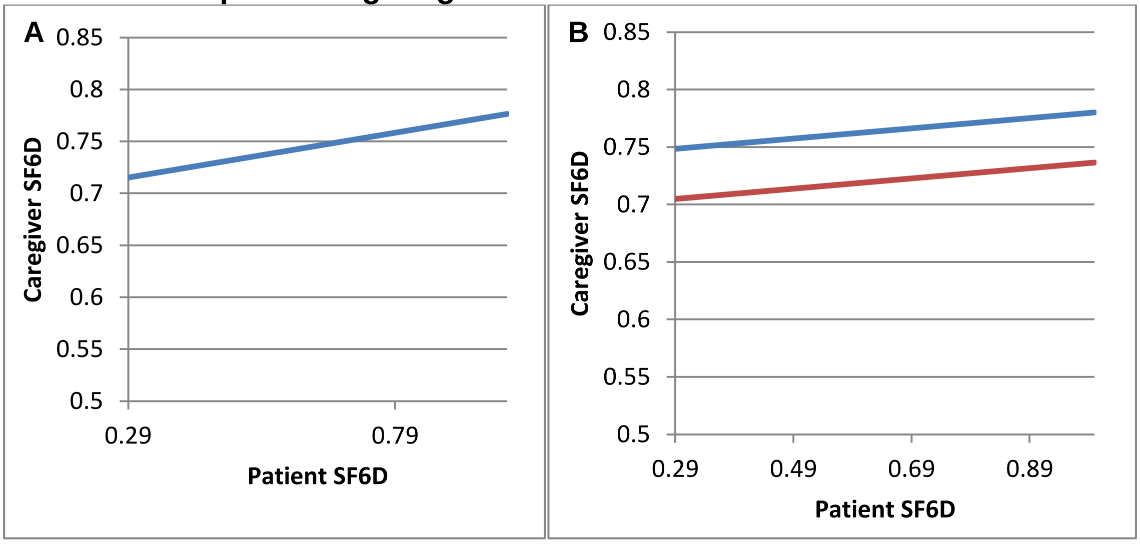
The model including only patient SF-6D and caregiver SF-6D shows a positive relationship between patient SF-6D values and caregiver SF-6D values but the relationship is not statistically significant. In this model the coefficient suggests that an increase in patient SF-6D of 0.20 is associated with an increase in caregiver SF-6D of 0.017 (Figure 36: A). Adding time spent caregiving to the model makes the gradient of the slope less steep (Figure 36: B);

with the inclusion of both patient SF-6D and time spent caregiving in the model an increase in patient SF-6D of 0.20 is associated with an increase in caregiver SF-6D of 0.004, and again the association is not statistically significant. In the model with the two variables, an increase in time spent caregiving from less than to more than 35 hours is associated with a reduction in caregiver SF-6D of 0.04 that is statistically significant.

With the addition of the control and conflicts variables the relationship between patient SF-6D values and caregiver SF-6D values remains positive (Figure 37: C). The coefficient shows that an increase in patient SF-6D of 0.20 is associated with an increase in caregiver SF-6D of 0.024. Again the coefficient is not statistically significant. An increase in time spent caregiving from less than to more than 35 hours is associated with a 0.034 reduction in caregiver SF-6D that is statistically significant. In the presence of internal and external conflicts caregiver SF-6D is 0.06 and 0.037 lower respectively than in the absence of these conflicts, and these coefficients are statistically significant.

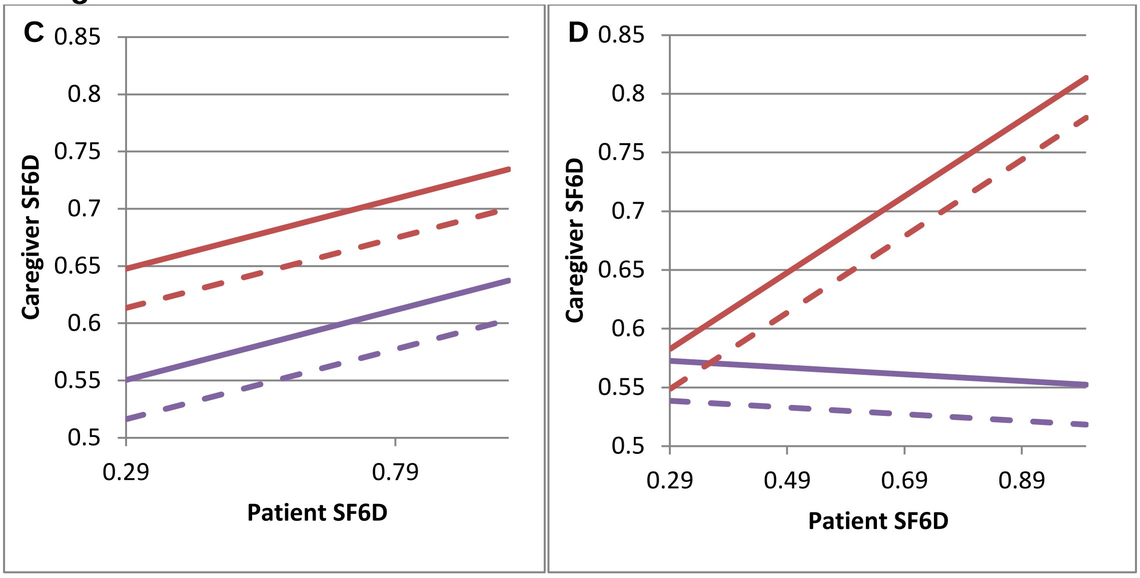
The final model includes an interaction between patient SF-6D and presence of external conflicts (Figure 37: D). The model shows that a change in patient SF-6D of 0.20 is associated with a change in caregiver SF-6D of 0.065 in the absence of external conflicts and -0.006 in the presence of external conflicts. That is, when caregivers feel dissatisfaction with one or more of their finances, relationship or leisure time, there is no change in their SF-6D values associated with patient improvements in SF-6D values. In contrast in the absence of such conflicts as patient SF-6D values improve so do caregiver SF-6D values.

**Figure 36: Relationship between patient SF-6D and caregiver SF-6D with and without time spent caregiving**



**Key:** on left model with patient SF-6D; on right model with patient SF-6D, time spent caring. On the model on the right the red line represents greater than 35 hours per week spent caregiving and the blue line less than 35 hours per week spent caregiving.

**Figure 37: Relationship between patient SF-6D, time spent caregiving and caregiver SF-6D with and without the interaction**



**Key:** on left model with all variables but no interaction; on right model with all variables and interaction for some patient SF-6D and external conflicts. Red lines represent absence of external conflicts, purple lines represent presence of external conflicts. Solid lines represent less than 35 hours caregiving per week, dashed lines more than 35 hours per week.

In terms of the control variables, the final model shows that lower caregiver SF-6D values are associated with older caregivers, caregivers being non-white, caregivers with lower education qualifications (no qualification as opposed to degree qualification). The coefficients for these variables were statistically significant. Other variables (caregiver and patient gender and the difference religion made in the patient's life) were not statistically significant but were retained in the model because they improved the AIC, BIC or diagnostic tests. The inclusion or exclusion of the statistically non-significant variables did not affect the key parameters of interest namely the coefficients for patient SF-6D and time spent caregiving. The difference in GHQ scores between patients and caregivers was included in the final model. This coefficient suggests that in a scenario where 2 caregivers had the same GHQ score, a caregiver caring for someone with a worse GHQ than them would have a better SF-6D score than a caregiver caring for someone with a better GHQ score than them.

The relationship between patient HRQOL, caregiver HRQOL and time spent caregiving is seen consistently across different caregiver groups when an effect of the household is included and when time spent caregiving is specified in an alternative form. For the 35-hours analysis the reduction in caregiver SF-6D associated with increased time spent caregiving varies between 0.031 and 0.042. The gain in caregiver SF-6D associated with a gain in patient SF-6D of 0.20 ranges from 0.056 to 0.065 in the absence of external conflicts, and in the presence of external conflicts ranges from -0.00005 to 0.008.

## Table 68: Summary table of effects

| | 35 hours | | | | | | 20 hours | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Base model | Caregiver groups | | | | House hold effect | Base model | Caregiver groups | | | | House hold effect |
| | | Partner | Sole carers | No care | Physical only | | | Partner | Sole carers | No care | Physical only | |
| | 395 | 290 | 338 | 341 | 333 | 395 | 474 | 353 | 411 | 414 | 403 | 474 |
| Changes in caregiver SF-6D associated with increased time spent caregiving | -0.034 | -0.04 | -0.042 | -0.036 | -0.031 | -0.036 | -0.022 | -0.023 | -0.017 | -0.024 | -0.019 | -0.020 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with no external conflicts | 0.065 | 0.062 | 0.056 | 0.058 | 0.062 | 0.061 | 0.059 | 0.052 | 0.053 | 0.059 | 0.057 | 0.055 |
| Changes in caregiver SF-6D associated with an increase in patient SF-6D of 0.20 with external conflicts | -0.006 | -0.00005 | 0.008 | -0.009 | -0.003 | -0.008 | 0.008 | 0.017 | 0.028 | 0.005 | 0.008 | 0.003 |

# 7 Discussion

## 7.1 Introduction

This chapter discusses the findings of the thesis. In the first part of the chapter the main results and findings from each of the previous chapters are outlined. The chapter then considers the strengths and weaknesses of the research in this thesis and contextualises the findings in relation to other evidence. Finally the chapter discusses implications for people doing research about caregiving and areas for further research.

## 7.2 Statement of findings

Chapter 2 of this thesis provides the background to key concepts. The systematic review in chapter 3 starts the research process by considering existing studies of the effect of caregiving on adults with chronic arthritis conditions. The systematic review identified no studies that had investigated the effect of patient HRQOL on caregiver's HRQOL and few studies that had considered the effect on caregivers of increased time spent caregiving or the role of environmental factors in this relationship. Instead, existing literature has tended to focus on the factors influencing caregiver depression or care-specific aspects of the caregiver experience such as caregiver perceived burden. The findings of the systematic review led to a secondary data analysis presented in chapters 4-6. Chapter 4 assesses existing datasets and their ability to answer a question about the relationship between patient and caregiver HRQOL. The chapter identifies that there are limitations in existing datasets in terms of the collection of validated measures of HRQOL, measures of time spent caregiving and the ability to link care-recipients and their caregivers. The Understanding Society dataset is identified from the available datasets and the data used to create pairs of people with arthritis and their caregivers so as to analyse the relationship between patient SF-6D values, time spent caregiving and caregiver SF-6D values and the other factors that influence this relationship. Chapter 6 describes the analysis completed, statistically significant factors associated with worse caregiver SF-6D values were increased time spent caregiving, worse patient SF-6D values, the presence of external conflicts, the presence of internal conflicts, caregivers being non-white, older caregivers, caregivers with lower educational qualifications and caregivers having a lower wellbeing score than the person they provided care for. An interaction was identified that suggested that in the absence of external conflicts such as financial concerns or leisure and partner dissatisfaction as patient SF-6D values increased so did caregiver SF-6D values. However, in the presence of external conflicts as patient SF-6D values increased, caregiver SF-6D values remained flat.

This finding was consistent across a variety of caregiver groups and specifications, adding confidence to the robustness of the observed findings.

## 7.3 Contribution to knowledge

No previous systematic reviews of the existing literature on the effects on caregivers of caregiving for someone with arthritis were identified. Therefore this thesis starts with a systematic review of the existing literature. The systematic review incorporates a range of study types and brings these together in a novel cross-study synthesis that combines evaluative studies with observational and qualitative designs. This thesis adds to knowledge by first, bringing together the existing literature about what is already known about the topic. Second, the systematic review adds to the existing knowledge base by identifying the limitations in the existing research and in particular the limited consideration of the role of secondary stressors (that is internal and external conflicts) in moderating caregiver outcomes and also the limitations in the dependent variables included in the analyses: few studies measure time spent caring, and no studies measure caregiver HRQOL. Third, the systematic review adds to existing knowledge by using caregiving theory to create a structure for the synthesis of factors influencing caregiver outcomes. The systematic review expands Pearlin's model of caregiver outcomes to consider a greater range of patient-related factors such as patient resources that may also influence caregiver HRQOL.

In the absence of relevant existing research, the thesis then quantifies the association between patient HRQOL and caregiver HRQOL and the other factors involved using a UK dataset, Understanding Society. This analysis contributes to knowledge by firstly creating a dataset for analysis in which the patient and caregiver pairs are linked, and then ordering the variables in Understanding Society within Pearlin's framework of caregiver outcomes. The analysis of the dataset then extends existing research by including a large sample of both patients and their caregivers and quantifying the association between patient and caregiver HRQOL and time spent caregiving. The analysis also extends existing research by formally examining the role that internal and external conflicts have on caregivers both in terms of the direct effect on caregiver HRQOL and also the moderating role they play on the effect of changes in patient HRQOL on caregiver HRQOL. In particular it identifies the role that external conflicts may play in moderating the association between patient and caregiver HRQOL. Within the context of NICE technology appraisals the relationship between patient HRQOL and caregiver HRQOL has rarely been quantified and discussion of caregiver effects has mainly been a qualitative consideration derived from patient expert evidence. The findings in this thesis demonstrate that it is possible to support qualitative considerations with quantitative analysis using measures that could be adopted within existing NICE technology appraisal methodology. Further, this analysis demonstrates the complexity of the relationship between patient HRQOL and caregiver HRQOL and acts to warn against adopting too simplistic an approach to considering caregiver effects without also considering other external and internal conflicts that arise from caregiving.

## 7.4 Strengths and weaknesses

The strengths of the thesis are: the systematic identification of existing research; the use of theory to guide the research; the measures used in the secondary dataset analysis; the size and UK context of the dataset analysis; and the consistency of the findings.

The systematic review uses pre-specified methods to identify, appraise and synthesise relevant research. The criteria used to identify studies are comprehensive and the review uses established tools to appraise the quality of the literature. The approach taken ensures that the research does not duplicate what is already known, informs the variables of interest in the analysis and supports specification of the model in the secondary dataset analysis. Having completed a systematic review there can be confidence that the secondary dataset analysis is novel and builds on existing research.

Both the systematic review and the secondary dataset analysis are contextualised within existing theory of caregiving and specifically Pearlin’s model of caregiver outcomes. This is a widely used framework for considering caregiver outcomes. The use of theory to guide the research has a number of advantages. First, it provides structure to the analysis of a very complex area and helps to focus the research to ensure that the potential variables of interest are identified and included in the analysis where these are available. Second, it helps to consider what might be expected to be seen in the secondary dataset analysis and to interpret the findings of the secondary dataset analysis. Third, the broad scope of the theory allows the extension of the framework to also consider in more detail the association between caregiver outcomes and patient-reported measures.

The Understanding Society dataset used in the secondary data analysis is a large UK dataset. The size of the dataset, even with missing values, is larger than other analyses identified in the systematic review and the UK source of data gives the thesis direct relevance to the context of reimbursement in England. Understanding Society includes a broad range of measures relevant to studying the outcomes of caregivers and includes HRQOL measured using the SF-12 and a measure of time spent caregiving.

The findings from the secondary dataset analysis are shown to be consistent. The reductions in caregiver SF-6D associated with increased time spent caring and the associations between patient SF-6D and caregiver SF-6D have been shown to be similar across a variety of caregiver subgroups, specification of time spent caring and with and without an effect of the household to account for clustering.

There are also a number of limitations to the research in this thesis.

Completing secondary data research rather than primary data collection means that not all variables that could be important are available for study. Possible effects such as the caregiver's subjective feelings about providing care (that is primary subjective stressors such as caregiver perceived burden) could not be accounted for in the analysis. Further, the measures of social support collected in Understanding Society are limited in the wave 1 used in the analysis. Judgement was also needed about how to categorise some variables within the framework for analysis; this was a particular problem for the psychological measures such as internal conflicts and resources.

The use of Pearlin's framework is both a strength and a possible weakness. Alternative caregiving theories may have led to a different framing of the research question, of selection of variables for the analysis and of the relationships that may be expected.

The time variable included in Understanding Society was included in analyses in a binary format <>20 hours and <>35 hours and was collected in a categorical manner. For inclusion in health economic modelling a continuous variable would be more appropriate, though such a variable is fraught with errors of measurement (70).

While the availability of the SF-12 in Understanding Society is a strength, in that it can be transformed to the SF-6D and used to calculate a QALY, this is also a weakness. The measure available, the SF-6D, is not the preferred measure for decision making by NICE in England. Further the SF-6D has widely recognised issues with capturing changes in some health states (172,173). Other measures such as caregiver-specific measures (66,157) may be more sensitive in picking up changes in caregiver quality of life, though subsequently including these in health economic evaluations using the terms of the current reference case required by NICE would be challenging.

Because the Understanding Society dataset only measures caregiving within a household, the associations with caregiver HRQOL may not be generalizable to caregiving outside of the household. This is because caregiving within the household is more likely to include personal tasks and tasks that are less easily combined into the caregiver's routine in a flexible way. The Understanding Society dataset does not include questions about the care being provided. Because care tasks are not measured in Understanding Society it is not possible to assess the extent to which the type of care task may influence caregiver HRQOL.

As with many large datasets Understanding Society has missing data. The missing data in Understanding Society is primarily because of participants not completing the self-completion questionnaire. Analysis of the missing data suggests that there may be a pattern to the missingness associated with race and health status, with participants who are non-white and have lower health status being less likely to complete the questionnaire. The analysis in this thesis is based on a completers analysis which means that observations with missing data were dropped. This means that the analysis is not the most efficient use of data and if the data are not missing completely at random could be prone to bias. Multiple imputation methods would have allowed for all observations to be used, but uses an assumption of missingness at random. An alternative approach to analysis could have been to have completed a multiple imputation analysis and compared this to outcomes using a completer analysis. However, within this dataset there is a suggestion that there may be more than one missingness mechanism and that the missingness is not only at random.

The analysis is cross-sectional. A longitudinal analysis would more appropriately allow conclusions to be drawn about changes in patient HRQOL and caregiver HRQOL over time. It would be possible to extend the research in this thesis to encompass longitudinal analysis because the Understanding Society dataset follows the same households each year and five-year data are now available, which means that changes in SF-6D over time could be studied and compared to the outcomes of the cross sectional analysis. However, since Wave 1, the SF12 has been collected as part of the self-completion questionnaire and not the interviewer-led questionnaire and therefore may be associated with non-random missingness which could affect the accuracy of a longitudinal analysis.

The analyses in this thesis only include effects to caregivers, while this is consistent with the NICE reference case for health economic evaluations (2) from a theoretical perspective such as welfare economics and utility maximisation, an analysis that sought to capture the effects of an intervention on society would have been more appropriate (177). Within the Understanding Society dataset it would be possible to expand the perspective of the analysis beyond patients and their caregivers to include the effects of a patient’s arthritis on all members of the household. Within the sample of households used in this analysis there are a small number of other people (N=89) living in these households who are neither patients nor caregivers. In addition, in the dataset there is a large sample of people (N=5480) living households that include a person with arthritis but with no caregiver resident.

The use of ordinary least squares regression in the analysis has a number of limitations:

First, although ordinary least squares regression is used to model associations between variables and SF-6D (178-181), SF-6D data is often skewed and is bounded at 1.00. These characteristics mean that the assumptions for ordinary least squares regression may not be met. In this analysis the plots of caregiver SF-6D values show left skew and the data ranges from the lower boundary of 0.35 to the upper boundary of 1.00. In addition, the plots of the residuals versus fitted (predicted) values show a pattern that suggests the data may be heteroscedastic. Alternative modelling approaches such as Tobit models, censored least absolute deviation models, latent class models, two-part models, beta regression and mixture models (182, 183) could have been explored after the OLS analysis was completed. Second, Pearlin’s model includes a wide range of variables some of which are related to each other. The presence of collinear predictors can lead to problems identifying which variable is appropriate to include as well as challenging interpretation of regression coefficients as the standard error of coefficients can be affected. The regression diagnostics did not suggest that variables in the final model were highly collinear and the variables in the final model were consistent with expectations from caregiving theory. However, when developing the model, the coefficients for some variables were sensitive to the addition or deletion of other variables (for example caregiver age and job status, and difference in patient and caregiver GHQ score and patient SF6D value) and some predictors had high pairwise correlations (for example patient and caregiver race and patient and caregiver age). Therefore, alternative approaches to modelling such as partial least square regression or principle components analysis may have been more appropriate. Third, stress-process models and Pearlin’s model are longitudinal e.g. they explain the proliferation of stress over time, therefore a longitudinal dataset and analysis would more accurately reflect the theoretical framework that forms the basis of the analysis in this thesis.

## 7.5 Findings in relation to other evidence

The profile of impairment in arthritis, that is physical impairment without cognitive impairment means that the findings in this study may not be expected to be the same as for caregiving studies from other populations or from mixed populations of caregivers (184).

Comparing the findings of the secondary dataset analysis with the existing literature, the direct of effect of patient HRQOL, time spent caring and internal and conflicts are as expected. In general the literature supports a positive association between patient and caregiver health outcomes whereby caregivers of patients with greater disabilities have worse health outcomes (185) and increased time spent caring is associated with worse caregiver outcomes (186–188). As per, Bobinac et al. (189) an effect of both time spent caring and caregiver HRQOL and patient HRQOL and caregiver HRQOL is identified.

However, the nature of the relationship is found to vary depending on the measure of time spent caring used. The finding that the presence of dissatisfaction with one of more of finances, leisure and relationships and the presence of the caregiver not feeling optimistic, relaxed or playing a useful role is associated with worse caregiver health outcomes is also expected given the manner in which these variables were measured.

Of the control variables the findings suggest that lower caregiver SF-6D is associated with older caregivers, non-white caregivers and caregivers with lower educational qualifications. Within the caregiving literature the effect of caregiving on these factors has not always been consistent (13,59,60). Some studies have identified that younger caregivers may be more subject to worse outcomes than older caregivers (13). Further, the association between race and caregiver outcomes is inconsistent within the literature and most likely depends on exact combination of race and ethnicity studied (59,178,191). However, the findings in this thesis are consistent with population studies (168,169) which tend to show worse SF-6D outcomes for people who are older, non-white and with lower educational qualifications.

The interaction identified in this thesis was between patient SF-6D values and presence of external conflicts (defined as presence of relationship dissatisfaction, financial concerns and leisure dissatisfaction) in the caregiver’s life. In the presence of external conflicts increases in caregiver SF-6D values associated with increases in patient SF-6D values were much smaller. An interaction was also assessed between time spent caregiving and internal and external conflicts, but was not found to be sufficiently consistent or strong for it to be included in the final model. The identification of an interaction was expected as per caregiving theory, where secondary stressors while being a source of negative outcomes in their own right, also moderate the effects of the primary stressors creating negative caregiver outcomes (73, 94). The reasons for an absence of interaction with time spent caregiving could be that the binary nature of the variable meant it was insufficiently sensitive to identify an interaction, or that the measures included in the composite internal conflicts measure were not the best exemplars of internal conflicts. Variables specifically measuring caregiver fulfilment and self-efficacy may have better identified an interaction.

## 7.6 Implications for research

The study in this thesis could be extended using the same principles to a longitudinal study. The five-year data in Understanding Society that are now available could provide corroboration of the results identified. The analysis could also be extended to datasets from other countries (for example HILDA in Australia) that could also offer further corroboration, and the analysis could also be extended to other disease areas to consider whether the same pattern of results is seen across other disease areas. Finally Understanding Society could be used to analyse the effects of illness within a household and use not only a sample of caregivers, but all household members and control for caregiving as an explanatory variable. This could help address questions around how the effects of caregiving are different from those of other family members who do not provide care (174,189).

For people studying caregiving and people developing databases that allow people to study caregiving, the findings of the thesis suggest that it is important to collect information about financial, leisure and relationship conflicts that caregivers are experiencing. Given the limitations of the measures included in the study, it is also recommended that Understanding Society incorporates a caregiving module into the questionnaire for example in the same way that the General Household Survey did in 2000. This would allow researchers to capitalise on the data available in the dataset. For other databases that collect measures from patients and their caregivers it is underlined that to support detailed analysis it is necessary to be able to uniquely identify within the dataset the patient and their caregiver.

Researchers (for example Brouwer (3)) have argued for the importance of accounting for the effects of caregiving in health economic evaluations. The findings of this study support an effect on caregiver HRQOL of patient HRQOL and time spent caring that could be accounted for in health economic evaluations. When designing health economic evaluations it is important to consider the multiple effects to caregivers, in terms of the effect on caregiver HRQOL of changes in time spent caring and changes in patient HRQOL. It should be possible to capture how time spent caregiving changes over the patient life time depending on their health status and how this affects caregiver HRQOL, as well as how patient HRQOL changes over the lifetime and the effect that this has on caregiver HRQOL.

The relationship between patient HRQOL and caregiver HRQOL, and time spent caregiving and caregiver HRQOL identified in this thesis could be taken forward and included in economic evaluations of treatments for arthritis. One way is suggested here, using economic modelling of rheumatoid arthritis as an example. In economic models of treatments for rheumatoid arthritis, patients enter the model with a set of baseline characteristics and a HRQOL value. This HRQOL value changes over time as the disease responds to treatment, as treatment effects wane and patients experience underlying progression of disease. These changes in HRQOL over time are used to calculate costs and benefits. Differences in costs and benefits mainly accrue between treatments because they are modelled as having differing response rates, differing treatment withdrawal rates and differing abilities to modify underlying disease progression. This creates different HRQOL profiles and also treatment costs (such as drug costs but also other disease-related costs such as hospitalisation) between the modelled groups. To include caregivers in the economic model, caregivers would be assigned a HRQOL value on entering the model based on a set of baseline characteristics, then as patient HRQOL changes over time, changes in caregiver HRQOL would also be included by relating changes in patient HRQOL to changes in caregiver HRQOL based on the calculations in this thesis. Patients who experienced greater worsening changes in HRQOL would also tend to have caregivers who would accrue larger decrements in utility. The differences in the decrements would then be accounted for in the calculation of the difference in benefits between modelled treatment groups. The relationship between time spent caregiving and caregiver HRQOL could also be accounted for in the model. To do this, the model would first need to calculate the likelihood of a patient requiring more than 35 hours of care per week (or alternatively more than 20 hours per week) given their baseline characteristics and HRQOL value. For patients requiring a greater amount care per week their caregiver would receive decrement in their utility based on the calculations in this thesis. This calculation could be updated over time as a greater proportion of caregivers found themselves providing more care. Differences in utility would accrue where treatments better prevented disease progression or provided better response rates and fewer patients entered a health state where the caregiver had to provide greater hours of care. .

## 7.7 Conclusions

This thesis set out to increase the understanding of the association between patient HRQOL, time spent caregiving and caregiver HRQOL. This thesis identifies that there is an association between patient HRQOL, time spent caregiving and caregiver HRQOL that can be quantified using existing datasets. As well as identifying the relationship between patient HRQOL and caregiver HRQOL the thesis also shows the importance of understanding and recognising the other factors that also play a role in determining caregiver HRQOL. In particular the financial, relationship and social difficulties faced by many caregivers (180) may act to reduce the beneficial effects that patient improvement in disease status can have.

From the perspective of NICE evaluations and in particular NICE technology appraisals, the effect of caregivers has rarely been included in health economic evaluations submitted to NICE and where evidence of an effect has been submitted, this has often only been considered qualitatively without formal modelling. The analysis in this thesis has shown that there is an effect to caregivers from changes in time spent caring and patient HRQOL that could be formally included in economic evaluations using measures such as those preferred by NICE. Although the focus of this analysis is on arthritis, there is no reason why the principles may not be applied to other disease areas.

From a wider health and social policy perspective, it is important to recognise that although caregiving within the household is an important mechanism of providing support for people who would not otherwise be able to manage, it does have affects to caregivers, and that factors not directly connected to caregiving can also interact with the direct effects of caregiving. Therefore financial concerns, family issues and leisure dissatisfaction also affect caregiver HRQOL and people developing caregiving policy or clinicians who interact with patients and their caregivers should account for both the direct and indirect effects arising from the caregiving role so as to minimise the negative outcomes that can arise.

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# Appendix 1: Search strategies

### Database: DARE

### Platform: Ovid SP

### Searched to 4th Quarter 2011

### Search Date 06 December 2011

1. caregiv$.mp. [mp=title, full text, keywords]
2. (care adj giv$).mp. [mp=title, full text, keywords]
3. carer$.mp. [mp=title, full text, keywords]
4. (informal adj care).mp. [mp=title, full text, keywords]
5. caretak$.mp. [mp=title, full text, keywords]
6. (care adj taker$).mp. [mp=title, full text, keywords]
7. (care adj taking).mp. [mp=title, full text, keywords]
8. (families adj caring).mp. [mp=title, full text, keywords]
9. (families adj6 support).mp. [mp=title, full text, keywords]
10. (support adj6 daily living).mp. [mp=title, full text, keywords]
11. ((sons or daughters or friends) adj2 care).mp. [mp=title, full text, keywords]
12. ((sons or daughters or friends) adj2 caring).mp. [mp=title, full text, keywords]
13. ((sons or daughters or friends) adj2 support).mp. [mp=title, full text, keywords]
14. ((sons or daughters or friends) adj2 supporting).mp. [mp=title, full text, keywords]
15. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 care).mp. [mp=title, full text, keywords]
16. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 caring).mp. [mp=title, full text, keywords]
17. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 support).mp. [mp=title, full text, keywords]
18. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 supporting).mp. [mp=title, full text, keywords]
19. (burden adj (inventory or scale or interview)).mp. [mp=title, full text, keywords]
20. artheros$.mp. [mp=title, full text, keywords]
21. polyarthrit$.mp. [mp=title, full text, keywords]
22. osteoarthri$.mp. [mp=title, full text, keywords]
23. spondylarthri$.mp. [mp=title, full text, keywords]
24. gout.mp. [mp=title, full text, keywords]
25. lupus erythemat$.mp. [mp=title, full text, keywords]
26. (psoria$ adj (arthrit$ or arthropath$)).mp. [mp=title, full text, keywords]

27. ((rheumatoid or reumatoid or rheumatic or reumatic or rheumat$ or reumat$) adj (arthrit$ or artrit$ or diseas$ or condition$ or module$)).mp. [mp=title, full text, keywords]
28. (ankylos$ or spondyl$).mp. [mp=title, full text, keywords]
29. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
30. 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28
31. 29 and 30

**Database: NHS EED**

**Platform: Ovid SP**

**Searched to 4th Quarter 2011**

**Search Date 06 December 2011**

1. exp Caregivers/
2. exp Spouses/
3. exp Social support/
4. exp interpersonal relations/
5. caregiv$.mp. [mp=title, text, subject heading word]
6. (care adj giv$).mp. [mp=title, text, subject heading word]
7. carer$.mp. [mp=title, text, subject heading word]
8. (informal adj care).mp. [mp=title, text, subject heading word]
9. caretak$.mp. [mp=title, text, subject heading word]
10. (care adj taker$).mp. [mp=title, text, subject heading word]
11. (care adj taking).mp. [mp=title, text, subject heading word]
12. (families adj caring).mp. [mp=title, text, subject heading word]
13. (families adj6 support).mp. [mp=title, text, subject heading word]
14. (support adj6 daily living).mp. [mp=title, text, subject heading word]
15. ((sons or daughters or friends) adj2 care).mp. [mp=title, text, subject heading word]
16. ((sons or daughters or friends) adj2 caring).mp. [mp=title, text, subject heading word]
17. ((sons or daughters or friends) adj2 support).mp. [mp=title, text, subject heading word]
18. ((sons or daughters or friends) adj2 supporting).mp. [mp=title, text, subject heading word]
19. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 care).mp. [mp=title, text, subject heading word]
20. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 caring).mp. [mp=title, text, subject heading word]
21. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 support).mp. [mp=title, text, subject heading word]

22. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 supporting).mp. [mp=title, text, subject heading word]
23. (burden adj (inventory or scale or interview)).mp. [mp=title, text, subject heading word]
24. exp Arthritis/ or exp Rheumatoid arthritis/
25. exp Osteoarthritis/
26. exp Gout/
27. exp Ankylosing spondylitis/
28. exp Lupus Erythematosus, Systemic/
29. exp Arthritis, Psoriatic/
30. exp Musculoskeletal Diseases/
31. artheros$.mp. [mp=title, text, subject heading word]
32. polyarthrit$.mp. [mp=title, text, subject heading word]
33. osteoarthri$.mp. [mp=title, text, subject heading word]
34. spondylarthri$.mp. [mp=title, text, subject heading word]
35. gout.mp. [mp=title, text, subject heading word]
36. lupus erythemat$.mp. [mp=title, text, subject heading word]
37. (psoria$ adj (arthrit$ or arthropath$)).mp. [mp=title, text, subject heading word]
38. ((rheumatoid or reumatoid or rheumatic or reumatic or rheumat$ or reumat$) adj (arthrit$ or artrit$ or diseas$ or condition$ or module$)).mp. [mp=title, text, subject heading word]
39. (ankylos$ or spondyl$).mp. [mp=title, text, subject heading word]
40. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 oe 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
41. 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39
42. 40 and 41

**Database: Cochrane Database of Systematic Reviews**

**Platform: Ovid SP**

**Searched: 2005 to November 2011**

**Search Date 06 December 2011**

1. caregiv$.mp. [mp=title, abstract, full text, keywords, caption text]
2. (care adj giv$).mp. [mp=title, abstract, full text, keywords, caption text]
3. carer$.mp. [mp=title, abstract, full text, keywords, caption text]
4. (informal adj care).mp. [mp=title, abstract, full text, keywords, caption text]
5. caretak$.mp. [mp=title, abstract, full text, keywords, caption text]
6. (care adj taker$).mp. [mp=title, abstract, full text, keywords, caption text]
7. (care adj taking).mp. [mp=title, abstract, full text, keywords, caption text]

8. (families adj caring).mp. [mp=title, abstract, full text, keywords, caption text]
9. (families adj6 support).mp. [mp=title, abstract, full text, keywords, caption text]
10. (support adj6 daily living).mp. [mp=title, abstract, full text, keywords, caption text]
11. ((sons or daughters or friends) adj2 care).mp. [mp=title, abstract, full text, keywords, caption text]
12. ((sons or daughters or friends) adj2 caring).mp. [mp=title, abstract, full text, keywords, caption text]
13. ((sons or daughters or friends) adj2 support).mp. [mp=title, abstract, full text, keywords, caption text]
14. ((sons or daughters or friends) adj2 supporting).mp. [mp=title, abstract, full text, keywords, caption text]
15. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 care).mp. [mp=title, abstract, full text, keywords, caption text]
16. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 caring).mp. [mp=title, abstract, full text, keywords, caption text]
17. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 support).mp. [mp=title, abstract, full text, keywords, caption text]
18. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 supporting).mp. [mp=title, abstract, full text, keywords, caption text]
19. (burden adj (inventory or scale or interview)).mp. [mp=title, abstract, full text, keywords, caption text]
20. artheros$.mp. [mp=title, abstract, full text, keywords, caption text]
21. polyarthrit$.mp. [mp=title, abstract, full text, keywords, caption text]
22. osteoarthri$.mp. [mp=title, abstract, full text, keywords, caption text]
23. spondylarthri$.mp. [mp=title, abstract, full text, keywords, caption text]
24. gout.mp. [mp=title, abstract, full text, keywords, caption text]
25. lupus erythemat$.mp. [mp=title, abstract, full text, keywords, caption text]
26. (psoria$ adj (arthrit$ or arthropath$)).mp. [mp=title, abstract, full text, keywords, caption text]
27. ((rheumatoid or reumatoid or rheumatic or reumatic or rheumat$ or reumat$) adj (arthrit$ or artrit$ or diseas$ or condition$ or module$)).mp. [mp=title, abstract, full text, keywords, caption text]
28. (ankylos$ or spondyl$).mp. [mp=title, abstract, full text, keywords, caption text]
29. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
30. 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28
31. 29 and 30

**Database: Cochrane Central Register of Controlled Trials**

**Platform: Ovid SP**

**Searched to 4th Quarter 2011**

**Search Date 06 December 2011**

1. exp Caregivers/
2. exp Spouses/
3. exp Social support/
4. exp interpersonal relations/
5. caregiv$.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
6. (care adj giv$).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
7. carer$.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
8. (informal adj care).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
9. caretak$.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
10. (care adj taker$).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
11. (care adj taking).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
12. (families adj caring).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
13. (families adj6 support).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
14. (support adj6 daily living).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
15. ((sons or daughters or friends) adj2 care).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
16. ((sons or daughters or friends) adj2 caring).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
17. ((sons or daughters or friends) adj2 support).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
18. ((sons or daughters or friends) adj2 supporting).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
19. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 care).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
20. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 caring).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
21. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 support).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
22. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 supporting).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]

23. (burden adj (inventory or scale or interview)).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
24. exp Arthritis/ or exp Rheumatoid arthritis/
25. exp Osteoarthritis/
26. exp Gout/
27. exp Ankylosing spondylitis/
28. exp Lupus Erythematosus, Systemic/
29. exp Arthritis, Psoriatic/
30. exp Musculoskeletal Diseases/
31. (psoria$ adj (arthrit$ or arthropath$)).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
32. ((rheumatoid or reumatoid or rheumatic or reumatic or rheumat$ or reumat$) adj (arthrit$ or artrit$ or diseas$ or condition$ or module$)).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
33. (ankylos$ or spondyl$).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
34. artheros$.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
35. polyarthrit$.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
36. osteoarthri$.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
37. spondylarthri$.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
38. gout.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
39. lupus erythemat$.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]
40. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 oe 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
41. 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39
42. 40 and 41

**Database: Health Technology Assessment**

**Platform: Ovid SP**

**Searched to 4th Quarter 2011**

**Search Date 06 December 2011**

1. exp Caregivers/
2. exp Spouses/
3. exp Social support/
4. exp interpersonal relations/
5. caregiv$.mp. [mp=title, text, subject heading word]

6. (care adj giv$).mp. [mp=title, text, subject heading word]
7. carer$.mp. [mp=title, text, subject heading word]
8. (informal adj care).mp. [mp=title, text, subject heading word]
9. caretak$.mp. [mp=title, text, subject heading word]
10. (care adj taker$).mp. [mp=title, text, subject heading word]
11. (care adj taking).mp. [mp=title, text, subject heading word]
12. (families adj caring).mp. [mp=title, text, subject heading word]
13. (families adj6 support).mp. [mp=title, text, subject heading word]
14. (support adj6 daily living).mp. [mp=title, text, subject heading word]
15. ((sons or daughters or friends) adj2 care).mp. [mp=title, text, subject heading word]
16. ((sons or daughters or friends) adj2 caring).mp. [mp=title, text, subject heading word]
17. ((sons or daughters or friends) adj2 support).mp. [mp=title, text, subject heading word]
18. ((sons or daughters or friends) adj2 supporting).mp. [mp=title, text, subject heading word]
19. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 care).mp. [mp=title, text, subject heading word]
20. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 caring).mp. [mp=title, text, subject heading word]
21. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 support).mp. [mp=title, text, subject heading word]
22. ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) adj2 supporting).mp. [mp=title, text, subject heading word]
23. (burden adj (inventory or scale or interview)).mp. [mp=title, text, subject heading word]
24. exp Arthritis/ or exp Rheumatoid arthritis/
25. exp Osteoarthritis/
26. exp Gout/
27. exp Ankylosing spondylitis/
28. exp Lupus Erythematosus, Systemic/
29. exp Arthritis, Psoriatic/
30. exp Musculoskeletal Diseases/
31. (psoria$ adj (arthrit$ or arthropath$)).mp. [mp=title, text, subject heading word]
32. ((rheumatoid or reumatoid or rheumatic or reumatic or rheumat$ or reumat$) adj (arthrit$ or artrit$ or diseas$ or condition$ or module$)).mp. [mp=title, text, subject heading word]
33. (ankylos$ or spondyl$).mp. [mp=title, text, subject heading word]
34. artheros$.mp. [mp=title, text, subject heading word]
35. polyarthrit$.mp. [mp=title, text, subject heading word]
36. osteoarthri$.mp. [mp=title, text, subject heading word]
37. spondylarthri$.mp. [mp=title, text, subject heading word]
38. gout.mp. [mp=title, text, subject heading word]

39. lupus erythemat$.mp. [mp=title, text, subject heading word]
40. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 oe 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
41. 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39
42. 40 and 41

**Database: Medline in Process and other non Indexed citations**

**Platform: Ovid SP**

**Searched to 07 December 2011**

**Search Date 08 December 2011**

1. exp Caregivers/
2. exp Social Support/
3. exp Spouses/
4. exp Interpersonal Relations/
5. caregiv$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
6. care giv$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
7. carer$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
8. (informal adj care).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
9. caretak$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
10. care taker$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
11. care taking.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
12. (families adj caring).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
13. (families adj6 support).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]

14. assistance.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
15. (support adj6 daily living).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
16. 34. (burden adj (inventory or scale or interview)).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
17. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
18. exp Arthritis, Psoriatic/ or exp Arthritis, Rheumatoid/ or exp Arthritis/ or exp Arthritis, Gouty/
19. exp Osteoarthritis, Hip/ or exp Osteoarthritis/ or exp Osteoarthritis, Spine/ or exp Osteoarthritis, Knee/
20. exp Spondylitis, Ankylosing/ or exp Spondylitis/
21. exp Spondylarthritis/
22. exp Gout/
23. exp Lupus Erythematosus, Systemic/
24. artheros$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
25. polyarthri$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
26. (psoria$ adj (arthriti$ or arthropath$)).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
27. ((rheumatoid or reumatoid or revmatoid or rheumatic or reumatic or revmatic or rheumat$ or reumat$ or revmarthrit$) adj3 (arthrit$ or artrit$ or diseas$ or condition$ or nodule$)).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
28. osteoarthri$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
29. (ankylos$ or spondyl$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
30. spondylarthri$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
31. gout.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
32. lupus erythemat$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]

33. 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32
34. 17 and 33

**Database: AMED**

**Platform: Ovid SP**

**Searched 1985 to November 2011**

**Search Date 06 December 2011**

1. exp Caregivers/
2. exp Social Support/
3. exp Spouses/
4. exp Interpersonal relations/
5. caregiv$.mp. [mp=abstract, heading words, title]
6. (care adj giv$).mp. [mp=abstract, heading words, title]
7. carer$.mp. [mp=abstract, heading words, title]
8. (informal adj care).mp. [mp=abstract, heading words, title]
9. caretak$.mp. [mp=abstract, heading words, title]
10. (care adj taker$).mp. [mp=abstract, heading words, title]
11. (care adj taking).mp. [mp=abstract, heading words, title]
12. (families adj caring).mp. [mp=abstract, heading words, title]
13. (families adj6 support).mp. [mp=abstract, heading words, title]
14. assistance.mp. [mp=abstract, heading words, title]
15. (support adj6 daily living).mp. [mp=abstract, heading words, title]
16. (burden adj (inventory or scale or interview)).mp. [mp=abstract, heading words, title]
17. exp Arthritis/
18. exp Gout/
19. exp Lupus erythematosus systemic/
20. exp Arthritis rheumatoid/
21. exp Osteoarthritis/
22. exp Spondylitis ankylosing/
23. exp Lupus/
24. artheros$.mp. [mp=abstract, heading words, title]
25. polyarthrit$.mp. [mp=abstract, heading words, title]
26. osteoarthri$.mp. [mp=abstract, heading words, title]
27. spondylarthri$.mp. [mp=abstract, heading words, title]
28. gout.mp. [mp=abstract, heading words, title]
29. lupus erythemat$.mp. [mp=abstract, heading words, title]

30. (psoria$ adj (arthrit$ or arthropath$)).mp. [mp=abstract, heading words, title]
31. ((rheumatoid or reumatoid or rheumatic or reumatic or rheumat$ or reumat$) adj (arthrit$ or artrit$ or diseas$ or condition$ or module$)).mp. [mp=abstract, heading words, title]
32. (ankylos$ or spondyl$).mp. [mp=abstract, heading words, title]
33. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
34. 17 or 18 or 19 or 20 or 21 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32
35. 33 and 34

**Database: EMBASE**

**Platform: Ovid SP**

**Searched to 1980 to 2011 week 48**

**Search Date 06 December 2011**

1. exp caregiver burden/ or exp caregiver/ or exp caregiver support/ or exp Caregiver Strain Index/
2. exp social support/
3. exp spouse/
4. human relation/ or family relation/ or social network/
5. caregiv$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
6. (care adj giv$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
7. carer$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
8. (informal adj care$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
9. caretak$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
10. (care adj taker$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
11. (care adj taking).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
12. (families adj caring).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
13. (families adj6 support).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
14. (support adj daily living).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

15. (burden adj (inventory or scale or interview)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
16. exp rheumatoid arthritis/
17. exp arthritis/ or exp chronic arthritis/ or exp psoriatic arthritis/ or exp knee arthritis/
18. exp knee osteoarthritis/ or exp hip osteoarthritis/ or exp osteoarthritis/
19. exp ankylosing spondylitis/ or exp osteoarthropathy/ or exp spondyloarthropathy/
20. exp gout/
21. exp systemic lupus erythematosus/
22. ((rheumatoid or reumatoid or rheumatic or reumatic or rheumat$ or reumat$) adj3 (arthrit$ or artrit$ or diseas$ or condition% or nodule$)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
23. osteoarthri$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
24. artheros$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
25. polyarthri$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
26. (psoria$ adj (arthrit$ or arthropath$)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
27. (ankylos$ or spondyl$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
28. spondylarthri$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
29. gout.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
30. (lupus adj erythema$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
31. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
32. 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30
33. 31 and 32

**Database: Health Management Information Consortium**

**Platform: Ovid SP**

**Searched 1979 to September 2011**

**Search Date 06 December 2011**

1. exp carers/
2. exp Informal care/
3. exp Partners/
4. exp Social support/
5. exp interpersonal relations/
6. caregiv$.mp. [mp=abstract, heading words, title]
7. care giv$.mp. [mp=abstract, heading words, title]
8. carer$.mp. [mp=abstract, heading words, title]
9. (informal adj care).mp. [mp=abstract, heading words, title]
10. caretak$.mp. [mp=abstract, heading words, title]
11. care taker$.mp. [mp=abstract, heading words, title]
12. care taking.mp. [mp=abstract, heading words, title]
13. (families adj caring).mp. [mp=abstract, heading words, title]
14. (families adj6 support).mp. [mp=abstract, heading words, title]
15. assistance.mp. [mp=abstract, heading words, title]
16. (support adj6 daily living).mp. [mp=abstract, heading words, title]
17. (burden adj (inventory or scale or interview)).mp. [mp=abstract, heading words, title]
18. exp Arthritis/ or exp Rheumatoid arthritis/
19. exp Osteoarthritis/
20. exp Gout/
21. exp Systema lupus erythematosus/
22. exp Musculoskeletal system diseases/
23. exp Ankylosing spondylitis/
24. artheros$.mp. [mp=abstract, heading words, title]
25. polyarthrit$.mp. [mp=abstract, heading words, title]
26. osteoarthri$.mp. [mp=abstract, heading words, title]
27. spondylarthri$.mp. [mp=abstract, heading words, title]
28. gout.mp. [mp=abstract, heading words, title]
29. lupus erythemat$.mp. [mp=abstract, heading words, title]
30. (psoria$ adj (arthrit$ or arthropath$)).mp. [mp=abstract, heading words, title]
31. ((rheumatoid or reumatoid or rheumatic or reumatic or rheumat$ or reumat$) adj (arthrit$ or artrit$ or diseas$ or condition$ or module$)).mp. [mp=abstract, heading words, title]
32. (ankylos$ or spondyl$).mp. [mp=abstract, heading words, title]
33. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
34. 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32
35. 33 and 34

**Database: Medline**

**Platform: Ovid SP**

**Searched 1948 to Week 3 November 2011**

**Search Date 06 December 2011**

1. exp Caregivers/
2. exp Social Support/
3. exp Spouses/
4. exp Interpersonal Relations/
5. caregiv$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
6. care giv$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
7. carer$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
8. (informal adj care).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
9. caretak$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
10. care taker$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
11. care taking.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
12. (families adj caring).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
13. (families adj6 support).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
14. assistance.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
15. (support adj6 daily living).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
16. (burden adj (inventory or scale or interview)).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]

17. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
18. exp Arthritis, Psoriatic/ or exp Arthritis, Rheumatoid/ or exp Arthritis/ or exp Arthritis, Gouty/
19. exp Osteoarthritis, Hip/ or exp Osteoarthritis/ or exp Osteoarthritis, Spine/ or exp Osteoarthritis, Knee/
20. exp Spondylitis, Ankylosing/ or exp Spondylitis/
21. exp Spondylarthritis/
22. exp Gout/
23. exp Lupus Erythematosus, Systemic/
24. artheros$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
25. polyarthri$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
26. (psoria$ adj (arthriti$ or arthropath$)).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
27. ((rheumatoid or reumatoid or revmatoid or rheumatic or reumatic or revmatic or rheumat$ or reumat$ or revmarthrit$) adj3 (arthrit$ or artrit$ or diseas$ or condition$ or nodule$)).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
28. osteoarthri$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
29. (ankylos$ or spondyl$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
30. spondylarthri$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
31. gout.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
32. lupus erythemat$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
33. 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32
34. 17 and 33

**Database: PsycInfo**

**Platform: Ovid SP**

**Searched 1967 to December week 1 2011**

**Search Date 06 December 2011**

1. exp Caregivers/
2. exp Social Support/
3. exp Spouses/
4. exp "Assistance (Social Behavior)"/
5. exp Interpersonal Relationships/
6. exp Caregiver Burden/
7. caregiv$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
8. care giv$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
9. carer$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
10. (informal adj care).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
11. caretak$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
12. care taker$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
13. care taking.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
14. (families adj caring).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
15. (families adj6 support).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
16. assistance.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
17. (support adj6 daily living).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
18. (burden adj (inventory or scale or interview)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
19. exp Arthritis, Psoriatic/ or exp Arthritis, Rheumatoid/ or exp Arthritis/ or exp Arthritis, Gouty/
20. exp Lupus/
21. exp Musculoskeletal Disorders/ or exp Joint Disorders/
22. artheros$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
23. polyarthrit$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

24. osteoarthri$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
25. spondylarthri$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
26. gout.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
27. lupus erythemat$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
28. (psoria$ adj (arthrit$ or arthropath$)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
29. ((rheumatoid or reumatoid or rheumatic or reumatic or rheumat$ or reumat$) adj (arthrit$ or artrit$ or diseas$ or condition$ or module$)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
30. (ankylos$ or spondyl$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
31. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
32. 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30
33. 31 and 32

**Database: Social Policy and Practice**

**Platform: Ovid SP**

**Searched to 2011 10**

**Search Date 06 December 2011**

1. caregiv$.mp. [mp=title, other title, abstract, heading words]
2. care giv$.mp. [mp=title, other title, abstract, heading words]
3. carer$.mp. [mp=title, other title, abstract, heading words]
4. (informal adj care).mp. [mp=title, other title, abstract, heading words]
5. caretak$.mp. [mp=title, other title, abstract, heading words]
6. care taker$.mp. [mp=title, other title, abstract, heading words]
7. care taking.mp. [mp=title, other title, abstract, heading words]
8. (families adj caring).mp. [mp=title, other title, abstract, heading words]
9. (families adj6 support).mp. [mp=title, other title, abstract, heading words]
10. assistance.mp. [mp=title, other title, abstract, heading words]
11. (support adj6 daily living).mp. [mp=title, other title, abstract, heading words]
12. (burden adj (inventory or scale or interview)).mp. [mp=title, other title, abstract, heading words]
13. artheros$.mp. [mp=title, other title, abstract, heading words]

14. polyarthrit$.mp. [mp=title, other title, abstract, heading words]
15. osteoarthri$.mp. [mp=title, other title, abstract, heading words]
16. spondylarthri$.mp. [mp=title, other title, abstract, heading words]
17. gout.mp. [mp=title, other title, abstract, heading words]
18. lupus erythemat$.mp. [mp=title, other title, abstract, heading words]
19. (psoria$ adj (arthrit$ or arthropath$)).mp. [mp=title, other title, abstract, heading words]
20. ((rheumatoid or reumatoid or rheumatic or reumatic or rheumat$ or reumat$) adj (arthrit$ or artrit$ or diseas$ or condition$ or module$)).mp. [mp=title, other title, abstract, heading words]
21. (ankylos$ or spondyl$).mp. [mp=title, other title, abstract, heading words]
22. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
23. 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21
24. 22 and 23

### Social Services Abstracts (via CSA illumina)

### 08.12.11

### N=26

### 1979 to current

**Search Query #39** ((TI= (**rheumatoid** or **reumatoid** or **rheumatic** or **reumatic** or **rheumat*** or **reumat***) OR AB= (**rheumatoid** or **reumatoid** or **rheumatic** or **reumatic** or **rheumat*** or **reumat***) or TI= (**osteoarthri*** or **artheros*** or **polyarthri*** or **arthrit*** or **arthropath*** or **ankylos*** or **spondyl*** or **gout** or **lupus**) or AB= (**osteoarthri*** or **artheros*** or **polyarthri*** or **arthrit*** or **arthropath*** or **ankylos*** or **spondyl*** or **gout** or **lupus**)) or(DE=(**arthritis**))) and((TI=(**caregiv*** OR **care giv***) OR AB=(**caregiv*** OR **care giv***) OR TI=(**carer***) OR AB=(**carer***) OR TI=(**informal care**) OR AB=(**informal care**) OR TI=(**caretak***) OR AB=(**caretak***) OR TI=(**care taking**) OR AB=(**care taking**) OR TI=(**caretaker***) OR AB=(**caretaker***) or TI=(**children caring**) OR AB=(**children caring**) OR TI=(**families caring**) OR AB=(**families caring**)) or(TI=((**families**) WITHIN 2 (**support**)) OR AB=((**families**) WITHIN 2 (**support**)) or TI=(**assistance**) OR AB=(**assistance**) OR TI=(**families caring**) OR AB=(**families caring**) OR TI=((**burden**) WITHIN 2 (**inventory** or **interview** or **scale**)) OR AB=((**burden**) WITHIN 2 (**inventory** or **interview** or **scale**)) OR TI=((**support**) WITHIN 6 (**daily living**)) OR AB=((**support**) WITHIN 6 (**daily living**))) or(DE=(**caregivers**) or(DE=**social support**) or(DE=**interpersonal relations**) or DE=(**couples** or **dyads** or **spouses**) or DE=(**caregiver burden** or **adult children**)))

### Sociological Abstracts

### 08 December 2011

### 1952 to current

### N=40

**Search Query #19** (((DE="**caregivers**") or(DE="**social support**") or(DE="**interpersonal relations**") or(DE=("**couples**" or "**dyads**" or "**spouses**")) or(DE=("**caregiver burden**" or "**adult children**"))) or(TI=(**caregiv*** OR **care giv***) OR AB=(**caregiv*** OR **care giv***) OR TI=(**carer***) OR AB=(**carer***) OR TI=(**informal care**) OR AB=(**informal care**) OR TI=(**caretak***) OR AB=(**caretak***) OR TI=(**care taking**) OR AB=(**care taking**) OR TI=(**caretaker***) OR AB=(**caretaker***)) or(TI=(**children caring**) or AB=(**children caring**) OR TI=(**families caring**) OR AB=(**families caring**) or TI=(**assistance**) OR AB=(**assistance**)) or(TI=(**families caring**) OR AB=(**families caring**) OR TI=(**burden inventory**) or TI=(**burden interview**) or TI=(**burden scale**) OR AB=(**burden inventory**) or AB=(**burden interview**) or AB=(**burden scale**) OR TI=(**daily living**) OR AB=(**daily living**) or TI=(**families support***) or AB=(**families support***))) and((DE="**arthritis**") or(TI= (**rheumatoid** or **reumatoid** or **rheumatic** or **reumatic** or **rheumat*** or **reumat***) OR AB= (**rheumatoid** or **reumatoid** or **rheumatic** or **reumatic** or **rheumat*** or **reumat***) or TI= (**osteoarthri*** or **artheros*** or **polyarthri*** or **arthrit*** or **arthropath*** or **ankylos*** or **spondyl*** or **gout** or **lupus**) or AB= (**osteoarthri*** or **artheros*** or **polyarthri*** or **arthrit*** or **arthropath*** or **ankylos*** or **spondyl*** or **gout** or **lupus**)))

**ASSIA (via CSA illumine)**

**08 December 2011**

**1987-current**

**N=69 hits**

**Search Query #32** (((DE=("**arthritis**" or "**musculoskeletal diseases**" or "**osteoarthritis**" or "**rheumatoid arthritis**")) or(DE="**gout**") or(DE="**lupus erythematosus**") or(DE="**ankylosing spondylitis**")) or(TI= (**rheumatoid** or **reumatoid** or **rheumatic** or **reumatic** or **rheumat*** or **reumat***) OR AB= (**rheumatoid** or **reumatoid** or **rheumatic** or **reumatic** or **rheumat*** or **reumat***)) or(TI= (**osteoarthri*** or **artheros*** or **polyarthri*** or **arthrit*** or **arthropath*** or **ankylos*** or **spondyl*** or **gout** or **lupus**)) or(AB= (**osteoarthri*** or **artheros*** or **polyarthri*** or **arthrit*** or **arthropath*** or **ankylos*** or **spondyl*** or **gout** or **lupus**))) and(((TI=(**caregiv*** OR **care giv***) OR AB=(**caregiv*** OR **care giv***) OR TI=(**carer***) OR AB=(**carer***) OR TI=(**informal care**) OR AB=(**informal care**) OR TI=(**caretak***) OR AB=(**caretak***) OR TI=(**care taking**) OR AB=(**care taking**) OR TI=(**caretaker***) OR AB=(**caretaker***)) or ((DE=("**informal care**" or "**carers**")) or (DE=("**married couples**" or "**elderly married couples**" or "**middle aged married couples**" or "**older married couples**" or "**previously married people**" or "**remarried couples**" or "**spouses**" or "**former spouses**" or "**husbands**" or "**elderly husbands**" or "**wives**" or "**ex wives**" or "**ex carers**")) or (DE=("**social support**" or "**perceived social support**")))) or(TI=(**children caring**) OR AB=(**children caring**) OR TI=(**families caring**) OR AB=(**families caring**) OR TI=((**families**) WITHIN 2 (**support**)) OR AB=((**families**) WITHIN 2 (**support**))) or(TI=(**assistance**) OR AB=(**assistance**) OR TI=(**families caring**) OR AB=(**families caring**) OR TI=((**burden**) WITHIN 2 (**inventory** or **interview** or **scale**)) OR AB=((**burden**) WITHIN 2 (**inventory** or **interview** or **scale**)) OR TI=((**support**) WITHIN 6 (**daily living**)) OR AB=((**support**) WITHIN 6 (**daily living**))))

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**6 December 2011**

(((((TI+(caregiv*))+OR+(AB+(caregiv*)))+OR+((TI+(care+giv*))+AND+(AB+(care+giv*)))+OR+((TI+(carer*))+OR+(AB+(carer*)))+OR+((TI+(informal+care*))+OR+(AB+(informal+care*)))+OR+((TI+(caretak*))+OR+(AB+(caretak)))+OR+((TI+(care+taker*))+OR+(AB+(care+taker*)))+OR+((TI+(care+taking))+OR+(AB+(care+taking)))+OR+((TI+(families+N2+support))+OR+(AB+(families+N2+support)))+OR+((TI+(families+caring))+OR+(AB+(families+caring)))+OR+((TI+(assistance))+OR+(AB+(assistance)))+OR+((TI+(support+adj6+daily+living))+OR+(AB+(support+adj6+daily+living)))+OR+((TI+(support+N6+daily+living))+OR+(AB+(support+N6+daily+living)))+OR+((MH+caregivers))+OR+(((MH+%22Spouses%2

2)))+OR+(((MH+%22Support%2c+Psychosocial%22)))+OR+(((MH+%22Interpersonal+Relations%22)))+OR+((TI+(burden+N2+(inventory+OR+scale+OR+interview)))+OR+(AB+(burden+N2+(inventory+OR+scale+OR+interview))))))+AND+(((((MH+%22Arthritis%2b%22)+OR+(MH+%22Arthritis%2c+Psoriatic%22)+OR+(MH+%22Arthritis%2c+Rheumatoid%2b%22)+OR+(MH+%22Gout%22)+OR+(MH+%22Spondylarthritis%2b%22)))+OR+(((MH+%22Osteoarthritis%2b%22)+OR+(MH+%22Osteoarthritis%2c+Knee%22)+OR+(MH+%22Osteoarthritis%2c+Hip%22)+OR+(MH+%22Osteoarthritis%2c+Wrist%22)))+OR+(((MH+%22Lupus+Erythematosus%2c+Systemic%2b%22)))+OR+((TI+(artheros*))+OR+(AB+(artheros*)))+OR+((TI+(polyarthrit*))+OR+(AB+(polyarthrit*)))+OR+((TI+(osteoarthri*))+OR+(AB+(osteoarthri*)))+OR+((TI+(spondylarthri*))+OR+(AB+(spondylarthri*)))+OR+((TI+(gout))+OR+(AB+(gout)))+OR+(((MH+%22Gout%22)))+OR+((TI+(lupus+erythemat*))+OR+(AB+(lupus+erythemat*)))+OR+((TI+(psoria*+N2+(arthrit*+OR+arthropath*)))+OR+(AB+(psoria*+N2+(arthrit*+OR+arthropath*))))+OR+((TI+((rheumatoid+OR+reumatoid+OR+rheumatic+OR+reumatic+OR+rheumat*+OR+reumat*)+N2+(arthrit*+OR+artrit*+OR+diseas*+OR+condition*+OR+module*)))+OR+(AB+((rheumatoid+OR+reumatoid+OR+rheumatic+OR+reumatic+OR+rheumat*+OR+reumat*)+N2+(arthrit*+OR+artrit*+OR+diseas*+OR+condition*+OR+module*))))+OR+((TI+(ankylos*+OR+spondyl*))+OR+(AB+(ankylos*+OR+spondyl*))))))

# Appendix 2: Data extraction tables

## Appendix Table 1: Overview of the included studies

| **Study**<br>**Location** | **Study design** | **Interventions**<br>**Number** | **Population** | **Care outcome(s)** | **Follow up** |
|---|---|---|---|---|---|
| **Intervention studies** | | | | | |
| **Evaluations of pharmaceutical treatments** | | | | | |
| Mittendorf et al. 2008 (142)<br>Multinational | Experimental (non RCT)<br>Prospective<br>Single group | Adalimumab 40mg every other week. N=505 | Patients with long standing RA who had received adalimumab during one of six phase I-III studies. | Resource questionnaire detailing personal help | Mean 1.57 years |
| Kavanaugh et al. 2010 (116,148)<br>Multinational | Experimental (RCT)<br>Prospective<br>Three groups | Golimumab 50mg once every 4 weeks N=146<br>Golimumab 100mg once every 4 weeks N=146<br>Placebo N=113 | Patients with active PsA despite therapy with DMARDs or NSAIDs. | Resource questionnaire including caregiver time lost from work. | Controlled to week 24<br>Follow up-up to 2 years |
| Genovese et al. 2010 (114)<br>Multinational | Experimental (RCT)<br>Prospective<br>Four groups | Golimumab 50mg once every 4 weeks plus methotrexate N=89<br>Golimumab 100mg once every 4 weeks plus methotrexate N=89<br>Golimumab 100mg once every 4 weeks plus placebo N=133<br>Placebo plus methotrexate N=133 | Patients were 18 years or older, diagnosis of RA using ACR 1987 criteria for at least 3 months before screening, on stable methotrexate. | Resources including time lost from work of caregiver | Controlled to week 52<br>Open label extension to 5 years |
| Kimball et al. 2007 (118)<br>USA | Experimental (non RCT)<br>Prospective<br>Single group | Etanercept 50mg weekly N=122 | Patients were 18 years or older, active PsA | Healthcare resource utilisation including assistance from friends and family | 24 weeks |
| **Evaluations of surgical interventions** | | | | | |
| Chow 2001 (111) | Non experimental | Total hip replacement N=23 | Adult informal carers and adult care receivers with | Robinsons caregiver stress index | 3 months |

| Study<br>Location | Study design | Interventions<br>Number | Population | Care outcome(s) | Follow up |
|---|---|---|---|---|---|
| UK | Prospective<br>Single group | | osteoarthritis who were having a primary single total hip replacement under the National Health Service. | | |
| Bachrach Lindstrom 2008 (108)<br><br>Sweden | Non experimental<br>Prospective<br>Single group | Surgery for unilateral total hip replacement N=229 | Patients assigned for surgery with unilateral total hip replacement due to osteoarthritis | Amount of help provided by relatives | 1 year |
| Orbell et al. 1998 (127)<br><br>Scotland | Non experimental<br>Prospective<br>Single group | Surgery for knee or hip replacement N=72 | Patients having primary Patients with osteoarthritis receiving joint replacement surgery of the knee or hip over a 1 year period. | Informal support measured by whether they received help with any activities of daily living on a list of 14<br>Hours of informal support provided in last week. | 9 months |
| **Evaluations of psychological Interventions** | | | | | |
| Martire et al. 2007 (125)<br><br>USA | Experimental (RCT)<br>Prospective<br>Three groups | Arthritis Self-Management Program, six weekly 2-hr sessions for people with OA (N=89)<br>Arthritis Self-Management Program, six weekly 2-hr sessions for people with OA and their partners (N=99)<br>Usual care (N=54) | Patients and their caregiving spouses. Patients were 50 years of age or older, married, and diagnosed with hip or knee OA. Additional criteria were that the individual had experienced pain of at least moderate intensity on most days over the past month, had difficulty with at least one instrumental activity of daily living (e.g., household tasks, driving), and received assistance from the spouse with at least one instrumental activity of daily living. | Measured from caregivers:<br>• Perceived Stress scale<br>• CES–D<br>• Caregiver mastery.<br>• Critical attitudes. Spouses' resentful attitudes toward their partners' pain coping during the past month was assessed<br>• Marital Adjustment Test | 6 months after the end of the intervention programme |
| Martire et al. 2003 (123)<br><br>USA | Experimental (RCT)<br>Prospective<br>Two groups | Arthritis Self-Management Program, six weekly 2-hr sessions for people with OA (N=11)<br>Arthritis Self-Management | Patients and their caregiving husbands. Patients had to be women with OA , 60 years of age or older, married and reside with husband. Women | Measured from caregivers:<br>• Caregiving stress with providing assistance for four IADLs and two ADL during the past month | 8 weeks (within 2 weeks of finishing a six week |

| **Study**<br>**Location** | **Study design** | **Interventions**<br>**Number** | **Population** | **Care outcome(s)** | **Follow up** |
|---|---|---|---|---|---|
| | | Program, six weekly 2-hr sessions for people with OA and their partners (N=13) | had to have experienced pain in the last month, had difficulty in carrying out either personal care or instrumental activities of daily living, received assistant from her husband with at least one daily activity and had not previously attended the programme. | • Caregiver mastery.<br>• CES–D | intervention programme) |
| **Evaluations of methods of service delivery** | | | | | |
| van der Sluis et al. 2009 (137)<br>Netherlands | Non experimental<br>Prospective<br>Two groups | A nurse practitioner as part of the MDT acting as case manager (N=78)<br>MDT without the nurse practitioner (N=69) | Adult patients with hand or wrist problems due to poly-inflammatory disease. | Informal care use (reflection of care used in last 3 months) | 6 months |
| Li et al. 2006 (121)<br>Canada | Experimental (RCT)<br>Prospective<br>Two groups | A physiotherapist or occupational therapist acting as case manager (N=73)<br>Care without the case manager (N=71) | Patients who required physiotherapy or occupational therapy and had not received rehabilitation treatment for RA in the last two years. | Productivity loss by caregivers. | 6 months |
| **Studies of association (regression and correlation)** | | | | | |
| **Studies with patients and people defined as a carer** | | | | | |
| Riemsma et al. 1999 (90)<br>Netherlands | Non experimental<br>Cross sectional<br>Single group | N/A<br>174 patients and their primary caregiver | Patients met four of the 1987 ACR criteria for RA | Measured from caregivers:<br>• Number of activities and time spent on activities of daily living and household activities<br>• Caregiver Burden Inventory (Novak and Guest)<br>• RAND-36; Dutch SF-36<br>• Size of social network<br>• Self efficacy expectations | N/A |
| Das Chagas Medeiros et al. | Non experimental<br>Cross sectional | N/A<br>62 patients and their primary caregiver | Patients had diagnosis of RA and attending clinic with primary caregiver | Measured from caregivers:<br>• *Carer burden Scale (Elmstahl )* | N/A |

| **Study<br>Location** | **Study design** | **Interventions<br>Number** | **Population** | **Care outcome(s)** | **Follow up** |
|---|---|---|---|---|---|
| 2000 (112)<br>Brazil | Single group | | | • HAQ<br>• SF-36,<br>• SRQ20 – screen for psychiatric disturbance<br>• Quality of relationship (Likert scale)<br>• Pain (VAS) | |
| Beckham and Burker 1995 (109)<br>USA | Non experimental<br>Cross sectional<br>Single group | N/A<br>51 patients and their caregiver | Patients were diagnosed as having RA according to the ACR criteria | Measured from caregivers:<br>• Zarit burden inventory/interview<br>• Life orientation test of optimism and pessimism | N/A |
| Stephens et al. 2006 (104)<br>USA | Non experimental<br>Prospective<br>Single group | N/A<br>101 women and their caregiving husbands | Female patients with primary diagnosis of OA and difficulty carrying out activities of daily living. Husband provided assistance in at least one activity of daily living<br>Husband was the person who provided most care<br>Both patients and husbands had to score 7 out of 10 on a test of cognitive functioning. | Measured from caregivers:<br>• CES D depression<br>• Husband life satisfaction<br>• Husband assessment of patient pain behaviour questionnaire<br>• Husband resentment of wife pain coping questionnaire derived from published research<br>• Strait Trait anger expression inventory<br>• Quality of marriage index | 6 months |
| Jacobi et al. 2003 (115)<br>Netherlands | Non experimental<br>Cross sectional analysis of a prospective study<br>Single group | N/A<br>N=134 patients and their carers (partner) | At least 16 years of age<br>Diagnosis of RA using 1987 ACR criteria | Measured from caregivers:<br>• Caregiver reaction Assessment<br>• Tasks required to care for the patient (divided into care tasks (personal care), home tasks (meals, cleaning laundry, shopping), and help tasks (moving outdoors, helping with visits, and financial business)<br>• Time spent on tasks (minutes for care tasks and hours for other tasks)<br>• Number of care days a week<br>• VAS scale of subjective burden<br>• Self rated burden - strain (VAS) | N/A |

| Study<br>Location | Study design | Interventions<br>Number | Population | Care outcome(s) | Follow up |
|---|---|---|---|---|---|
| | | | | • EQ-5D (descriptive system and VAS)<br>• Change in time investments and financial investments (income reduction) | |
| **Patients and partners and a care specific outcome** | | | | | |
| Manne and Zautra1990 (89)<br>USA | Non experimental<br>Cross sectional<br>Single group | N/A<br>N=103 patients and husbands | Husband must not have arthritis or another illness causing significant limitations in his daily functioning<br>Wife must rate RA as the most serious illness she has. | Measured from partners:<br>• Burden scale (Teresi and colleagues, 1978) | N/A |
| Walsh et al. 1999 (139)<br>USA | Non experimental<br>Cross sectional<br>Single group | N/A<br>N=43 patients and partners | Couple had to be living together in a committed relationship, that the couple was willing to participate and that one of the partners did not have rheumatoid arthritis | Measured from partners:<br>• Zarit burden inventory/interview | N/A |
| Strating et al. 2007 (132)<br>Netherlands | Non experimental<br>Cross sectional analysis of a prospective study<br>Single group | N/A<br>N=61 patients and partners | Rheumatoid arthritis other criteria not reported | Measured from partners:<br>• Caregiver Strain Index (Robinson, 1984) | N/A |
| Porter et al. 2008 (128)<br>USA | Non experimental<br>Cross sectional<br>Single group | N/A<br>N=38 patients and partner | Diagnosis of OA of the knee<br>Having a spouse or partner in a committed relationship<br>Over the age of 18 years<br>English speaking | Measured from partners:<br>• Caregiver Strain Index (Robinson 1984; scale 0-13) | N/A |

| **Study**<br>**Location** | **Study design** | **Interventions**<br>**Number** | **Population** | **Care outcome(s)** | **Follow up** |
|---|---|---|---|---|---|
| Reich et al. 2006 (129)<br>USA | Non experimental<br>Cross sectional<br>Two groups. OA and fibromyalgia. *Only OA data extracted*. | N/A<br>N=32 patients and partner | Implied: patients with fibromyalgia and/or osteoarthritis, who were living with a partner or spouse | Measured from partners:<br>• Caregiver Burden Scale (Poulshock and Deimling) | N/A |
| **Patients only and a care specific outcome** | | | | | |
| Dixon et al. 2006 (145)<br>UK | Non experimental<br>Cross sectional<br>Single group | N/A<br>N= 349 patients | Patients aged 18 years or older with arthroses of the knee | Time caregivers spent with patient in the last 6 weeks | N/A |
| **Descriptive analysis** | | | | | |
| Leardini et al. 2004 (119)<br>Italy | Non experimental<br>Retrospective<br>Single group | N/A<br>N=254 patients | Patients with a diagnosis of OA made according to ACR criteria | Informal care provided by caregivers: care included direct care: cleaning, preparation of meals etc) and supervision, measured as working days lost and other losses | 12 months |
| Leardini et al. 2002 (120)<br>Italy | Non experimental<br>Retrospective<br>Single group | N/A<br>N=200 patients | Patients aged 18 to 65 diagnosed with RA according to ACR 1987 criteria and at least one contact with the rheumatologic Institute in 1997 | Caregiver time off work (working days lost, permanent reduction or loss of working activities): divided into direct care (cleaning, preparation of meals) and supervision | 12 months |
| **Qualitative study** | | | | | |
| Sanchez-Ayendez 1998 (131)<br>Puerto Rico | Non experimental<br>Cross sectional<br>Single group | N/A<br>N=30 | Female caregivers of people with severe or aggressive rheumatoid arthritis, osteoarthritis or systemic lupus erythematosus. Other criteria not reported. | General Wellbeing schedule<br>Carer interview – open ended questions revolved around the tasks and every day dynamics involved in caregiving and sources of conflict encountered in carrying out caregiver role. | NA |

## Appendix Table 2: Study participants

| Study | Patient population | Patient disease information | Caregiver population | Care information |
|---|---|---|---|---|
| Intervention | | | | |
| Mittendorf et al. 2008 (142) (RA) | Age: 55 (median)<br>% female: 77<br>Race: 99% White<br>% not working: 44%<br>Education: N/R | Duration: 12.4<br>TJC 15<br>SJC 8<br>Comorbidities: N/R | NR | NR |
| Kavanaugh 2010 (116,148) (PsA) | Age: 46; 48; 47 (mean)<br>% female: 39; 41; 39<br>% White race: 97; 97; 97<br>% not working: N/R<br>Education: N/R | Duration:7.2; 7.7; 7.6<br>TJC 24; 23; 22<br>SJC 14; 12; 13<br>PASI 10; 11; 8.4<br>BSA 16; 18; 15<br>Comorbidities: N/R | NR | NR |
| Genovese et al. 2010 (114) (RA) | Age: 52; 50; 51; 52<br>% female: 81; 81; 80; 82<br>% White race: N/R<br>% not working: N/R<br>Education: N/R | Duration 4.5; 6.7; 5.9; 6.5<br>TJC 26; 23; 22; 21<br>SJC 13; 12. 11; 12<br>HAQ 1.38; 1.38, 1.38; 1.25<br>Comorbidities N/R | NR | NR |
| Kimball et al. 2007 (118) (PsA) | Age: 48 (mean)<br>% female: 45<br>% White race: 85<br>% not working: 13<br>Education: N/R | Duration:7.2<br>TJC 10; SJC 6<br>BSA 27<br>Comorbidities: significant excluded | NR | NR |
| Chow, 2001 (111) (OA) | Age: 70 (mean)<br>% female: 65<br>% White race: NR<br>% not working: NR<br>Education: NR | Duration: N/R<br>NHP: 20.9<br>VAS Pain 72.2<br>Comorbidities: N/R | Age: 63 (mean)<br>% female: 57<br>% White race: NR<br>% not working: 78<br>Education: N/R | 78.3% spouses<br>21.7% daughters<br>83% co-resident |
| Bachrach-Lindstrom et al. 2008 (108) (OA) | Age: 70 (mean)<br>% female: 49<br>% White race: NR<br>% not working: 76<br>Education: NR | Duration: N/R<br>NHP: 29 (men)<br>NHP: 36 (women)<br>Comorbidities: N/R | NR | NR |
| Orbell et al. 1998 (127) (OA) | Age: 68 (mean)<br>% female: 60<br>% White race: NR | Duration: N/R<br>VAS pain (worst) 80.94<br>VAS pain (rest) 21.4 | NR | NR |

|  |  |  |  |  |
|---|---|---|---|---|
|  | % not working: NR<br>Education: NR | Comorbidities: N/R |  |  |
| Martire et al. 2007 (125) (OA) | Age: 68;69;68 (mean)<br>% female: 72/74/72<br>% White race: 92<br>% not working: NR<br>Education: 14.6;14.3;14.2 | Duration 15.3; 14.3; 16.1<br>WOMAC total 39;36;40<br>Comorbidities N/R | Age: 68;70;70 (mean)<br>% female: 28/26/28<br>% White race: 92<br>% not working: NR<br>Education: 14.5;14.6;14.0 | 100% spouses (average marriage duration 41 years)<br>100% coresident |
| Martire et al. 2003 (123) (OA) | Age: 72 (mean)<br>% female: 100<br>% White race: 96<br>% not working: NR<br>Education: 13.8 | Duration: 18<br>AIMS pain 18.0; 14.5<br>HAQ 11.4;10.69<br>Comorbidities: 0.41 | Age: 74 (mean)<br>% female: 0<br>% White race: 96<br>% not working: NR<br>Education: 14.6 | 100% spouses (average marriage duration 46.3 years)<br>100% coresident |
| van der Sluis et al. 2009 (137) (poly inflammatory) | Age: 54;53 (mean)<br>% female: 67;72<br>% White race: NR<br>% not working: 67;76<br>Education: NR | Duration: N/R<br>MHQ:50.5;46.7<br>Comorbidities: N/R | NR | NR |
| Li 2006 (121) (RA) | Age: 54; 57(mean)<br>% female: 87; 79<br>% White race: NR<br>% not working: 67; 62<br>Education:<br>High school 49; 45<br>University 38; 38<br>Post graduate 13; 17 | Duration: 11;13<br>ACR functional class 2 or 3 76%; 75%<br>Comorbidities: 48%;38% > 2 comorbid conditions | NR | NR |
| **Association** |  |  |  |  |
| Reimsma et al. 1999 (90) (RA) | Age: 62 (mean)<br>% female: 59<br>% White race: NR<br>% not working: NR<br>Education:<br>Lower 37%<br>Medium 29%<br>High 34% | Duration 18.7<br>RAND-36 physical 4.13; pain 6.14<br>Comorbidities: 52% = 0; 37% = 1; 11% 2 or more | Age: 58 (mean)<br>% female: 56<br>% White race: NR<br>% not working: 67<br>Education: Lower 37%<br>Medium 35%<br>High 32% | 77% spouse<br>15% child<br>8% other<br>(duration of relationship 36yrs)<br>Duration of care 11 years<br>85% coresident<br>Mean 33 hours care per week<br>ADL tasks 2.42 mean<br>Household tasks 6.36 mean |
| Das Chagas Medeiros et al. 2000 (112) | Age: 62 (mean)<br>% female: 59<br>% White race: NR | Duration 8.3<br>Functional class 1 11%; 2 41%; 3 36%; 4 13% | Age: 40 (mean)<br>% female: 82<br>% White race: NR | 33% son or daughter<br>24% spouse<br>18% mother |

|  |  |  |  |  |
|---|---|---|---|---|
| (RA) | % not working: NR<br>Education:<br>Illiterate 14.5<br>Literate 19.3<br>Basic grade 54.8<br>High school 11.3<br>University 0 | Comorbidities NR | % not working: 55<br>Education:<br>Illiterate 9.7<br>Literate 14.5<br>Basic grade 45.2<br>High school 27.4<br>University 3.2 | 25% other<br>Care duration 5.4 years<br>74% coresident<br>5% formal care<br>39% other informal care |
| Beckham and Burker 1995 (109)<br>(RA) | Age: 59 (mean)<br>% female: 64<br>% White race: 95<br>% not working: NR<br>Education: 12.6 | Duration 12<br>Steinbrocker functional class 1 3%; 2 77%; 3 20%<br>Comorbidities excluded | NR | 86% spouses<br>14% other relative |
| Jacobi et al. 2003 (115)<br>(RA) | Age: 62 (mean)<br>% female: 84<br>% White race: NR<br>% not working: 85<br>Education:<br>Low 61.1%<br>Middle 30.1%<br>High 8.8% | Duration 12.7<br>Mean EQ-5D 0.48<br>Comorbidities NR | Age: 63 (mean)<br>% female: 18<br>% White race: NR<br>% not working: 64<br>Education:<br>Primary 13.8%<br>Middle/lower vocational 73.2%<br>Higher vocational/university 13% | 100% partner (in Jacobi et al. 2003)<br>Care duration 11.4 years<br>90% coresident (in van exel)<br>Formal support 26%<br>Informal support 68%<br>Mean hours of caregiving per week 26.4<br>Caregiving hours per day 3.9<br>Number of care giving tasks 6.8 (out of possible 16) |
| Stephens et al. 2006 (104)<br>(OA) | Age: 69 (mean)<br>% female: 100<br>% White race: 97<br>% not working: 86<br>Education:13.3 | Duration 19.7<br>AIMS pain subscale 17<br>Comorbidities NR | Age: 71 (mean)<br>% female: 0<br>% White race: 97<br>% not working: 75<br>Education: NR | 100% spouse (married average 42 years)<br>100% coresident |
| Manne and Zautra 1990 (89)<br>(RA) | Age: 55 (mean)<br>% female: 100<br>% White race: 96<br>% not working: 52<br>Education: mean 1-3 years of college | Duration 17<br>Mean activity limitation 15.4 (range 0-46)<br>Average 1 flare up a month with average duration 2 weeks<br>Comorbidities NR | Age: NR<br>% female: 0<br>% White race: 96<br>% not working:NR<br>Education: NR | 100% spouse<br>100% coresident |
| Walsh et al. 1999 (139)<br>(RA) | Age: 55 (mean)<br>% female: 63<br>% White race: 96<br>% not working: 52 | Duration 14.2<br>TJC 6.7 SJC 8.9<br>SF-36 physical functioning 46.1; SF-36 pain 52.7 | Age: 58 (mean)<br>% female: 37<br>% White race: 95<br>% not working: 37 | 100% spouse (married average 30.9 years)<br>100% coresident |

|  |  |  |  |  |
|---|---|---|---|---|
|  | Education: 14.3 | Comorbidities NR | Education: 14.9 |  |
| Strating et al. 2007 (132)<br>(RA) | Age: 60 (mean)<br>% female: 67<br>% White race: NR<br>% not working: NR<br>Education:<br>Education scale 1-6 (1 = primary and 6 =university degree) = 3.3 | Duration 14<br>33.2 Gronigen Activity Restriction scale<br>Comorbidities NR | Age: 60 (mean)<br>% female: 33<br>% White race: NR<br>% not working: NR<br>Education: Education scale 1-6 (1 = primary and 6 =university degree) = 3.2 | 100% spouse<br>100% coresident |
| Porter et al. 2008 (128)<br>(OA) | Age: 64 (mean)<br>% female: 45<br>% White race: 82<br>% not working: NR<br>Education: 66% college education | Duration NR<br>AIMS Pain subscale 5.1<br>AIMS physical disability 1.95<br>Comorbidities NR | Age: 62.5 (mean)<br>% female: 55<br>% White race: NR<br>% not working: NR<br>Education: Reported to be similar to patient | 100% spouse<br>100% coresident |
| Reich et al. 2006 (129)<br>(OA) | Age: 59 (mean)<br>% female: NR<br>% White race: 100<br>% not working: NR<br>Education: NR | Duration NR<br>WOMAC functional disability 2.44<br>Comorbidities NR | Age: 62 (mean)<br>% female: NR<br>% White race: 100<br>% not working: NR<br>Education: NR | 100% spouse<br>100% coresident |
| Dixon et al 2006 (145)<br>(OA) | NR | NR | NR | NR |
| Others |  |  |  |  |
| Leardini et al. 2004 (119)<br>(OA) | Age: 66<br>% female: 76<br>% White race: NR<br>% not working: 79<br>Education: NR | Duration 8.6<br>Localised to knee 21%; 2-4 joints 63%; poly-articular 15%<br>Comorbidities 55% | NR | NR |
| Leardini et al. 2002 (120)<br>(RA) | Age: 55<br>% female: 81<br>% White race: NR<br>% not working: 81<br>Education: 57% did not finish compulsory schooling | Duration by class only ACR I 6.1; II 9.9; III 13.4; IV 20.8<br>Mean HAQ 1.71<br>Comorbidities NR | NR | NR |
| Sanchez-Ayendez 1998 | Age: 76 Median<br>% female: 73 | 57% suffering chronic pain more than 10 years | Age: 52<br>% female: 100 | 90% daughters<br>10% sisters |

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| (131) | % White race: NR<br>% not working: 100%<br>Education: | 30% 5-10 years<br>13% 3-5 years<br>On HAQ 50% indicated much difficulty in functional ability and 44% some difficulty<br>Severity NR<br>Comorbidities NR | % White race: NR<br>% not working: 43<br>Education: NR | Care duration 8 years<br>30% coresident<br>No formal support<br>All other informal support<br>All described completing daily routine tasks as well as other non daily tasks |

## Appendix Table 3: Explanatory and dependent variables in studies of regression

| Study Record | Dependent variable | Explanatory variables clinical and care task related | Explanatory variables psychosocial | Explanatory variables demographic |
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| Riemsma et al. 1999 (90) | Carer Subjective burden<br>Carer mental health<br>Carer Objective burden | **Patient:**<br>Disease duration, comorbidities, health status: physical, pain and affect, fatigue,<br>**Carer:**<br>Physical health status, mental health, objective burden | **Patient:**<br>Social support, problematic social support, loneliness, self efficacy expectations towards coping with RA and mobilising social support, no of friends, no of children<br>**Carer:**<br>Self efficacy expectations towards giving help (one measure for activities of daily living and another for household tasks), social network, caregiver subjective burden | **Patient:**<br>Sex, age, education, urbanisation, income<br>*Riemsma 1998*: marital status<br>**Carer:**<br>Sex, age, education, income, Relationship to patient |
| Das Chagas Medeiros et al. 2000 (112) | Carer burden scale | *Only final model presented, variables that were considered but removed before model finalised not reported.*<br>**Patient**<br>Mental health, general health status, Physical aspect (SF-36),<br>**Carer**<br>Mental health, Pain scale | *Only final model presented, variables that were considered but removed before model finalised not reported.*<br>**Patient**<br>Quality of relationship<br>**Carer**<br>Quality of relationship | *Only final model presented, variables that were considered but removed before model finalised not reported.* |
| Beckham and Burker 1995 (109) | Caregiver burden<br>Caregiver optimism<br>Caregiver pessimism | *Single model described in text only*<br>**Patient**<br>Disease severity (functional class)<br>AIMS pain<br>AIMS physical disability | *Single model described in text only*<br>**Patient:**<br>Self efficacy expectations<br>distorted cognitions | *Single model described in text only*<br>**Patient:**<br>Age<br>Education |
| Stephens et al. 2006 (104) | Carer depressive symptoms | **Patient**<br>Pain severity<br>Depressive symptoms<br>Anger | **Patient:**<br>Pain disclosure<br>**Carer:** | **Patient**<br>Education<br>**Carer** |

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| | Carer Life satisfaction<br><br>Carer anger | **Carer**<br>Physical health<br>Depressive symptoms<br>Cognitive status<br>Anger | Husband report of pain behaviour<br>Life satisfaction<br>Marital satisfaction<br>Anger<br><br>**Interaction**<br>Pain and pain disclosure/behaviour | Income<br>Age<br>Number of children<br>Education<br><br>**Household**<br>Income |
| Jacobi et al 2003 (115) | Each of the five dimensions of the Caregiver reaction assessment<br><br>Self rated burden<br><br>Willingness to accept<br><br>Willingness to pay | *Only final model presented, variables considered are inferred from text*<br><br>**Patient**<br>EQ-5D<br>Disease duration<br>Receipt of professional home care<br>On waiting list for professional care<br>If other people were involved in care process (other informal carer)<br><br>**Carer:**<br>EQ-5D,<br>Care tasks, home tasks, help tasks,<br>Care duration<br>Care days<br>Time spent caring (hours per week)<br>Changes in time spent in different activities<br>Changes in finances | *Only final model presented, variables considered are inferred from text*<br><br>**Carer**<br>Caregiver reaction assessment | *Only final model presented, variables considered are inferred from text*<br><br>**Patient:**<br>Age<br>Gender<br>Residence location<br>Education income<br><br>**Carer:**<br>Age<br>Gender<br>Education level<br>Change in income<br>Employment status<br>Partner caregiver<br>Income |
| Manne and Zautra1990 (89) | Husband psychological adjustment | **Patient:**<br>Time since diagnosis<br>Frequency of flare ups<br>Duration of flare ups<br>Pain<br>Activity limitations | **Patient:**<br>Characterological blame<br>behavioural self blame<br>cognitive restructuring<br>wishful thinking<br>psychological adjustment<br>perceived negative and positive response from husband<br>wife perception of negative remarks<br>wife perception of positive remarks | NR |

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|  |  |  | **Husband:**<br>Coping efficacy,<br>Vulnerability,<br>Husband critical remarks,<br>*Caregiver burden* |  |
| Walsh et al. 1999 (139) | Partner CES D<br><br>Partner didactic adjustment scale | **Patient**<br>Disease duration<br>joint count<br>CES D<br>SF-36<br><br>**Partner**<br>CES D<br>SF-36 | **Patient**<br>Relative source of distress index<br>social support<br>burden<br>dyadic adjustment scale<br>**Partner**<br>Relative source of distress index<br>social support<br>caregiving burden<br>dyadic adjustment scale | Age,<br>Education,<br>Year married *(unclear if age and education are for both patient and caregiver)* |
| Strating et al. 2007 (132) | Partner distress (depression and anxiety subscales of GHQ) | **Patient**<br>Disease duration<br>Disability | **Patient**<br>Negative transactions, marital quality<br>**Partner**<br>*Caregiving burden*, Negative transactions, marital quality<br>**Interaction terms**<br>Disability x burden,<br>Negative transactions x marital quality,<br>Burden x negative transactions | **Patient**<br>Gender<br>Age<br>Education<br>**Partner**<br>Gender<br>Age<br>Education |
| Dixon et al. 2006 (145) | Days of care received | **Patient**<br>EQ-5D domains:<br>• Mobility problems<br>• Self care problems<br>• Problems with usual activities<br>• Pain<br>• Anxiety/depression | None | None |

## Appendix Table 4: Results intervention studies

| Study Record | Results |
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| **Pharmaceutical treatments** | |
| Mittendorf et al. 2008 (142,152–154) | **Patient outcome:**<br>Mean pain VAS was 33.52 at baseline and 29.87 at week 144 (treatment effect maintained)<br>Morning stiffness decreased from mean 45.99 minutes at baseline to 24.53 minutes at week 144 (p<0.05)<br>Data for other outcomes are stated to have improved but data are not shown<br>**Care outcome:**<br>The mean duration of free of charge personal help received per patient was 119.18 (SD 389.27) hours in 6 months prior to baseline and 91.32 (SD 270.43) per standardised 6 months during study period. Median 0 at both time points (sig NR).<br>Some participants will have been on adalimumab as part of the Phase I-III studies, therefore the baseline results may not be the start of treatment. |
| Kavanaugh et al. 2010 (116,117,148,149) | **Patient outcome**<br>For the primary outcome measure of ACR 20 48% of patients in the combined golimumab group had an ACR20 response compared to 9% of patients in the placebo group (p<0.01).<br>**Care outcome**<br>It is stated that golimumab was significantly better than placebo in reducing time lost from work for caregivers at week 24 (p<0.05). No numerical data are presented. |
| Genovese et al 2010 (114,150) | **Patient outcome**<br>For the outcome measure ACR20 at week 14 55.6% in the combined golimumab plus methotrexate group had an ACR20 response compared to 33.1% in the placebo group (p<0.001). For the HAQ-DI outcome, the improvement from baseline at week 24 was -0.44 in the combined golimumab plus methotrexate group and -0.13 in the placebo group (p<0.001).<br>**Care outcome:**<br>Abstract states through week 24 there were no statistically significant improvements in employability, time lost to work from caregivers, or healthcare resource consumption. Time lost to work by patients and caregivers decreased from weeks 24 to 52. No numerical data are presented. |
| Kimball et al. 2007 (118,146,147) | **Patient outcomes:**<br>77% of patients were classified as responders according to physician global assessment at 24 weeks (95% CI: 74.64-79.55%)<br>**Care outcome**<br>Number of patients requiring care and/or transportation assistant 8.2% at baseline, 3.4% as week 12, 2.7% at week 24 (P<0.001 for both 12 week and 24 week comparisons with baseline).<br>Mean number of days per month of time off required to provide care and/or transportation assistance 0.99 at baseline 0.12 at week 12 |

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| | and 0.03 at week 24 (p<0.001 for both week 12 and week 24 comparisons with baseline). Standard deviations not reported |
| **Surgical Interventions** | |
| Chow<br>2001 (111) | **Patient outcomes**<br>NHP: before operation mean score was 20.9 and after operation the mean score was 9..9 (p<0.001)<br>Pain VAS before operation mean VAS score was 72.2 and after operation 12.7 (p<0.001)<br><br>**Care outcomes**<br>Before total hip replacement 47.8% of the carers felt it to be quite stressful while 43.5% felt it to be moderately or very stressful (8.7% report no stress). After total hip replacement 52.2% remained feeling quite stressed, but reduced number who felt moderately or very stressed and increased number who reported no stress.<br>Robinson caregiver stress index: Mean stress score before the hip operation was 13.0 and after 10.0.<br>There was a 23% reduction in the carer's mean stress score (p<0.06) |
| Bachrach-Lindstrom et al.<br>2008 (108) | **Patient outcomes**<br>EQ-5D index: Baseline 0.47 (men), 0.48 (women); one week before surgery 0.40 and 0.37 respectively, one year after surgery 0.88 and 0.85 respectively (significance results not reported)<br>WOMAC physical functioning : Baseline 40 (men), 38 (women); one week before surgery 35 and 32 respectively, one year after surgery 94 and 91 respectively (p<0.001 for both men and women)<br>NHP total score: Baseline 29 (men), 36 (women); one week before surgery 33 and 36 respectively, one year after surgery 3 and 7 respectively (p<0.001, for both men and women)<br><br>**Care outcomes**<br>Proportion requiring home help from relatives:<br>Baseline 25% (men), 38% (women); one week before surgery 49% and 68% respectively, one year after surgery 6% and 16% respectively (statistical tests reported only for the differences between men and women at individual time points, not over time). Text reports that that at one year follow up there was a statistically significant decrease in need for help from 58% to 11% p<0.001 |
| Orbell et al.<br>1998 (127) | **Patient outcomes**<br>CES D: baseline 9.40, 3 months after surgery 7.42, 9 months after surgery 7.53 (NS; baseline vs 9 months)<br>HADS: baseline 9.29. 3 months after surgery 7.39, 9 months after surgery 7.76 (p<0.01)<br>Pain checklist: baseline 22.26 3 months after surgery 4.94, 9 months after surgery 3.72 (p<0.01)<br>Pain resting: VAS: : baseline 21.38 3 months after surgery 4.21, 9 months after surgery 5.28 (p<0.01)<br>Pain worst: VAS: : baseline 80.94 3 months after surgery 19.82, 9 months after surgery 23.26 (p<0.01)<br>Functional activity: baseline 18.25; 3 months after surgery 19.82 , 9 months after surgery 26.35 (p<0.01)<br><br>**Care outcomes**<br>Number of tasks with which help is received: baseline 2.01, 3 months after surgery 1.33, 9 months after surgery 1.07 (p<0.01)<br>Number of hours of informal care: baseline 2.42, 3 months after surgery 3.83, 9 months after surgery 7.08 (p<0.01)<br>36% reported no hours of informal care support before or after surgery.<br>Increase in use of formal services also reported |

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| **Psychological Interventions** | |
| Martire et al. 2007 (124–126,141) | **Patient outcomes (ITT)**<br>WOMAC total score:<br>PES: pre = 38.58, post, = 36.39, 6 months = 33.49; CES: pre = 35.69, post =34.51, 6 months =34.47; UC: pre = 40.25, post = 39.56, 6 months = 37.73 (no statistically significant differences for any comparisons between interventions)<br>Arthritis Self efficacy total score:<br>PES: pre = 143.20, post, = 148.78, 6 months = 150.15; CES: pre = 147.64, post =147.71, 6 months =151.62; UC: pre = 136.21, post = 138.31, 6 months = 139.48 (no statistically significant differences for any comparisons between interventions)<br><br>**Care outcome (ITT)**<br>All values are PES, CES and UC respectively means (SD)<br>Perceived stress:<br>Preintervention 12.65 (0.72) 12.36 (0.68) 14.52 (0.90) ; Postintervention 12.94 (0.72) 11.84 (0.69) 14.32 (0.91); 6 months 12.51 (0.74) 12.37 (0.71) 14.41 (0.94) (no statistically significant differences any comparisons between interventions)<br>Depressive symptoms:<br>Preintervention 4.90 (0.54) 5.19 (0.51) 5.92 (0.68) Postintervention 5.73 (0.59) 5.02 (0.56) 6.63 (0.74) 6 months 5.27 (0.59) 5.22 (0.57) 5.95 (0.75) (no statistically significant differences for any comparisons between interventions)<br>Caregiver mastery:<br>Preintervention 43.74 (0.76) 44.19 (0.73) 42.41 (0.98) Postintervention 43.53 (0.74) 43.78 (0.71) 41.96 (0.95) 6 months 43.82 (0.74) 44.81 (0.71) 42.39 (0.95) (no statistically significant differences for any comparisons between interventions)<br>Critical attitudes<br>Preintervention 6.55 (0.25) 6.55 (0.24) 6.33 (0.33), Postintervention 6.65 (0.25) 6.31 (0.24) 6.31 (0.32) 6 months 6.38 (0.25) 6.52 (0.24) 6.81 (0.32) (no statistically significant differences for any comparisons between interventions) |
| Martire et al. 2003 (123) | **Patient outcome**<br>No main effects for time or interactions between time and group were observed for pain, disability, depressive symptomatology, spousal emotional support or spousal insensitive responses. There was a significant time x group interaction effect for arthritis self efficacy (p=0.01).<br><br>**Care outcome**<br>No main effects for time or interactions between time and group were observed for caregiving stress, depressive symptomatology, or for caregiving mastery. |
| **Methods of service delivery** | |
| Van der Sluis et al. 2009 (137) | **Patient outcomes:**<br>No statistically significant differences were found between groups at T0, T1 and T2 for patient satisfaction (T1 3.9 vs 4.1 , p=0.638; T2 3.9 vs 4.1, p=0.275)<br>No statistically significant differences were found between groups at T0, T1 and T2 for hand function related QoL (T1 49.3 vs 52.8, p=0.258; T2 48.8 vs 52.0, p=0.337), Effects of time on hand function related QoL was also not statistically significant in either group |

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| | **Care outcome:**<br>Valued at 8 euros an hour<br>For the control group cost of informal care at T0, T1 and T2 was 458, 563 and 626 euros respectively<br>For the intervention group cost of information care at T0, T1 and T2 was 272, 391, 309 euros respectively<br>Mixed model analyses correcting for initial discrepancies between group did not reveal statistically significant differences between groups in mean total costs of home or informal care (only 1 model is shown, which seems to include both homecare and informal care costs) |
| Li et al. 2006 (121,151) | **Patient outcome**<br>44% of the PTM group and 18.8% of the TTM group met the clinical responder criteria p=0.004.<br>For secondary outcomes statistically significant differences were identified only for knowledge questionnaire p<0.01 both at discharge and at 6 months and for RA coping efficacy at 6 months. (p=0.03). Analyses were completed on mean differences from baseline between groups, rather than mean outcome of groups.<br><br>**Care outcome:**<br>In the PTM group 27% reported caregiver time loss vs 16.7% in the TTM group.<br>Costs of caregiver time loss in Canadian dollars for the 6 month study period are reported as $321 for the PTM group and $295 for the TTM group. (It is implied though unclear that this is valued assuming an hourly wage of $22.32 representing the average hourly wage for a 47.1 year old man (representing the average caregiver in the study)). Nothing further is stated about these data. |

## Appendix Table 5: Results cross sectional studies: regression

| Study Record | Results |
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| Riemsma et al. 1999 (90,130) | *Subjective burden*<br>• Factors related to subjective burden: objective burden ($p<0.001$), carers self efficacy towards household activities ($p<0.01$), carers physical health status($p<0.05$), patients number of children in neighbourhood ($p<0.05$)<br>• Carer relationship to patient and carer sex also included in model but not statistically significant<br>• Higher perceived subjective burden linked to higher objective burden, lower perceived efficacy in completing household tasks, lower carer physical health, and patients with fewer children in neighbourhood.<br>*Mental health*<br>• Factors related to mental health: carer relationship to patient ($p<0.05$), carers physical health status ($p<0.01$), carer self efficacy towards household activities ($p<0.05$), number of children of patient in neighbourhood ($p<0.01$)) and patient fatigue ($p<0.05$)<br>• Carer objective burden and carer sex also included in model but not statistically significant<br>• Worse mental health linked to poorer physical health, worse self efficacy expectations towards household tasks, higher patient fatigue and patient having fewer children in neighbourhood, and carer was a partner.<br>*Amount of help received*<br>• Significant factors related to amount of help received: patient physical health status ($p<0.001$)), patient marital status ($p<0.001$), age of patient ($p<0.05$), sex of caregiver ($p<0.001$)<br>• Patient self efficacy expectations towards coping with RA was included in the model but not statistically significant<br>• Higher amounts of help received if physical health status is worse, the patient and carer are married, the carer is male and if the patient has low self efficacy expectations towards coping with RA. |
| Das Chagas Medeiros et al. 2000 (112) | *Caregiver burden scale*<br>• Factors influencing caregiver burden scale = (in order of importance) caregiver mental health ($p=0.0001$), caregiver quality of relationship ($p=0.0001$), caregiver pain ($p=0.001$), patient quality of relationship ($p=0.001$), patient physical aspect ($p=0.003$), patient mental health ($p=0.007$) patient general health status ($p=0.014$)<br>• Caregiver burden was higher in patients and carers reporting worse mental health, lower perceived relationship quality, caregiver increased pain, and reduced physical, and mental health of patient. |
| Beckham and Burker 1995 (109,143) | *No model presented* "patient self-efficacy expectation scores were the single greatest predictor of caregiver burden and caregiver optimism. Patient self-efficacy expectations were related to caregiver burden ($R^2$ 0.14 $p=0.003$) and related to caregiver optimism ($R^2$ 0.07 $p=0.04$). Patients whose self-efficacy expectations regarding arthritis symptoms were lower also have caregivers who reported greater burden and less optimism. Patients AIMS physical disability was the single significant predictor of caregiver pessimism ($R^2$ 0.11 $p=0.01$) with increased physical disability associated with greater caregiver pessimism". |
| Stephens et al. 2006 (104,113,140) | Druley 2003<br>*Husband depressive symptoms at Time 2 (T2):*<br>• Factors associated with husband depressive symptoms at T2: husband depressive symptoms at T1 ($p<0.001$),<br>• Husbands depressed at T1 showed more depression at T2<br>*Husband anger at T2:* |

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| | • Factors influencing husbands anger at T2: husband education (p<0.05), husband anger T1 (p<0.001), patient depressive symptoms T1 (p<0.05), patient anger at T1 (p<0.001).<br>• Husbands with less education and more anger with wives who were more depressed and angry at T1 showed higher levels of anger at T2.<br>Stephens et al. 2006:<br>*Coefficients only given for wives pain, pain disclosure/ behaviour, and interaction term.*<br>• (Controlling for income and husbands physical health) wives pain, pain disclosure and the interaction between pain and pain disclosure were not statistically significant predictors of husbands' depressive symptoms at T1. Neither were wives' pain, pain behaviour or the interaction between pain and pain behaviour.<br>• (Controlling for husbands age, cognitive status, and number of children) wives pain, pain disclosure and the interaction between pain and pain disclosure were not statistically significant predictors husbands' life satisfaction at T1. Although wives pain and pain behaviour were not significant predictors of husband's life satisfaction at T1, the interaction between pain and pain behaviour was.<br>• (Controlling for T1 depression, income and husband's physical health), wives pain disclosure and the interaction between pain and pain disclosure were statistically significant predictors of husbands' depressive symptoms at T2, wives pain was not significantly associated. Neither were wives' pain, pain behaviour or the interaction between pain and pain behaviour.<br>• (Controlling for T1 life satisfaction and number of children) wives pain, pain disclosure and the interaction between pain and pain disclosure were not statistically significant predictors husbands' life satisfaction at T2. Neither were wives pain and the interaction between pain and pain behaviour, although pain behaviour was.<br>• Women with more pain and who expressed more pain behaviours had husbands who had less life satisfaction at time 1.<br>• Women with more pain and who disclosed more of their pain had husbands who were more depressed at time 2. |
| Jacobi et al. 2003 (110,115,133–136,138) | *Self esteem subscale of CRA*<br>• Factors influencing self esteem subscale of CRA: carer pain/discomfort (p<0.001), and receipt of professional home care (p<0.01).<br>• Reduced self esteem of the caregiver was associated with patients having problems with ADL, and patients receiving home care.<br>*Lack of family support subscale of the CRA*<br>• Factors influencing lack of family support subscale of the CRA: carer mobility (presence of problems) (p<0.001), patient problems with self care (p<0.001), carer giver time spent on home tasks (p<0.01), performing of help tasks (p<0.05) and care days per week (p<0.01)<br>• Greater burden from lack of family support was associated with caregiver having problems with mobility, the patient had problems with self care activities, the caregiver provided more help tasks and as the number of care days per week increased. The burden was lower if more time was spent on home tasks.<br>*Financial problems subscale of the CRA*<br>• Factors influencing the financial problems subscale of the CRA: carer mobility (presence of problems) (p<0.001), patient age (p<001), patient problems in self care (p<0.001)<br>• Greater burden from financial problems was associated with the caregiver had problems with mobility, and if the patient had problems with self-care activities. The scores on this dimension decreased as the age of the patient increased.<br>*Disrupted schedule subscale of the CRA*<br>• Factors influencing the disrupted schedule subscale of the CRA: patient age (p<0.05), caregivers performing care tasks (p<0.001), caregivers performing help tasks (p<0.001) and care days per week (p<0.001)<br>• Greater burden from schedule disruption was associated with lower age of patient, if the caregiver performed care tasks and help tasks |

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| | and with increasing number of care days per week.<br>*Loss of physical strength subscale of the CRA*<br>• Factors influencing loss of physical strength subscale of the CRA: carer mobility problems (p<0.001), presence of carer pain and discomfort (p<0.001), patient difficulties in self care activities (p<0.01 or activities of daily living (p<0.05), and carer providing help tasks (p<0.05)<br>• Greater burden from loss of physical strength of the caregiver was associated with the caregiver having problems with mobility, problems with pain/discomfort, if the patient had problems with self-care activities or ADL and if the caregiver performed help tasks<br><br>Van Exel<br>*Two models presented, one which includes only the CRA subscales and one which includes the CRA subscale plus carer and care recipient outcomes*<br><br>*Self rated burden:*<br>• Model 1: Self rated burden (VAS 0-100, 100 =much too straining) was significantly related to CRA subscale disrupted schedule (p<0.001) and CRA subscale self esteem (p=0.001)<br>• Model two the same CRA subscales were significant and in the same direction (disrupted schedule; p=0.03; self esteem, p=0.003), care recipient health status was also statistically significant (p=0.03)<br>• The CRA dimensions disrupted schedule and loss of physical strength and care recipient health status were associated with overall subjective burden. Replacing health status with the disaggregated health profile suggested that patient problems with usual activities significantly contribute to caregiver burden.<br><br>Brouwer<br>*Two models presented, one(model 1) which includes patient and carer characteristics and changes in time investment and financial investment and one(model 2) which includes patient and carer characteristics and changes in time investment and financial investment and also caregiving tasks and time invested in tasks*<br><br>*Self rated burden*<br>• Model 1: self rated burden was associated with quality of life of patient (p=0.002), patient on waiting list for professional care (p<0.015), reduced income (t p<0.014), total time invested in informal carer (p=0.009)<br>• Model 2: self rated burden was associated with quality of life of patient (p=0.002), patient on waiting list for professional care (p<0.034), reduced income (p<0.027), and house spent on housecleaning (p=0.015).<br>• The results of model 1 indicate that lower patient quality of life scores are associated with higher caregiver subjective burden scores. Caring for a patient who is on a waiting list for professional care also associated with higher burden scores. Reduced income was associated with lower subjective burden and more time spent providing care increases the subjective burden. In model 2, total time is separated into the different time components. Time spent on house cleaning was asspcoated with higher subjective burden.<br><br>Van den Berg<br>*Amount required for a carer to accept providing another hour of care* |

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| | • The amount required for a carer to accept providing another hour of care was associated with income, gender, carer occupation, carer EQ-5D, carer opportunity costs to paid and unpaid work, CRA subscale 3 lack of family support, CRA subscale 5 care related self esteem, subjective burden (VAS), the type of care required personal care and support, not wanting to provide further care, patient sex, patient education , whether patient was on the waiting list or in receipt of professional care . All significant at the 95% CI<br>• Informal caregivers' WTA is associated with: income, male gender (higher), occupation (housewife or house husband compared to other), informal caregivers' and patients' EQ-5D, opportunity costs (compared to no opportunity costs), subjective burden ('lack of family support', 'care-derived self-esteem', and VAS) and care tasks. Characteristics of the care recipients play also a role: male gender (higher), low education leads to higher WTA compared to high education. Being on a waiting list for professional or residential care raises the WTA and receiving professional care lowers<br><br>Van de Berg:<br>*Single model for each of the 2 dependent variables presented*<br><br>*Log amount required for a carer to accept providing another hour of care*<br>• The only variable significantly associated with the log of caregivers WTA was the start (p<0.000)<br><br>*Log amount caregiver willing to pay for someone else to provide an extra hour of care*<br>• Factors associated with log of caregivers willingness to pay were low income vs middle income (p=0.033) and income unknown vs income middle (p<0.020). F-test for the joint influence is not statistically significant. |
| Manne and Zautra1990 (89,122) | *Husband adjustment*<br>• Statistically significant factors associated with husband psychological adjustment – coping efficacy, vulnerability, wife perceptions of negative remarks<br>• Worse adjustment in husbands was associated with worse coping, higher perceived vulnerability and greater negative remarks as perceived by wife. |
| Walsh et al. 1999 (139) | *Statistical significance of coefficients not reported in text*<br>*Partner CES D score*<br>• Factors in final model patient age, patient burden inventory, patient dyadic adjustment scale, patient's positive network support, partner physical role, partner relative source of distress, partner social functioning<br>• Higher levels of partner depression associated with older patient age, patient perceiving themselves as less of a burden, lower levels of patient relationship satisfaction, lower patient perceived positive network support, partner better physical function, partner greater distress and partner reduced social functioning.<br>• Text states, psychological, social and physical problems with the partner all seem to increase the likelihood of the well partner becoming depressed. Patient's RA status does not seem to be directly involved in mediating depression, although partner's relationship with patient does seem to play a role.<br><br>*Partner dyadic adjustment (relationship satisfaction)*<br>• Factors in final model: patient burden inventory, patient dyadic adjustment scale, patients general health, partners negative network support, patient vitality, partner vitality, carer burden |

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| | • Higher levels of satisfaction with relationship was associated with patients perceiving themselves to be less of a burden, higher levels of patient relationship satisfaction, patient's reduced health, partner lower perceived negative network support, partner lower perceived burden of caring for patient, higher levels of vitality in patients and partners |
| Strating et al. 2007 (132) | 5 models presented (1) with constant; (2) with gender, age, education, disease duration, disability, burden (patient and partner models) (3) as 2 but with interaction disability x burden (patient and partner models) (4) as 3 but with negative transactions and marital quality (patient and partner models) (5) as 4 but with interactions for negative transactions x marital quality (partner model) and burden x negative transactions (partner model) and marital quality x burden (patient model).<br>*Partner distress:*<br>• In the model (2) without any interaction terms partner perceived burden was associated (p<0.05) with greater distress (for partners),<br>• Introducing interaction terms (model 3) burden remained a significant predictor (p<0.05) of partner distress but the interaction between patient disability and partner burden was also significant (the effect of partners burden on their distress was higher where patient's had greater levels of disability) (p<0.05)<br>• Introducing further interactions (model 5) the interaction of negative transactions and marital quality and burden and negative transactions was also significant (both p<0.05). Author reports a weak direct effect of marital quality on partner's distress where its strength was moderated by negative transactions between patients and partners.<br>• In final model increased partner distress was associated (p<0.05) with being female, higher perceived caregiver burden, interaction between burden and disability (the effect of partners burden on their distress was higher where patients had greater levels of disability), interaction between negative transactions and marital quality and interaction between caregiver burden and negative transactions. |
| Porter et al 2008 (128) | **Correlations no regression models presented**<br>*Partner holding back*<br>• Correlated with higher caregiver strain (0.34; p<0.05), and negative affect (0.32; p<0.10). It was also correlated with patient psychologic disability (0.51; p<0.001) and patient catastrophising (0.58; p<0.001).<br>*Partner self efficacy for pain communication*<br>• Correlated only with partner positive affect (0.35; p<0.05). |
| Reich et al. 2006 (129) | **Correlations no regression models presented**<br>• No statistically significant correlations identified between caregiver burden and patient uncertainty of illness (-0.24), patient functional disability (0.10), patient average pain (0.05), partner supportiveness(0.16) and patient relationship satisfaction (-0.13) |
| Dixon et al. 2006 (144,145) | 3 models are presented for dataset as a whole (not arthritis specific, one with EQ-5D score, one with separate EQ-5D levels and domains and one including EQ-5D levels and domains and gender, age, ethnicity and occupation.<br>*Carer time in days*<br>• Significant associations were identified for some self care problems vs no problems (p<0.01), and severe problems with usual activities vs no problems (p<0.01).<br>• Great time spent caring was associated with patients having selfcare problems and difficulties with usual activities |

## Appendix Table 6: Results: cross sectional studies categorical analysis

| Study Record | Results |
|---|---|
| Leardini et al. 2004 (119) | **Categorical analysis by severity:**<br>*Unclear if this is only informal care or also productivity loss form carers. Labelled as informal care*<br>Direct care was valued at 6.20 Euros an hour equivalent to a wage of a daily help, and supervision valued at 3.46 Euros equivalent to the wage of a house maid. Productivity losses were based on human capital approach in terms of salary evaluation and estimated according to data from the National Statistics Institute.<br>Grade 1: doubtful narrowing of joint space and possible osteophytes: Euro 144 per patient per year Informal care<br>Grade 2: definite osteophytes and possible narrowing of joint space: Euro 501 per patient per year informal care<br>Grade 3: moderate multiple osteophytes, definite narrowing of joint space, and some sclerosis and possible deformity of bone ends: Euro 887 per patient per year informal care<br>Grade 4: large osteophytes, marked narrowing of joint space, severe sclerosis and definite deformity of bone ends: Euro 1758 per patient per year informal care |
| Leardini et al. 2002 (120) | **Categorical analysis by severity:**<br>Valued with salary evaluation for days lost, for house wives replacement cost approach used. The same method was used to estimate monetary value for the informal care provided during leisure time (6.4 euros an hour to quantify direct care, and 3.3 Euros and hours use used to estimate caregivers supervision).<br><br>**Main caregiver:**<br>Loss of work ACR I 0; ACR II 0, ACR III 0 ACR IV 1 (Euro cost 2698.5)<br>Working days lost ACR I 2 users (88.3 Euros); ACR II 8 users (149.2 Euros); ACR III 17 users (1167.3 Euros); ACR IV 12 users (1033.0 euros) ($p<0.001$)<br>Hours of informal care : ACR I 7 user (739.3 Euros); ACR II 24 users (3457.4 euros); ACR III 31 users (5985.5 euros), ACR IV 36 users (7159.0 euros) ($p<0.0001$)<br>**Other caregivers:**<br>Hours of informal care: ACR I 1 user (13.9 euros); ACR II 10 users (944.8 euros); ACR III 16 users (811.0 euros); ACR IV 22 users (1514.7 euros)<br>**Patient:**<br>Loss of work ACR I 2 patients (744.5 euros); ACR II 10 patients (3894.4 euros), ACR III 6 patients (2278.2 euros) ACR IV 7 patients (Euro cost 3042.8)<br>Working days lost ACR I 19 users (488.9 Euros); ACR II 21 users (1120.3 Euros); ACR III 25 users (1941.1 Euros); ACR IV 15 users (1801.2 euros) ($p<0.03$)<br><br>ACR I = completely capable to perform the usual activities of daily life (self care, vocational and avocational)<br>ACR II – capable of performing the usual self care and vocational activities but limited in avocational activities<br>ACR III – capable of performing the usual self care activities, but limited in vocational and a vocational activities<br>ACR IV = limited in ability to perform self care, vocational and avocational activities. |

## Appendix Table 7: Results qualitative study

| Study Record | Results |
|---|---|
| Sanchez-Ayendez 1998 (131) | **Verbatim quotes from article**<br>"Taking care of your elderly parents is primarily a woman's responsibility. Women are more reliable. Sons do not help as much or in the same ways". (p78)<br>"I am the oldest daughter and it is my obligation as the eldest. You know, men do not look after their parents in the same way, even if he [ailing father] is a man. The oldest daughter is generally the one who since youth is taught to be responsible for all and to maintain family relations". (p78)<br>"I was the youngest of the sisters and my parents and grandparents always told me that the youngest daughter was the one who had to look after the parents when they aged". (p79)<br>"My father left her [mother] when we were young. My oldest brother was 13; He [father] left for New Jersey and never sent any money. She insisted that we stay in school. She cleaned houses, ironed clothes . . . any job she could perform. How can we forget all that? We were poor but there was always food on the table. She put me through the two years of secretarial school because she wanted me, her only daughter, to have a better opportunity at life. I cannot turn my back on her. It is my obligation as a daughter". (p79)<br>"We were always close. She was the oldest of us and I was the youngest. She always looked after me and has been a wonderful aunt to my daughter. Even now with her arthritis, she helps me look after my grandchildren. My mother raised us to look after each other. It is my duty as a sister. Besides, we always got along well". (p79)<br>"She was an excellent mother. She gave us so much love! It is not so easy to look after her now that her condition requires so much attention. It requires a lot of work. But how can I say that I love her and not take care of her? I cannot be like my youngest sister who just stops by to visit". (p79)<br>"We always got along well. She was my favourite sister and I was hers despite our age differences. Since neither of us got married, we always lived together and helped each other. What am I supposed to do now that she needs me? Put her in an institution? Never as long as I am in good health! What kind of a sisterly love would that be? I couldn't do that to her. That is not how we were brought up to love one another and care for one another". (p80)<br>"My mother tries to help but she herself needs help. I could do it [bathing sick father] myself but he [father] refuses to allow my seeing him naked…, My youngest brother stops by every day after work and takes care of the bath. I am lucky that he lives close by and must pass their house on his way home from work. My other two brothers do not live close-by and they come *to* visit them every other weekend so I can't depend on them for assistance with the bath…, *or* anything else for that matter". (p80)<br>"I could bathe him but he [Father] cried the first time I had to do it. He was desperate ["desesperado"] .and yelling why God had allowed him |

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| | to live *to* have his only daughter see him naked and bathe him like a baby! . . . Now my son and husband help. . . . But it was not easy to convince him [father]. He [father] always comments that he never expected to see the day when he would be treated like a child". (p80) |
| | "I leave work and try to beat the traffic jam. When I reach her house [mother's], the first thing I do is have a cup of coffee. She [mother] always has the cup ready and some cheese and soda crackers. You see, she tries to do as much as she can but her condition does not allow her to use a broom or mop or lift a heavy pan. So I sit down for just a little while and she informs me of everything that goes on in the family: who has called, who has visited, etc. Then, while we talk, I cook something . . .and make sure that she has enough for dinner that evening and lunch the next day; nothing fancy: chicken or fish with some rice or "viandas" [starchy Puerto Rican vegetables], or if not, a soup. While the meal is being cooked, I make sure that she takes a bath and help her sit on the chair inside the tub for her legs cannot always go over the edge. She cannot rub her back nor reach her feet, so I do it for her. I wash her hair twice a week most of the time. Once she is out of the tub, I put her nightgown on and straighten the bed linen. Once she is dressed, we go to the kitchen and I tidy up the kitchen and clean the mess I've made. If she feels like eating, I serve her; if not, I leave everything ready for later in the evening when she feels up to it. Every other day I pass a quick broom and mop; the serious cleaning I do during the weekend. All these things take about two hours and then I go home to do the same for my husband and children!" (p81) |
| | "During the weekends I must clean my house and his [father's]; I work during the week. He is a man and is not very tidy. My mother was the one who always did household chores and prepared meals. At 82, I cannot expect him to do what he never did when my mother was alive. My Saturday begins at 6:00 AM. I go to his home early because my daughter comes to visit with the grandchildren during Saturday afternoons and sometimes we go *to* the mall or grocery shopping together. Besides, he always gets up at *5:30* in the morning, no matter what. On Friday evening I put his clothes in the washer and dry them overnight. I bring everything with me [clothes, towels, bed linen] and arrive at his house at *6:30-7:00.* He is already up and dressed. If I have not had breakfast at home, I have coffee and some bread. We talk and I always do the bathroom first. . . Then I put the clean clothes in the drawers, change the sheets and towels, broom and mop the floors, dust and polish the furniture. I've learned to be fast and his apartment is small! I finish around 10 in the morning and fix him lunch. I make sure that he has enough of the medicaments and any other thing he might need. Then I come home and start with the bathrooms and bed linen and towels. I wash and iron my clothes and my children's during the week. . . . I bring him home for lunch every Sunday and he sits around the whole afternoon: He can't walk a lot . . . his condition doesn't allow it. In the afternoon I prepare the meals for the whole week; both ours and his. I prepare different meals for him because he is on a low sodium-low fat diet. Sometimes he sits in the kitchen with me and we talk; during the week we don't talk much because I'm always on the go. . . . If he needs a haircut, I'm the one who usually drives him to the barber; if not, my son. My brother is always busy. I'm also the one who takes him to his medical appointments". (p82) |
| | "The physician's office opens at 7:00 in the morning; although he does not arrive until ten or so. My husband takes the children to school and I take her to the physician's office; it is near my school. We are there very early, like around 6:45. I take her inside the office and seat her. Then I go to a nearby Burger King and bring her coffee and a pastry. At home what she has had is just a glass of milk for she likes to be relaxed when drinking her coffee.. Then I leave for school. She calls my sister-in-law when the doctor is through with her, usually around 11:00-11:30 and my sister-in-law picks her up and brings her home. If I cannot arrange things with my sister-in-law because she cannot take off time from her office, then I must use one of my sick-leaves from school and not go to work". (p83) |
| | "I try to fit her appointments with my class schedule. But there are times when it is not easy and I must leave her all by herself at the physician's office because the wait is long. This semester, I teach some days during the afternoon and others in the morning. If the |

appointment is on one of the days that I teach in the afternoon, I take her to the physician's office around 11:00 in the morning. I make sure that she eats a snack before we leave because she will have a long wait. She also takes a fruit or something else in her bag to munch. I leave her at the doctor's office and go to work. When I finish at 4:00 or 500, I go to pick her up. Sometimes I still have to wait because the doctor has not seen her. . . . She and I have had 10 work this out because otherwise I would have to miss work. Luckily for me, my work schedule is flexible. There are other people who bring their parents to that physician and they have to miss a day from work". (p83)

"We try to leave as early as possible in the morning. It is not easy for her [mother] because she has a lot of pain in the mornings. In the mornings she is much more stiff than in the afternoon. But I have to pick up my youngest grandchild at day care at 1:00 and the others leave school at different times after 2:00. At times, the physician does not come in until later than usual and I have to leave her alone at the office, pick up my youngest grandchild, go with my grandchild to the office, and pick her up. I get very anxious and she gets upset and the baby gets upset. At times I find myself incriminating her. It is not her fault and then I feel awful. It is not easy when she has a medical appointment because one never knows how long the wait will be at the physician's office. Many times there is something unexpected and I get tense". (p84)

"She took care of everything; she is very good at that. She got most of us to cooperate. She even called our brother in Chicago and he came for a week. He was the one who stayed in the hospital those nights. We all helped in the best way we could. Even some of the eldest grandchildren helped during the day since it was summer and they were out from school. Not everyone helped the same but most helped in something. When he was released from the hospital, Myriam brought him home with her. She also worked out a schedule of who would stay with him when he was at her home once she had to go back to work after she used her vacation-time for the operation and the first week at home. But she was the one in charge of everything. . . . Once he was fully recuperated he moved back into his apartment". (p85)

**MOST STRESSFUL TASKS (respondents asked to name 3 most stressful tasks) %**
Transportation/ Escort to medical appointments (all) 100.0 (daughters) 88.9 (sisters) 100.0
Household chores (all) 70.0 (daughters) 77.8 (sisters) 33.3
Personal grooming (all) 63.3 )daughters) 63.0 (sisters) 66.7
Washing / ironing clothes (all) 60.0 (daughters) 66.6 (sisters) 0.0
Meal preparation (all) 46.7 (daughters) 66.6 (sisters) 0.0 (p86)

"Bathing her is difficult too. I generally do it before going to bed and am exhausted by then. I don't do it earlier because when I arrive I am tired from work and like to rest for about an hour or so; depending on what I must do. . . . I get up at 5:20 in the morning and leave for work by 6:30 at the latest. . . . I rest for a while and begin fixing dinner for the two of us. She can't lift a heavy pot. Then we both watch the soap opera and I talk on the phone to my children or one of my sisters - it depends. By that time, it is about 9:30 and I am sleepy. . . . One must be careful with her bath. I sit her on the: chair very carefully. I'm gentle when bathing her because her skin is very delicate and she may bleed. Her bath takes about 20-30 minutes between bathing, drying and dressing her [mother has rheumatoid arthritis and can barely move her elbows and shoulders]. When I wash her hair it takes longer. She gets tired from all this. I can't rush her. . . . And all I want is to go to bed and collapse". (p86)

"I guess what stresses me the most is cleaning his apartment. The irony of it all is that I have a cleaning woman who comes in twice a week to my house to help me. But she charges a lot and we can't afford to have her another day. My daughter contributes for one of those two days now that she moved in with her son. My brother and sister who live in the United States do not help us on a regular basis and his Social Security check isn’t a lot. It covers some basic things but not all. But my siblings don’t seem to understand this. Luckily, his apartment is a small two bedroom apartment. I spend one of my two days off from work cleaning his house and buying his food. We have a company deliver lunch to his house from Monday to Friday and he eats the same for lunch and dinner. But I always like to prepare him some soup in case he doesn’t feel like eating the same thing twice in the same day. We bring him over on Sundays and sometimes go out for lunch. He has been very good at adapting because he refuses to move in with us. . . . But he can’t clean well because of his condition and his poor eyesight. So I dust, broom, mop, clean the bathroom, and wash and dry the towels, sheets and his clothes. . . . I also change the bed. . . . I guess what I find more tiresome is that I don’t like to do the heavy cleaning in my own house and that I must do his on Saturday mornings when I would love to be at case in my house. Don’t forget that I leave the house at 8:00 in the morning on Saturdays in order to be able to buy his groceries when there are few people in the supermarket. I’m always in a rush on Saturday from seven until one in the afternoon”. (p87)

HELPS THE MOST (one person) %
Husband (all) 26.7 (daughters) 25.9 (sisters) 33.3
Daughter (all) 26.7 (daughters) 29.6 (sisters) 0.0
Sister (all) 16.7 (daughters) 18.5 (sisters) 0.0
Brother (all) 13.3 (daughters) 14.8 (sisters) 0.0
Sister-in-law (all) 6.7 (daughters) 7.4 (sisters) 0.0
Niece (all) 6.7 (daughters) 0.0 (sisters) 66.6
Mother (all) 3.3 (daughters) 3.7 (sisters) 0.0

OTHERS WHO HELP (two persons) %
Sister (all) 23.3 (daughters) 25.9 (sisters) 66.6
Daughter (all) 23.3 (daughters) 22.2 (sisters) 33.3
Son (all) 16.7 (daughters) 22.2 (sisters) 0
Brother (all) 13.3 (daughters) 11.1 (sisters) 66.6
Sister-in-law (all) 13.3 (daughters) 11.1 (sisters) 33.3
Niece (all) 13.3 (daughters) 11.1 (sisters) 33.3
Nephew (all) 6.7 (daughters) 7.4 (sisters) 0.0
Husband (all) 3.3 (daughters) 3.3 (sisters) 0.0
Nephew's wife (all) 3.3 (daughters) 0.0 (sisters) 33.3 (p88)

A. Problems related to family (%)

- Problems with siblings: all 80.0 (n = 30); daughters 85.2 (n = 27); sisters 33.3 (n = 3)
- Problems with frail elder: all 63.3 (n = 30) ; daughters 70.4 (n = 27) ; sisters 0.0
- Problems with husband: all 57.9 (n = 19) ; daughters 40.7 (n = 11) ; sisters 0.0
- Problems with offspring: all 57.1 (n = 28) ; daughters 78.9 (n = 15) ; sisters 33.3 (n = 3)

B. Problems with employment: all 94.1 (n=17) ; daughters 100.0(n=14) ; sisters 66.6(n=3)

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| | C. Problems related to main carer role<br>• Doubts as to proper accomplishment of caregiving tasks : all 33.3 (n = 30) ; daughters 37.0 (n = 27) ; sisters 0.0<br>• Finances: all 26.7 (n = 30) ; daughters 25.9 (n = 27) ; sisters 33.3 (n = 3)<br>D. Problems related to personal/health matters<br>• Personal/leisure time: all 76.7 (n = 30) ; daughters 77.7 (n = 27) ; sisters 66.6 (n = 3)<br>• Lack of sleep/Anxiety/Fatigue: all 59.3 (n = 30) ; daughters 55.6 (n = 27) ; sisters 33.3 (n = 3)<br>• Management of own household: all 100.0 (n = 21) ; daughters 77.8 (n = 21) ; sisters 0.0<br>"All" pertains to total in sample who fall into the category i.e.: "problems with husband" = those who have a husband, divorced women not included: "problems with employment" = only those who are employed. and not total sample of 30 carers Total N of those ID whom category applies included in parenthesis. (p89)<br><br>“She [sister who lives about 10 miles from her] knows that I do the best that I can. I have a husband who is driving me crazy with his adjustment to retirement and I must look after these two babies [grandchildren]. She dares to complain that I am not cleaning his house [elderly father's] the way I should! . . . I'm not a maid! I have many things to do! Why doesn't she go over every now and then and help? She stops by just to visit. All she helps with is buying his medicines. That is not the most time-consuming chore! Neither her husband nor sons come even once a week to help bathe him [father]! At least my husband and sons help! . . . My two brothers live in the United States and I can't depend on them. She is very much aware of that. . . . And even my two brothers sometimes dare to criticize from far away!” (p90)<br><br>“I have a sister and a brother who live in San Juan. They help as much as they can . . . well maybe not as much but they help. What bothers me very much is that they complain about how I do certain things. Even my sister-in-law dares to criticize! They don’t understand her [frail sister] like I do. . . . Besides, they don’t have to deal with the situation every day and every single hour. , , . It is very easy to criticize when you don’t have to face the situation day-after-day”. (p90)<br><br>“There are times when he is really feeling bad because he hurts more or can’t do as much-or little-as he can by himself. . . . He gets very depressed and seeing him like that depresses me. To make matters worse, he doesn’t want me to leave and plays this guilt-trip on me. It works! . . . When I must leave because I have to go home to sleep, I feel really awful! I don’t need that. I tell him that he should be thankful that he has his children who care for him. . . . But since I’m the one who visits daily, I am the one who is always faced with this guilt-trip and the depression”. (p91)<br><br>“I get very tired. I wish that I could have her at home with us but there isn’t that much space at our house. I’m always rushing from one place to another: work, her apartment [frail mother’s], and then my house. . . . My workday demands a lot; it is not that easy to do what I do. Then, everyday the same: work, her place, and mine. I am very tired in the evenings. . . . I must take half-a-day or the whole day off when I take her to her medical appointments. Not all my bosses are equally understanding. . . . When she underwent surgery I used my remaining vacation- time to stay in the hospital with her and throughout the rehabilitation period. I even had tn ask for three extra days that were taken off from my sick leave”. (p92)<br><br>“I yearn for the day when I can sleep a Saturday until barely eight in the morning or just stay at home doing household chores without having to rush from one place to the other. . . . Or just lay in bed doing absolutely nothing or reading a “Vanidades” [Latin American female- |

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|  | oriented journal]!" (p92)<br>"There are times when I feel angry at him. Can you believe that? My own father who.was so good to me! I feel so guilty afterwards! What kind of a daughter am I to feel such an awful thing! It doesn't help at all to have such feelings". (p93)<br>"Everybody has an opinion of their own as to how I should divide my time. I sometimes wonder if I'm the one who is incorrect and don't know how to handle the situation. . . . There are times when I resent being the one who has to take care of everything. But immediately I feel guilty and ashamed. How can I think that I am a good daughter and have these thoughts? She was a wonderful mother, completely devoted to us. . . . What kind of a daughter am I?" (p93) |

# Appendix 3: Critical appraisal of studies

## Appendix Table 8: Critical appraisal: Pharmaceutical interventions

| **Evaluation criteria** | **Genovese et al. 2010** (114) | **Kavanaugh 2010 et al.** (116,148) | **Kimball et al. 2007** (118) | **Mittendorf et al. 2008** (142) |
|---|---|---|---|---|
| Study Setting well described? | Yes | Yes | Yes | Yes |
| *Eligible population well described and appropriate?* | Yes | Yes | Yes | Yes (from original studies) |
| *Participants represent eligibles?* | Yes | Yes | Yes | Yes |
| *Were relevant personal (prognostic) characteristics of participants reported?* | Yes | Yes | Yes | Yes |
| *Exposure & comparison interventions well described & valid?* | Yes | Yes | N/A – no comparison | N/A – no comparison |
| *Allocation to exposure and comparison groups: random or by measurement?* | Yes - random | Yes - random | N/A – no comparison | N/A – no comparison |
| *Outcome of randomisation tamper resistant (allocation concealed)?* | Yes | Yes | N/A – no comparison | N/A – no comparison |
| *If allocated by measurement, was it accurate? Blind to outcomes? Objective? (ignore if randomised)* | N/A | N/A | N/A – no comparison | N/A – no comparison |
| *Participants and/or staff blind to exposure and comparison?* | Yes | Yes | Open-label | Open-label |
| *Compliance with exposure and comparison adequate?* | Unclear | Unclear | Unclear | Unclear |
| *Contamination acceptably low?* | Yes, up to week 14, after week 14 early escape may mean placebo data is biased | Yes, up to week 16, after week 16 early escape may mean placebo data is biased | N/A – no comparison | N/A – no comparison |
| *Co-interventions: were any other interventions similar in both groups?* | Yes | Yes | N/A – no comparison | N/A – no comparison |
| *All participants accounted for at study conclusion?* | Accounted for only in data to week 24 | Accounted for only in data to week 24 | Not all analyses include the full number of participants – the reasons for this are not accounted for. | Not all analyses include the full number of participants – the reasons for this are not accounted for. |
| *Could interventions be applied in usual practice?* | Yes, licensed pharmaceutical | Yes, licensed pharmaceutical | Yes, licensed pharmaceutical | Yes, licensed pharmaceutical |

|  | intervention | intervention | intervention | intervention |
|---|---|---|---|---|
| *Outcome measures well described & valid (Objective)?* | Subjective outcome measures collected from clinician and patient | Subjective outcome measures collected from clinician and patient | Subjective outcome measures collected from clinician and patient | Subjective outcome measures collected from clinician and patient |
| *Blinded outcome measurement?* | Yes Independent assessor | Yes Independent assessor | No Open label | No Open label |
| *Were all important outcomes assessed?* Are results presented for all outcomes measured? | Yes | Yes | Yes | Yes |
| *Similar follow-up time in exposure & comparison groups?* | Yes | Yes | N/A – no comparison | N/A – no comparison |
| *Was follow-up time meaningful?* | Unclear 24 weeks may not be sufficiently long to capture care outcomes | Yes (for care outcomes week 24 and week 52 data (week 52 uncontrolled) | Unclear 24 weeks may not be sufficiently long to capture care outcomes | Yes |
| *Exposure and comparison groups similar at baseline? If not, were these adjusted?* | Yes | Yes | N/A – no comparison | N/A – no comparison |
| *Intention to treat analysis?* | Yes | Yes | No | No |
| *Estimates of Intervention effects given or calculable?* | Yes (patient)<br>No (Care) | Yes | Yes | Yes |
| *Precision of intervention effects given or calculable?* | No (specific p values not given) | Yes | No (specific p values not given) | No (no p values or confidence intervals) |
| *Analytical methods appropriate?* | Yes | Yes | Yes | Yes |
| *Are the study results internally valid (i.e. unbiased)?* | Unclear for care | Yes | No comparator group | No comparator group |
| *Are results precise enough to be meaningful? If not, was power sufficient?* | No for care | Yes | Yes | Unclear |
| *Can the applicability of the results (i.e. external validity) be determined?* | Yes | Yes | Yes | Yes |
| **Overall study quality**<br>Were there any fundamental flaws in the study | Low<br>For patient data this trial would be rated as High. For carer data as no effect sizes are presented. It is rated Low | High | Medium<br>Not controlled, but large sample size of over 1000 patients for a technology already licensed for this population | Medium<br>Not controlled, but large sample size of over 500 patients for a technology already licensed for this population |

## Appendix Table 9: Critical appraisal: surgical intervention studies

| **Evaluation criteria** | **Bachrach-Lindstrom et al. 2008** (108) | **Chow 2001** (111) | **Orbell et al.1998** (127) |
|---|---|---|---|
| Study Setting well described? | Yes | No. Location not described | Yes |
| *Eligible population well described and appropriate?* | Yes | Yes | Unclear. People receiving treatment for osteoarthritis are described as being excluded from the study. But the treatments are not described. |
| *Participants represent eligibles?* | Yes. Consecutive patients | Unclear. All eligible contacted, characteristics of non respondents not reported. | Yes. All eligible contacted, characteristics of non respondents reported. |
| *Were relevant personal (prognostic) characteristics of participants reported?* | No. Details of patient sample provided, but no details about amount of care being received reported | No. No details of amount of care provided | Yes |
| *Exposure & comparison interventions well described & valid?* | No – no comparison | No – no comparison | No – no comparison |
| *Allocation to exposure and comparison groups: random or by measurement?* | No – no comparison | No – no comparison | No – no comparison |
| *Outcome of randomisation tamper resistant (allocation concealed)?* | No – no comparison | No – no comparison | No – no comparison |
| *If allocated by measurement, was it accurate? Blind to outcomes? Objective? (ignore if randomised)* | No – no allocation | No – no allocation | No – no allocation |
| *Participants and/or staff blind to exposure and comparison?* | No – no comparison | No – no comparison | No – no comparison |
| *Compliance with exposure and comparison adequate?* | Yes – surgical intervention, proportion not receiving surgery reported and excluded from analysis | Yes – surgical intervention, analysis only includes those receiving surgery | Yes – surgical intervention, analysis only includes those receiving surgery |
| *Contamination acceptably low?* | N/A – no comparison | N/A – no comparison | N/A – no comparison |
| *Co-interventions: were any other interventions similar in both groups?* | N/A – no comparison | N/A – no comparison | N/A – no comparison |
| *All participants accounted for at study conclusion?* | Yes – all participants accounted for at end of study | Yes – all participants accounted for at end of study | Yes – all participants accounted for at end of study |
| *Could interventions be applied in usual practice?* | Yes – standard intervention | Yes – standard intervention | Yes – standard intervention |

| | | | |
|---|---|---|---|
| *Outcome measures well described & valid (Objective)?* | Subjective patient reported outcomes<br>Patient: Patient reported outcomes<br>Care: Care reported from perspective of patient | Subjective patient and carer reported outcome measures | Subjective patient reported outcomes<br>Patient: Patient reported outcomes<br>Care: Care reported from perspective of patient |
| *Blinded outcome measurement?* | N/A – no allocation | N/A – no allocation | N/A – no allocation |
| *Were all important outcomes assessed?* Are results presented for all outcomes measured? | Data for all outcomes described are reported | Data for all outcomes described are reported | Data for all outcomes described are reported |
| *Similar follow-up time in exposure & comparison groups?* | N/A – no comparison | N/A – no comparison | N/A – no comparison |
| *Was follow-up time meaningful?* | Yes | Unclear, yes for patients but unclear if for carers | Yes |
| *Exposure and comparison groups similar at baseline? If not, were these adjusted?* | N/A – no comparison | N/A – no comparison | N/A – no comparison |
| *Intention to treat analysis?* | N/A – no allocation | N/A – no allocation | N/A – no allocation |
| *Estimates of Intervention effects given or calculable?* | Yes. Baseline, 1 week before surgery and 1 year after surgery scores provided | Yes. Individual scores given for each participant | Yes. Baseline, 3 months after surgery and 9 months after surgery score reported |
| *Precision of intervention effects given or calculable?* | Yes. P values provided | Yes. Individual scores given for each participant | Yes. P values given |
| *Analytical methods appropriate?* | N/A – no comparison | N/A – no comparison | N/A – no comparison |
| *Are the study results internally valid (i.e. unbiased)?* | No comparison | No comparison | No comparison |
| *Are results precise enough to be meaningful? If not, was power sufficient?* | Yes | No. Only 23 participants analysed | Unclear. Only 72 patients analysed |
| *Can the applicability of the results (i.e. external validity) be determined?* | Yes | No | No |
| **Overall study quality**<br>Were there any fundamental flaws in the study | Low<br>Case series. No comparison<br>This is a standard intervention a comparison group would have been difficult to implement vigorously and ethically. | Low<br>Case series. No comparison<br>This is a standard intervention a comparison group would have been difficult to implement vigorously and ethically. | Low<br>Case series. No comparison<br>This is a standard intervention a comparison group would have been difficult to implement vigorously and ethically. |

## Appendix Table 10: Critical appraisal: psychological interventions and service delivery interventions

| **Evaluation criteria** | **Martire et al. 2003** (123) | **Martire et al. 2007** (125) | **Li 2006** (121) | **Van der Sluis et al. 2009** (137) |
|---|---|---|---|---|
| Study Setting well described? | Yes | Yes | Yes | Yes |
| *Eligible population well described and appropriate?* | Yes | Yes | Yes | Yes |
| *Participants represent eligibles?* | Unclear only 24 couples in study | Yes | Yes | Yes |
| *Were relevant personal (prognostic) characteristics of participants reported?* | Yes. But only for the group as a whole | Yes | Yes | Yes |
| *Exposure & comparison interventions well described & valid?* | Yes | Yes | Yes | No – control group not described |
| *Allocation to exposure and comparison groups: random or by measurement?* | Random | Random | Random | Historical control |
| *Outcome of randomisation tamper resistant (allocation concealed)?* | Unclear | Unclear | Unclear | Not random |
| *If allocated by measurement, was it accurate? Blind to outcomes? Objective? (ignore if randomised)* | N/A random | N/A random | N/A random | Yes |
| *Participants and/or staff blind to exposure and comparison?* | Not blinded | Yes (staff)<br>No (participants) | Unclear | Not blinded |
| *Compliance with exposure and comparison adequate?* | No. Intervention 5.31 sessions out of 6 attended by patients and 5.00 on average by husbands<br>Control: average attendance was 3.45 | Yes. Attendance at PES 5.2 (SD 1.3) and CES 5.1 (SD 1.4). | No. In the control group only 27 out of 71 received the assigned treatment, compared with 62 out 0f 73 in the intervention group | Yes |
| *Contamination acceptably low?* | Yes. No contamination | Fairly high approximately a quarter did not receive the specified intervention. 21 groups did not receive patient intervention and 28 did not receive couple intervention. It is therefore assumed that these | Yes. Those who did not receive the assigned intervention received no care rather than the intervention/control | Yes |

| | | | | |
|---|---|---|---|---|
| | | groups received their usual care. | | |
| *Co-interventions: were any other interventions similar in both groups?* | Unclear | Yes | Yes | Unclear |
| *All participants accounted for at study conclusion?* | Yes | Yes | Yes | No. differences in N's across assessments not accounted for |
| *Could interventions be applied in usual practice?* | Standard management programme vs adapted management programme | Standard management programme vs adapted management programme vs usual care | Comparisons of two management programmes both of which are implemented in Canada | Yes. Both represent standard practice. Although the control is not described. |
| *Outcome measures well described & valid (Objective)?* | Subjective patient and carer reported outcome measures | Subjective patient and carer reported outcome measures | Subjective patient reported outcome measures | Subjective patient reported outcome measures |
| *Blinded outcome measurement?* | No | Yes | Unclear | Unclear |
| *Were all important outcomes assessed?* Are results presented for all outcomes measured? | Yes | Yes | Yes | Yes |
| *Similar follow-up time in exposure & comparison groups?* | Yes | Yes | Yes | Yes |
| *Was follow-up time meaningful?* | Yes, to capture effects of intervention but not long enough to identify if outcomes of intervention were maintained outside of the intervention context | Yes measurements both after intervention and at follow up to see if effects maintained | Yes | Unclear. Six months appears a fairly short period to evaluate an alternative MDT configuration |
| *Exposure and comparison groups similar at baseline? If not, were these adjusted?* | Significantly higher pain reported in the control group | Yes measured and found not to be different exception for depression in patients with OA, CES group had more depressive symptoms than PES group. | Yes. Pre treatment differences assessed and found not to be different (care outcomes not included in this) | Pre treatment differences assessed and found not to be different<br>Care outcomes visually look very different |
| *Intention to treat analysis?* | Yes | Yes | Yes | No |
| *Estimates of Intervention effects given or calculable?* | Yes | Yes | No | Yes |
| *Precision of intervention effects given or* | Yes | Yes | Yes | No |

| | | | | |
|---|---|---|---|---|
| *calculable?* | | | | |
| *Analytical methods appropriate?* | Yes | Yes | Yes | Unclear |
| *Are the study results internally valid (i.e. unbiased)?* | Yes | Yes | No. The rate of non completion of the intervention is considerable | No. historical control with no description of control group |
| *Are results precise enough to be meaningful? If not, was power sufficient?* | With 24 couples it is unlikely that the study had sufficient power to demonstrate a difference | Unclear | Unclear | Unclear |
| *Can the applicability of the results (i.e. external validity) be determined?* | Yes | Yes | Yes | No, no description of control |
| **Overall study quality**<br>Were there any fundamental flaws in the study | Medium | Medium | Low | Low |

## Appendix Table 11: Critical appraisal: cross sectional studies of association

| | Beckham and Burker 1995 (109) | Das Chagas Medeiros et al. 2000 (112) | Jacobi et al. 2003 (115) | Riemsma et al. 1999 (90) | Stephens et al. 2006 (104) |
|---|---|---|---|---|---|
| Study Setting well described? | Yes | Yes | Yes | Yes | Yes |
| Eligible population well described and appropriate? | No, methods of selecting patients from the sampling frame not described | Yes | Yes | Yes | Yes |
| Participants represent eligibles? | Unclear | Yes | Some differences between the participants and eligible are described | Some differences between the participants and eligible are described | Differences between the participants and eligibles are described |
| Were relevant personal characteristics (or disease stage) in participants reported? | No, characteristics of the sample were insufficiently described | Yes | Yes | Yes | Yes |
| Selection of exposure group. | Unclear, methods of identifying people from the sampling frame not described | All patients attending with a primary caregiver asked to take part. However, by restricting to patients attending with a primary caregiver this may have led to a biased sample | All eligible patients contacted | Consecutive patients asked | All eligible patients contacted |
| Was the selection of explanatory variables based on a sound theoretical basis? | Yes, a theoretical model of adaptation in RA is described | No theoretical framework described | Yes, the perspective of the authors is described | Yes, stress process models of caregiving are described | Yes, a theoretical perspective is described in the linked papers |
| Was the contamination acceptably low? | N/A – no comparator | N/A – no comparator | N/A – no comparator | N/A – no comparator | N/A – no comparator |
| How well were likely confounding factors identified and controlled? | Yes, Factors controlled for included demographic | Unclear, a full list of explanatory variables not provided | A good selection of demographic and clinical variables are identified, much less | Yes, Factors controlled for included demographic | Unclear, a full list of explanatory variables that were considered is not |

| | | | | | |
|---|---|---|---|---|---|
| | information, clinical information and psycho-social outcomes | | consideration is given to psycho-social outcomes. | information, clinical information and psycho-social outcomes | provided. |
| Were the outcome measures and procedures reliable? | Yes, Published outcome measures used, reliability and validity of these outcomes is described in most cases | Yes, measures mainly published with validation to the Brazilian context described | Yes, published outcome measures are used | Yes, Published outcome measures used, reliability and validity of these outcomes is described in most cases | Yes, Published outcome measures used, reliability and validity of these outcomes is described in most cases |
| Were the outcome measurements complete? | Cross sectional.<br>Unclear if all participants filled in all outcome measures | Cross sectional.<br>Unclear if all participants filled in all outcome measures | Cross sectional:<br>In some linked papers the sample size is significantly reduced by non-completion | Cross sectional<br>For some outcomes the N is less than the sample. However, these are explicitly stated. | 6 month follow-up – attrition from time 1 to time 2 is accounted for. |
| Were all the important outcomes assessed? | Study includes a range of demographic, clinical and pyscho-social outcomes | Study includes a range of demographic, clinical and pyscho-social outcomes | The lack of psycho-social outcomes measured is considered a weakness | Study includes a range of demographic, clinical and pyscho-social outcomes | Study includes demographic and psycho-social outcomes, clinical outcomes are more poorly described. |
| Was there a similar follow-up time in exposure and comparison groups? | N/A cross sectional | N/A cross sectional | N/A cross sectional | N/A cross sectional | N/A cross sectional |
| Was follow-up time meaningful? | N/A cross sectional | N/A cross sectional | N/A cross sectional | N/A cross sectional | N/A cross sectional |
| Was the study sufficiently powered to detect an intervention effect (if one exists)? | No intervention effect | No intervention effect | No intervention effect | No intervention effect | No intervention effect |
| Were multiple explanatory variables considered in the analyses? | Yes | Unclear, a full list of explanatory variables considered is not provided | Yes | Yes | Unclear, a full list of explanatory variables considered is not provided |
| Were the analytical methods appropriate? | Unclear, the development of the | Unclear | Yes | Yes | Unclear |

| | | | | | |
|---|---|---|---|---|---|
| | model is not described | | | | |
| Was the precision of association given or calculable? Is association meaningful? | No, results of regression reported only in text with no model provided | Yes | Yes | Yes | No, other factors controlled for in the model, other than those that are the focus of the study are poorly described |
| Are the study results internally valid (i.e. unbiased)? | Unclear, as analysis and data collection methods insufficiently described | Unclear, as analysis methods insufficiently described | Yes | Yes | Yes |
| Are results precise enough to be meaningful? If not, was power sufficient? | Unclear– sample size is 65 which may not be sufficient for analyses | Unclear– sample size is 62 which may not be sufficient for the analyses | Unclear – the sample size of approximately 134 is fairly small and in some analyses less than a 100. | Yes – although the sample size is still comparatively small | Yes – although the sample size is still comparatively small (N=101) |
| Can the applicability of the results (i.e. external validity) be determined? | No | Yes | Yes | Yes | Yes |
| **Overall study quality** | Low | Medium | High | High | Medium |

| | **Manne and Zautra1990** (89) | **Porter et al. 2008** (128) | **Reich et al. 2006** (129) | **Strating et al. 2007** (132) | **Walsh et al. 1999** (139) |
|---|---|---|---|---|---|
| Study Setting well described? | Yes | Yes | No | Yes | Yes |
| Eligible population well described and appropriate? | Yes | No, how patients were selected from the sampling frame is not described | No | Yes | No, how patients were selected from the sampling frame is not described |
| Participants represent eligibles? | Differences between the participants and eligibles are | Not described | Not described | Differences between the participants and eligibles are | Not described |

| | | | | | |
|---|---|---|---|---|---|
| | described | | | described | |
| Were relevant personal characteristics (or disease stage) in participants reported? | Yes | Not comprehensively | No, gender is not provided | Yes | Yes |
| Selection of exposure group. | All eligible patients contacted | Unclear, selection of patients from the sampling frame not described | Unclear, selection of patients from the sampling frame not described | All eligible patients contacted | Unclear, selection of patients from the sampling frame not described |
| Was the selection of explanatory variables based on a sound theoretical basis? | Yes, theories of coping and adjustment are described in the linked paper | No theoretical framework described | No theoretical framework described | Yes, stress process theories are referenced in study development | No theoretical framework described |
| Was the contamination acceptably low? | N/A – no comparator | N/A – no comparator | N/A – no comparator | N/A – no comparator | N/A – no comparator |
| How well were likely confounding factors identified and controlled? | Factors controlled for included clinical information and psycho-social outcomes. Demographic information appears to be less adequately collated | No, factor controlled for includes only patient pain | No, no controlling factors | Yes, Factors controlled for included demographic information, clinical information and psycho-social outcomes | Yes, Factors controlled for included demographic information, clinical information and psycho-social outcomes |
| Were the outcome measures and procedures reliable? | Yes, Published outcome measures used, reliability and validity of these outcomes is described in most cases | Yes, Published outcome measures used, reliability and validity of these outcomes is described in most cases | Yes, Published outcome measures used, reliability and validity of these outcomes is described in most cases | Yes, Published outcome measures used, reliability and validity of these outcomes is described in most cases | Yes, Published outcome measures used, reliability and validity of these outcomes is described in most cases |
| Were the outcome measurements complete? | Cross sectional. Unclear if all participants filled in all outcome measures | Cross sectional. Unclear if all participants filled in all outcome measures | Cross sectional. Unclear if all participants filled in all outcome measures | Cross sectional. Because of non-completion sample is a subset with N=61 | Cross sectional. Because of non-completion sample is a subset with N=43 |
| Were all the important outcomes assessed? | Study includes a range of | The outcomes measures collected | The outcomes measures collected | Study includes a range of | Study includes a range of |

| | | | | | |
|---|---|---|---|---|---|
| | demographic, clinical and pyscho-social outcomes | included both clinical and psycho-social outcomes. However, these were not included in the analyses as explanatory variables | included both clinical and psycho-social outcomes. However, these were not included in the analyses as explanatory variables | demographic, clinical and pyscho-social outcomes | demographic, clinical and pyscho-social outcomes |
| Was there a similar follow-up time in exposure and comparison groups? | N/A cross sectional | N/A cross sectional | N/A cross sectional | N/A cross sectional | N/A cross sectional |
| Was follow-up time meaningful? | N/A cross sectional | N/A cross sectional | N/A cross sectional | N/A cross sectional | N/A cross sectional |
| Was the study sufficiently powered to detect an intervention effect (if one exists)? | No intervention effect | No intervention effect | No intervention effect | No intervention effect | No intervention effect |
| Were multiple explanatory variables considered in the analyses? | Yes | No – pain is only outcome controlled for | No – no factors controlled for | Yes | Yes |
| Were the analytical methods appropriate? | Yes | No – potential explanatory variables not controlled for | No – potential explanatory variables not controlled for | Yes | Yes |
| Was the precision of association given or calculable? Is association meaningful? | Yes | No, results reported only in text with no model provided | No | Yes | Yes |
| Are the study results internally valid (i.e. unbiased)? | Yes | No | No | Yes | Yes |
| Are results precise enough to be meaningful? If not, was power sufficient? | Yes – although the sample size is still comparatively small | Unclear– sample size is 38 which is unlikely to be sufficient for the analyses | Unclear– sample size is 32 which is unlikely to be sufficient for the analyses | Unclear – sample size is 61 which is small given the analyses | Unclear– sample size is 43 which is unlikely to be sufficient for the analyses |
| Can the applicability of the results (i.e. external validity) be determined? | Yes | Yes | No | Yes | Yes |
| **Overall study quality** | Medium | Low | Low (for the | Medium | Medium |

| | | | | | |
|---|---|---|---|---|---|
| *Were there any fundamental flaws in the study* | | | caregiver analysis) | | |

| | **Dixon et al. 2006** (145) | **Leardini et al. 2004** (119) | **Leardini et al. 2002** (120) | **Qualitative quality assessment** | **Sanchez-Ayendez 1998** (131) |
|---|---|---|---|---|---|
| | PATIENT | PATIENT | PATIENT | | CAREGIVER |
| Study Setting well described? | Yes | Yes | Yes | Does the study seek to answer a clear question? | Yes |
| Eligible population well described and appropriate? | Yes | Yes | Yes | Is there a "fit" between the research question and the method chosen? | No rationale for the methods used, but for the research questions methods seem generally appropriate |
| Participants represent eligibles? | Unclear, for artherosis analysis no demographic data are presented. | Unclear, not described | Unclear, not described | Were the participants relevant to the research question and was the selection well reasoned? | Yes, but no reasoning given for the focus of the sample chosen |
| Were relevant personal characteristics (or disease stage) in participants reported? | No, for artherosis analysis no demographic data are presented. | Yes, basic demographic and clinical data are presented narratively | Yes but limited to age, as well as duration of disease, time from onset to diagnosis, HAQ and SF36 | Is it likely that several perspectives/angles were represented in the data? | This is a very specific sample: female, middle aged, Puerto Rican, lower middle and middle-middle class |
| Selection of exposure group. | Secondary analysis of existing dataset | No selection of exposure group | No selection of exposure group | Were the data generation methods appropriate for the research objectives and setting? Data collection well described and valid? | Questions used in the interviews not given. No information about checking of participants checking the data |
| Was the selection of explanatory variables based on a sound theoretical | No theoretical perspective | No selection of explanatory variables | No selection of explanatory | Role and influence of the investigator | No |

| | | | | | |
|---|---|---|---|---|---|
| basis? | described in the study | | variables | described? | |
| Was the contamination acceptably low? | N/A – no comparison | N/A – no comparison | N/A – no comparison | It is likely that all important data were generated? | Within a specific context of instrumental tasks |
| How well were likely confounding factors identified and controlled? | Analysis only includes EQ-5D levels as predictors. | No controlling factors | No controlling factors | Was the duration of the study period sufficient to capture all relevant data? | Study period not given |
| Were the outcome measures and procedures reliable? | Yes, published and validated measure | The methods of collecting the data are poorly described. The collection of data through the patient records is described but a questionnaire is mentioned that is not described and the lost productivity and informal care information is unlikely to have been available from the patient records | Patient questionnaire may not have been reliable due to retrospective nature. Reliability of the costs provided by the hospital centres is not considered | Is there clear rationale for timing of data generation and analysis? | No timing given |
| Were the outcome measurements complete? | Cross sectional. Because of non-completion sample is a subset of the full dataset | Unclear | Unclear | Were the data appropriately analysed and the findings corroborated? | Methods of analysis not described. Corroboration limited to visits by study authors to check interview responses |
| Were all the important outcomes assessed? | The analysis includes no other variables other than EQ-5D levels | The types of costs collected are appropriate | The types of costs collected are appropriate | Were key findings consistent with multiple data sources? | Interviews and quantitative questionnaires are used |
| Was there a similar follow-up time in exposure and comparison groups? | N/A cross sectional | N/A – no comparison | N/A – no comparison | Were findings cross-checked? | Not stated |

| | | | | | |
|---|---|---|---|---|---|
| Was follow-up time meaningful? | N/A cross sectional | The study is cross sectional but is described as retrospective over the preceding 12 months | The study is cross sectional but patients appears to have been requested to recall costs over preceding 12 months | Are the findings developed in direct relationship to illustrative data? | Yes, quotes and quantitative questionnaire data support the findings |
| Was the study sufficiently powered to detect an intervention effect (if one exists)? | No intervention effect | No intervention effect | No intervention effect | Is there sufficient detail to evoke a vivid picture of the topic being investigated? | Yes, detail of the findings is appropriate |
| Were multiple explanatory variables considered in the analyses? | The lack of demographic and psycho-social variables is considered a limitation | No | No | How comprehensive and relevant are the conclusions? | The conclusions are comprehensive but given the sample specific to a context |
| Were the analytical methods appropriate? | Yes, noting above comments on explanatory variables | Simple descriptive analysis | Simple descriptive analysis | Are the findings well reasoned and coherent? | Yes |
| Was the precision of association given or calculable? Is association meaningful? | Yes | No | No | Are the major and minor concepts clearly identified? | Not given |
| Are the study results internally valid (i.e. unbiased)? | No | No | No | Are the results of this qualitative study credible? | Yes |
| Are results precise enough to be meaningful? If not, was power sufficient? | Yes | No | No | Has the researcher effectively communicated the participants' experience? | Yes |
| Can the applicability of the results (i.e. external validity) be determined? | No, because demographic information not provided | Yes | Yes | Does this study inform my practice? | No given the specific context of the findings |

| | | | | | |
|---|---|---|---|---|---|
| **Overall study quality**<br>*Were there any fundamental flaws in the study* | Low (for the analysis that meets the criteria for this review) | Low (specific cost context, age of study, limited description of cost categories and explanation of outcomes) | Low (specific cost context, age of study, limited description of cost categories and explanation of outcomes) | **Overall study quality** | Low (due to limited generalisability of the sample and no description of methods of analysis of theoretical framework). |

# Appendix 4: Databases for secondary dataset analysis

## Appendix Table 12: Databases for secondary dataset analysis

| Database | Location | Data availability | Sample | Health questions | Care questions | Time spent caregiving | Link patient and caregiver | Question about condition and response category |
|---|---|---|---|---|---|---|---|---|
| ***Health and Aging surveys*** | | | | | | | | |
| English Longitudinal Study of Ageing (ELSA) (15) | England | Yes (ESDS) 2002, 2004, 2006, 2008, ongoing | N=approx. 8,000 at wave 4<br>Individuals, couples included if 1 person **over 50**. | Likert general health + ADL limitations | Yes (giving and receiving care) | Yes (continuous hours in week range 0-168) | In some cases (spousal caregivers where one or more in couple is over 50) | Yes, Arthritis including rheumatoid arthritis |
| Survey of Health, Ageing and Retirement in Europe (SHARE)<br>(harmonised with ELSA) | Europe (not UK) | Yes (RAND) 2004, 2006, 2008 | N=31,000<br>Individuals, couples included if 1 person **over 50**. | Likert general health + ADL limitations | Yes (giving and receiving care) | Yes (continuous hours in week) | In some cases (spousal caregivers where one or more in couple is over 50) | Yes, Arthritis |
| Australian Longitudinal Study of Ageing (ALSA) | Australia | By request only Some older waves available on ICPSR (to 2000)<br>Started 1992 ongoing. | N=2087<br>Individuals aged **70 years or more** (inc spouses if aged over 65 and other people in household only if over 70). | Likert general health + ADL limitations | Yes (giving and receiving care) | Yes (continuous hours in week) | In some cases (spousal caregivers if aged over 65 and other caregivers in household if over 70). | Yes, Arthritis – rheumatoid arthritis |
| Health and Retirement Study (HRS) | USA | Yes (HRS or via RAND)<br>Starting 1992 | N=30,617<br>Individuals **aged 51** | Likert general health + ADL limitations | Yes (giving and receiving | Yes (categorical hours in | In some cases (spousal caregivers if | Yes, Arthritis - rheumatoid |

|  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|
|  |  | every 2 years | **and over** (spouses of individuals also interviewed) |  | care) | month (3 categories) | aged over 51) | arthritis |
| Longitudinal Study of Aging and National Health | USA | Yes (CDC)<br>2 surveys 1984-1990 and 1994-2000 | N=9,447<br>People **70 years of age and over** | Likert general health + ADL limitations | Yes (receipt of care) | Time (number of days in past two weeks) | No link (not couple or household level data) | Yes, Arthritis |
| ***Health surveys*** |  |  |  |  |  |  |  |  |
| Health Survey for England | England | Yes (ESDS)<br>Ongoing annual | In 2006, 30,068 households | Yes<br>EQ-5D | Yes (not every year) | No | No link (no question asking to who care is given) | Yes, Arthritis |
| Medical Expenditure Panel Survey (MEPS) | USA | Yes (MEPS)<br>Ongoing annual | 1997:<br>13,000 household<br>32,000 people | Likert general health + ADL limitations | Yes (not every year) | Time (days per month and hours per visit) | Unclear (asked who provides care, but unclear if this is linked to a unique identifier) | Yes, Arthritis |
| General Practice Patient Survey (GPPS) | England | Yes (GPPS)<br>Ongoing 6 monthly | Over a million surveys sent out approx. 430,000 returned. | Yes<br>EQ-5D | Yes (provides care) | Yes (categorical hours per week) | No link (individuals only) | Yes, Arthritis |
| ***Caregiver surveys*** |  |  |  |  |  |  |  |  |
| Survey of carers in households | England | Yes (ESDS)<br>2009/2010<br>One off | 2,401 individual caregivers | Likert general health | Yes (provides care) | Time (categorical hours per week) | No link (caregivers only) | No, physical disability only |
| ***Other household surveys*** |  |  |  |  |  |  |  |  |
| Understanding Society/BHPS/United Kingdom Household Longitudinal Study | UK | Yes (ESDS)<br>Wave 1 2009<br>Wave 2 2010<br>Ongoing annual | 30,000 households<br>50,000 people | Yes<br>SF-12 | Yes (provision of care) | Time (categorical hour per week) | Yes (caregiving within household) | Yes, Arthritis |
| General Household survey / *General* | Great Britain | Yes (ESDS) to 2006 (became | 10,000 households<br>23,000 people | Likert general health + ADL | Yes (provides | Time (categorical | Yes (household survey) | Yes, Arthritis |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| *Lifestyle Survey*<br>*Carers module completed 2000* | | GLS in 2008 now disbanded) | | limitations | care) | hours per week) | | (free response with ICD codes) |
| Family Resources survey | Great Britain | Yes (ESDS) Annual since 1993 | 24,000 households | Limitations of health | Yes | Yes (categorical hours per week) | Yes (caregiving within household) | No |
| Scottish Household Survey | Scotland | Yes (ESDS) continuous | Main Householder only<br>N=27,238 | Limitations of health for household members | Yes (receipt and provision of care) | Yes (categorical hours per week) | No (main householder only) | Yes, Arthritis |
| Panel Study of Income Dynamics (PSID) | USA | Yes<br>Annual since 1968 (2009, include diary with categories of caregiving but may not be publically available) | 5,000 families<br>18,000 individuals<br>394 for diary | Likert general health + ADL limitations | Yes (provision of care) | In 2009 diary sample a care diary was completed | Link for diary sample | Yes, Arthritis |
| The Household, Income and Labour Dynamics in Australia (HILDA) Survey | Australia | Yes (University of Melbourne) Annual since 2001 | Wave 11:<br>9835 households<br>25391 individuals | Yes SF-36 | Yes (provision of care) | Yes (hours per week spent caregiving) | Yes (caregiving within household) | Yes, arthritis |
| ***Other non household surveys*** | | | | | | | | |
| The ONS Longitudinal Study - England and Wales | England and Wales | **Application**<br>From census data derived once every 10 years | 1% of population of England and Wales | Likert general health + ADL limitation | Yes (provision of care) | No | No link (no question asking to who care is given) | No |
| ***Arthitis specific cohorts (UK only)*** | | | | | | | | |
| BSRBR | UK | No<br>Since 2001 (six monthly follow | 14,000 patients | Disease specific + EQ-5D | No | No | No | Arthritis – rheumatoid arthritis |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | up) | | | | | | |
| NOAR | England Norfolk | No<br>Since 1989 (followed every one year for first 5 years and then every 5 years for next 20 | Unclear | Disease specific | No | No | No | Arthritis – rheumatoid arthritis |
| ERAS/ERAN | ERAS 9 Hospitals in England<br>ERAN 21 centres UK | No<br>ERAS =1986-1998, ERAN started 2002 based on ERAS model | ERAS > 1500<br>ERAN 1158 in 2010 | ERAN Disease specific + SF-36 | No | No | No | Arthritis – rheumatoid arthritis |
| Yorkshire Early Arthritis Register (YEAR): Leeds Early Arthritis Project (LEAP); | England, Yorkshire | No | Approx. 1600 | Unclear | No | No | No | Arthritis – rheumatoid arthritis |

# Appendix 5: Summary of the measures from Understanding Society used in the analysis

## Appendix Table 13: Summary of the measures from Understanding Society used in the analysis

| Variable | Nature of the data | Question | Response options | Source | Missing values | Use in analysis |
|---|---|---|---|---|---|---|
| **Dependent variable and key explanatory variables** | | | | | | |
| SF12: general health | Categorical | In general, would you say your health is... | Excellent / Very good/ Good/ Fair/ Poor | Interview | Caregiver: 1<br>Patient: 0 | Transformed to caregiver SF-6D<br>Range: 34-1.00<br>Missing values 3<br>Transformed to patient SF-6D<br>Range: .35-1.00<br>Missing values 2 |
| SF12: typical activities | Categorical | …moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf...Does your health now limit you a lot, limit you a little or not limit you at all? | Yes, limited a lot / Yes, limited a little / No, not limited at all | Interview | Caregiver: 0<br>Patient: 0 | |
| SF12: climbing stairs | Categorical | Climbing several flights of stairs...does your health now limit you a lot, limit you a little, or not limit you at all? | Yes, limited a lot / Yes, limited a little / No, not limited at all | Interview | Caregiver: 0<br>Patient: 2 | |
| SF12: limits work | Categorical | During the past 4 weeks, how much of the time have you accomplished less than you would like as a result of your physical health? | All of the time / Most of the time / Some of the time / A little of the time / None of the time | Interview | Caregiver: 0<br>Patient: 0 | |
| SF12: kind of work | Categorical | During the past 4 weeks, how much of the time were you limited in the kind of work or other regular daily activities you do as a result of your physical health? | All of the time / Most of the time / Some of the time / A little of the time / None of the time | Interview | Caregiver: 0<br>Patient: 0 | |
| SF12: emotional problems | Categorical | During the past 4 weeks, how much of the time have you accomplished less than you would like as a result of any emotional problems | All of the time / Most of the time / Some of the time / A little of the time / None of the time | Interview | Caregiver: 0<br>Patient: 1 | |
| SF12: emotional | Categorical | During the past 4 weeks, how much of the time did you work or | All of the time / Most of the time / Some of the time / A | Interview | Caregiver: 1<br>Patient: 4 | |

| | | | | | | |
|---|---|---|---|---|---|---|
| problems less care | | other regular daily activities less carefully than usual as a result of any emotional problems, such as feeling depressed or anxious? | little of the time / None of the time | | | |
| SF12: pain interfere | Categorical | During the past 4 weeks, how much did pain interfere with your normal work including both work outside the home and housework? Did it interfere... | Not at all / A little bit / Moderately / Quite a bit / Extremely | Interview | Caregiver: 1<br>Patient: 2 | |
| SF12: calm | Categorical | How much of the time during the past 4 weeks have you felt calm and peaceful? | All of the time / Most of the time / Some of the time / A little of the time / None of the time | Interview | Caregiver: 0<br>Patient: 1 | |
| SF12: energy | Categorical | How much of the time during the past 4 weeks did you have a lot of energy? | All of the time / Most of the time / Some of the time / A little of the time / None of the time | Interview | Caregiver: 0<br>Patient: 0 | |
| SF12: downhearted | Categorical | How much of the time during the past 4 weeks have you felt downhearted and depressed? | All of the time / Most of the time / Some of the time / A little of the time / None of the time | Interview | Caregiver: 0<br>Patient: 0 | |
| SF12: social | Categorical | During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities like visiting friends or relatives? | During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities like visiting friends or relatives? | Interview | Caregiver: 2<br>Patient: 1 | |
| Hours of care | Categorical | Now thinking about everyone who you look after or provide help for both those living with you and not living with you - in total, how many hours do you spend each week looking after or helping (him/her/them)? | 0 - 4 hours per week<br>5 - 9 hours per week<br>10 - 19 hours per week<br>20 - 34 hours per week<br>35 - 49 hours per week<br>50 - 99 hours per week<br>= >100 hours per week<br>Varies < 20 hour<br>varies 20 hours or > | Interview | Caregiver: 6 | As two binary variables:<br>1. Less or more than 35 hours<br>1 = < 35 hrs<br>2 = > 35 hrs<br>Missing values 140<br>2. Less or more than 20 hours<br>1 = < 20 hrs |

|  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
|  |  |  |  |  |  | 2 = > 20 hrs<br>Missing values 6 |
| **Moderating variables** |  |  |  |  |  |  |
| Employment status | Categorical | Please look at this card and tell me what best describes [your] current employment situation? | Self employed<br>Paid employment<br>Unemployed<br>Retired<br>Maternity leave<br>Looking after family or home<br>Full time student<br>Long term sick/disabled<br>Government training scheme<br>Other | Interview | Caregiver: 15 (other) | Binary<br>Working =1<br>Not working = 2<br><br>Working includes:<br>• self employment,<br>• paid employment, student,<br>• government training scheme |
| Dependent children | Continuous | - | Range 0-5 | Pre-person interview calculations | Caregiver: 0 | As continuous variable and also as a binary variable absence or presence of children |
| Financial situation (current) | Categorical | How well would you say you yourself are managing financially these days? Would you say you are... | Living comfortably / Doing alright / Just getting by / Finding it quite difficult / Finding it very difficult | Interview | Caregiver: 0 | As a binary variable of presence of financial concerns including:<br>• Finding it quite difficult<br>• Finding it very difficult<br>• Worse off than you are now<br>• Completely dissatisfied<br>• Mostly dissatisfied<br>• Somewhat dissatisfied |
| financial situation (future) | Categorical | Looking ahead, how do you think you will be financially a year from now, will you be... | Better off / Worse off than you are now / Or about the same? | Interview | Caregiver: 21 |  |
| financial situation (finances) | Categorical | Please tick the number which you feel best describes how dissatisfied or satisfied you are with the following aspects of your current situation.<br>-The income of your household | Completely dissatisfied / Mostly dissatisfied / Somewhat dissatisfied / Neither satisfied or dissatisfied / Somewhat satisfied / Mostly satisfied / Completely satisfied | Self completion | Caregiver: 112 |  |
| Satisfaction with leisure | Categorical | Please tick the number which you feel best describes how dissatisfied or satisfied you are with the following aspects of your current situation.<br>-The amount of leisure time you have | Completely dissatisfied / Mostly dissatisfied / Somewhat dissatisfied / Neither satisfied or dissatisfied / Somewhat satisfied / Mostly satisfied / Completely satisfied | Self completion | Caregiver: 114 | As a binary variable of presence of leisure concerns including:<br>• Completely dissatisfied<br>• Mostly dissatisfied<br>• Somewhat |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | | | dissatisfied |
| relationship with partner | Categorical | The boxes on the following line represent different degrees of happiness in your relationship. The middle point, “happy”, represents the degree of happiness of most relationships. Please tick the box which best describes the degree of happiness, all things considered, of your relationship. | Extremely unhappy / Fairly unhappy / A little unhappy / Happy / Very happy / Extremely happy / Perfect | Self completion | Caregiver: 91 | As a binary variable presence of relationship unhappiness including:<br>• Extremely unhappy<br>• Fairly unhappy<br>• A little unhappy |
| Presence of external strain | Continuous | - | Range: 1-3 | - | Caregiver: 76 | Calculated for analysis as presence of one or more of financial concerns, leisure concerns, relationship concerns |
| WEMWS: Feeling useful | Categorical | I’ve been feeling useful | None of the time / Rarely / Some of the time / Often / All of the time | Self completion | Caregiver: 112 | Calculated as binary variable not feeling useful including:<br>• None of the time<br>• Rarely |
| WEMWS: Feeling relaxed | Categorical | I’ve been feeling relaxed | None of the time / Rarely / Some of the time / Often / All of the time | Self completion | Caregiver: 120 | Calculated as binary variable not feeling relaxed including:<br>• None of the time<br>• Rarely |
| WEMWS: Feeling optimistic | Categorical | I’ve been feeling optimistic about the future | None of the time / Rarely / Some of the time / Often / All of the time | Self completion | Caregiver: 112 | Calculated as binary variable not feeling optimistic including:<br>• None of the time<br>• Rarely |
| Caregiver presence of internal strain (derived) | Continuous | - | Range: 1-3 | - | Caregiver: 121 | Calculated for analysis as presence of one or more of not feeling useful, not feeling relaxed, not feeling optimistic |

| **Control variables: demographics** | | | | | | |
|---|---|---|---|---|---|---|
| Age | Continuous | - | Caregiver Range: 16-90<br>Patient Range: 19-93 | Calculated by US from household data | 0 | As US |
| Gender | Binary | And you are [sex from household grid] ? | Male = 1 Female = 2 | Interview | 0 | As US |
| Race | Categorical | What is your ethnic group? | White UK; White Irish; White other; Mixed white and black Caribbean; Mixed white and Asian; Mixed other; Indian; Pakistani; Bangladeshi; Chinese; Asian other; Caribbean; African; Black other; Arabic; Other; Refused | Interview | 1 caregiver<br>1 patient | Calculated as a binary variable including: White UK; White Irish; White other:<br>White = 1 Other = 2 |
| Education | Categorical | Can you tell me the highest educational or school qualification you have obtained? | Degree / Other higher / A level / GCSE / Other / None | Interview | Caregiver: 1<br>Patient: 1 | As US |
| Household income | Continuous | - | Range: 0-20,000 in last month | Calculated by US from household data | 0 | As US |
| Household location | Binary | - | Urban = 1 Rural = 2 | Calculated by US from data | 0 | As US |
| **Control variables: Other health and wellbeing** | | | | | | |
| Arthritis duration | Continuous | - | Range: 0-69 years | Interview | Patient 9 | Calculated from US variables current age and age condition first occurred |
| GHQ | Interval | - | Range: 0-36 | Calculated by US from individual questions in self completion questionnaire | Caregiver: 102<br>Patient: 140 | As US |
| Life | Categorical | Please tick the number which | Completely dissatisfied / | Self | Caregiver: | As US |

| | | | | | | |
|---|---|---|---|---|---|---|
| satisfaction | | you feel best describes how dissatisfied or satisfied you are with the following aspects of your current situation.<br>-Your life overall | Mostly dissatisfied / Somewhat dissatisfied / Neither satisfied or dissatisfied / Somewhat satisfied / Mostly satisfied / Completely satisfied | completion | 109<br>Patient: 148 | |
| **Control variables: Resources** | | | | | | |
| Religion | Categorical | How much difference would you say religious beliefs make to your life? Would you say they make... | A great difference / Some difference / A little difference / No difference | Interview | Caregiver: 2<br>Patient: 2 | As US |
| WEMWS: Dealing with problems | Categorical | I've been dealing with problems well | None of the time / Rarely / Some of the time / Often / All of the time | Self completion | Caregiver: 110<br>Patient: 142 | Calculated as binary variable not dealing with problems well including:<br>• None of the time<br>• Rarely |
| WEMWS: Thinking clearly | Categorical | I've been thinking clearly | None of the time / Rarely / Some of the time / Often / All of the time | Self completion | Caregiver: 112<br>Patient: 143 | Calculated as binary variable not thinking clearly including:<br>• None of the time<br>• Rarely |
| WEMWS: Close to other people | Categorical | I've been feeling close to other people | None of the time / Rarely / Some of the time / Often / All of the time | Self completion | Caregiver: 113<br>Patient: 141 | Calculated as binary variable not feeling close to others including:<br>• None of the time<br>• Rarely |
| WEMWS: Able to make up own mind | Categorical | I've been able to make up my own mind about things | None of the time / Rarely / Some of the time / Often / All of the time | Self completion | Caregiver: 105<br>Patient: 137 | Calculated as binary variable not able to make up own mind including:<br>• None of the time<br>• Rarely |

# Appendix 6: Diagnostics for 35 hours model with control variables and no interaction

### Stem-and-leaf plot for studentized residuals

Residuals rounded to nearest multiple of .01, plot in units of .01

```
 -3** | 09
 -2** |
 -2** |
 -2** | 46
 -2** | 39,35,22
 -2** | 17,14,10,08,05
 -1** | 96,86,84,84,83,81
 -1** | 77,70,70,65,64,63,63,61
 -1** | 55,54,54,52,49,47,46,45
 -1** | 39,34,33,32,29,29,27,26,25,24,23,22,20,20,20
 -1** | 19,19,17,17,16,15,13,12,11,11,09,09,08,08,07,07,06,06,05,04, ... (24)
 -0** | 98,98,96,95,95,95,94,93,91,90,88,88,87,87,87,86,86,86,86,85, ... (27)
 -0** | 79,79,77,76,73,73,72,71,69,69,69,68,68,68,66,66,66,65,65,65, ... (27)
 -0** | 58,56,55,54,53,53,52,51,51,49,46,43,43,40
 -0** | 39,38,37,37,36,35,34,32,32,32,32,32,32,30,30,29,27,25,24,24,21
 -0** | 19,19,18,17,16,15,14,14,12,12,12,12,11,11,11,11,10,08,07,05, ... (27)
  0** | 01,02,02,03,03,04,05,05,05,05,06,08,08,08,10,10,11,11,11,11, ... (32)
  0** | 20,20,20,20,22,23,25,25,26,27,27,27,30,32,33,33,34,36,36,38,39
  0** | 40,40,41,41,42,42,42,42,44,45,45,45,45,46,47,48,48,48,50,51, ... (34)
  0** | 61,61,61,62,64,66,66,67,67,68,69,69,69,70,72,73,73,74,74,74, ... (29)
  0** | 80,81,81,82,83,84,84,85,85,90,91,91,91,92,92,93,94,94,95,95,96,97,99
  1** | 01,02,02,04,05,06,06,06,07,08,08,09,09,09,10,11,14,15,16,17, ... (24)
  1** | 21,22,26,27,28,28,29,31,31,32,33,33,34,36,36,37
  1** | 40,40,40,41,41,43,43,45,50,51,55,55,56
  1** | 60,61,64,65,66,74,79
  1** | 82,83,87,87,92,99
  2** | 19
  2** |
  2** |
  2** | 62
  2** | 84
```

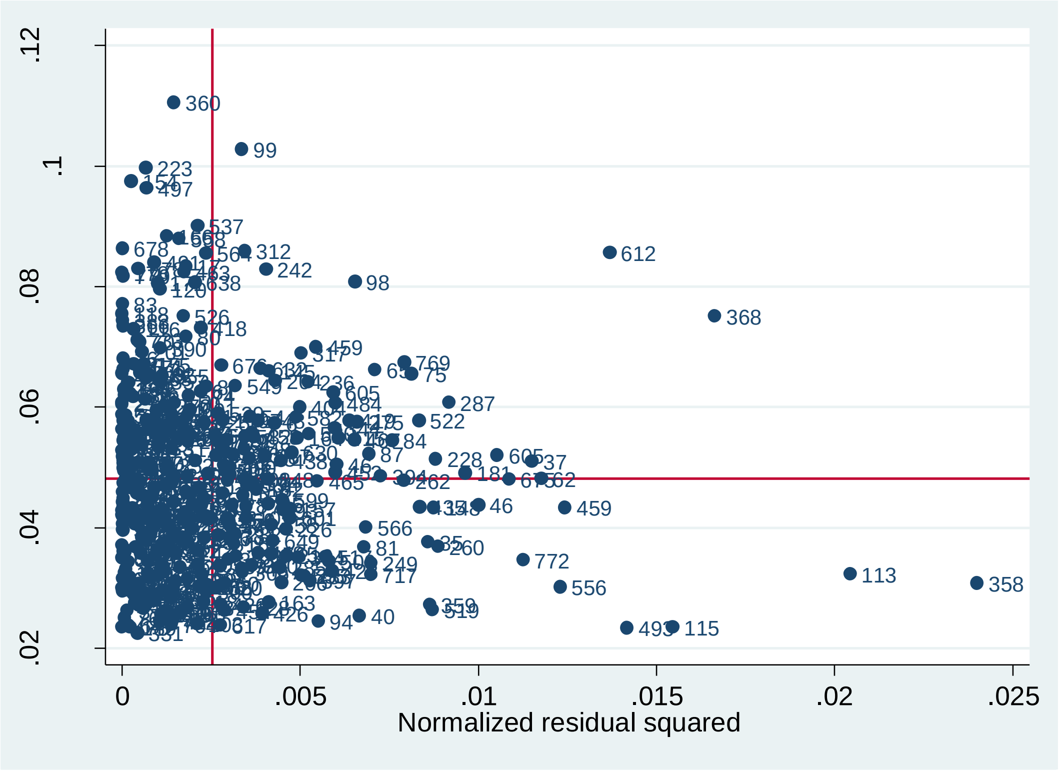
### Stem-and-leaf plot for leverage

Leverage rounded to nearest multiple of .0001, plot in units of .0001

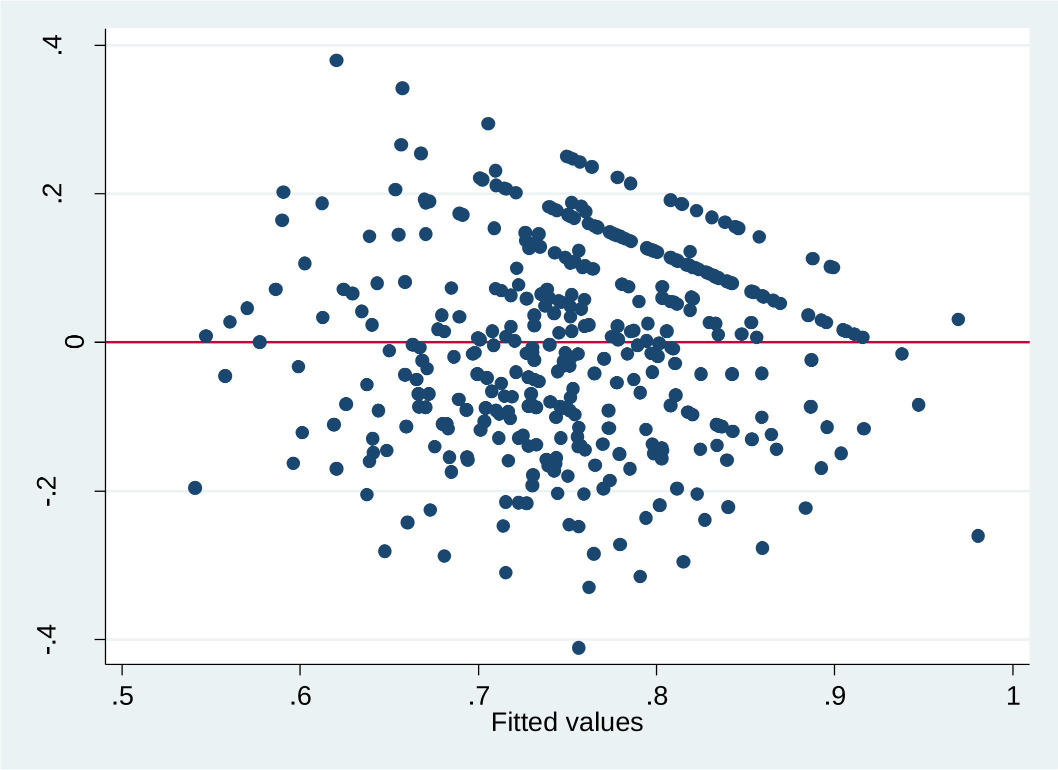
```
   2** | 25,34,35,35,35,38,38,39
   2** | 40,45,45,48,51,54,56,56,57,58,59
   2** | 62,62,62,64,66,68,68,71,72,72,73,76,76,78,79
   2** | 82,85,89,89,93,94,94,94,94,95,95,96
   3** | 00,01,02,02,02,03,05,05,05,07,08,09,09,11,13,14,16,16,18
   3** | 20,20,21,22,22,23,24,25,27,29,31,31,33,35,35,37,38,39,39
   3** | 41,43,44,45,47,48,50,50,51,52,52,54,57,58,58,59
   3** | 60,60,62,63,64,64,65,67,68,68,70,72,73,76,76,77,78,78
   3** | 81,83,84,84,85,88,90,90,93,93,96,96,98,98
   4** | 01,02,03,04,04,05,06,06,07,10,11,13,13,13,14,14,15,16,16,17,18,19,19
   4** | 20,20,20,20,21,22,22,22,23,26,28,28,30,30,32,33,33,33,34,35, ... (25)
   4** | 40,40,42,43,44,46,49,49,54,54,55,55,56,57,59
   4** | 61,65,66,66,66,67,72,73,74,75,76,76,77,78,79,79
   4** | 80,80,80,81,82,86,86,87,88,89,90,91,92,95,95,96,97
```

```
 5** | 00,01,03,03,05,05,06,07,07,08,08,08,10,11,11,11,15,16,19
 5** | 20,21,21,21,22,23,25,26,28,30,30,31,33,34,35
 5** | 40,42,44,44,44,45,45,46,46,46,47,48,49,49,50,50,51,51,53,53, ... (26)
 5** | 60,63,64,65,66,70,74,75,76,76,77,77,77,78,78,78,78,79,79
 5** | 82,84,85,86,87,88,90,92,95,96
 6** | 01,02,06,06,07,07,08,14,17,19
 6** | 20,23,24,26,30,30,32,35,35,35
 6** | 41,41,42,43,44,49,53,54,56,56,58
 6** | 60,62,63,64,67,69,72,72,75
 6** | 81,90,92,98
 7** | 00,09,12,17
 7** | 30,32,36
 7** | 44,51,51,55
 7** | 71
 7** | 95
 8** | 06,07,08,18
 8** | 23,24,28,30,34
 8** | 40,55,56
 8** | 60,64
 8** | 80,84
 9** | 01
 9** |
 9** |
 9** | 63,75
 9** | 97
10** |
10** | 28
10** |
10** |
10** |
11** | 05
```

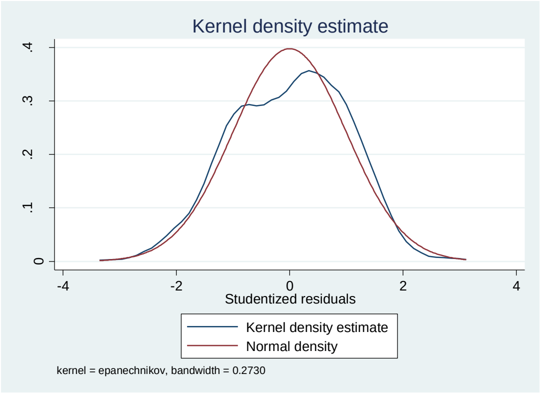
**Leverage plot**

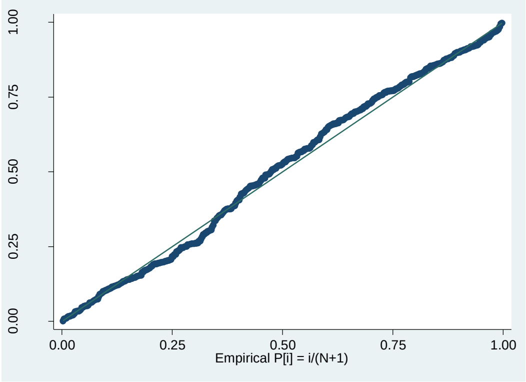


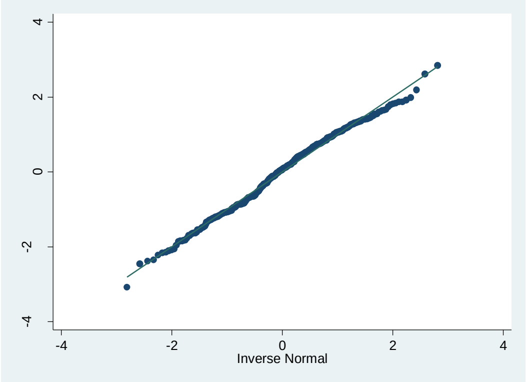
## Homoscedasticity of Residuals

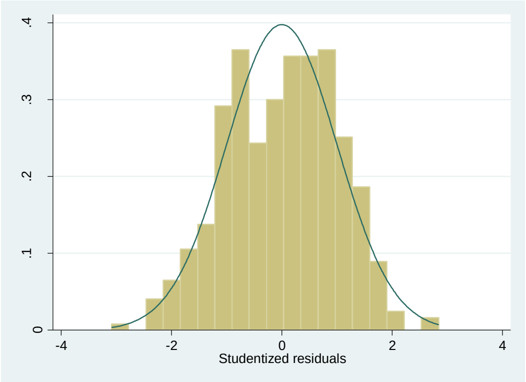


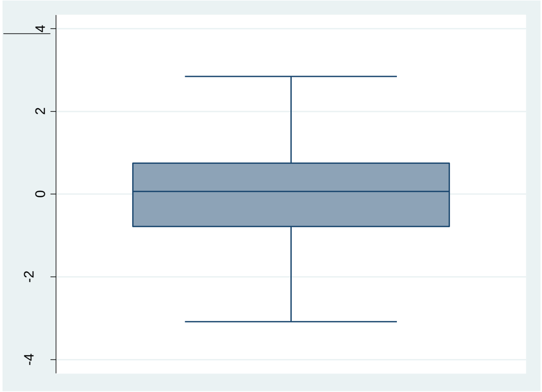
## Normality of residuals











## Cameron & Trivedi's decomposition of IM-test

| Source | chi2 | df | p |
|---|---|---|---|
| Heteroskedasticity | 143.94 | 161 | 0.8287 |
| Skewness | 18.48 | 18 | 0.4245 |
| Kurtosis | 5.91 | 1 | **0.0150** |
| Total | 168.33 | 180 | 0.7235 |

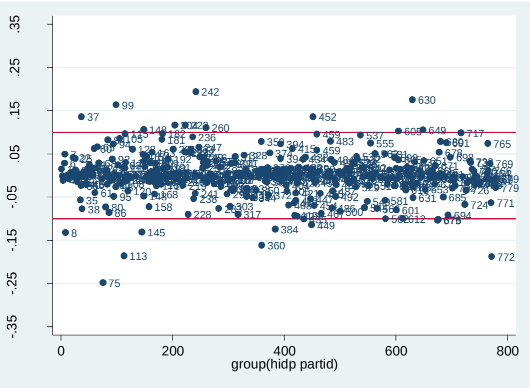
## Breusch-Pagan / Cook-Weisberg test for heteroskedasticity

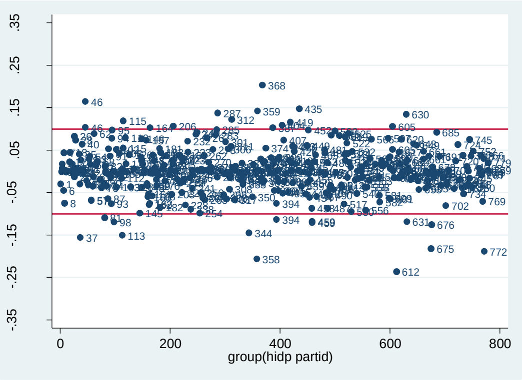
| | |
|---|---|
| Ho:<br>Variables: | Constant variance<br>fitted values of care_bsl_SF-6D |
| chi2(1) =<br>Prob > chi2 = | 3.13<br>0.0770 |

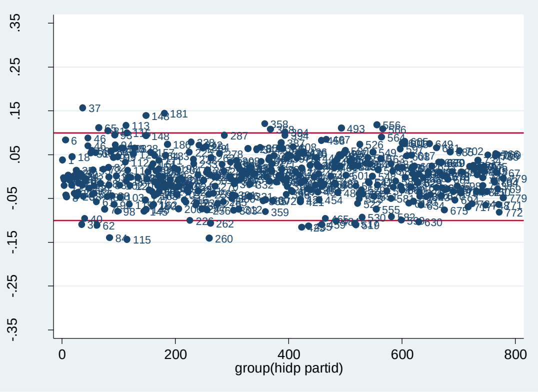
## Assessment of multicoliniarity (VIF)

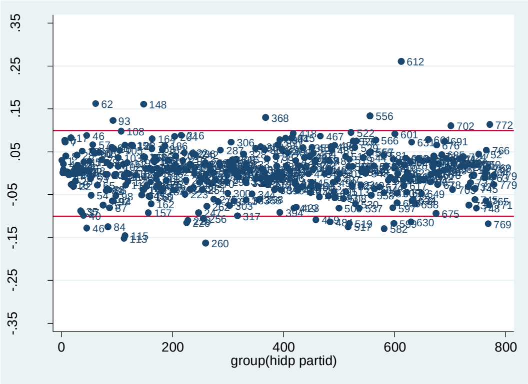
| **Variable** | **VIF** | **1/VIF** |
|---|---|---|
| Patient SF-6D | 1.34 | 0.746764 |
| Caregiver external conflicts | 1.11 | 0.898738 |
| Time spent caregiving | 1.14 | 0.877258 |
| Caregiver internal conflicts | 1.11 | 0.904802 |
| Job status | 1.47 | 0.679336 |
| GHQ difference | 1.27 | 0.788888 |
| Caregiver age | 1.96 | 0.509845 |
| Caregiver gender | 2.17 | 0.460876 |
| Caregiver Race | 1.24 | 0.806519 |
| Caregiver Education Ref degree | - | - |
| Other higher | 1.79 | 0.558416 |
| A level | 2.25 | 0.444879 |
| GCSE | 2.56 | 0.391207 |
| Other | 1.67 | 0.598057 |
| None | 3.45 | 0.290268 |
| Patient gender | 2.22 | 0.450360 |
| Religion Ref a great diff | - | - |
| Some difference | 1.57 | 0.637916 |
| A little difference | 1.56 | 0.640279 |
| No difference | 1.73 | 0.577752 |
| Mean VIF | 1.76 | |

## DF Beta plots for key explanatory variables and effect modifiers









# Appendix 7: Diagnostics for 35 hours model with patient SF-6D and external conflicts interaction

### Stem-and-leaf plot for studentized residuals

Residuals rounded to nearest multiple of .01, plot in units of .01

```
 -2** | 99
 -2** |
 -2** | 49,48,41
 -2** | 39
 -2** | 15,14,11
 -1** | 98,93,84,81
 -1** | 77,74,73,71,71,69,69,69
 -1** | 59,56,56,55,54,54,54,53,51,50,50,42
 -1** | 39,38,37,36,35,33,33,32,31,27,26,25,23,20
 -1** | 18,18,18,17,15,14,13,10,09,09,07,07,06,06,06,06,05,04,03,02, ... (25)
 -0** | 99,99,99,99,98,97,97,97,97,96,94,93,93,93,93,93,92,91,89,87, ... (25)
 -0** | 79,76,74,74,74,73,72,71,71,70,70,70,68,67,66,66,65,65,64,63, ... (27)
 -0** | 59,58,58,56,51,51,49,47,45,44,41,40,40
 -0** | 39,39,38,38,37,37,37,37,36,35,35,35,35,34,31,30,29,29,28,27, ... (31)
 -0** | 19,15,14,13,13,12,12,11,10,10,10,10,09,08,08,07,07,07,06,06, ... (26)
  0** | 00,00,00,01,04,04,06,06,07,08,08,10,11,11,11,11,11,12,12,13, ... (25)
  0** | 20,20,20,21,21,21,23,24,25,25,27,28,31,31,32,32,33,33,33,34, ... (27)
  0** | 41,42,42,43,44,44,44,45,45,45,46,47,48,48,48,50,51,51,52,52, ... (30)
  0** | 60,60,63,63,64,64,65,66,68,69,70,70,70,70,72,72,75,75,75,76, ... (27)
  0** | 80,80,80,82,85,85,88,88,89,91,91,93,94,95,97,98,98,98,98,99
  1** | 00,01,01,01,02,02,02,03,03,05,05,06,09,09,10,11,13,14,14,15,15,17,17
  1** | 20,20,20,23,24,24,25,25,25,26,26,27,29,30,32,35,35,36,36,36,38,38
  1** | 40,41,42,42,43,43,44,45,51,51,52,57
  1** | 61,62,65,67,68,70,71,75,76
  1** | 86,89,99
  2** | 06
  2** | 30
  2** |
  2** | 66
  2** | 81
```

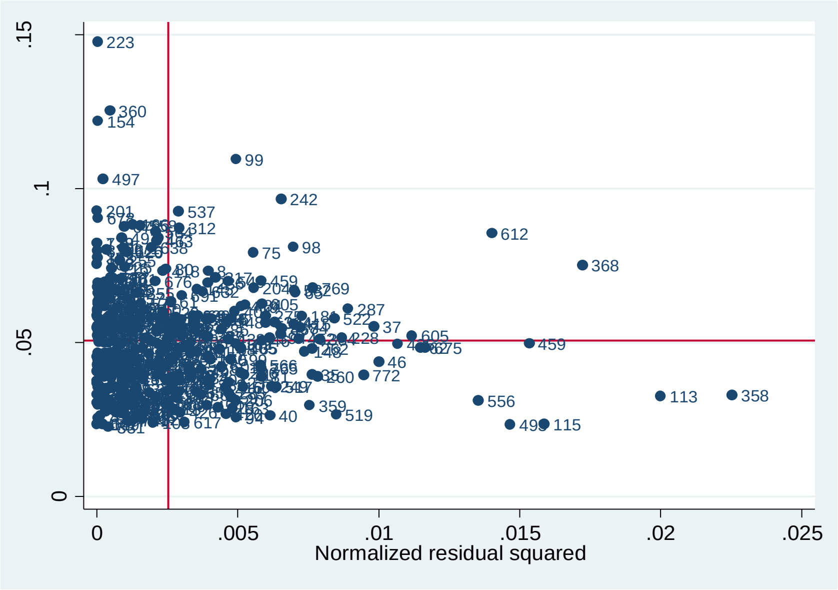
### Stem-and-leaf plot for leverage

Leverage rounded to nearest multiple of .001. plot in units of .001

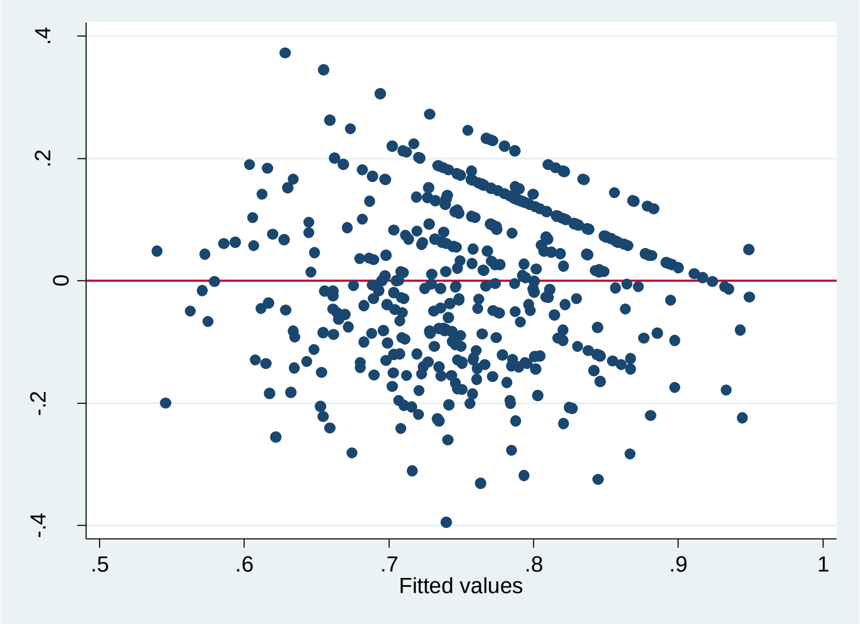
```
  2* | 33444444
  2. | 555666667777777778889999
  3* | 0000000000000001111112222333333333444444 4
  3. | 55555566666666677778888888899999999999
  4* | 00000000001111111111222222223333333334444 44444
  5* | 000000000011111111122222222233333333334444 4444
  5. | 555555555555555555666666677777777777778888888888888889999999
  6* | 00000111112222333333344
  6. | 55556667777777777888899
  7* | 000000111133444
  7. | 567889
  8* | 000011122344
  8. | 667888
```

```
 9* | 133
 9. | 7
10* | 3
10. |
11* | 0
11. |
12* | 2
12. | 5
13* |
13. |
14* |
14. | 8
```

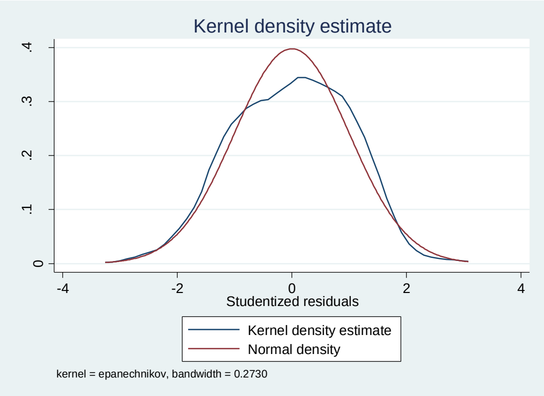
## Leverage plot

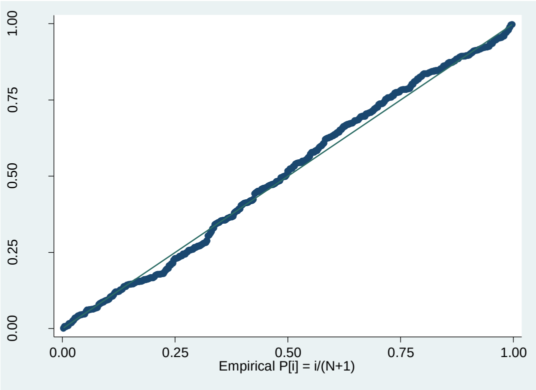


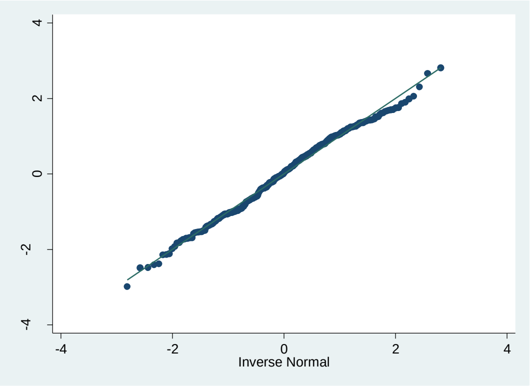
## Homoscedasticity of Residuals

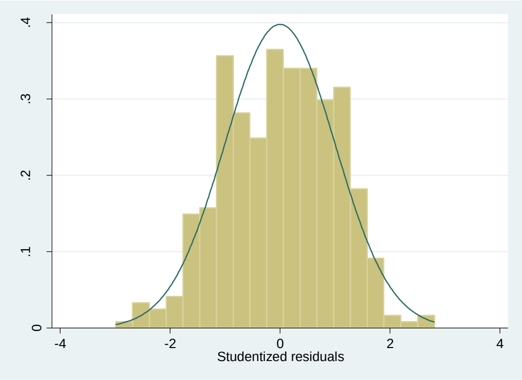


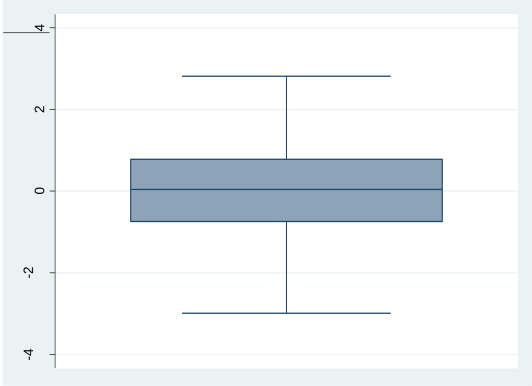
## Normality of residuals











## Cameron & Trivedi's decomposition of IM-test

| Source | chi2 | df | p |
|---|---|---|---|
| Heteroskedasticity | 164.51 | 178 | 0.7575 |
| Skewness | 18.42 | 19 | 0.4943 |
| Kurtosis | 6.76 | 1 | **0.0093** |
| Total | 189.69 | 198 | 0.6517 |

## Breusch-Pagan / Cook-Weisberg test for heteroskedasticity

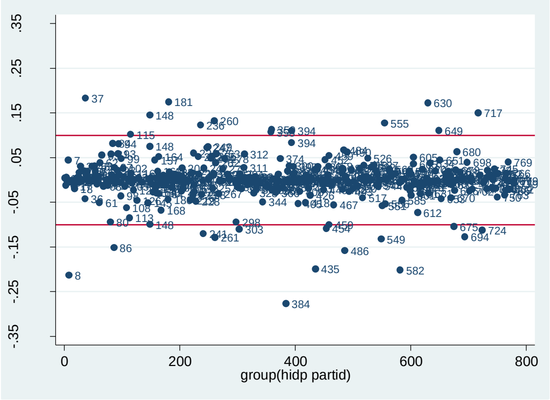
| | |
|---|---|
| Ho: | Constant variance |
| Variables: | fitted values of care_bsl_SF-6D |
| chi2(1) = | 3.67 |

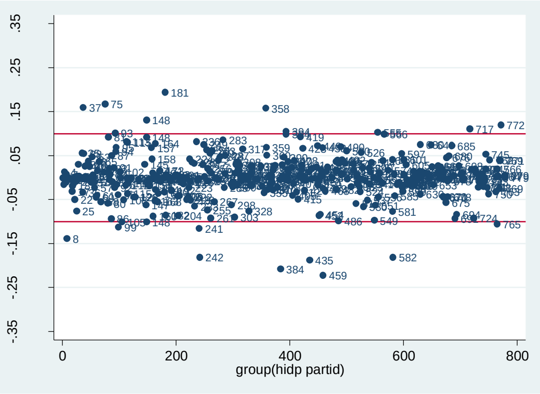
| | |
|---|---|
| Prob > chi2 = | 0.0554 |

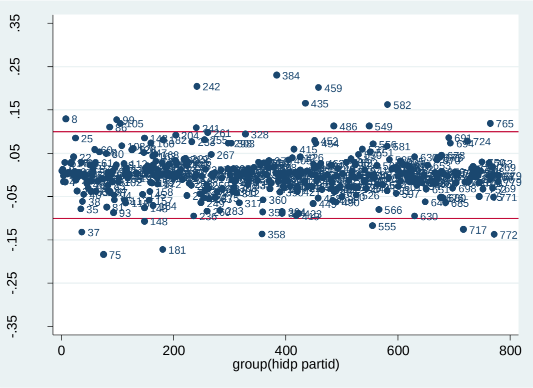
## Assessment of multicoliniarity (VIF)

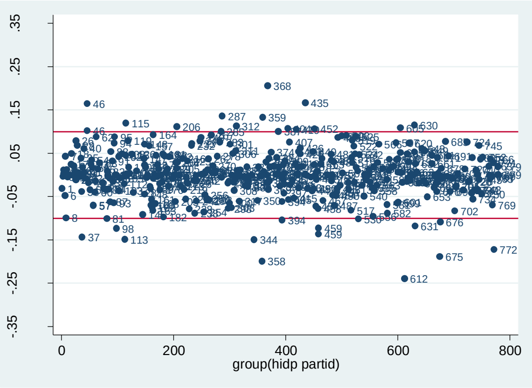
| Variable | VIF | 1/VIF |
|---|---|---|
| Patient SF-6D | 2.78 | 0.359366 |
| Caregiver external conflicts | 27.26 | 0.036688 |
| Patient SF-6D x external conflicts | 27.02 | 0.037010 |
| Time spent caregiving | 1.14 | 0.877226 |
| Caregiver internal conflicts | 1.12 | 0.896012 |
| Job status | 1.47 | 0.678821 |
| GHQ difference | 1.27 | 0.788480 |
| Caregiver age | 1.96 | 0.509183 |
| Caregiver gender | 2.19 | 0.457001 |
| Caregiver Race | 1.25 | 0.801168 |
| Caregiver Education Ref degree | - | - |
| Other higher | 1.82 | 0.550718 |
| A level | 2.25 | 0.444847 |
| GCSE | 2.56 | 0.390396 |
| Other | 1.67 | 0.598055 |
| None | 3.46 | 0.288814 |
| Patient gender | 2.26 | 0.443076 |
| Religion Ref a great diff | - | - |
| Some difference | 1.57 | 0.637902 |
| A little difference | 1.56 | 0.639939 |
| No difference | 1.73 | 0.577457 |
| Mean VIF | 4.54 | |

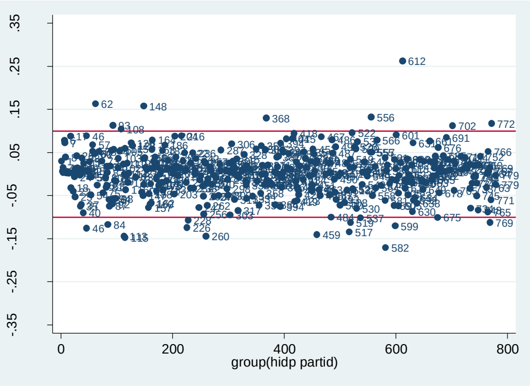
## DF Beta plots for key explanatory variables and effect modifiers






.35
.25
.15
.05
-.05
-.15
-.25
-.35
0
200
400
600
800
group(hidp partid)


.35
.25
.15
.05
-.05
-.15
-.25
-.35
0
200
400
600
800
group(hidp partid)


.35
.25
.15
.05
-.05
-.15
-.25
-.35
0
200
400
600
800
group(hidp partid)

# Appendix 8: Diagnostics for 35 hours model with patient SF-6D and external conflicts interaction and time and internal conflicts interaction

### Stem-and-leaf plot for studentized residuals

Residuals rounded to nearest multiple of .01, plot in units of .01

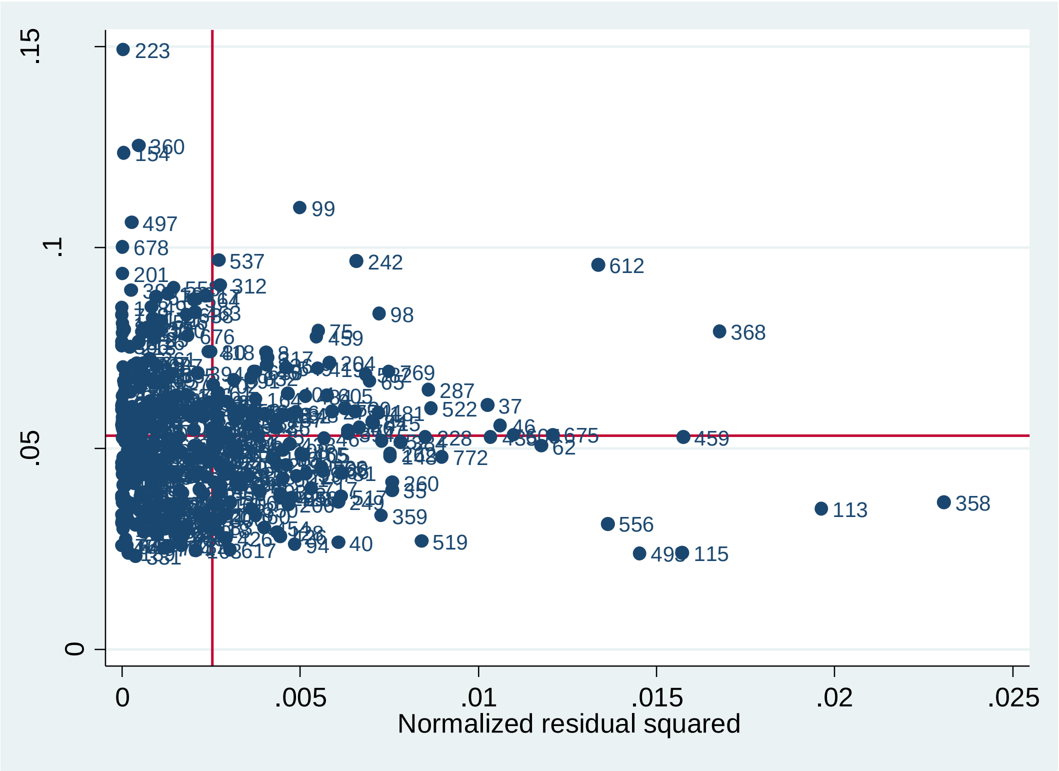
```
-3** | 03
-2** |
-2** |
-2** | 51,47
-2** | 37,36,20
-2** | 16,09,03
-1** | 88,86,80
-1** | 76,72,72,72,72,70,70,67,62
-1** | 59,58,55,54,53,53,53,52,50,49,41
-1** | 37,36,36,35,34,33,31,31,31,29,25,23,22,21,20
-1** | 19,16,14,13,12,11,10,09,08,08,07,07,06,06,04,03,03,03,02,02, ... (28)
-0** | 99,99,98,97,97,96,96,95,94,92,91,91,91,91,90,89,87,85,85,83
-0** | 79,78,78,77,76,73,73,72,72,72,71,70,69,69,69,67,67,66,65,65, ... (27)
-0** | 59,59,59,57,56,53,52,51,50,48,44,44,43,41,40,40,40
-0** | 39,38,38,37,37,36,36,34,33,33,32,30,29,28,28,27,26,25,25,24, ... (25)
-0** | 19,19,17,17,17,16,15,13,13,10,10,09,09,09,09,08,07,07,07,06, ... (30)
 0** | 01,01,02,03,03,05,05,07,07,09,09,09,10,10,12,12,12,12,12,14, ... (24)
 0** | 20,21,21,22,22,22,23,23,23,25,25,26,28,30,33,33,34,35,36,36, ... (24)
 0** | 40,40,40,41,41,42,43,44,45,45,45,46,46,47,48,49,49,49,49,50, ... (33)
 0** | 60,60,61,61,62,65,65,66,67,67,69,70,71,72,72,73,73,75,75,76, ... (26)
 0** | 80,80,81,81,82,84,86,87,88,89,89,91,92,92,92,94,95,98,99
 1** | 00,00,00,01,02,03,03,03,04,04,04,06,06,07,08,11,11,12,12,12, ... (24)
 1** | 20,21,21,21,22,23,23,24,26,28,28,28,30,31,31,31,33,34,35,36,37,38,39
 1** | 40,42,43,44,44,45,48,48,49,49,50,55,59
 1** | 63,65,66,67,68,68,73,74
 1** | 84,86
 2** | 03,06
 2** | 31
 2** |
 2** | 63,78
```

### Stem-and-leaf plot for leverage

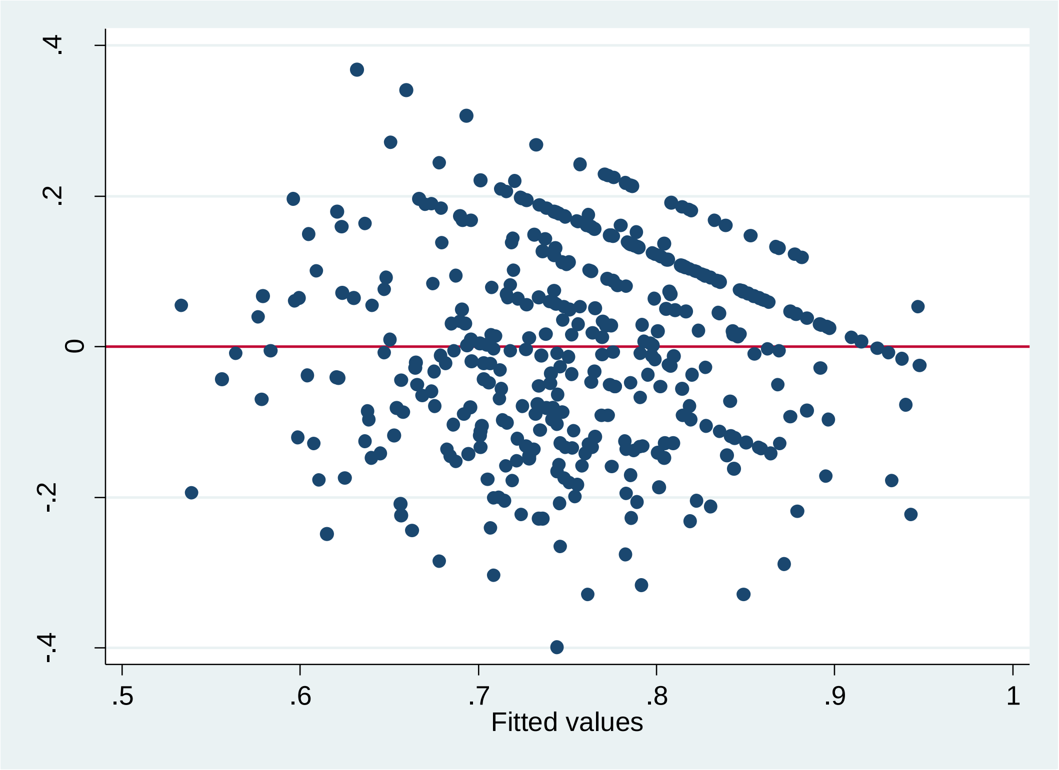
Leverage rounded to nearest multiple of .001, plot in units of .001

```
  2* | 3444
  2. | 555566666777888899999
  3* | 00000011111112222333334444444
  3. | 55555666666666677777778888888888999999
  4* | 00001111111122233333333333344444444444444
  4. | 5555555666666677777777888888888888999999999999
  5* | 00000111111111122222222222333333334444444444
  5. | 5555555555566666667777777778888888888999999999999999999
  6* | 000000000011111111112222233333344444
  6. | 55667777777888888899999
  7* | 00000111111234444
  7. | 56777889999
  8* | 000001223344
  8. | 5578889
  9* | 014
  9. | 677
 10* | 0
 10. | 6
 11* | 0
 11. |
 12* | 4
 12. | 5
 13* |
 13. |
 14* |
 14. | 9
```

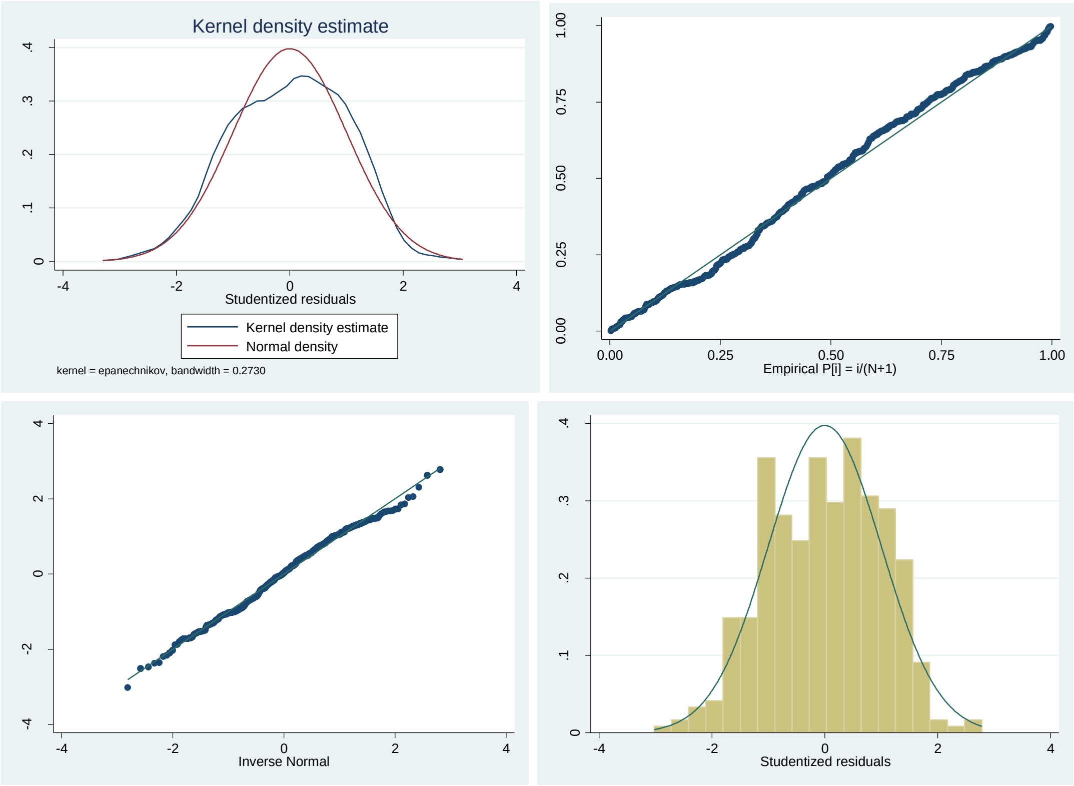
### Leverage plot

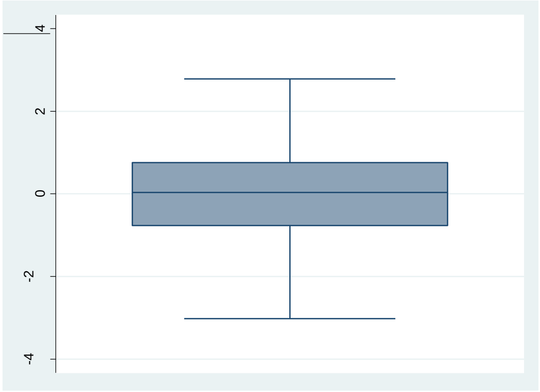


## Homoscedasticity of Residuals



## Normality of residuals





## Cameron & Trivedi's decomposition of IM-test

| Source | chi2 | df | p |
|---|---|---|---|
| Heteroskedasticity | 189.12 | 195 | 0.6053 |
| Skewness | 19.38 | 20 | 0.4970 |
| Kurtosis | 6.78 | 1 | **0.0092** |
| Total | 215.29 | 216 | 0.5009 |

## Breusch-Pagan / Cook-Weisberg test for heteroskedasticity

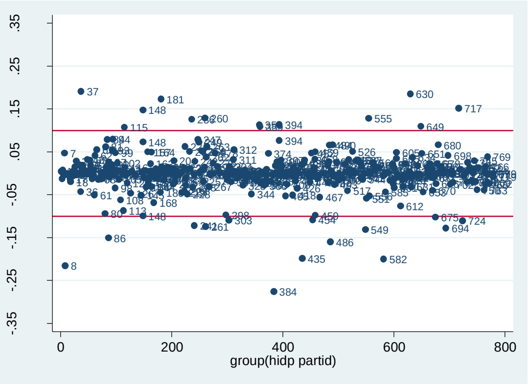
| | |
|---|---|
| Ho:<br>Variables: | Constant variance<br>fitted values of care_bsl_SF-6D |
| chi2(1) =<br>Prob > chi2 = | 3.27<br>0.0707 |

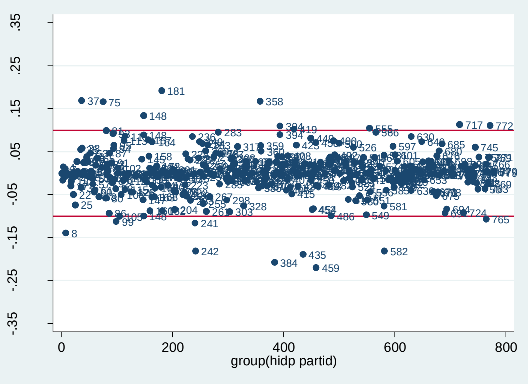
## Assessment of multicoliniarity (VIF)

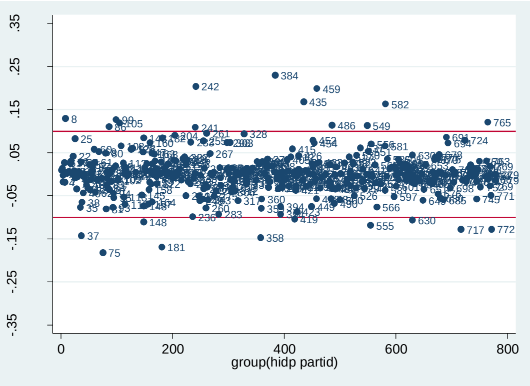
| **Variable** | **VIF** | **1/VIF** |
|---|---|---|
| Patient SF-6D | 2.78 | 0.359206 |
| Caregiver external conflicts | 27.29 | 0.036639 |
| Patient SF-6D x external conflicts | 27.07 | 0.036942 |
| Time spent caregiving | 2.88 | 0.346774 |
| Caregiver internal conflicts | 1.55 | 0.646100 |
| Time spent caregiving x internal conflicts | 3.24 | 0.308824 |
| Job status | 1.47 | 0.678642 |
| GHQ difference | 1.27 | 0.787193 |
| Caregiver age | 1.97 | 0.507888 |
| Caregiver gender | 2.20 | 0.454330 |
| Caregiver Race | 1.25 | 0.801167 |
| Caregiver Education Ref degree | - | - |
| Other higher | 1.82 | 0.550718 |
| A level | 2.25 | 0.444794 |
| GCSE | 2.56 | 0.390024 |
| Other | 1.67 | 0.598026 |
| None | 3.47 | 0.288470 |
| Patient gender | 2.27 | 0.440329 |
| Religion Ref a great diff | - | - |
| Some difference | 1.58 | 0.632031 |
| A little difference | 1.56 | 0.639821 |

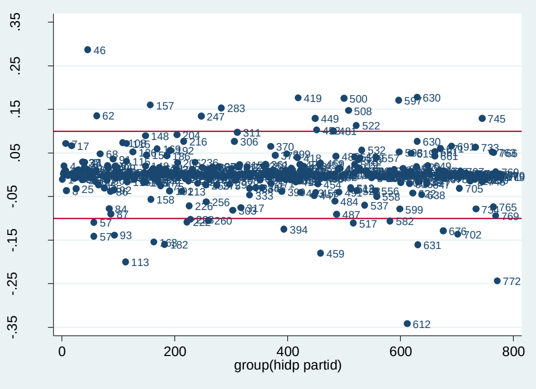
|  |  |  |
|---|---|---|
| No difference | 1.73 | 0.576730 |
| Mean VIF | 4.59 |  |

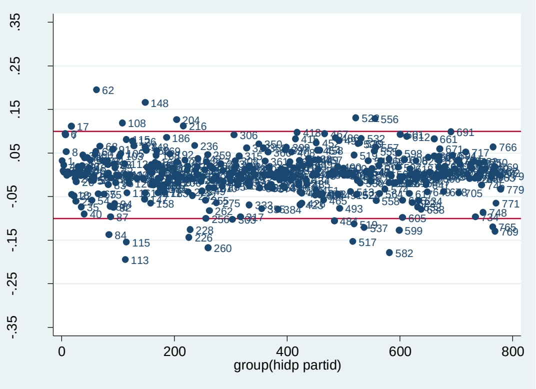
## DF Beta plots for key explanatory variables and effect modifiers

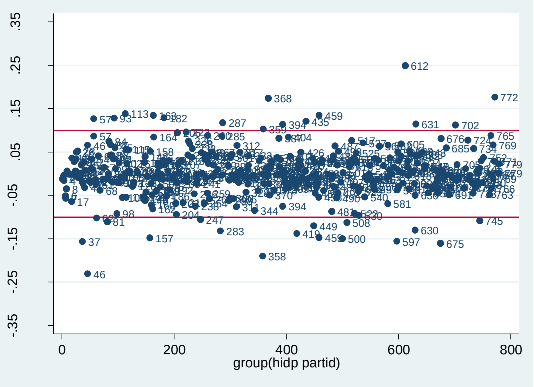












# Appendix 9: Models using the 20 hours specification of time spent caregiving

## Appendix Table 14: Model with time spent caring and conflicts variables (20 hours)

| | ***a*** | | ***b(20)*** | | ***c(20)*** | |
|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | **With patient SF-6D** | | **With patient SF-6D and time spent caring** | | **‘b’ plus external and internal conflicts** | |
| | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring<br>Ref less than 20 hours | | | -0.044 | **0.000** | -0.040 | **0.002** |
| Patient SF-6D | 0.086 | 0.103 | 0.045 | 0.409 | 0.001 | 0.980 |
| Presence external conflict<br>Ref absent | | | | | -0.029 | **0.025** |
| Presence internal conflict<br>Ref present | | | | | 0.081 | **0.000** |
| Constant | 0.690 | 0.000 | 0.736 | 0.000 | 0.731 | 0.000 |
| Number of obs | 691 | | 685 | | 552 | |
| Prob > F | 0.1031 | | 0.0004 | | 0.0000 | |
| R- squared | 0.0039 | | 0.0228 | | 0.0989 | |
| Adj R-squared | 0.0024 | | 0.0199 | | 0.0923 | |
| Root MSE | .15503 | | .15348 | | .14666 | |
| AIC | -613.2268 | | -620.7342 | | -547.773 | |
| BIC | -604.1506 | | -607.1459 | | -526.2053 | |
| Link test | 0.578 | | 0.96 | | 0.99 | |
| RESET | 0.89 | | 0.38 | | 0.72 | |

## Appendix Table 15: Model with caregiver dependent children and job status variables (20 hours)

| | ***c(20)*** | | ***d(20)*** | | ***e(20)*** | | ***f(20)*** | |
|---|---|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | **‘b’ + internal and external conflicts** | | **‘c’ + job status** | | **‘d’ and presence children** | | **‘d’ and number children** | |
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring<br>Ref less than 20 hours | -0.040 | **0.002** | -0.027 | **0.040** | -0.028 | **0.033** | -0.028 | **0.034** |
| Patient SF-6D | 0.001 | 0.980 | 0.009 | 0.879 | 0.008 | 0.893 | 0.008 | 0.889 |
| Presence external conflict<br>Ref absent | -0.029 | **0.025** | -0.034 | **0.009** | -0.035 | **0.008** | -0.035 | **0.008** |
| Presence internal conflict<br>Ref present | 0.081 | **0.000** | 0.075 | **0.000** | 0.075 | **0.000** | 0.076 | **0.000** |
| Job status<br>Ref presence of job | | | -0.058 | **0.000** | -0.057 | **0.000** | -0.057 | **0.000** |
| Number of children | | | | | | | 0.010 | 0.498 |
| Presence of children<br>Ref none | | | | | 0.020 | 0.430 | | |
| Constant | 0.731 | 0.000 | 0.768 | 0.000 | 0.768 | 0.000 | 0.768 | 0.000 |
| Number of obs | 552 | | 538 | | 538 | | 538 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R- squared | 0.0989 | | 0.1210 | | 0.1221 | | 0.1218 | |
| Adj R-squared | 0.0923 | | 0.1128 | | 0.1122 | | 0.1119 | |
| Root MSE | .14666 | | .14509 | | .14514 | | .14516 | |
| AIC | -547.773 | | -544.3806 | | -543.0126 | | -542.8452 | |
| BIC | -526.2053 | | -518.6534 | | -512.9976 | | -512.8302 | |
| Link test | 0.99 | | 0.70 | | 0.47 | | 0.52 | |
| RESET | 0.72 | | 0.51 | | 0.30 | | 0.37 | |

## Appendix Table 16: Model with patient and caregiver sociodemographic variables (20 hours)

| | ***d(20)*** | | ***g(20)*** | | ***h(20)*** | | ***i(20)*** | |
|---|---|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | **'c' + job status** | | **d + caregiver sociodemographic** | | **e + patient sociodemographic** | | **e + household characteristics** | |
| | | | **CAREGIVER** | | **PATIENT** | | | |
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring<br>Ref less than 20 hours | -0.027 | **0.040** | -0.024 | 0.062 | -0.020 | 0.128 | -0.026 | **0.049** |
| Patient SF-6D | 0.009 | 0.879 | 0.009 | 0.881 | 0.001 | 0.979 | 0.004 | 0.946 |
| Presence external conflict<br>Ref absent | -0.034 | **0.009** | -0.036 | **0.005** | -0.031 | **0.017** | -0.034 | **0.010** |
| Presence internal conflict<br>Ref present | 0.075 | **0.000** | 0.071 | **0.000** | 0.071 | **0.000** | 0.075 | **0.000** |
| Job status Ref presence of job | -0.058 | **0.000** | -0.033 | **0.046** | -0.064 | **0.000** | -0.057 | **0.000** |
| Age | | | -0.001 | **0.021** | 0.000 | 0.963 | | |
| Gender Ref Male | | | -0.010 | 0.423 | 0.006 | 0.634 | | |
| Race Ref white | | | -0.075 | **0.000** | -0.059 | **0.002** | | |
| Education | | | | | | | | |
| Reference degree level | | | - | | - | | | |
| Other higher | | | 0.015 | 0.599 | -0.029 | 0.394 | | |
| A level | | | -0.025 | 0.329 | -0.026 | 0.432 | | |
| GCSE | | | -0.011 | 0.647 | -0.048 | 0.173 | | |
| Other | | | -0.056 | 0.086 | -0.039 | 0.254 | | |
| None | | | -0.050 | **0.030** | -0.068 | **0.014** | | |
| Household location Reference urban | | | | | | | 0.010 | 0.523 |
| Household income | | | | | | | 6.29e-07 | 0.889 |
| Constant | 0.768 | 0.000 | 0.855 | 0.000 | 0.829 | 0.000 | 0.766 | 0.000 |
| Number of obs | 538 | | 536 | | 536 | | 538 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R- squared | 0.1210 | | 0.1698 | | 0.1567 | | 0.1218 | |
| Adj R-squared | 0.1128 | | 0.1491 | | 0.1357 | | 0.1102 | |
| Root MSE | .14509 | | .14174 | | .14331 | | .1453 | |
| AIC | -544.3806 | | -559.4863 | | -547.7039 | | -540.8234 | |
| BIC | -518.6534 | | -499.5084 | | -487.7261 | | -506.5205 | |
| Link test | 0.70 | | 0.45 | | 0.67 | | 0.67 | |
| RESET | 0.51 | | 0.66 | | 0.34 | | 0.46 | |

## Appendix Table 17: Model with patient and caregiver resource variables (20 hours)

| | ***d(20)*** | | **j(20)** | | **k(20)** | | **l(20)** | | **m(20)** | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | **'c' + job status** | | **d plus caregiver religion** | | **e plus caregiver resources** | | **e plus patient religion** | | **e plus patient resources** | |
| | | | **SPECIFICATION CAREGIVER RESOURCE** | | | | **SPECIFICATION PATIENT RESOURCE** | | | |
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring Ref less than 20 hours | -0.027 | **0.040** | -0.027 | **0.038** | -0.030 | **0.017** | -0.030 | **0.022** | -0.023 | 0.107 |
| Patient SF-6D | 0.009 | 0.879 | -0.001 | 0.981 | -0.030 | 0.587 | 0.006 | 0.913 | -0.069 | 0.280 |
| Presence external conflict Ref absent | -0.034 | **0.009** | -0.033 | **0.009** | -0.019 | 0.127 | -0.033 | **0.011** | -0.031 | **0.027** |
| Presence internal conflict Ref present | 0.075 | **0.000** | 0.081 | **0.000** | 0.052 | **0.000** | 0.079 | **0.000** | 0.077 | **0.000** |
| Job status Ref presence of job | -0.058 | **0.000** | -0.057 | **0.000** | -0.064 | **0.000** | -0.057 | **0.000** | -0.058 | **0.000** |
| Able to make up mind Ref no or rarely | | | | | 0.002 | 0.903 | | | 0.021 | 0.234 |
| Able to deal problems Ref no or rarely | | | | | 0.049 | **0.001** | | | -0.013 | 0.472 |
| Thinking clearly Ref no or rarely | | | | | 0.077 | **0.000** | | | 0.025 | 0.185 |
| Feeling close to others Ref no or rarely | | | | | -0.010 | 0.460 | | | 0.025 | 0.101 |
| Religion | | | | | | | | | | |
| Ref a great difference | | | **-** | | | | - | | | |
| Some difference | | | 0.062 | **0.001** | | | -0.003 | 0.847 | | |
| A little difference | | | 0.045 | **0.023** | | | 0.017 | 0.383 | | |
| No difference | | | 0.071 | **0.000** | | | 0.037 | **0.023** | | |
| Constant | 0.768 | 0.000 | 0.721 | 0.000 | 0.728 | 0.000 | 0.754 | 0.000 | 0.774 | 0.000 |
| Number of obs | 538 | | 536 | | 530 | | 536 | | 461 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R- squared | 0.1210 | | 0.1540 | | 0.2309 | | 0.1338 | | 0.1434 | |
| Adj R-squared | 0.1128 | | 0.1412 | | 0.2175 | | 0.1207 | | 0.1263 | |
| Root MSE | .14509 | | .1426 | | .13672 | | .14453 | | .14413 | |
| AIC | -544.3806 | | -557.8873 | | -595.1966 | | -543.5207 | | -467.7897 | |
| BIC | -518.6534 | | -519.3301 | | -552.4678 | | -504.9635 | | -426.4558 | |
| Link test | 0.70 | | 0.38 | | 0.78 | | 0.47 | | 0.93 | |
| RESET | 0.51 | | 0.40 | | 0.55 | | 0.53 | | 0.98 | |

## Appendix Table 18: Model with other patient and caregiver health and wellbeing variables (20 hours)

| | *d(20)* | | n(35) | | o(35) | | p(35) | |
|---|---|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | **'c' + job status** | | **d plus patient health and wellbeing** | | **d plus caregiver health and wellbeing** | | **d plus difference patient and caregiver** | |
| | | | **PATIENT** | | **CAREGIVER** | | | |
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring | -0.027 | **0.040** | | | | | | |
| Ref less than | | | -0.031 | **0.033** | -0.020 | 0.081 | -0.025 | 0.061 |
| Patient SF-6D | 0.009 | 0.879 | -0.121 | 0.096 | -0.028 | 0.571 | 0.132 | **0.039** |
| Presence external conflict | | | | | | | | |
| Ref absent | -0.034 | **0.009** | -0.028 | 0.055 | 0.004 | 0.752 | -0.034 | **0.010** |
| Presence internal conflict | | | | | | | | |
| Ref present | 0.075 | **0.000** | 0.062 | **0.000** | 0.027 | **0.031** | 0.061 | **0.000** |
| Job status | | | | | | | | |
| Ref presence of job | -0.058 | **0.000** | -0.056 | **0.000** | -0.056 | **0.000** | -0.049 | **0.001** |
| Duration of arthritis | | | 0.000 | 0.590 | - | | | |
| Life satisfaction | | | | | | | | |
| Ref: Completely dis | | | - | | - | | | |
| Mostly dis | | | -0.051 | 0.130 | -0.011 | 0.817 | | |
| Somewhat dis | | | -0.031 | 0.286 | 0.009 | 0.830 | | |
| Neither | | | -0.067 | 0.024 | -0.031 | 0.454 | | |
| Somewhat sat | | | -0.023 | 0.428 | -0.004 | 0.924 | | |
| Mostly sat | | | 0.016 | 0.590 | 0.0155 | 0.702 | | |
| Completely sat | | | 0.009 | 0.797 | 0.046 | 0.282 | | |
| GHQ | | | -0.001 | 0.351 | -0.013 | **0.000** | | |
| GHQ difference | | | | | | | -0.005 | **0.000** |
| Constant | 0.768 | 0.000 | 0.875 | 0.000 | 0.936 | 0.000 | 0.684 | 0.000 |
| Number of obs | 538 | | 460 | | 525 | | 478 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R- squared | 0.1210 | | 0.1480 | | 0.3507 | | 0.1797 | |
| Adj R-squared | 0.1128 | | 0.1232 | | 0.3355 | | 0.1693 | |
| Root MSE | .14509 | | .14425 | | .12531 | | .14029 | |
| AIC | -544.3806 | | -462.1009 | | -678.0768 | | -514.193 | |
| BIC | -518.6534 | | -404.2637 | | -622.6527 | | -485.0058 | |
| Link test | 0.70 | | 0.25 | | 0.85 | | 0.10 | |
| RESET | 0.51 | | 0.38 | | 0.007 | | 0.38 | |

## Appendix Table 19: Model including control variables (20 hours)

| | ***d(20)*** | | **q(20)** | | **r(20)** | | **s(20)** | |
|---|---|---|---|---|---|---|---|---|
| **Caregiver SF-6D** | **'c' + job status** | | **d plus GHQ difference** | | **Q Plus demographics** | | **R Plus resources** | |
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring | | | | | | | | |
| Ref less than 20 hours | -0.027 | **0.040** | -0.025 | 0.061 | -0.023 | 0.087 | -0.024 | 0.079 |
| Patient SF-6D | 0.009 | 0.879 | 0.132 | **0.039** | **0.137** | **0.035** | **0.138** | **0.034** |
| Presence external conflict | | | | | | | | |
| Ref absent | -0.034 | **0.009** | -0.034 | **0.010** | -0.035 | 0.010 | -0.034 | 0.011 |
| Presence internal conflict | | | | | | | | |
| Ref present | 0.075 | **0.000** | 0.061 | **0.000** | 0.058 | 0.000 | 0.060 | 0.000 |
| Job status | | | | | | | | |
| Ref presence of job | -0.058 | **0.000** | -0.049 | **0.001** | -0.027 | 0.109 | -0.028 | 0.094 |
| GHQ difference | | | -0.005 | **0.000** | **-0.005** | **0.000** | **-0.005** | **0.000** |
| Caregiver age | | | | | -0.001 | 0.097 | -0.001 | 0.118 |
| Caregiver race Ref white | | | | | **-0.057** | **0.013** | **-0.057** | **0.015** |
| Education Ref degree | | | | | - | | - | |
| Other higher | | | | | 0.009 | 0.754 | 0.012 | 0.697 |
| A level | | | | | -0.023 | 0.380 | -0.018 | 0.497 |
| GCSE | | | | | -0.010 | 0.699 | -0.006 | 0.824 |
| Other | | | | | -0.063 | 0.059 | -0.058 | 0.082 |
| None | | | | | **-0.050** | **0.037** | -0.047 | 0.051 |
| Caregiver gender Ref Male | | | | | -0.017 | 0.365 | -0.016 | 0.384 |
| Patient gender Ref Male | | | | | -0.019 | 0.310 | -0.018 | 0.356 |
| Religion Ref great difference | | | | | | | - | |
| Some difference | | | | | | | -0.027 | 0.150 |
| A little difference | | | | | | | 0.002 | 0.917 |
| No difference | | | | | | | 0.009 | 0.626 |
| Constant | 0.768 | 0.000 | 0.684 | 0.000 | 0.767 | 0.000 | 0.763 | 0.000 |
| Number of obs | 538 | | 478 | | 476 | | 474 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R- squared | 0.1210 | | 0.1797 | | 0.2168 | | 0.2244 | |
| Adj R-squared | 0.1128 | | 0.1693 | | 0.1913 | | 0.1937 | |
| Root MSE | .14509 | | .14029 | | .13803 | | .1379 | |
| AIC | -544.3806 | | -514.193 | | -518.6662 | | -514.4149 | |
| BIC | -518.6534 | | -485.0058 | | -452.0195 | | -435.352 | |
| Link test | 0.70 | | 0.10 | | 0.18 | | 0.13 | |
| RESET | 0.51 | | 0.38 | | 0.29 | | 0.32 | |

## Appendix Table 20: Model including the patient SF-6D and external conflicts interaction (20 hours)

| **Caregiver SF-6D** | **No interaction s(20)** | | **Patient SF-6D X external conflicts** | |
|---|---|---|---|---|
| | Coefficient | p | Coefficient | p |
| Time spent caring Ref less than 20 hours | -0.024 | 0.079 | -0.022 | 0.099 |
| Patient SF-6D | **0.138** | **0.034** | 0.300 | **0.003** |
| Presence external conflict Ref absent | **-0.034** | **0.011** | 0.105 | 0.112 |
| Presence internal conflict Ref present | **0.060** | **0.000** | 0.062 | **0.000** |
| SF-6D x external conflicts | -0.028 | 0.094 | -0.256 | **0.032** |
| Job status Ref: in employment | -0.028 | 0.094 | -0.029 | 0.082 |
| GHQ difference | **-0.005** | **0.000** | -0.005 | **0.000** |
| Caregiver age | -0.001 | 0.118 | -0.001 | 0.101 |
| Caregiver race Ref white | **-0.057** | **0.015** | -0.059 | **0.011** |
| Caregiver Education | | | | |
| Reference degree level | - | | - | |
| Other higher | 0.012 | 0.697 | 0.005 | 0.871 |
| A level | -0.018 | 0.497 | -0.016 | 0.538 |
| GCSE | -0.006 | 0.824 | -0.006 | 0.824 |
| Other | -0.058 | 0.082 | -0.056 | 0.091 |
| None | -0.047 | 0.051 | -0.049 | **0.045** |
| Caregiver gender Ref Male | -0.016 | 0.384 | -0.019 | 0.303 |
| Patient gender Ref Male | -0.018 | 0.356 | -0.024 | 0.231 |
| Religion Ref a great difference | - | | - | |
| Some difference | -0.027 | 0.150 | -0.028 | 0.133 |
| A little difference | 0.002 | 0.917 | 0.001 | 0.976 |
| No difference | 0.009 | 0.626 | 0.008 | 0.649 |
| Constant | 0.763 | 0.000 | 0.683 | 0.000 |
| Number of obs | 474 | | 474 | |
| Prob > F | 0.0000 | | 0.0000 | |
| R- squared | 0.2244 | | 0.2323 | |
| Adj R-squared | 0.1937 | | 0.2001 | |
| Root MSE | .1379 | | 13736 | |
| AIC | -514.4149 | | -517.2325 | |
| BIC | -435.352 | | -434.0084 | |
| Link test | 0.13 | | 0.10 | |
| RESET | 0.32 | | 0.32 | |

## Appendix Table 21: Models including different caregiving groups (20 hours)

| **Caregiver SF-6D** | **Whole sample** | | **Caring for partner** | | **Sole carer** | | **Receives care** | | **Physical** | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring | | | | | | | | | | |
| Ref less than | -0.022 | 0.099 | -0.024 | 0.151 | -0.017 | 0.249 | -0.024 | 0.087 | -0.019 | 0.202 |
| Patient SF-6D | 0.300 | **0.003** | 0.258 | **0.016** | 0.264 | **0.014** | 0.295 | **0.003** | 0.286 | **0.006** |
| Presence external conflict | | | | | | | | | | |
| Ref absent | 0.105 | 0.112 | 0.066 | 0.388 | 0.030 | 0.686 | 0.110 | 0.097 | 0.101 | 0.162 |
| Presence internal conflict | | | | | | | | | | |
| Ref present | 0.062 | **0.000** | 0.071 | **0.000** | 0.067 | **0.000** | 0.056 | **0.000** | 0.068 | **0.000** |
| SF-6D x external conflicts | -0.256 | **0.032** | -0.175 | 0.203 | -0.123 | 0.351 | -0.269 | **0.024** | -0.248 | 0.052 |
| Job status Ref: present | -0.029 | 0.082 | -0.046 | **0.037** | -0.038 | **0.048** | -0.007 | 0.654 | -0.030 | 0.107 |
| GHQ difference | -0.005 | **0.000** | -0.005 | **0.000** | -0.005 | **0.000** | -0.004 | **0.000** | -0.005 | **0.000** |
| Caregiver age | -0.001 | 0.101 | 0.0003 | 0.664 | -0.001 | 0.238 | -0.001 | 0.095 | -0.001 | 0.139 |
| Caregiver race Ref white | -0.059 | **0.011** | -0.060 | 0.092 | -0.035 | 0.197 | -0.070 | **0.002** | -0.048 | 0.061 |
| Caregiver Education | | | | | | | | | | |
| Reference degree level | - | | - | | - | | - | | - | |
| Other higher | 0.005 | 0.871 | -0.026 | 0.478 | 0.002 | 0.962 | 0.023 | 0.419 | 0.016 | 0.599 |
| A level | -0.016 | 0.538 | -0.047 | 0.163 | -0.015 | 0.621 | -0.021 | 0.421 | -0.019 | 0.503 |
| GCSE | -0.006 | 0.824 | -0.017 | 0.614 | -0.002 | 0.932 | -0.015 | 0.545 | -0.001 | 0.960 |
| Other | -0.056 | 0.091 | -0.072 | 0.059 | -0.058 | 0.114 | -0.060 | 0.088 | -0.056 | 0.129 |
| None | -0.049 | **0.045** | -0.079 | **0.009** | -0.056 | **0.035** | -0.034 | 0.154 | -0.044 | 0.078 |
| Caregiver gender Ref Male | -0.019 | 0.303 | 0.121 | 0.062 | -0.022 | 0.334 | -0.014 | 0.435 | -0.024 | 0.231 |
| Patient gender Ref Male | -0.024 | 0.231 | 0.109 | 0.091 | -0.025 | 0.286 | -0.004 | 0.848 | -0.022 | 0.302 |
| Religion Ref a great diff | - | | - | | - | | - | | - | |
| Some difference | -0.028 | 0.133 | -0.017 | 0.439 | -0.031 | 0.134 | -0.019 | 0.321 | -0.010 | 0.639 |
| A little difference | 0.001 | 0.976 | 0.0133 | 0.579 | 0.003 | 0.883 | 0.001 | 0.959 | 0.028 | 0.224 |
| No difference | 0.008 | 0.649 | 0.020 | 0.340 | 0.005 | 0.803 | 0.007 | 0.711 | 0.035 | 0.069 |
| Constant | 0.683 | 0.000 | 0.516 | 0.000 | 0.699 | 0.000 | 0.680 | 0.000 | 0.665 | 0.000 |
| Number of obs | 474 | | 353 | | 411 | | 414 | | 403 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R- squared | 0.2323 | | 0.2252 | | 0.2299 | | 0.1999 | | 0.2375 | |
| Adj R-squared | 0.2001 | | 0.1810 | | 0.1925 | | 0.1613 | | 0.1996 | |
| Root MSE | 13736 | | .13823 | | .13989 | | .12811 | | .1371 | |
| AIC | -517.2325 | | -375.8701 | | -430.9034 | | -507.0538 | | -438.4024 | |
| BIC | -434.0084 | | -298.5407 | | -350.5315 | | -426.5365 | | -358.4237 | |
| Link test | 0.10 | | 0.48 | | 0.19 | | 0.16 | | 0.13 | |
| RESET | 0.32 | | 0.76 | | 0.56 | | 0.22 | | 0.30 | |

# Appendix 10: Diagnostics for 20 hour model without interaction

## Stem-and-leaf plot for studentized residuals

Residuals rounded to nearest multiple of .01 plot in units of .01

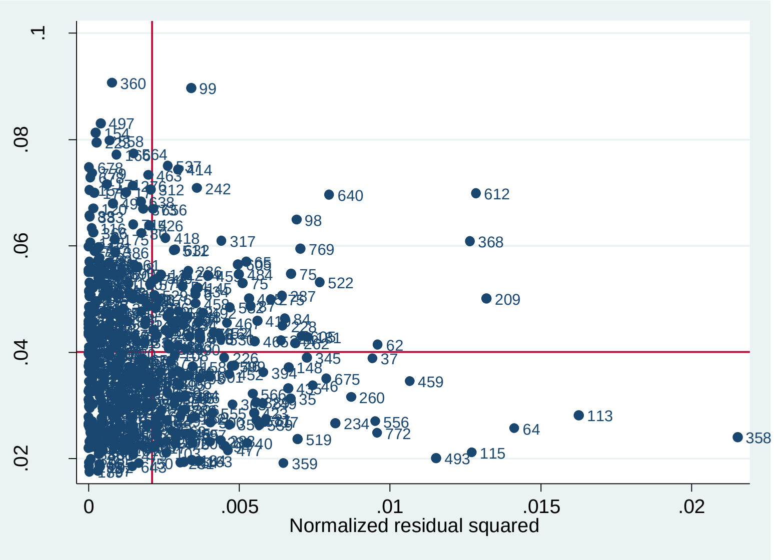
```
 -32* | 0
-31* |
-30* |
-29* |
-28* |
-27* |
-26* |
-25* | 832
-24* | 4
-23* | 3
-22* | 5
-21* | 422
-20* |
-19* | 633
-18* | 6644100
-17* | 8751
-16* | 665221
-15* | 9775
-14* | 9551
-13* | 822200
-12* | 765543332210
-11* | 9988866655443222110
-10* | 66532222210
  -9* | 99988743211
  -8* | 87655444433322100
  -7* | 875555552211110
  -6* | 7655433222111
  -5* | 988877554333
  -4* | 98766544443322111110
  -3* | 96655410
  -2* | 877776665544432
  -1* | 999887665422110
  -0* | 9887777755555443211
   0* | 0003356678899
   1* | 01112244555667889
   2* | 01233444577888
   3* | 0011123445556667999
   4* | 000122244667899
   5* | 0011223335669
   6* | 2444555556667788899
   7* | 002333344457789
   8* | 0012234556678899
   9* | 011222344445555667
  10* | 00113445567
  11* | 000344456777899
  12* | 000112245667788
  13* | 000223357889
  14* | 3466788
  15* | 00025
  16* | 0002346
  17* | 46677
  18* | 58
  19* | 8
  20* | 3
  21* | 2
  22* |
  23* |
  24* | 9
  25* |
  26* |
  27* | 8
```

## Stem-and-leaf plot for leverage

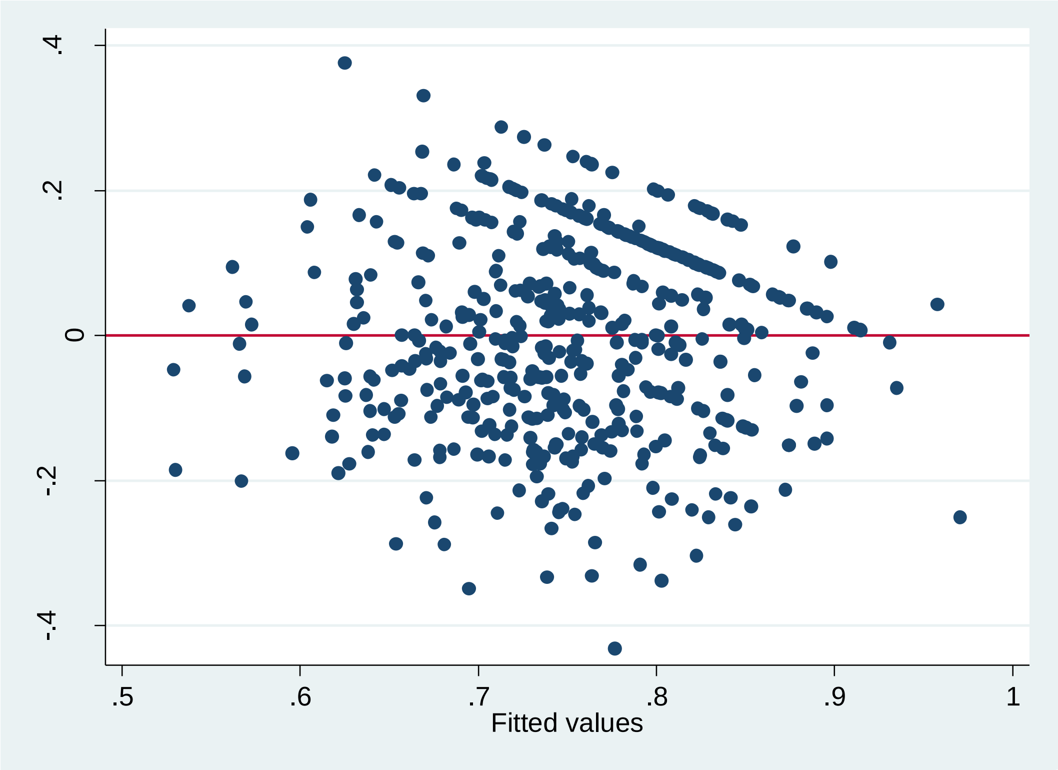
Leverage rounded to nearest multiple of .0001 plot in units of .0001

```
1** | 76,78
1** | 85,85,86,90,91,92,93,93,94,96,97
2** | 00,01,07,08,09,11,11,14,16,16
2** | 20,21,21,21,21,22,23,23,24,24,24,24,25,25,26,29,29,29,29,30, ... (35)
2** | 40,40,43,46,47,47,48,48,48,49,49,50,50,51,52,53,53,57,57,59
2** | 60,60,61,62,62,62,62,63,64,64,64,65,65,66,67,69,70,70,70,70, ... (32)
2** | 80,80,82,86,86,87,88,91,91,92,92,92,93,93,95,95,96,96,97,98
3** | 01,02,02,03,03,03,04,04,04,04,07,07,09,10,10,11,12,12,13,13, ... (28)
3** | 20,20,21,22,22,23,25,26,26,27,27,27,27,27,29,29,31,32,33,37, ... (25)
3** | 42,42,42,43,44,45,46,46,46,47,49,50,51,51,51,52,52,53,54,55, ... (26)
3** | 60,60,60,60,61,61,62,62,62,63,63,64,65,67,68,69,69,71,71,71, ... (26)
3** | 80,80,80,80,81,83,83,84,84,85,87,89,89,90,90,93,95,95,96,96,97,98,98
4** | 00,03,04,05,06,07,07,07,10,10,12,13,13,15,15,16,18,18,19,19
4** | 21,21,22,22,23,23,24,25,26,26,26,26,28,28,30,30,30,31,31,32, ... (30)
4** | 42,42,42,44,44,45,46,46,50,50,52,52,52,53,54,55,56,57,57,57,58,59
4** | 60,60,60,63,64,64,67,67,69,69,71,73,74,75,75,75,75,75,76,77,77,78
4** | 83,84,85,86,87,88,88,91,91,96,98
5** | 00,00,01,01,02,02,02,05,06,07,07,07,08,08,08,09,12,13,14,15,16,18
5** | 21,22,24,24,28,28,28,30,30,31,32,34,36
5** | 40,41,44,44,46,46,47,47,47,48,49,50,51,52,53,55,57,57,58,59
5** | 61,62,64,65,66,69,70,71,73,77
5** | 88,91,92,94,95,98,99
6** | 07,09,10,12,15
6** | 24,25,33,39
6** | 41,49,56,57
6** | 69,69,70
6** | 80,84,97,99
7** | 00,01,05,06,09,14,16
7** | 29,33,37
7** | 44,48,51
7** | 72,74
7** | 95,98
8** | 13
8** | 31
8** |
8** |
8** | 97
9** | 07
```

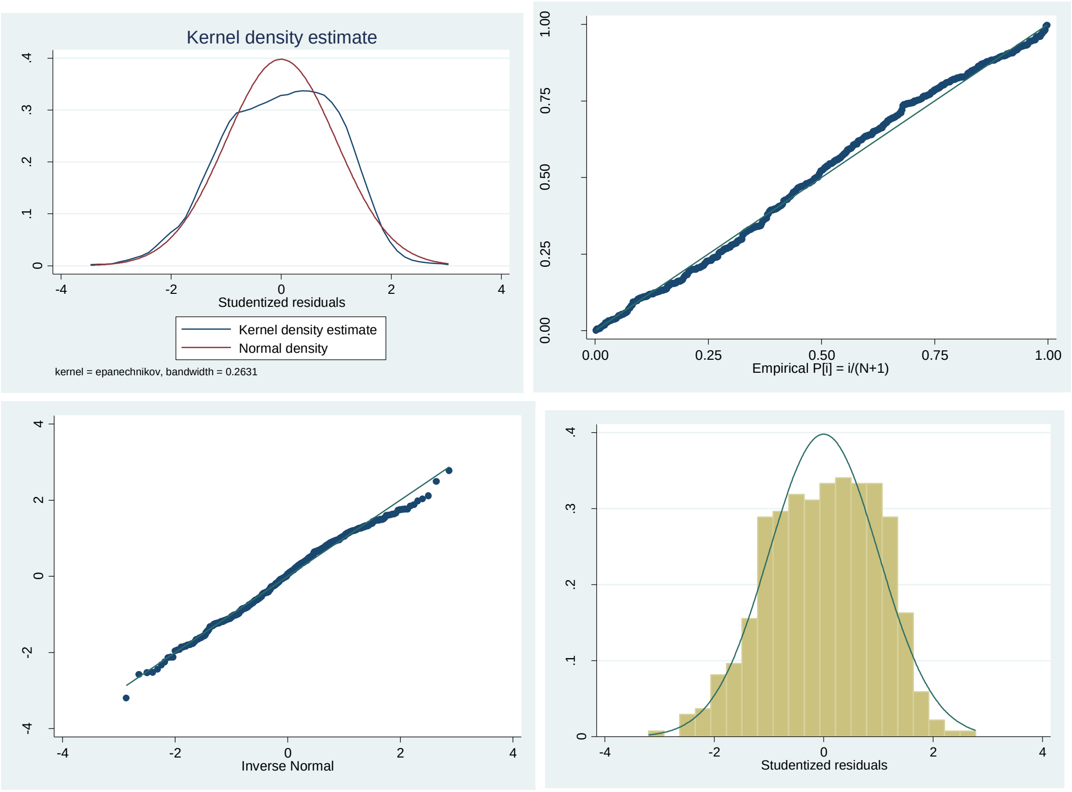
## Leverage plot

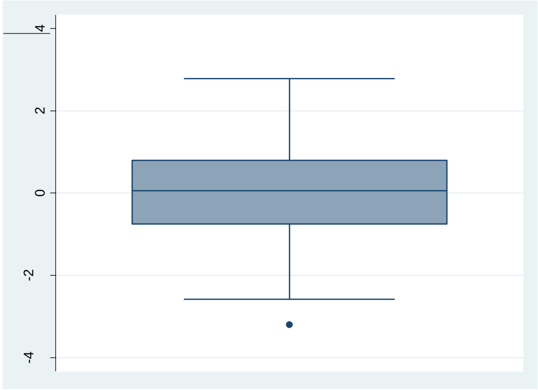


## Homoscedasticity of Residuals



## Normality of residuals





## Cameron & Trivedi's decomposition of IM-test

| Source | chi2 | df | p |
|---|---|---|---|
| Heteroskedasticity | 127.52 | 161 | 0.9759 |
| Skewness | 23.04 | 18 | 0.1890 |
| Kurtosis | 6.90 | 1 | **0.0086** |
| Total | 157.47 | 180 | 0.8860 |

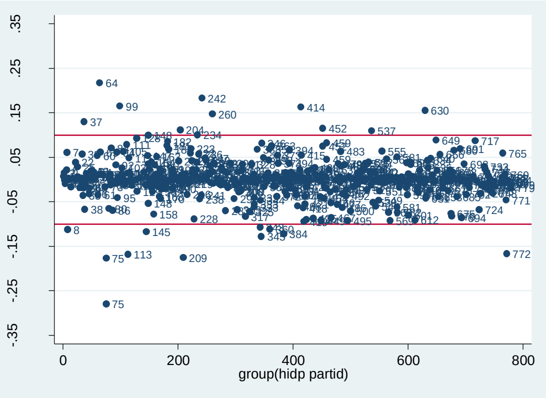
## Breusch-Pagan / Cook-Weisberg test for heteroskedasticity

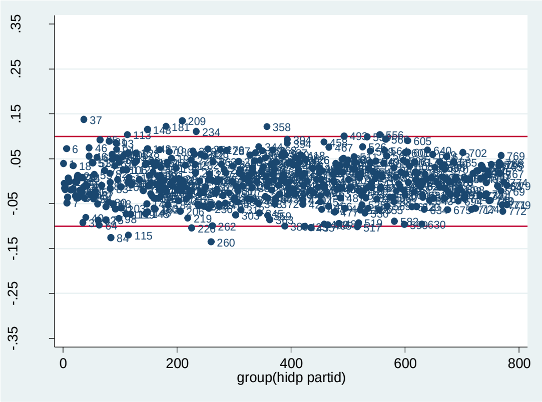
| | |
|---|---|
| Ho:<br>Variables: | Constant variance<br>fitted values of care_bsl_SF-6D |
| chi2(1) =<br>Prob > chi2 = | 1.16<br>0.2806 |

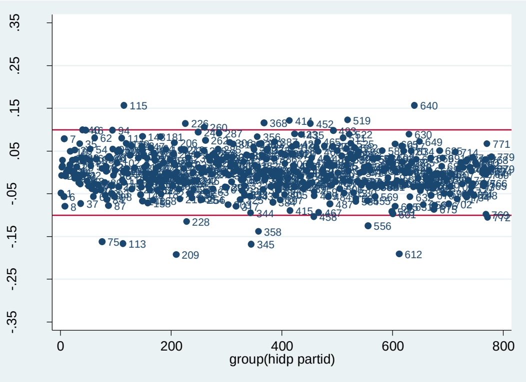
## Assessment of multicoliniarity (VIF)

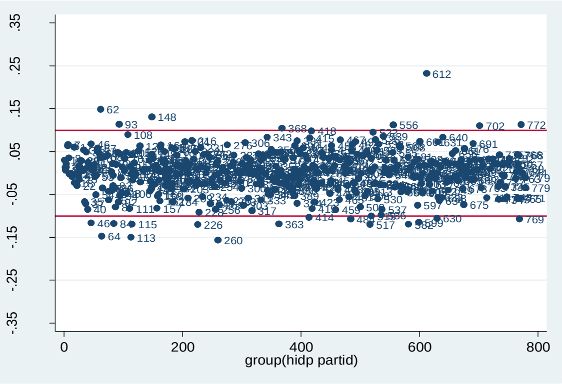
| **Variable** | **VIF** | **1/VIF** |
|---|---|---|
| Patient SF-6D | 1.32 | 0.756980 |
| Caregiver external conflicts | 1.09 | 0.918141 |
| Time spent caregiving | 1.16 | 0.864641 |
| Caregiver internal conflicts | 1.08 | 0.927016 |
| Job status | 1.48 | 0.676990 |
| GHQ difference | 1.24 | 0.804095 |
| Caregiver age | 1.94 | 0.516523 |
| Caregiver gender | 2.21 | 0.452387 |
| Caregiver Race | 1.24 | 0.807182 |
| Caregiver Education Ref degree<br>Other higher<br>A level<br>GCSE<br>Other<br>None | -<br>1.84<br>2.23<br>2.62<br>1.60<br>3.50 | -<br>0.542203<br>0.448803<br>0.382168<br>0.626085<br>0.285700 |
| Patient gender | 2.25 | 0.444473 |
| Religion Ref a great diff<br>Some difference<br>A little difference<br>No difference | -<br>1.58<br>1.56<br>1.75 | -<br>0.634456<br>0.641173<br>0.570838 |
| Mean VIF | 1.76 | |

# DF Beta plots for key explanatory variables and effect modifiers









# Appendix 11: Diagnostics for 20 hour model with SF-6D and external conflicts interaction

### Stem-and-leaf plot for studentized residuals

Residuals rounded to nearest multiple of .01 plot in units of .01

```
-31* | 4
-30* |
-29* |
-28* |
-27* | 51
-26* |
-25* | 6
-24* | 52
-23* | 5
-22* |
-21* | 0
-20* | 10
-19* | 82
-18* | 9611
-17* | 7770
-16* | 86531
-15* | 998763321
-14* | 9980
-13* | 9887721
-12* | 8775544322
-11* | 999888765333110
-10* | 8777666655544443320
 -9* | 7654333200
 -8* | 8776654443322211
 -7* | 9877644320
 -6* | 9986544321111000
 -5* | 98876544311000
 -4* | 988886554332210
 -3* | 97766444332222
 -2* | 87666433222221100
 -1* | 988876544432221000
 -0* | 9887632221
  0* | 1122344455567777788 8
  1* | 0112355567888
  2* | 01122224444556889
  3* | 1123344445557
  4* | 00112222345555779
  5* | 011122234555677889
  6* | 123444456668889
  7* | 11133345577888999
  8* | 111334555666789
  9* | 012244567799
 10* | 123355558889
 11* | 0001123344468
 12* | 0001122222244557889
 13* | 0122244566799
 14* | 2677888
 15* | 00223889
 16* | 03578
 17* | 247
 18* | 36
 19* | 23
 20* |
 21* | 19
 22* |
 23* |
 24* |
```

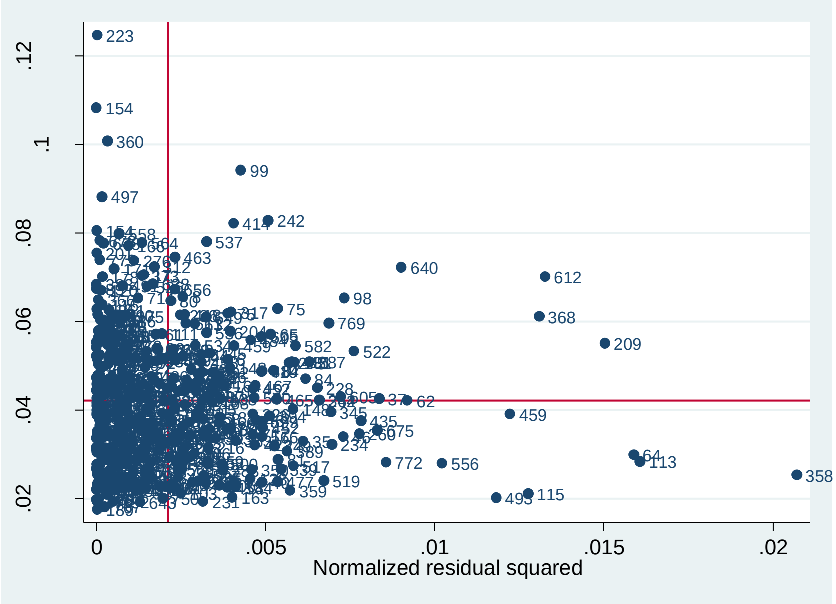
```
 25* | 3
26* |
27* | 6
```

## Stem-and-leaf plot for leverage

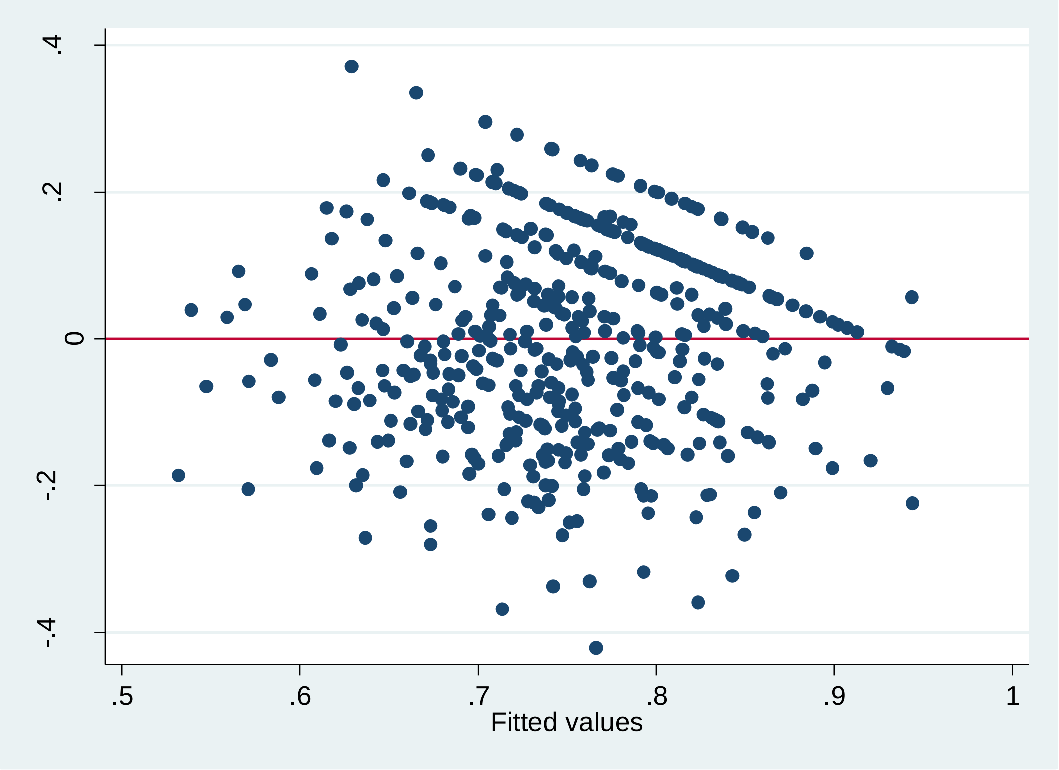
leverage rounded to nearest multiple of .001 plot in units of .001

```
  1. | 889999
  2* | 0000011112222222222222233333333333344444444444444
  2. | 55555555555555555566666677777777778888888888888888899999999
  3* | 0000000000000111111111111122222222222233333333333333444444444444444
  3. | 55555555555555555556666666666666777777778888888888888888899999999999
  4* | 0000000000011111111112222222222222333333333333333334444444444444
  4. | 5555555555566666666666666677777777777777777788888888899999999
  5* | 000001111111111112222222222222223333333344444444
  5. | 555555555666677777777777788889999
  6* | 00000001111222222223334
  6. | 555567778888
  7* | 0001222444
  7. | 578888
  8* | 0123
  8. | 8
  9* | 4
  9. |
 10* | 1
 10. | 8
 11* |
 11. |
 12* |
 12. | 5
```

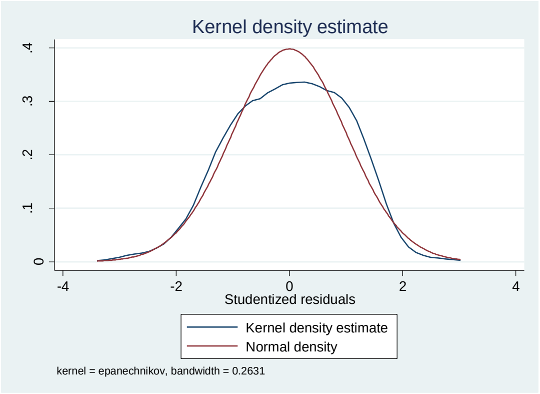
## Leverage plot

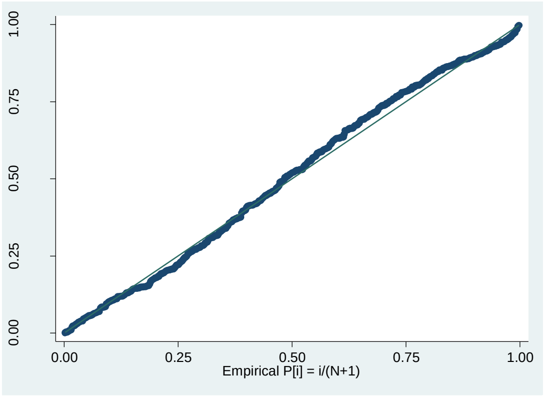


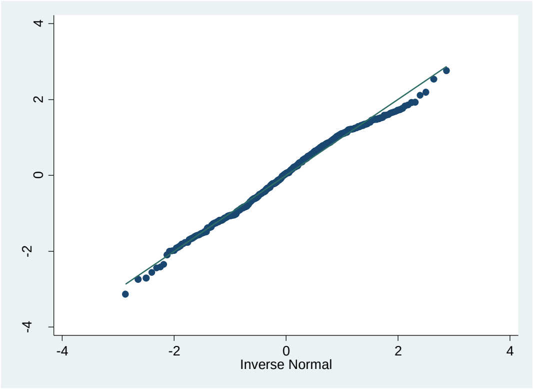
## Homoscedasticity of Residuals

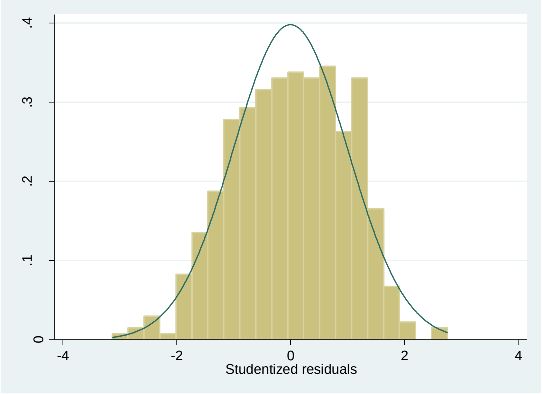


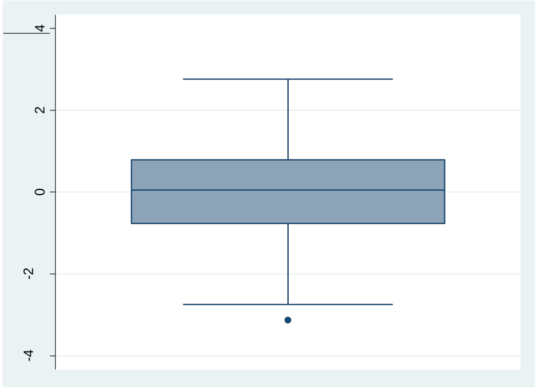
## Normality of residuals











## Cameron & Trivedi's decomposition of IM-test

| Source | chi2 | df | p |
|---|---|---|---|
| Heteroskedasticity | 147.01 | 178 | 0.9567 |
| Skewness | 22.10 | 19 | 0.2795 |
| Kurtosis | 6.45 | 1 | **0.0111** |
| Total | 175.56 | 198 | 0.8728 |

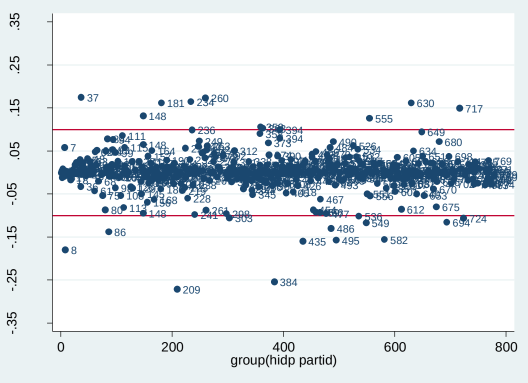
## Breusch-Pagan / Cook-Weisberg test for heteroskedasticity

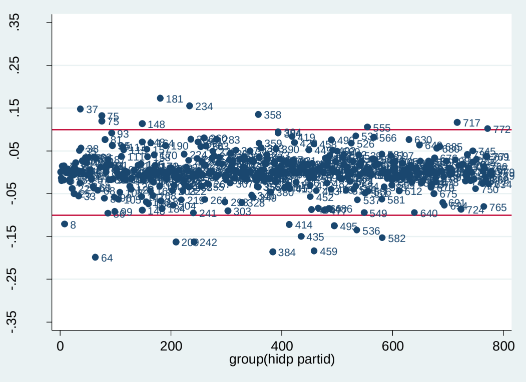
| | |
|---|---|
| Ho:<br>Variables: | Constant variance<br>fitted values of care_bsl_SF-6D |
| chi2(1) =<br>Prob > chi2 = | 1.59<br>0.2070 |

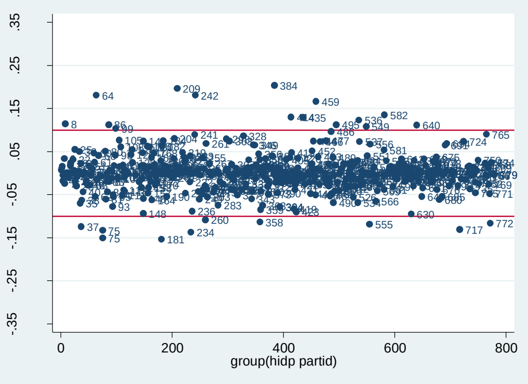
## Assessment of multicoliniarity (VIF)

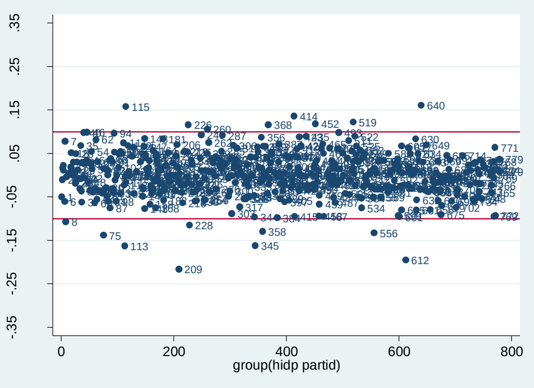
| **Variable** | **VIF** | **1/VIF** |
|---|---|---|
| Patient SF-6D | 3.00 | 0.332961 |
| Caregiver external conflicts | 26.61 | 0.037574 |
| Patient SF-6D x External conflicts | 26.96 | 0.037091 |
| Time spent caregiving | 1.16 | 0.862271 |
| Caregiver internal conflicts | 1.09 | 0.919646 |
| Job status | 1.48 | 0.676490 |
| GHQ difference | 1.24 | 0.804023 |
| Caregiver age | 1.94 | 0.515947 |
| Caregiver gender | 2.22 | 0.449902 |
| Caregiver Race | 1.24 | 0.805343 |
| Caregiver Education Ref degree | | |
| Other higher | 1.86 | 0.536200 |
| A level | 2.23 | 0.448379 |
| GCSE | 2.62 | 0.382168 |
| Other | 1.60 | 0.625648 |
| None | 3.50 | 0.285583 |
| Patient gender | 2.29 | 0.437016 |
| Religion Ref a great diff | | |
| Some difference | 1.58 | 0.633962 |
| A little difference | 1.56 | 0.640415 |
| No difference | 1.75 | 0.570698 |
| Mean VIF | 4.52 | |

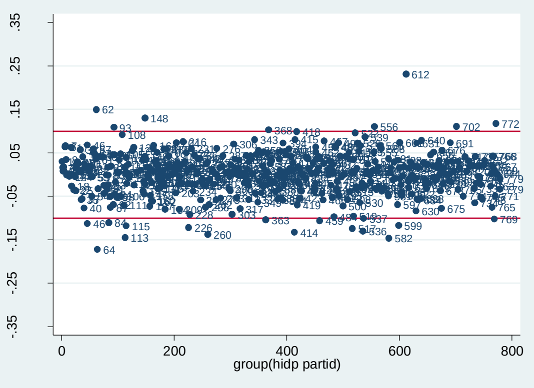
# DF Beta plots for key explanatory variables and effect modifiers











# Appendix 12: Models removing possible influential observations

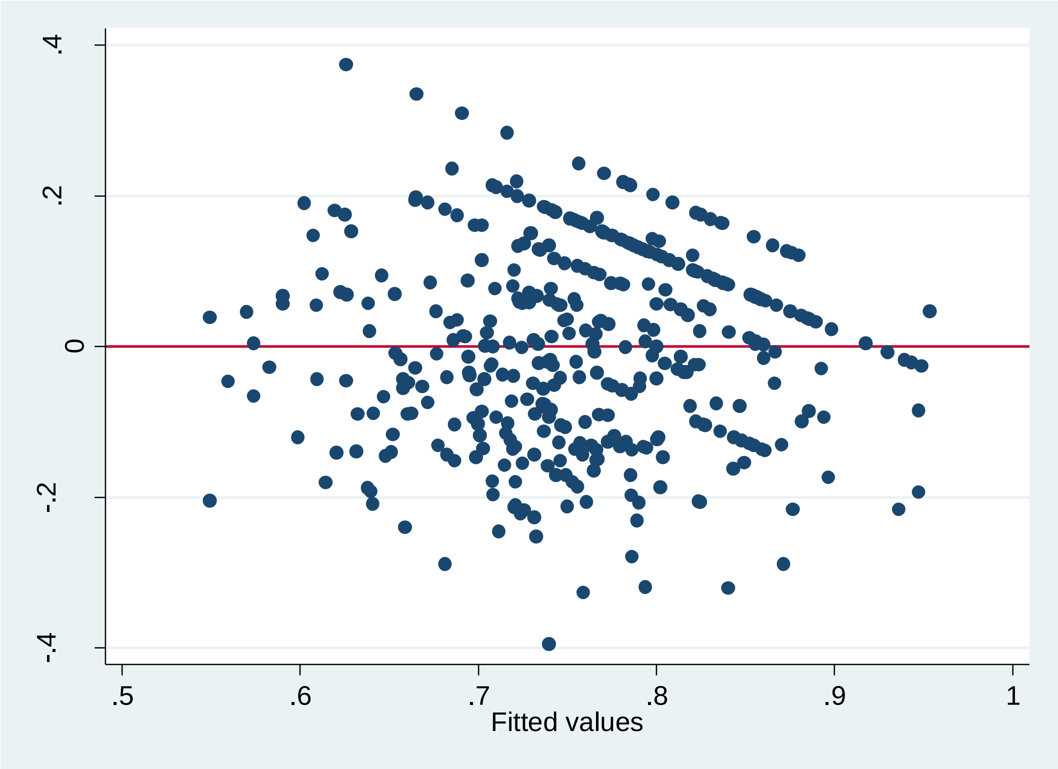
## Appendix Table 22: Models removing possible influential observations (35 hours)

| **Caregiver SF-6D** | **SF-6D external interaction only** | | **removing influential observations (612, 46, 772, 384)** | | **SF-6D external interaction Time internal interaction** | | **Removing influential observations (612, 46, 772, 384)** | |
|---|---|---|---|---|---|---|---|---|
| | Coefficient | p | Coefficient | p | Coefficient | p | Coefficient | p |
| Time spent caring Ref < 35 hours | **-0.034** | **0.034** | -0.032 | **0.044** | -0.045 | 0.080 | -0.037 | 0.152 |
| Patient SF-6D | **0.325** | **0.002** | 0.364 | **0.000** | **0.324** | **0.002** | 0.363 | **0.000** |
| Presence external conflict Ref absent | **0.157** | **0.030** | 0.160 | **0.026** | **0.156** | **0.032** | 0.159 | **0.027** |
| Presence internal conflict Ref present | **0.064** | **0.000** | 0.060 | **0.000** | **0.059** | **0.001** | 0.058 | **0.001** |
| SF-6D x external conflicts | **-0.354** | **0.006** | -0.362 | **0.005** | **-0.351** | **0.007** | -0.360 | **0.005** |
| time x internal conflicts | | | | | 0.017 | 0.587 | 0.007 | 0.816 |
| Job status Ref present | -0.013 | 0.457 | -0.013 | 0.476 | -0.013 | 0.452 | -0.013 | 0.477 |
| GHQ difference | **-0.005** | **0.000** | -0.005 | **0.000** | **-0.005** | **0.000** | -0.005 | **0.000** |
| Caregiver age | **-0.001** | **0.013** | -0.001 | **0.011** | **-0.001** | **0.012** | -0.001 | **0.011** |
| Caregiver race Ref white | **-0.072** | **0.004** | -0.064 | **0.010** | **-0.072** | **0.004** | -0.064 | **0.010** |
| Caregiver Education Ref degree level | - | | - | | - | | - | |
| Other higher | -0.017 | 0.608 | -0.027 | 0.408 | -0.017 | 0.608 | -0.026 | 0.410 |
| A level | -0.025 | 0.380 | -0.030 | 0.291 | -0.025 | 0.377 | -0.030 | 0.292 |
| GCSE | -0.010 | 0.706 | -0.018 | 0.497 | -0.010 | 0.719 | -0.018 | 0.505 |
| Other | **-0.069** | **0.050** | -0.075 | **0.029** | **-0.069** | **0.050** | -0.075 | **0.030** |
| None | **-0.057** | **0.028** | -0.063 | **0.015** | **-0.057** | **0.030** | -0.063 | **0.016** |
| Caregiver gender Ref Male | -0.030 | 0.132 | -0.032 | 0.107 | -0.031 | 0.123 | -0.033 | 0.105 |
| Patient gender Ref Male | -0.040 | 0.058 | -0.050 | **0.018** | -0.041 | 0.053 | -0.050 | **0.018** |
| Religion Ref a great difference | - | | - | | - | | - | |
| Some difference | -0.015 | 0.471 | -0.023 | 0.253 | -0.016 | 0.442 | -0.023 | 0.246 |
| A little difference | -0.005 | 0.842 | -0.006 | 0.786 | -0.004 | 0.848 | -0.006 | 0.791 |
| No difference | 0.008 | 0.664 | 0.006 | 0.738 | 0.008 | 0.678 | 0.006 | 0.743 |
| Constant | 0.710 | 0.000 | 0.707 | 0.000 | 0.715 | 0.000 | 0.709 | 0.000 |
| Number of obs | 395 | | 390 | | 395 | | 390 | |
| Prob > F | 0.0000 | | 0.0000 | | 0.0000 | | 0.0000 | |
| R- squared | 0.2549 | | 0.2635 | | 0.2555 | | 0.2636 | |
| Adj R-squared | 0.2171 | | 0.2257 | | 0.2157 | | 0.2237 | |
| Root MSE | 0.13579 | | .13324 | | 0.13592 | | .13341 | |
| AIC | -436.9204 | | -445.9284 | | -435.2317 | | -443.9856 | |
| BIC | -357.3427 | | -366.6055 | | -351.6751 | | -360.6965 | |
| Link test | 0.34 | | 0.29 | | 0.32 | | 0.29 | |
| RESET | 0.33 | | 0.25 | | 0.26 | | 0.26 | |

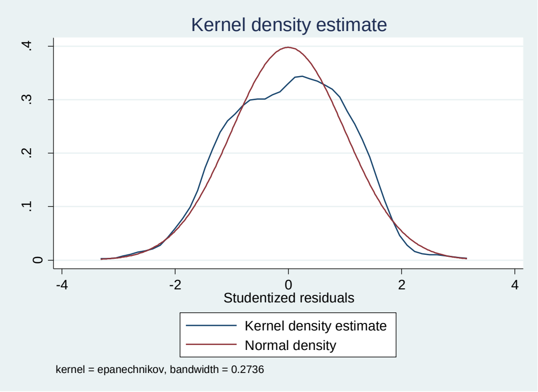
# Appendix 13: Diagnostics for 35 hour model removing possible influential observations

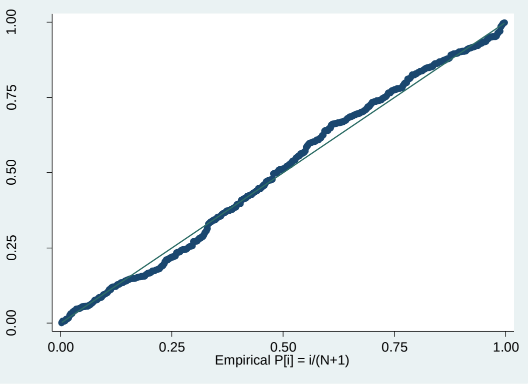
Model for 35 hours time spent caring with interaction for patient SF-6D and external conflicts

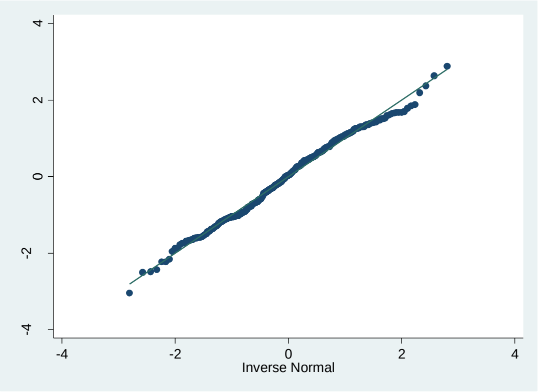
## Homoscedasticity of Residuals

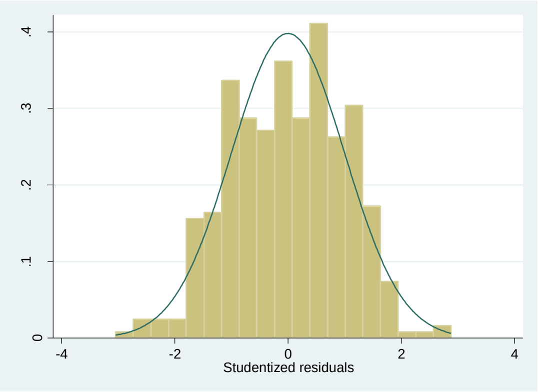


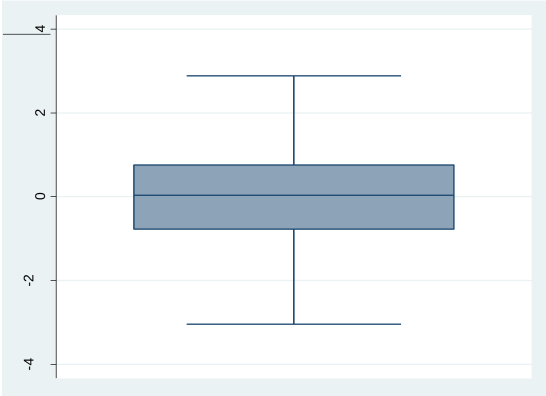
## Normality of residuals











### Cameron & Trivedi's decomposition of IM-test

| Source | chi2 | df | p |
|---|---|---|---|
| Heteroskedasticity | 157.75 | 178 | 0.8602 |
| Skewness | 18.96 | 19 | 0.4597 |
| Kurtosis | 5.96 | 1 | **0.0146** |
| Total | 182.67 | 198 | 0.7756 |

### Breusch-Pagan / Cook-Weisberg test for heteroskedasticity

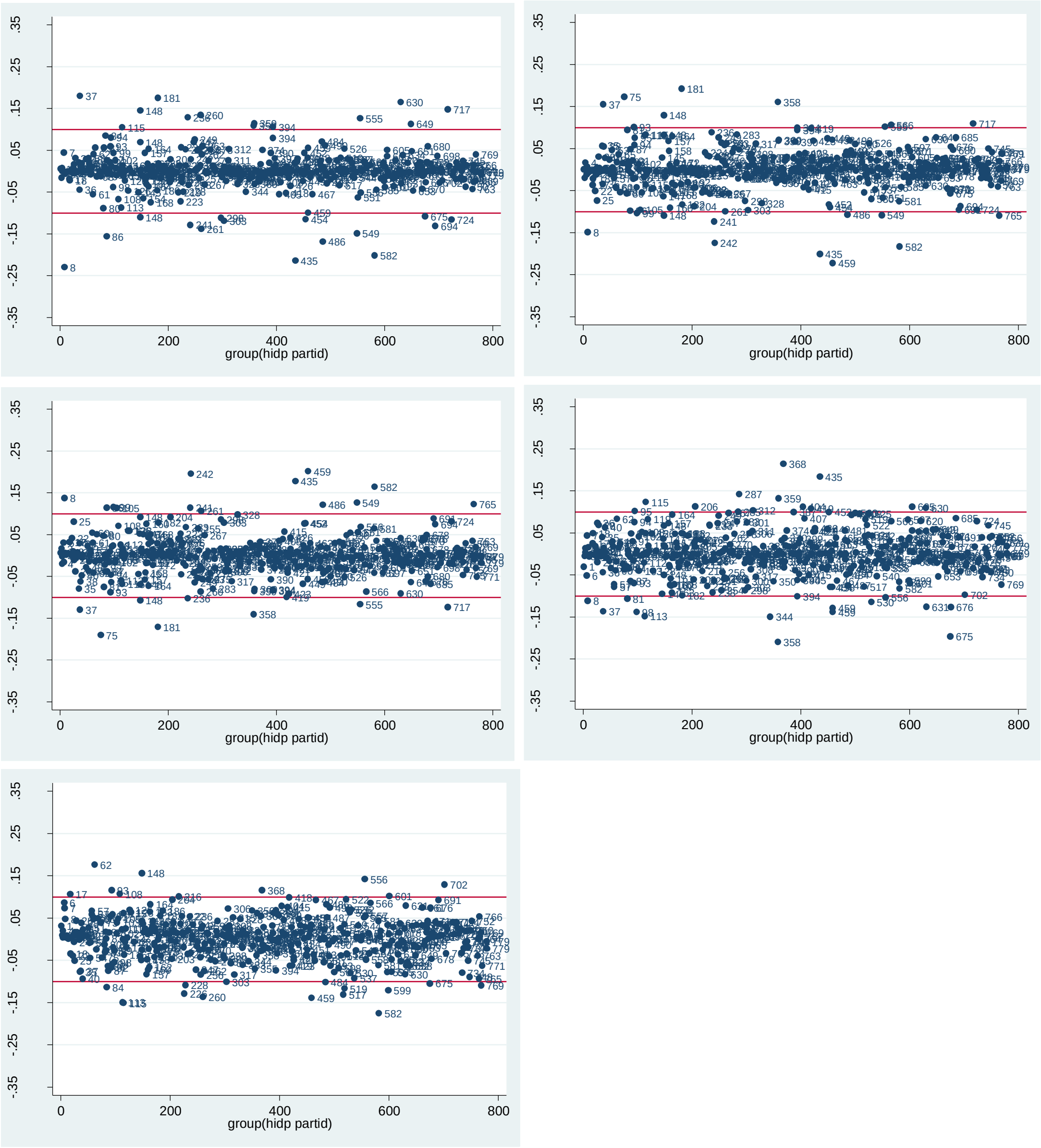
| | |
|---|---|
| Ho:<br>Variables: | Constant variance<br>fitted values of care_bsl_SF-6D |
| chi2(1) =<br>Prob > chi2 = | 2.78<br>0.0953 |

### Assessment of multicoliniarity (VIF)

| **Variable** | **VIF** | **1/VIF** |
|---|---|---|
| Patient SF-6D | 2.80 | 0.357643 |
| Caregiver external conflicts | 27.46 | 0.036418 |
| Patient SF-6D x External conflicts | 27.29 | 0.036642 |
| Time spent caregiving | 1.14 | 0.873530 |
| Caregiver internal conflicts | 1.13 | 0.888738 |
| Job status | 1.49 | 0.670279 |
| GHQ difference | 1.27 | 0.788130 |
| Caregiver age | 1.99 | 0.502373 |
| Caregiver gender | 2.19 | 0.455771 |
| Caregiver Race | 1.24 | 0.805646 |
| Caregiver Education Ref degree | | |

| | | |
|---|---|---|
| Other higher | 1.84 | 0.544512 |
| A level | 2.27 | 0.440627 |
| GCSE | 2.56 | 0.390860 |
| Other | 1.69 | 0.593244 |
| None | 3.47 | 0.288531 |
| Patient gender | 2.26 | 0.441958 |
| Religion Ref a great diff | 1.56 | 0.641722 |
| Some difference | 1.55 | 0.643260 |
| A little difference | 1.72 | 0.581065 |
| No difference | | |
| Mean VIF | 4.57 | |

## DF Beta plots for key explanatory variables and effect modifiers



# Appendix 14: Models including the effect of the household

## Appendix Table 23: Models including the effect of the household (35 and 20 hours)

| **Caregiver SF-6D** | **Model 35 hours** | | **Model 35 hours with effect of household** | | **Model 20 hours** | | **Model 20 hour with effect of household** | |
|---|---|---|---|---|---|---|---|---|
| Time spent caring Ref less than | **-0.034** | **0.034** | -0.036 | **0.023** | -0.022 | 0.099 | -0.012 | 0.132 |
| Patient SF-6D | **0.325** | **0.002** | 0.303 | **0.002** | 0.300 | **0.003** | 0.277 | **0.003** |
| Presence external conflict Ref absent | **0.157** | **0.030** | 0.152 | **0.030** | 0.105 | 0.112 | 0.110 | 0.082 |
| Presence internal conflict Ref present | **0.064** | **0.000** | 0.061 | **0.000** | 0.062 | **0.000** | 0.059 | **0.000** |
| SF-6D x external conflicts | **-0.354** | **0.006** | -0.345 | **0.006** | -0.256 | **0.032** | -0.260 | **0.021** |
| Job status Ref present | -0.013 | 0.457 | -0.007 | 0.692 | -0.029 | 0.082 | -0.023 | 0.144 |
| GHQ difference | **-0.005** | **0.000** | -0.005 | **0.000** | -0.005 | **0.000** | -0.005 | **0.000** |
| Caregiver age | **-0.001** | **0.013** | -0.001 | **0.008** | -0.001 | 0.101 | -0.001 | 0.063 |
| Caregiver race Ref white | **-0.072** | **0.004** | -0.067 | **0.005** | -0.059 | **0.011** | -0.055 | **0.015** |
| Caregiver Education Ref degree | - | | - | | - | | - | |
| Other higher | -0.017 | 0.608 | -0.013 | 0.686 | 0.005 | 0.871 | 0 .006 | 0.845 |
| A level | -0.025 | 0.380 | -0.024 | 0.372 | -0.016 | 0.538 | -0.019 | 0.455 |
| GCSE | -0.010 | 0.706 | -0.013 | 0.627 | -0.006 | 0.824 | -0.008 | 0.722 |
| Other | **-0.069** | **0.050** | -0.066 | **0.044** | -0.056 | 0.091 | -0.058 | 0.065 |
| None | **-0.057** | **0.028** | -0.053 | **0.035** | -0.049 | **0.045** | -0.047 | **0.045** |
| Caregiver gender Ref Male | -0.030 | 0.132 | -0.023 | 0.219 | -0.019 | 0.303 | -0.011 | 0.535 |
| Patient gender Ref Male | -0.040 | 0.058 | -0.037 | 0.070 | -0.024 | 0.231 | -0.021 | 0.263 |
| Religion Ref a great diff | - | | - | | - | | - | |
| Some difference | -0.015 | 0.471 | -0.015 | 0.452 | -0.028 | 0.133 | -0.030 | 0.112 |
| A little difference | -0.005 | 0.842 | -0.002 | 0.937 | 0.001 | 0.976 | -0.001 | 0.971 |
| No difference | 0.008 | 0.664 | 0.004 | 0.848 | 0.008 | 0.649 | 0.000 | 0.999 |
| Effect of household | | | Constant .009 | .002 | | | Constant .010 | .002 |
| | | | Residual .008 | .002 | | | Residual .008 | .002 |
| | | | **p=0.0004** | | | | **p< 0.0000** | |
| Constant | 0.710 | 0.000 | 0.717 | 0.000 | 0.683 | 0.000 | 0.695 | 0.000 |
| Number of obs | 395 | | Number of obs = 395 | | 474 | | Number of obs = 474 | |
| Prob > F | 0.0000 | | Number of groups = 359 | | 0.0000 | | Number of groups = 431 | |
| R- squared | 0.2549 | | Log likelihood = 244.08371 | | 0.2323 | | Log likelihood = 286.4015 | |
| Adj R-squared | 0.2171 | | Wald chi2(19) = 124.83 | | 0.2001 | | Wald chi2(19) = 125.01 | |
| Root MSE | 0.13579 | | Prob > chi2 = 0.0000 | | 13736 | | Prob > chi2 = 0.0000 | |
| AIC | -436.9204 | | -444.1674 | | -517.2325 | | -528.803 | |
| BIC | -357.3427 | | -356.6319 | | -434.0084 | | -437.2564 | |
| Link test | 0.34 | | | | 0.10 | | | |
| RESET | 0.33 | | | | 0.32 | | | |