

**The effect of gender role constructs on help-seeking and carer burden in male carers of
people with multiple sclerosis**

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Declaration

I declare that the research reported is my own, and not submitted for any other academic award.

Thesis Abstract

This portfolio is comprised of four sections:

Critical Literature Review: A systematic ethnographic meta-synthesis was conducted that aimed to provide an account of the lived experience of a spouse/partner caring for their partner with multiple sclerosis. Twenty studies met the eligibility criteria for inclusion into the synthesis and six themes emerged. A line of argument synthesis is presented as a model and suggestions for further research and clinical implications are discussed.

Research Report: Multiple sclerosis commonly presents within middle age and disproportionately effects women, meaning male partners adopt caring roles. Studies indicate men's attitudes towards help-seeking are influenced by their beliefs about idealised gender behaviours, and commonly the need to uphold an ideal of independence and stoicism acts as a barrier to engaging support. It was hypothesised gender constructs could predict attitudes to help-seeking and level of carer burden. Results indicated they explained significant variance in carer burden but not help-seeking. A model of the influence of gender role constructs on aspects of the carer experience is presented. Recommendations are made for engaging male informal carers in aspects of self-care and sourcing support.

Reflective Critique: A critique of both the systematic meta-synthesis and the research project are presented. Reflections and learning points are discussed, with particular reference to aspects of recruitment and methodology.

Service Evaluation: NICE guidance recommends cancer patients receive assessment of psychological distress and a tiered pathway for psychological care. This service evaluation focused on the implementation of these recommendations. Initially, an audit of the current screening for psychological distress was conducted within an oncology department. A pilot study was then conducted to assess the implementation of using psychological distress screening tools within the breast cancer team. The successful pilot study necessitated developing recommendations for broadening the use of screening tools and developing a pathway for psychological care.

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Section 1.0: Critical Literature Review

**Our Disease: A qualitative meta-synthesis of the experiences of spousal/partner caregivers
of people with multiple sclerosis**

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Abstract

Purpose: To provide a conceptually comprehensive account of the lived experiences of caregiving spouses/partners of people with multiple sclerosis, which can be used to better enable health professionals to provide appropriate support services.

Method: A systematic review of qualitative studies reporting the experiences of caregiving spouses/partners was conducted. Relevant articles were identified and analysed using a meta-ethnographic synthesis.

Results: Twenty studies met eligibility criteria, of which 18 were included in the final meta-synthesis. Six major concepts were identified: *Acceptance and Appreciation*, *Commitment*, *Becoming the Carer*, *Living with Loss*, *Shifting Sands*, and *Setbacks with Services*. A model of carer experience is presented as a line of argument to synthesise the findings. Suggestions are made regarding the types of supportive interventions that might be effective for spousal carers.

Conclusion: The findings increase our understanding about the experiences of partners caring for people with multiple sclerosis. Spousal carers can adapt to the challenges associated with change and loss, and have the potential to develop appreciation, acceptance and hope. Services need to be sensitive to the fluctuating demands placed upon carers and be flexible in their support.

1.1 Introduction

Multiple sclerosis (MS) is a chronic progressive neuro-inflammatory autoimmune disease that affects more than 100,000 people in the UK. Typically MS is diagnosed between the ages of 20 and 40 years, and is one of the most common causes of non-traumatic neuro-disability amongst the middle aged (Rodriguez et al., 1994). Of particular note, MS has a gender bias towards females of 2:1 (Inglese, 2006) and this has implications for the likely gender bias for carers (amongst heterosexual couples).

The rather idiosyncratic nature of the disease often means that initial diagnosis can be a protracted or delayed process (Thorne, Con, McGuinness, McPherson, & Harris, 2004). The disease is highly variable in its initial presentation and diagnosis is further complicated by the relapsing and remitting nature of the symptoms. In 85% of individuals the initial diagnosis occurs during this relapsing and remitting phase (Galea, Ward-Abel, & Heesen, 2015), but 50% move into the progressive stage of the disease and this significantly increases the likelihood of increased disability.

MS is characterised by a triad of physical, cognitive and affective symptoms. Physically, the greatest cause of disability comes from effects on mobility (Ford, Gerry, Johnson, & Tennant, 2001) and fatigue (Krupp & Christodoulou, 2001). Cognitive difficulties are experienced by 40-60% of people with MS (pwMS), which includes deficits in executive functioning and memory (Chiaravalloti & DeLuca, 2008). There is also a high prevalence of anxiety (Beiske et al., 2008) and depression (Siegert & Abernethy, 2005).

The diverse range of disease effects, unpredictable individual presentation and idiosyncratic progression provide a unique set of challenges for those in a caring role. Cognitive and affective changes appear to be most burdensome for carer's psychological well-being

(Figved, Myhr, Larsen, & Aarsland, 2007). At least 30% of pwMS require care at home and this is often provided by spouses or partners (Minden, Frankel, Hadden, Srinath, & Perloff, 2004), who are commonly placed in a caregiving role at a time when a couple is trying to manage the demands of a relationship, children, and a career. The physical, emotional and cognitive consequences of MS can have a profound impact on their lives, including increasing the risk of reduced employment and financial difficulties (Hakim et al., 2000), as well as separation and divorce (Berneiser et al., 2014). Given the gender bias of disease presentation it is more common to find males acting as carers, which distinguishes MS from other neurological conditions.

Services supporting pwMS and their families face challenges relating to the idiosyncratic nature of the disease, including having to deal with rapidly changing care needs at diagnosis and assisting in decisions about when professional care should be involved (Gibson & Frank, 2002). Carers report barriers and difficulties in accessing appropriate care (Aoun, Kristjanson, & Oldham, 2006; Bowen, MacLehose, & Beaumont, 2011), making responsive and effective services a pertinent issue for professionals.

1.1.1 Current Literature

Prior to the meta-ethnography reported here, a scoping systematic review of carers of pwMS was undertaken which revealed that the majority of published studies are empirical in nature and largely utilise quantitative methodologies to explore diverse impacts including psychological well-being, economic changes, and role and relationship changes. Within this corpus of literature, symptoms and effects contingent on caring are largely categorised as stressors conferring burden (Cheung & Hocking, 2004a), consistent with the general literature on caring and the predominant model (and related models) of caregiving by Lazarus and Folkman (1984). The majority of studies focus almost exclusively on the negative impacts of providing

care; however, more recently research has begun to examine the benefits associated with caregiving (Buchanan & Huang, 2012; Pakenham & Cox, 2009) which reflects a growing literature examining resilience and post-traumatic growth through offering care.

An increase in phenomenologically-informed literature has added nuance and richness to the reporting of the direct, lived experience of carers and how MS affects them. Previously published reviews have adopted a narrative approach (Uccelli, 2014) and to date only one meta-synthesis has been conducted (Topcu, Buchanan, Aubeeluck, & Garip, 2016) focusing on the development of a conceptual understanding of quality of life amongst carers of pwMS. Here we propose a broader aim, to provide a synthesis regarding the lived experience of the carers without an a priori conceptual focus.

Synthesis should not simply seek to summarise concepts, as would be expected in a traditional narrative literature review but should provide a new conceptual understanding of the data, or conceptual innovation (Strike & Posner, 1983). The meta-ethnographic approach developed by Noblit and Hare (1988) has gained currency in synthesising patients' experiences of healthcare (Malpass et al., 2009). This approach "seeks to develop a deliberately interpretative approach to synthesis by translating studies into one another thereby providing new interpretations'. The aim of meta-ethnography is to arrive at an interpretation that is greater than that offered by the individual studies making up its constituent parts" (Britten & Pope, 2012, p. 41). The interpretations and concepts from selected studies are used as raw data for synthesis and can be utilised via different methods. *Reciprocal translation* is one such method and involves examining concepts and interpretations across studies. It is a process of constant comparison, as one would typically undertake in dealing with primary data in qualitative research, to determine which concepts may have an overarching commonality or relationship (Noblit & Hare, 1988).

Ultimately, this process permits the researcher to develop new constructs, which have been described as *third order constructs* (Schutz, 1962) or *synthetic constructs* (Dixon-Woods et al., 2006). Several authors (Campbell et al., 2003; Munro et al., 2007) and the Cochrane Qualitative and Implementation Methods Group (2015) have subsequently used a second form of synthesis, referred to as a *line of argument*, to provide a model for further developing the conceptual understanding of the material that has been synthesised.

1.1.2 Aim

The aim of the synthesis was to focus on spousal/partner carers of pwMS and their experience of caring and their caring relationship, to enable a conceptually richer understanding of the experience of being a carer, and better inform the provision and development of services.

1.2 Method

1.2.1 Data Collection

A systematic literature search was conducted in January 2016 and again in March 2017 using the EBSCOhost Research Databases Interface, which includes the following computerised databases: CINAHL Plus with Full Text, Cochrane Database of Systematic Reviews, MEDLINE with Full Text, Psychology and Behavioral Sciences Collection, SocINDEX with Full Text. The CHIP tool (Shaw, 2010; 2011) was used to formulate the search strategy and search terms (see Table 1) to identify the research literature on experience of caregivers of people with multiple sclerosis. Results were limited to peer-reviewed academic journals and duplicates were excluded electronically and by hand, as recommended by Kwon, Lemieux, McTavish, and Wathen (2015). This yielded 242 articles.

Table 1

CHIP tool to formulate search strategy and search terms

Context	<i>Multiple sclerosis</i> : multiple sclerosis AND
How	<i>Qualitative methods</i> : qualitative* OR focus group OR interview OR grounded theory OR narrative AND
Issues	<i>Experience of caregiving</i> : care giving OR coping OR needs assessment OR caregiver burden OR caregiver support OR caring AND
Population	<i>Informal carers</i> : couple* OR carer*s OR caregiver*s OR informal caregiver*s

1.2.2 Selecting Literature

Determining studies for inclusion was achieved by two researchers independently reviewing the abstracts and identifying suitable studies using the following predetermined inclusion criteria:

- Full text access written in English
- A focus on MS spousal/partner caregivers
- A qualitative methodology

Conversely, the primary initial exclusion criterion eliminated studies with insufficient emphasis on partner-caregivers qualitative experience: this included studies with mixed groups of carers (e.g. parents, siblings) where primary data did not sufficiently discriminate spousal carers. Mixed-method studies were also excluded where they had insufficient primary data to synthesise. The studies were appraised using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (2013). No studies were excluded because of poor quality (Appendix A).

Structured instruments may not produce consistent judgements about the inclusion of qualitative papers in a systematic review and can cause dilemmas in choosing between the

quality of research and the potential impact of its findings (Dixon-Woods et al., 2007).

Therefore, the researchers also used the framework developed by Dixon-Woods et al. (2007) to determine whether a paper was a Key Paper (KP), Satisfactory (SAT), Irrelevant (IRR) or Fatally Flawed (FF).

1.2.3 Design

Meta-ethnography was chosen to conduct this review given it is primarily an interpretive method that achieves synthesis by identifying concepts in primary studies and integrating them into a higher order theoretical structure (Dixon-Woods et al., 2005). It is perhaps the most well-developed method for synthesising qualitative data (Britten et al., 2002), and has been used to synthesise a range of qualitative studies in diverse health care settings (Britten et al., 2002; Campbell et al., 2003; Downe, Finlayson, Walsh, & Lavender, 2009; Elmir, Schmied, Wilkes, & Jackson, 2010; Pound et al., 2005).

Translation of studies into one another encourages the researcher to understand and transfer ideas, concepts and metaphors across different studies, whilst the meta-ethnographic approach also emphasises the preservation of meaning and structure of relationships between concepts within any given study (Campbell et al., 2012). We utilised the seven-step process for conducting meta-ethnography (Noblit & Hare, 1988):

1. Identifying the research interest
2. Deciding what is relevant (mapping, searching, selecting literature)
3. Repeatedly reading the studies and extracting key concepts
4. Determining how the studies are related
5. Translating the studies into one another (constant comparison)
6. Synthesising translations by identifying overarching concepts

7. Expressing the synthesis

1.2.4 Data Analysis

The first step in the meta-synthesis process comprised repeated reading of the studies to allow immersion in the literature. Two researchers conducted this analysis separately and identified the main concepts of each study, as well as study characteristics that provided context for the interpretations. This included the aim of each study, participant details, and data collection method.

Many published meta-ethnographies make use of the notion of first, second and third order constructs (Schutz, 1962), and we found this useful to preserve meaning. Initially studies were reviewed, and relevant participant data was extracted in the form of direct quotations (first order constructs). This was then placed in a grid alongside the interpretations of the data by primary study authors (second order constructs). The research team analysed and discussed this data to develop and refine third order constructs, which formed an interpretation of the overarching themes across the studies synthesised. To ensure the original context and meaning of the raw data was preserved during the synthesis a systematic approach using tabular framework, similar to Gough, Oliver, and Thomas (2012), was adopted. Maintaining this information in a grid format ensured the themes reflected both the participants' accounts and the analysis by the primary authors.

1.3 Results

The results of the search and appraisal process yielded 20 papers (Figure 1), which are summarised in Appendix B. Two papers (Blank & Finlayson, 2007; Chen & Habermann, 2013) were excluded from the synthesis as they were deemed irrelevant. Their focus was too narrow, on

advanced care directives (Blank & Finlayson, 2007) and coping strategies (Chen & Habermann, 2013).

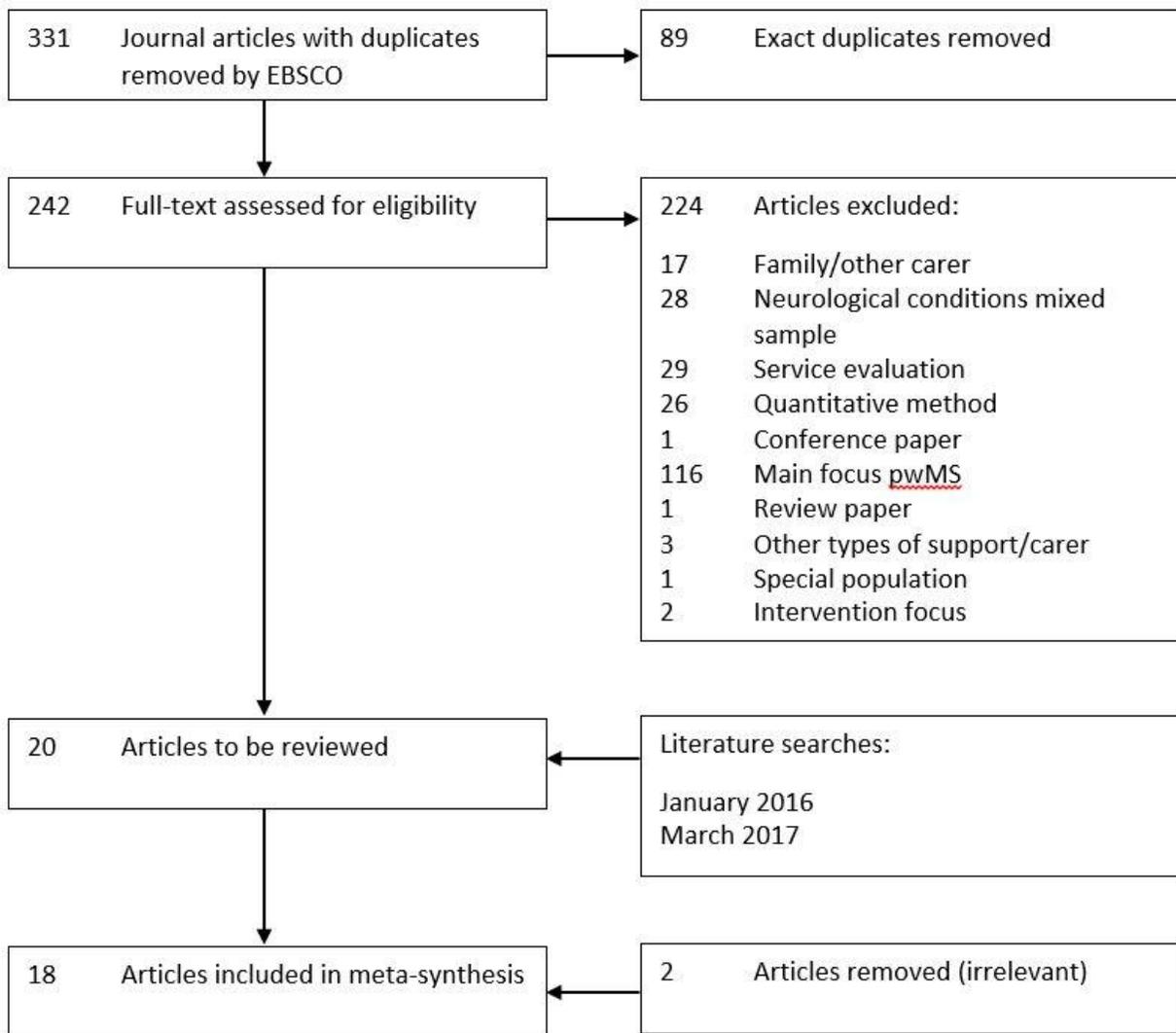


Figure 1. Literature search process for the inclusion of articles in the meta-synthesis.

The meta-synthesis yielded six third order constructs: Acceptance and Appreciation, Commitment, Setbacks with Services, Shifting Sands, Becoming the Carer, and Living with Loss (see Table 2). These constructs are discussed below.

Table 2

Themes (third order constructs) derived from studies included in the review

<i>Third Order Themes</i>	<i>Second Order Themes and Description</i>	<i>Illustrative Quotations (First Order Constructs)</i>
Acceptance and Appreciation	<ul style="list-style-type: none"> <i>Developing strength and a sense of purpose through caregiving.</i> Through caregiving, partners can take on new tasks, learn to be flexible and focus on positives, managing new responsibilities and developing new skills. Carers can develop a belief in their own ability to cope (Boland, Levack, Hudson, & Bell, 2012) and sometimes embrace the role of carer (Hughes, Locock, & Ziebland, 2013). They can look for positives, such as being grateful for periods of remission and having abilities whilst they are intact (Boland et al., 2012). <i>Relationship gains of journeying together.</i> The relationship can go through positive phases of being In-Sync where partners collaborate to problem solve (Starks, Morris, Yorkston, & Gray, 2010), and peaks where partners are seen as essential to each other’s lives, support and admire one another (Boland et al., 2012). Partners protect or advocate for one another (Courts et al., 2005; Esmail, Huang, Lee, & Maruska, 2010) and their acceptance can be a major source of support in the relationship (Esmail et al., 2010). Intimacy and closeness can be maintained (Esmail, Munro, & 	<p>“I’d say I’m handling things better now”; “I’ve always felt it a bit rewarding about the way we have stayed together” (Cheung & Hocking, 2004a).</p> <p>“I think it has brought us closer” (Courts, Bewton, & McNeal, 2005).</p> <p>“I probably consider myself quite a brave person” (Boland et al., 2012).</p> <p>“I do see myself as his carer, I’m very proud to be that” (Hughes et al., 2013).</p> <p>“It’s made me a lot more aware... try and think good things about it” (Boland et al., 2012).</p> <p>“I can do all this because I love him” (Boeije, Duijnstee, & Grypdonck, 2003).</p> <p>“I think we both need each other”; “Still journeying the journey together... I just think it’s worth the journey” (Boland et al., 2012).</p> <p>“No, I love him. He is my husband, I don’t think any less of him” (Mutch, 2010).</p> <p>“She’s my best friend. So I guess it’s the closeness” (Esmail et al., 2007).</p>

Gibson, 2007), and a marriage may become stronger depending on partner attitude (Mutch 2010).

Commitment

- *Love, duty, obligation and inevitability.* Being the partner of a person with MS inevitably leads to being their carer, as their complex needs cannot be met by professional services alone (Boeije & Van Doorne-Huiskes, 2003). Carers feel responsible for their partners (Esmail et al, 2010) and become resigned to caregiving (Boeije & Van Doorne-Huiskes, 2003) due to marital loyalty, love, obligation (Mutch, 2010), guilt leading to a commitment to prevent admission or the idea of virtual reciprocity (Boeije et al., 2003; Boeije & Van Doorne-Huiskes, 2003).
- *Relationship fluctuations.* Coping styles of partner and MS sufferer can conflict or complement one another; couples must learn when to help and when

“In sickness and in health, you know it’s just the way it’s going to be and I’ve accepted it” (Mutch, 2010).

“I’m still married to her and I still take that very seriously”; “I couldn’t put him in a home, I don’t think I could. I couldn’t stand the feelings of guilt”; “When something like this hits you, you expect the other party to do right by you” (Boeije et al., 2003).

“I told my wife ‘well you didn’t marry with MS so if you want to leave you can’. She says ‘I’m in it for the long run’”; “I felt very guilty because I really felt it’s my responsibility to look after him” (Esmail et al., 2010).

“People say, ‘Why don’t you put him in a home?’, and I tell them, ‘This is my husband! I will not put him in a nursing home.’” (DesRosier, Catanzaro, & Piller, 1992).

“Till death... I intend to keep that promise although it is hard at times”; “It is a duty, because the love was soon gone” (Boeije & Van Doorne-Huiskes, 2003).

“Quite often I’m happy to be at home, she wants to get out” (Boland et al., 2012).

Setbacks with Services

to pull back from helping (Boland et al., 2012). Conflicting attitudes and approaches to problem solving lead to conflicts in the relationship (Starks et al., 2010). The relationship can also go through positive phases.

- *Information gathering.* Carers may initially have to hunt for information for a diagnosis or a better understanding of MS as it may not be readily available (Heward, Gough, & Molineux, 2011). Initial diagnosis can initially give a sense of relief, but this then leads to realisations about the nature of MS (Boland et al., 2012).
- *Barriers.* Support services are difficult to access, limited, inflexible, inconsistent and have restricted admission criteria (Cheung & Hocking, 2004a; McKeown, Porter-Armstrong, & Baxter, 2004). Human barriers (lack of understanding) and environmental barriers (wheelchair accessibility) can also cause problems (Courts et al., 2005).

“It sends a message to me that she doesn’t care enough about me to try and be here as long as she can”; “We totally disagree on that” (Starks et al., 2010).

“All the information we have received... it’s not readily available. I think it’s getting better with more people having access to the internet” (Heward et al., 2011).

“I was quite pleased to be diagnosed, but at this stage I didn’t know that MS just kept on getting worse” (Boland et al., 2012).

“MS is a whole life situation and there is so much that isn’t addressed... we didn’t get enough information to make empowering choices” (Courts et al., 2005).

“Despite all the funding programmes... There were all these criteria and he just didn’t seem to fit into any slot” (Cheung & Hocking, 2004a).

“We need public awareness” (Courts et al., 2005).

“It is made worse by the fact of the inconsistencies of the agencies”; “It took a year and two months for her to get one (a wheelchair)” (McKeown et al., 2004).

Shifting Sands

- *MS characteristics.* When MS type is relapse/remitting or gradual onset meaningful activities can be continued. Slower progression can lead to life role changes being more on time, with a positive effect on adaptation. Progressive MS with acute onset, faster progression and few remissions acts as a barrier to adaptation (Starks et al., 2010). Level of care given will depend on the partners condition (Hughes et al., 2013), and coping abilities will depend on the phase of MS (Esmail et al., 2007; Mutch, 2010).

“Most of the time lately I’ve been sort of 75% husband, 30% carer... it varies depending on my partners condition” (Hughes et al., 2013).

“We’re managing at the moment because he’s not as bad as he was” (Mutch, 2010).

“When you’re in denial and you have a burst of energy and you think that you’re as normal as everybody else... you’re sadly mistaken” (Esmail et al., 2007).

Becoming the Carer

- *Gender roles.* Caregiving impacts on established roles (Esmail et al., 2007; Rollero, 2016), and may be congruent for women but not for men. Men’s roles include protecting their wives’ energy expenditure and feelings of self-worth, whereas women encourage continued functioning and independence (Courts et al., 2005). Sexual relationship is also re-evaluated, and communication is important to adapt to changes (Esmail et al., 2010; Esmail et al., 2007).

“You are thrown into a role”; “Men as caregivers... we are not really used to that”; “She keeps going until she is about to drop, and I keep pulling her back saying ‘slow down’”; “Sometimes I’m pushing him to do things he wouldn’t ordinarily do” (Courts et al., 2005).

“Since her illness, I have started doing domestic tasks... it’s a very different side of myself... I feel like a housewife sometimes!” (Rollero, 2016).

“The man always seems to... instigate the role when it comes to having sex with his partner... my wife has come to the point where she is starting to do that” (Esmail et al., 2010).
- *Changes of roles and duties in the relationship.* Having a carer role leads to extra responsibilities and a change in the relationship (Cheung & Hocking, 2004a). MS sufferers experience a

“I felt I was leaning on Ted slightly, now he is leaning on me” (Cheung & Hocking, 2004a).

change in status, for example from strong capable men to person requiring nursing care and feeling like a burden (Esmail et al., 2010). A relationship may no longer be companionable, perceived as equal, with partners seen as sole parents, housekeepers, and carers rather than as one half of a couple (Heward et al., 2011) which impacts on the caregivers' mood (Boeije & Van Doorne-Huiskes, 2003).

- *Rejecting or accepting the identity of carer.* If disruptions to life roles come at the wrong time, and lead to a loss of identity and self-worth, carers are more likely to reject changes in identity (Starks et al., 2010). Coping involves acceptance of the diagnosis and getting on with it (Boland et al., 2012). Carers move through stages of accepting support through a gradual process of taking on more and more until they reach crisis and can no longer cope alone (McKeown et al., 2004). The identity of carer may be embraced alongside other roles or rejected (Heward, Molineux, & Gough, 2006; Hughes et al., 2013).

“I want us to have a relationship, not to be, you know, caregiver” (Esmail et al., 2010).

“My wife is more dependent on me, and that contributes to conflicts and tensions”; “When he was grumpy... I could not withdraw from it and I got gloomy too” (Boeije & Van Doorne-Huiskes, 2003).

“It’s never Alison and Tim, it’s Alison, Alison and the kids” (Heward et al., 2011).

“MS has screwed us up because you can’t work, you can’t make money and we can’t do the things we wanted to do” (Starks et al., 2010).

“You’ve got to do one of two things; you either get yourself in a mess or... get on with it” (Boland et al., 2012).

“It’s a gradual process and you have taken more and more on” (McKeown et al., 2004).

“I do see myself as his carer, I’m very proud to be that”; “When people say to me ‘you’re his carer’, I say, ‘no, I’m not, I’m his wife’” (Hughes et al., 2013).

“... I used to do that but I wouldn’t have called myself a carer. There’s a difference between that and what I do now. Carer is a nice name for a slave or dogsbody” (Heward et al., 2006).

- Living with Loss
- *Change of employment.* Becoming a carer can lead to loss of self as a person with paid employment valued by society, loss of self-esteem and perceived inferiority (Cheung & Hocking, 2004a). Alternatively, carers may be forced into the role of breadwinner. Reshaping identity can lead to difficult decisions regarding employment (Heward et al., 2011).

“At odd times I get a flash that somebody is regarding me in a lesser light because I don’t work, (because) I don’t have any sort of identity that they can respect, or relate to” (Cheung & Hocking, 2004a).

“I have decided to take retirement... to look after myself in a way as well. It was a very tough decision to make” (Heward et al., 2011).
 - *Future planning.* Carers develop a sense of needing to live in the present moment as thinking about the future can lead to distress and uncertainty (Boland et al., 2012; Mutch, 2010; Rollero, 2016). Unpredictability of the disease leads to a day by day approach (Cheung & Hocking, 2004a).

“I don’t think about it crippling her... I take it day by day” (Boland et al., 2012).

“I don’t worry about tomorrow as I have no control over tomorrow” (Cheung & Hocking, 2004a).

“I had certain plans, things I wanted to do in my golden years, but I can’t do any of those things... I don’t feel in control of my future at all” (Starks et al., 2010).

“What is next? I don’t know!” (Mutch, 2010).

“I always think about [the] future, about what I can do. In this period, I am planning to buy another home, on the ground floor, so that she will be able to move freely and easily even if she will be in a wheelchair” (Rollero, 2016).
 - *Loss of social contacts and family support.* Loss of support from family and friends via not wanting to become involved (Cheung & Hocking, 2004a;

“(Some of our friends) have admitted that they can’t handle seeing Ted in a wheel chair”; “(My wife’s family) never once in 17 years picked up the phone

Rollero, 2016) or lack of understanding (Courts et al., 2005). Restricted social outings due to barriers such as finances, equipment needs, lack of suitable facilities (Cheung & Hocking, 2004a; Esmail et al., 2010) and the amount of time it takes to plan and do things (Mutch, 2010). Family and friends do not offer, or have withdrawn, support (McKeown et al., 2004).

- *Loss of partner*: Changes in bodily function, cognition and personality can cause a sense of loss of a partner or co-parent due to altered dynamics of companionship (Cheung & Hocking, 2004a). The gradual nature of adapting to caregiving can make a relationship closer or more distant but causes a change due to the physical and mental demands of a progressive disease (Boeije et al., 2003). Intimacy and physical contact can decrease

and said ‘can we do something for you’, not once” (Cheung & Hocking, 2004a).

“At the beginning relatives and friends were all supportive and sympathetic. However, once we came back home we were alone and I felt the complete responsibility... I was alone with my hard caregiving work” (Rollero, 2016).

“The biggest thing... or problem is the public view of MS... even her own parents don’t comprehend how difficult it is for her” (Courts et al., 2005).

“It sometimes takes me three quarters of an hour just for her to eat a piece of toast” (Mutch, 2010).

“At the start he was so proud that he wouldn’t let anyone know, now nobody bothers asking him anymore” (McKeown et al., 2004).

“You have to break away from the person (who) was a lover to a person that you’re caring for” (Cheung & Hocking, 2004a).

“She has become a patient, and a partner is not the same as a patient” (Boeije et al., 2003).

“Sometimes I feel he is not attracted to me”; “I don’t feel that sort of closeness” (Esmail et al., 2010).

due to fatigue, physical disability, and stress
(Esmail et al., 2010).

“Our relationship has changed... it has become more
distanced... a partner is not at all like a patient”
(Boeije & Van Doorne-Huiskes, 2003).

1.3.1 Acceptance and Appreciation – “I’m happy with what I done...I’ve been forced to be a better person” (Cheung & Hocking, 2004a, p. 160)

Appreciation and Acceptance of being a carer, contingent on the disabilities of their partner, was a construct evident in several studies and was associated with expression of loss, which Lindgren, Burke, Hainsworth, and Eakes (1992) refer to as *chronic sorrow*. Yet, for some respondents there also appears a capacity to acknowledge positives of being a carer, alongside adversity engendered by MS. Respondents indicated that living with MS had forged intimacy – “it’s made us closer together” (Esmail et al., 2007, p. 172), and was expressed in a recognition that the experience is something shared – “...we were still journeying the journey together even though his part was different to my part” (Boland et al., 2012, p. 1372). Appreciation was evidenced in both an acknowledgement of what the person with MS endured, as well as what being a carer had brought them, which was often an enriched appreciation of their partners’ difficulties and coping skills (Boland et al., 2012).

Acceptance appeared evidenced not as capitulation to the effects of MS but as a process towards equanimity which assisted in their coping, alongside hope and an appreciation of both the minutiae of daily life and anticipation of planned pleasurable events. What was not fully discerned from the data was how carers moved from positions of rejecting or denying difficulties to appreciation and hope. For some it seemed to emerge from reflecting on their relationships and a positive evaluation of commitment, and active election to be in the relationship rather than feeling compelled through guilt – “accept what is coming and make the most of it” (Hainsworth, 1996, p. 38).

1.3.2 Commitment – “In Sickness and in Health...” (Mutch, 2010)

The third order theme of *Commitment* was expressed in a number of ways. In several papers commitment appeared borne by feelings of reciprocity in the relationship, as noted by Mutch (2010), such that in different circumstances a partner would offer similar support. This was particularly noted in relation to marital vows; however, *Commitment* was not exclusive to spousal carers since not all carers had a formalised marriage. Commitment also encompassed a sense of duty and obligation, where it is a promise to care that binds a relationship as well as love. Respondents expressed remorse if they were unable to care or surrendered care to professionals (Boeije et al., 2003; DesRosier et al., 1992). The choice to make an active commitment to become a carer appeared gendered with men explicitly articulating duty; however, both men and women expressed dutiful commitment as associated with compunction, feeling trapped, and fatalistically being caught in the inevitability of the situation (Boeije et al., 2003).

1.3.3 Becoming the Carer

Becoming the Carer is a construct relating to the progression from rejecting through resisting to accepting the role of a carer (Hughes et al., 2013; McKeown et al., 2004), with the crystallisation of the carer identity recognised through reflections on undertaking caring tasks. Most studies presented primary data describing struggles spouses experienced with their identification as a carer. Nevertheless, there were some instances where carers positively acknowledged how they had grown in their new role through the experiences to which they had been exposed and the skills they had developed (Cheung & Hocking, 2004a; Boeije et al., 2003) – “I have grown into it little by little... I’ve grown used to it” (male spouse; Boeije et al., 2003, p. 246).

1.3.4 Living with Loss

The concept of *Living with Loss* translated across all papers. It was evidenced in the loss of carer's previous valued identities, such as a spouse/partner or worker, and the loss of a place in society (Cheung & Hocking, 2004a). There also appeared expression of unexpected losses of relationships with friends and family, with respondents often reporting shock and anger relating to an unmet expectation of practical and emotional support (Cheung & Hocking, 2004a; Courts et al., 2005). However, it is losses within the caring dyad that appear central to this concept, expressed through altered and reduced intimacy and shared activities. Respondents' most overt distress seemed to centre on loss of dreams and an anticipated future, including both immediate plans and the desire for a shared older adulthood (Cheung & Hocking, 2004a; Courts et al., 2005). This loss may be more poignant for those of retirement age, but perhaps reflects a bias of older participants in some of the studies included in the synthesis.

1.3.5 Shifting Sands

By its very nature, disease process in MS is unpredictable in both timing and severity, and this is reflected in the third order construct of *Shifting Sands*. The primary data contained expressions that overwhelmingly focused on the negative aspects of erratic relapse and crises. The construct of *Shifting Sands* reflects not only changes for the person with MS, but also within the carer and the caring dyad. Carers are required to adjust and adapt to changing demands, and in turn this requires flexible decision making across a range of domains (McCurry, 2013) – “Like a lot of things, it's all peaks and troughs... we don't really have a routine” (Boland et al., 2012, p. 4). There also appears a frequently expressed attitudinal shift adopted by many carers to a present focus – “...I take it day by day...” (Boland et al., 2012, p. 5); Boland et al. (2012) suggest this is a defence against unnecessary stress of worrying about the future.

1.3.6 Setbacks with Services

A construct translated across most studies was *Setbacks with Services*, and this appeared framed in stages as the MS progresses. Initially it relates to difficulties in obtaining a diagnosis and the struggle to find relevant information about the disease (Heward et al., 2011). As the disease progresses and care needs evolve, *Setbacks* encompasses difficulties accessing appropriate support, both practical and emotional, with frustration expressed regarding logistics of, and barriers to, access (DesRosier et al, 1992). Finally, it relates to services' understanding of, and responsive to, carers' wishes and needs to relinquish care to professionals (Boeije et al., 2003; DesRosier et al., 1992; McKeown et al., 2004). At the point when professional care might be desirable services need to be aware of a couple's goals and how these reflect their underlying values and love for one another, and this is also embodied in the construct of *Commitment*. A significant behavioural manifestation of such goals is the aim to care for spouses at home for as long as possible – “But now I think I can't put him in a nursing home, even if his situation got worse” (female spouse; Boeije & Van Doorne-Huiskes, 2003, p. 237). Indeed, delivery of services may be enhanced if professionals are aware that apparent resistance to professional care may emerge not from denial about the difficulty of care, or the sacrifice of a carer's own well-being, but as an expression of a strong reciprocal bond. These values may be overtly expressed as the reason why there is resistance towards a person with MS entering residential or nursing care, and this is expressed in the first order construct of two studies (Boeije et al., 2003; McKeown et al., 2004).

1.3.7 Line of Argument

The overarching characteristic of the synthesis was the caregiving dyad, and the caring experience was constructed within this reciprocal relationship. It is conceptualised in a model

(Figure 2) where the attitude of the carer to caring and their perception of the caregiving dyad fundamentally influence the caregiving experience. The constructs of *Commitment*, *Becoming the Carer*, and *Acceptance and Appreciation* appear to be moderators of the carer’s attitude toward caring. The constructs of *Loss*, *Shifting Sands* and *Setbacks with Services* are concrete and practical factors that impact directly on the caregiving dyad. In the model these processes are dynamic, and the carer experience is one that is continually being constructed and reconstructed.

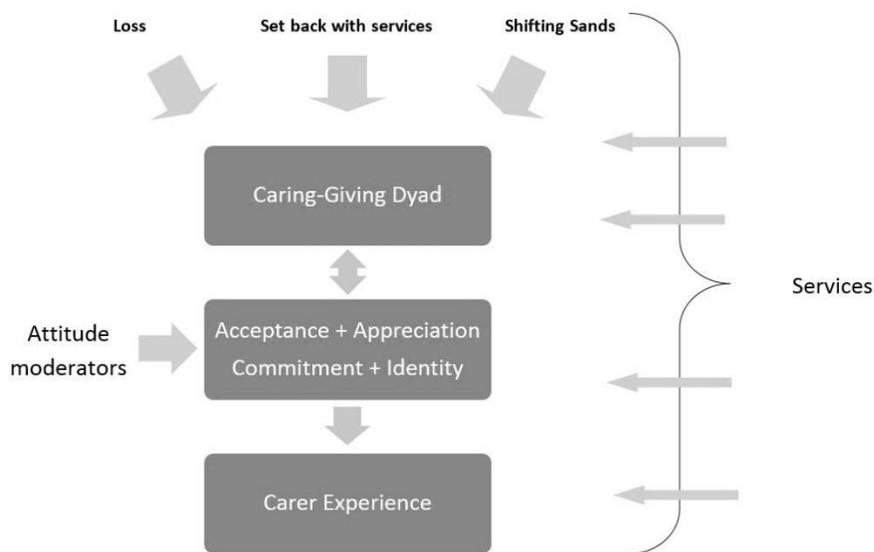


Figure 2. Line of synthesis - model of spousal carer experience.

1.4 Discussion

The aim of this systematic meta-ethnographic synthesis was to provide an insight into the experiences of carers for pwMS, greater in breadth and conceptual richness than either individual studies alone or a narrative review of the literature. Utilising Noblit and Hare’s (1988) methodology this goal produced six thematic constructs of carer’s experience. This synthesis also sought to provide possible directions for services to assist carers, and this is discussed below.

There are models of caregiving experiences offered in psychological literature that are pertinent to carers for pwMS (Nolan, Grant, & Keady, 1996). These models provide a temporal description of the carer's experience that is reflected in the concepts of grief, loss and acceptance. Some of these concepts echo themes synthesized in this study, for example the stages of *Taking It On* and *Working Through It* in Nolan et al's. (1996) six stage model seem to resonate with the concept of *Commitment*. Furthermore, ideas of chronic sorrow (Lindgren et al., 1992) experienced by carers, which suggest emotional reactions to recurrent losses and the reliving of past losses, echo our concept of *Shifting Sands*. The underlying processes in these models are arguably influenced by transactional models of stress, notably Lazarus and Folkman's (1984), which can be conceptualised as push models – stress upon the carer is the primary instigator of change and adaptation occurs as they seek to mitigate distress. However, this meta-synthesis has highlighted that carers also disclose positive experiences, evidenced and encapsulated in the concepts of *Commitment*, *Becoming the Carer* and particularly *Acceptance and Appreciation*. Such positive aspects of the caring experience are also reflected in quantitative studies (Buchanan & Huang, 2012; Pakenham, 2005; Pakenham & Cox, 2009).

It remains unclear how carers construct both positive and negative experiences, although discourse within the dyad appears important to frame experience positively and is evidenced in Starks et al's. (2010) understanding of couples being In-Sync and able to reflect on their experiences. This idea of dyad synchrony and reflective process as fostering more effective coping and resilience has been taken forward in the Actor-Partner Interdependence Model (APIM), gaining prominence in exploring interpersonal processes within caregiving dyads (Ackermann, Ledermann, & Kenny, 2010; Kenny, Kashy, & Cook, 2006). Indeed in adopting the APIM model with pwMS and carer couples, Pakenham and Samios (2013) suggest that such

reflective, mindfulness-based processes may be an adaptive skill in coping. This is supported by a recent systematic review (Li, Yuan, & Zhang, 2015) of 14 studies including over 800 carers that found evidence of improved psychological well-being through the use of Mindfulness-Based Stress Reduction treatments.

Topcu et al's. (2016) meta-synthesis of MS carers took a critical analytical synthesis methodology with the aim of developing a line of argument model focused upon quality of life for carers. The reciprocal translation undertaken by Topcu et al. (2016) produced nine third order constructs, two of which had similarities with those presented in the current synthesis.

'Experiences of Change and Loss in a Shifting Context', which is concerned with experiences of adjusting to an unpredictable disease, corresponds somewhat with the construct of 'Shifting Sands' in the current synthesis. Also, the construct 'Experiences of Support' described by Topcu et al. (2016) had similarities to the construct 'Setback with Services' in the current synthesis in recognising the difficulties in finding appropriate support. However, the two papers differ significantly in their line of argument, with Topcu et al's. model appearing similar to the Stress Process Model (Pearlin et al., 1981), but in contrast the current paper arguably demonstrates a unique focus on the caregiving dyad and the process of constructing the carers experience.

The third order themes from this meta-synthesis may have application beyond the diagnosis of MS to a range of neurodegenerative conditions, particularly dementia and Parkinson's disease, where decisions concerning the transition to professional care are common. The decision to place a loved one in a care home is known to be among the most difficult experiences for family caregivers with people with dementia (Caron & Bowers, 2003; Liken, 2001; Ryan & Scullion, 2000). Carers have often made significant personal sacrifices to sustain care at home and experience apprehension, exhaustion, deep sorrow, and fractured relationships

when making the decision regarding placement (Park, Butcher, & Maas, 2004). A meta-ethnographic study summarising family caregivers' experiences in relinquishing the care of a person with dementia to a nursing home reported family caregivers felt responsible for the placement decision and experienced feelings of guilt and shame about their inability to maintain the role of care provider (Graneheim, Johansson, & Lindgren, 2014). Such distress is likely to arise from the dilemma of prioritising the carers' self-care and more appropriate care for the person with MS against values of commitment. Findings herein suggest a need for services to show awareness and response to the construct of commitment, where couple goals can be based around caring at home for as long as possible. Services have an opportunity to recognise the importance of commitment in the caring dyad and the distress that may accompany any perceived breach of this, and explicitly support carers in transitioning from home to residential care.

We would argue that services must better understand the interpersonal context in which they wish to intervene and then tailor interventions for the caring dyad across a range of support domains. This includes providing information and support services, as well as assisting with psycho-educational interventions to improve couple communication and relationship skills. Communication is central to how a couple negotiate their caregiving dyad (Esmail et al., 2010) and how they may (or may not) face MS together. Furthermore, therapeutic strategies that 'target the abstraction of positive meaning' (Boland et al., 2012, p. 1373) to assist carers in developing more adaptive attitudes towards the caregiving dyad can be recommended by services and can underpin the development of attitudes and skills that accompany emotional growth (Pakenham & Cox, 2009). Finally, services need to be better attuned to monitoring the needs of the carer and cared for as a unit to reflect the dynamic processes that occur, and by offering such a focus and

flexibility may mitigate some of the barriers evidenced within the construct *Setbacks with Services*.

1.4.1 Methodological Considerations

Methodologically the studies appeared homogenous. Although differing in group and individual interview data, they were informed by related theoretical backgrounds and methodology. Participants were of similar ages and although no significant remarks were made regarding socioeconomic background, race or ethnicity, all studies emerge from Western countries. We therefore may assume developed healthcare and support, though the nature of this may vary. The majority of studies in this meta-synthesis make reference to one or more of the other papers and therefore translation between studies was perhaps more straight forward than a heterogeneous group, as suggested by Britten and Pope (2012).

A potential limitation of this synthesis arises through the application of inclusion criteria, which may have inadvertently missed material in non-peer reviewed research and book chapters. Early peer review by academics expert in this field may have mitigated such omissions. This synthesis is also limited by the fact that the studies included generally report data from older adults who appear to require a reasonably high level of care. The findings from this meta-synthesis must therefore be interpreted with caution: this is an important caveat given many people with MS will experience prolonged periods of low care needs punctuated by episodes of high care needs during relapses. An additional consideration is the influence of the reviewers' professional background (both clinical psychologists working in physical health for 19 years and 25 years, the former with 12 years working with people with MS), which may have influenced the translation of concepts through preconceived narratives and conceptual frameworks. It is

recommended that future research teams include others who may be more naïve to the area of long-term neurological conditions.

1.4.2 Conclusion

The findings of this meta-synthesis highlight the range of experiences of spousal/partner carers for pwMS. The line of argument model presents a view of how particular aspects of context and attitudinal beliefs are critical in how carers' experience is constructed. The insights from this meta-synthesis can be used to guide the development and delivery of support services, tailored to the needs of carers and sensitive to their values.

The current meta-synthesis indicated there is a dearth of qualitative literature examining impact of gender of spousal caregivers for pwMS. The role of gender in caregiving has received significant attention in other areas such as cancer (Schrank et al., 2016), and has been highlighted as a lacuna in an earlier review (Corry & While, 2009). This review revealed only two qualitative studies looking specifically at gender issues (Esmail et al., 2007; Boeijs & Van Doorne-Huiskes, 2003), yet the skewed gender ratio of 2:1 of females with MS would suggest there are a significant number of men undertaking caring at a crucial point in their lives which would warrant a more focused investigation. A richer understanding of the often-neglected male caregiving experience would permit greater insight into the needs and barriers men face in accessing support to undertake their caring roles.

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Section 2.0: Research Report

The effect of gender role constructs on help-seeking and carer burden in male carers of people with multiple sclerosis

Word Count: 8,622

Abstract

Multiple sclerosis is a chronic neurological disease that is commonly diagnosed in middle age and has a gender bias towards females. Consequently middle-aged men (as partners and husbands) are the caregivers, a unique group in comparison to carers for other long-term neurological conditions. Previous research has indicated that male carers respond differently to their female counterparts in terms of carer burden and perception of social support. The gender role construct literature has reported that gender role conflict and gender role flexibility have an influence upon men's attitudes to seeking help and support. The aim of this study was to investigate if gender role conflict and gender role flexibility have an influence upon help-seeking attitudes and carer burden within this unique group of carers. Data was collected from an international sample of 68 participants, and was primarily analysed using hierarchical regression analysis. Results indicated that gender role conflict and gender role flexibility explained a significant variance in burden, but did not predict attitudes towards help-seeking. A path analysis model is presented that indicates the relationships between the gender role constructs, help-seeking, perceived social support, and burden. These findings are the first to report how gender role constructs effect carer coping and provide direction for supportive and educational clinical interventions that are applicable to other groups of male carers.

2.1 Introduction

2.1.1 Multiple Sclerosis

Multiple sclerosis (MS) is a chronic neurological disease of the central nervous system, characterised by demyelination of axons, axonal loss, gliosis, and inflammation of the brain and spinal cord (Cosh & Carslaw, 2014). It is the commonest chronic neurological disease to afflict young and middle-aged adults (National Multiple Sclerosis Society, 2003), and has a global incidence of 2.3 million (Multiple Sclerosis International Federation, 2013).

Disease presentation in MS is highly variable which often makes diagnosis a difficult and prolonged process and reliant on a combination of clinical evaluation and differential diagnosis and imaging investigations (Milo & Miller, 2014). MS is usually classified into four main types according to disease course: relapsing-remitting (RR), primary progressive (PP), secondary progressive (SP), and progressive relapsing (PR); individuals frequently have relapsing-remitting disease at the onset and then move to the secondary-progressive phase (Cosh & Carslaw, 2014).

The clinical manifestations of MS are diverse. The most common systemic symptoms of the disease are fatigue and pain. Other common physical symptoms include sensory disturbance such as parathesias, visual disturbance consequent on optic neuritis, and motor system abnormalities including weakness of muscles and gait difficulties. Cognitive decline is a significant aspect of MS, and people with MS (pwMS) may develop deficits in executive functioning and memory. Symptoms of depression and anxiety are also typically displayed in pwMS, and may be present as a reactive response to the disease process or a symptom of the disease itself (Cosh & Carslaw, 2014; Minagar, 2014).

Amongst chronic diseases MS is the leading cause of disability in young and middle-aged adults and markedly affects various aspects of day-to-day life (Giovannoni et al., 2016). MS

patients tend to be less physically active than both their healthy peers (Mostert & Kesselring, 2002; Reider, Salter, Cutter, Tyry, & Marrie, 2017) and those with other chronic conditions, such as asthma or angina (Motl & Pilutti, 2012). The disease also leads to diminished working capacity. For example, Lunde et al. (2014) reported that in Denmark as few as 33% of male and 32% of female MS patients aged 55-66 years were employed in contrast to 75% and 69% of males and females respectively in the general population. Similar findings have also been reported in New Zealand (Pearson et al., 2016). Together, these effects impose a heavy burden on families of pwMS who must cope and adapt to the impact of the disease on daily living and future plans (Sullivan, Mikail, & Weinshenker, 1997).

Informal carers of pwMS, such as spouses or partners, are commonly placed in a caregiving role at a time when a couple have to manage the competing demands of a relationship, children, and career. The various physical, emotional, and cognitive consequences of MS can impose significant challenges to their lives, with increased risk of separation and divorce (Berneiser et al., 2014). A striking gender bias in MS towards females of 3:1, which is a unique phenomenon compared to other chronic neurological conditions, means it is more common to find males in a caring role (Bove et al., 2016).

2.1.2 The Costs of Being an Informal Carer

There is a consensus that caring has a detrimental effect on informal carers of people with long-term neurological conditions such as MS, Alzheimer's disease, Parkinson's disease, motor neurone disease, and stroke (McCabe, Firth, & O'Connor, 2009). Due to the various behavioural, cognitive, and psychological impairments that result from these diseases, caring is significantly more burdensome for these patients than for those without a neurological condition (Mitchell et al., 2015).

There is a well-established link between being an informal carer and physical and mental health (Schulz & Sherwood, 2008). McKeown, Porter-Armstrong, and Baxter (2003) conducted a meta-analysis of 24 studies including 2097 carers that revealed being an informal carer of a person with MS leads to adverse effects on physical and psychological health, social isolation, and deterioration in financial state. More recently, Giordano et al. (2016) utilised a cross-sectional design of caring dyads and similarly reported poorer physical health, including reports of difficulties with mobility and pain, in informal carers.

2.1.3 Informal Carers and Caring Burden and the Relationship to Mental Health

The concept of *carer burden* was first described by Zarit, Reever, and Bach-Peterson (1980) and further developed by Haley and Pardo (1989) and Vitaliano, Russo, Young, Becker, and Maiuro (1991). It can be defined as the allostatic (comprehensive, physical and emotional) load an informal carer is under due to their role. Pearlin, Lieberman, Menaghan, and Mullan's (1981) stress process model (Figure 3), and later work with informal carers of people with Alzheimer's dementia (Pearlin, Mullan, & Semple, 1990), has informed much of the research into levels of carer burden, how informal carers cope, and the impact caring has on their physical and mental health. This stress process model highlights the importance of contextual factors of the wider environment, including level of support that is received, differentiating two kinds of stressors: primary stressors including cognitive status, challenging behaviours, and difficulties with activities of daily living of the care-recipient; and secondary stressors, problems that arise from the primary stressors including relationship conflict, role strain between caring and work, and economic difficulties.

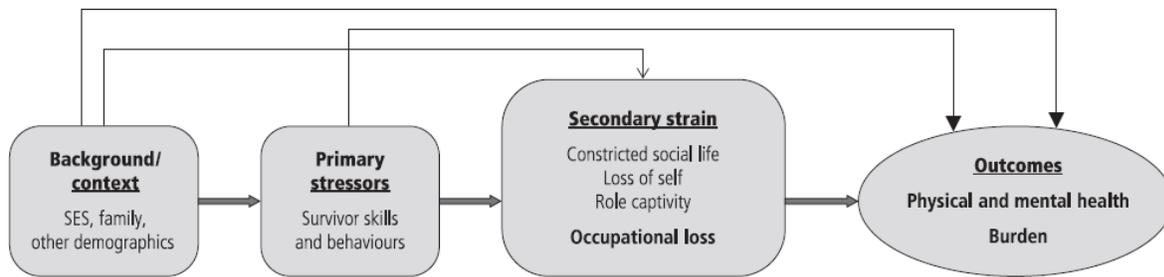


Figure 3. The Stress Process Model (adapted from Kniepmann, 2012).

The stress process model differentiates two factors that mediate stress. Firstly, coping which is described as strategies to manage the situation or the meaning and so reduce the stress effects. This may include being flexible in the application of coping strategies, which is Lazarus and Folkman’s (1984) Knowing How hypothesis. Secondly, social support which is concerned with practical support such as assistance with household chores, respite, and emotional support.

2.1.4 Social Support

Social support is defined as “the structural character of social relationships, such as the number of contacts we have or how often we spend time with those people” (Donnellan, Bennett, & Soulsby, 2016, p. 1222), and also encompasses the quality of social contacts and social networks (Gluyas, Mathers, Hennessy Anderson, & Ugalde, 2016). Five distinct dimensions of social support are identifiable: emotional, affectionate, informational, tangible (practical assistance), and positive social interaction (availability of others to do enjoyable activities together) (Sherbourne & Stewart, 1991). These supports can be formal (from professional services) or informal (from family and friends).

Research strongly indicates that perceived social support plays a vital role in moderating and mediating a range of quality of life outcomes for informal carers (Burnette, Duci, & Dhembo, 2017). Higher perceived social support is linked to reduced carer burden (Haley,

Levine, Brown, & Bartolucci, 1987), better mental health, and greater life satisfaction (Han et al., 2014). Bambara, Turner, Williams, and Haselkorn (2014) demonstrated that increased levels of perceived social support were associated with lower levels of depressive symptoms among caregivers caring for a veteran with MS.

Despite this, the time consuming nature of care makes it increasingly difficult to maintain close social contacts. Indeed, Pakenham (2001) found that social interaction was significantly restricted in informal carers of pwMS, and length of time spent actively caring is the main predictor for loss of social support and increased caregiver burden. This experience by informal carers of pwMS is also reflected in qualitative studies in which themes of abandonment and isolation are reported (Appleton, Robertson, Mitchell, & Lesley, in press).

2.1.5 The Role of Gender in Caring

Research suggests that female informal carers exhibit higher levels of burden, a poorer quality of life, and rely more on emotional as opposed to practical coping styles in comparison to male informal carers. However, this characterisation has been criticised given male informal carers are largely underrepresented in the literature (Baker & Robertson, 2008; Chappell, Dujela, Smith, 2015; Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014; Spindelov, Adam, & Fairhurst, 2017).

Male informal carers appear to be poorer at accessing both formal and informal social support compared to their female counterparts (Greenwood & Smith, 2015). A sample of 106 informal carers of pwMS reported a significant difference in need for social support, women identifying a greater need (Lee, Pieczynski, DeDios-Stern, Simonetti, & Lee, 2015), possibly attributable to previous negative experiences in requesting support and insufficient information regarding services' availability. Male informal carers also report guilt and ambivalence in

requesting help, possibly due to their expressed commitment to the duty of caring (Greenwood & Smith, 2015).

From the few studies to date that have examined gender differences among caregivers of pwMS, findings have been equivocal. Some studies suggest that caregiver gender has no impact on distress (Giordano et al., 2016; Riviera-Navarro et al., 2009). Although Buchanan, Radin, and Huang (2010) report greater burden among male carers, Knight, Devereux, and Godfrey (1997) found that wives exhibited higher burden scores than husbands. Indeed, a large scale study of 1333 carers, of which two thirds were male, found that female carers of pwMS reported greater levels of stress and burden and higher levels of medication use for psychological concerns. Male carers reported more physical concerns, with the authors hypothesising that males somatise their psychological distress (McKenzie et al., 2015).

Nevertheless, there is substantial evidence that male informal carers of pwMS are poor at seeking help and social support. Whilst women tend to report greater caregiving strain but access support (off-setting caring demands by increasing coping resources), men appear to access support less often (Greenwood & Smith, 2015). This may arise because of lack of service information and attitudes of male informal carers towards seeking support (Greenwood & Smith, 2015), particularly for male carers of pwMS (Addington-Hall, Sibley, & Payne, 2012; Sibley, Payne, & Addington-Hall, 2012). Lee et al. (2015) compared gender-related coping styles and found that men with higher emotional needs had a lower quality of life, which was explained by them not engaging social supports. Therefore, not accessing support can be considered an ineffective coping strategy (Roscoe, Corsentino, Watkins, McCall, & Sanchez-Ramos, 2009), which puts the informal carer and those they care for at risk in terms of physical and mental

health. Gender socialisation theory may offer useful perspectives for explaining this ineffective coping strategy.

2.1.6 Men's Attitudes to Seeking Help

The theoretical basis for the literature around masculinity and gender roles makes an important distinction between sex and gender: "... with *sex* referring to the biological attributes that result from being male or female and *gender* denoting the psychological and sociocultural attributes that are associated with a biological sex, such as masculinity and femininity." (Levant, 2011, p. 766).

The concept of masculinity arises from this, as a socially defined set of behavioural norms that are enacted on an individual level. Traditional masculinity still appears to fall within certain stereotyped characteristics that appear little changed from the work of David and Brannon (1976), namely: do not be feminine, be respected for achievements, do not show weakness, and seek adventure and risk.

It has been argued that this ideology of masculinity produces "predictable and unfortunate results" (Levant, 2011, p. 766), such as an emphasis on dominance, extreme self-reliance, and restricted emotionality. If operating within contemporary lifestyles, these 'ideal' masculine traits may produce conflict between heterosexual couples as women work fulltime and continue to hold the burden of care for children and house work - traditional 'woman's work' (Schulte, 2014). Yet simultaneously, men are under pressure to conform to modern values of nurturing children, expressing their emotions, sharing housework, and curbing aggression and risk-taking. The tension between traditional masculine ideals and behaving in ways more consonant with modern, progressive values gives rise to what the researchers in the field have termed gender role strain (GRS), or more recently gender role conflict (GRC).

GRC can be conceptualised as a form of stress, perhaps akin to a cognitive dissonance, where there is a tension between how one behaves and expectations (from the self and others) about how one should behave, and a fear of not ‘being a man’ (O’Neil, 1981). To mitigate this stress, it is argued that men with higher levels of GRC adopt maladaptive coping styles (Hallam & Morris, 2014). Carver and Connor-Smith (2010) have characterised this as disengagement-focused coping that includes avoidant behaviours and attitudes, such as using alcohol and drugs (Locke & Mahalik, 2005), and a denial of distress and a resistance to help-seeking (Levant, Wimer, Williams, Smalley, & Noronha, 2009). In addition to these avoidant strategies, GRC appears to have deleterious effects on well-being. A review of studies by O’Neil (2008) revealed a negative correlation between GRC and self-esteem, and a positive correlation between GRC and both anxiety and depression.

2.1.7 Gender Role Flexibility

However, not all men adhere so closely to these stereotyped masculine ideals, or they appear to embrace them in some contexts and reject them in others (Silverstein, Auerbach, & Levant, 2002). This suggests some men display flexibility around their gender construct.

Understanding of flexibility in gender roles originates from the work of Bem (1974) and her concept of androgyny, which challenges previous bipolar concepts of gender since individuals could express both masculine and feminine behaviours depending on the situational appropriateness of the behaviour (Bem, 1974). Bem (1974) and Bem, Martyna, and Watson (1976) claimed this state of androgyny was psychologically more adaptive as it permits greater psychological adjustment.

Gender role flexibility (GRF) has been proposed as a cognitive asset that fosters successful coping with the changing conditions of daily life. A study by Martin, Andrews,

England, Zosuls, and Ruble (2017) involving young children suggested that GRF may reflect a distinct thinking process that enables androgynous individuals to detect situational characteristics, thus facilitating the adoption of diverse coping strategies to handle different demands of situations. This idea of coping flexibility fits with Lazarus and Folkman's (1984) model of adaptation, 'goodness of fit' - being able to adjust one's coping resources to meet situational demands.

2.1.8 Study Aims

To date, only two studies have investigated the effect of gender role construct variables in influencing the psychological well-being of male informal carers (Baker & Robertson, 2008; Bai, Liu, Baladon, & Rubio-Valera, 2017). However, the focus of these studies were with older male informal carers who were caring for partners with Alzheimer's disease. Therefore, the current study was designed to investigate the relative influence of gender constructs on MIC's attitudes to help-seeking and carer burden in contrast to known variables, with the intention that the findings may inform interventions for MICs.

It was hypothesised that attitudes to help-seeking and carer burden are affected by gender role constructs; specifically that GRC and GRF would predict and contribute significant variance in attitudes of help-seeking and carer burden, in comparison to other known predictors of demographic variables and social support measures.

2.2 Method

2.2.1 Participants

The study sample consisted of an opportunistic sample of adult (18 years or older) male informal carers of pwMS. Participants were recruited through specialist MS nurses in the UK,

Channel Islands, and the Isle of Man, and also via MS-related Facebook groups, Twitter, and MS-related online forums and websites. Facebook and Twitter paid advertisements were used in a limited and focused way to increase recruitment. Participation was on a volunteer basis but participants could opt to enter a free prize draw with the chance of winning one of four £50/\$50 Amazon vouchers. The current study was approved by the University of Leicester Research Ethics Committee, NHS Health Research Authority, Guernsey Ethics Committee, Jersey Ethics Committee, and the Isle of Man Ethics Committee (Appendix C). Participants were presented with study information explaining the purpose, procedure, rights, confidentiality, potential risks and benefits of the study, as well as contacts for the primary researchers and the institutional review board.

2.2.2 Materials

Demographic details elicited were age, length of time spent caring, length of time in relationship, number of children, age of children, and number of hours spent working. Participants were also asked to report the number of hours of professional care they receive for support with physical needs, the number of hours of professional support (G.P, Consultant, and other health professionals) they receive, and the number of hours spent attending psychological therapy/counselling/support groups for themselves, as an informal carer. These measures can be viewed as secondary measures of help-seeking and social support, but also differentiate between support for the male informal carer and for the patient.

Gender role conflict was assessed using the Gender Role Conflict Scale Short Form (GRCS-SF; Wester, Vogel, O'Neil, & Danforth, 2012), which is a shortened version of the Gender Role Conflict Scale (O'Neil, Helms, Gable, David, & Wrightsman, 1986) and measures the negative consequences that emerge for men who experience restricted gender roles. It

consists of 16 items divided into four subscales: Restricted Emotionality (RE); Success, Power, and Competition (SPC); Restrictive Affectionate Behaviour Between Men (RABBM); and Conflicts Between Work and Family Relations (CBWFR). Participants rate their agreement with each item on a six-point Likert scale (1 = “strongly disagree” to 6 = “strongly agree”); higher scores indicate a greater degree of conflict. The four subscales have previously demonstrated good internal reliability ($\alpha = .77$ for the RE and CBWFR; $\alpha = .78$ for the RABBM; $\alpha = .80$ for the SPC; Wester et al., 2012).

Caregiver strain was measured using the Zarit Burden Interview (ZBI; Zarit et al., 1980), which assesses the subjective level of burden experienced by caregivers. It consists of 22 items that are statements relating to physical health, psychological well-being, finances, and social life. Participants are asked to respond to the statements on a five-point Likert scale (0 = “never” to 4 = “nearly always”); higher scores indicate higher perceived burden. The ZBI has previously demonstrated good internal reliability ($\alpha = .92$; Herbert, Bravo, & Preville, 2000). A shortened 12-item version of the scale, the Brief- ZBI (B-ZBI), was developed by Bédard et al. (2001) and has demonstrated good correlations with the long version (0.92 to 0.97).

Social support was assessed using the eight-item modified Medical Outcomes Study Social Support Survey (mMOS-SS; Moser, Stuck, Silliman, Ganz, & Clough-Gorr, 2012), which is an abbreviated version of the original 20-item MOS-SS (Sherbourne, & Stewart, 1991). The mMOS-SS has two subscales covering two domains (emotional and instrumental [tangible] social support) composed of four items each designed to maintain the theoretical structure of the MOS-SS and identify potentially modifiable social support deficits. The mMOS-SS has previously demonstrated good internal reliability ($\alpha = .93$; Moser et al., 2012).

Participants' willingness and openness to seeking professional help was measured using the Willingness to Seek Help Questionnaire (WSHQ; Cohen, 1999). It is a 25-item self-report questionnaire that asks participants to rate how much they identify with each item on a four-point Likert scale (0 = "Do not identify with the statement at all" to 3 = "identify completely with statement"); higher scores indicate greater willingness to seek help. The WSHQ has previously demonstrated good internal reliability ($\alpha = .85$; Cohen, 1999).

The short form of the Personality Attributes Questionnaire (PAQ; Spence & Helmreich, 1978) was incorporated to assess how people view themselves on traditional masculine/instrumental and feminine/expressive traits. Responses are recorded on a five-point Likert-scale for eight items on each subscale. Factor analysis supports the validity of the masculine/instrumental and feminine/expressive subscales (Helmreich, Spence, & Wilhelm, 1981; Wilson & Cook, 1984), with validity shown to be preserved across various socio-economic and age groups (Spence & Helmreich, 1978).

2.2.3 Design

A cross-sectional design was used, which examined the relative influence of the gender-related constructs of GRC and GRF on attitudes in help-seeking and perceived social support. This was in relation to dependent variables that are known to predict greater social support, attitudes, and behaviour such as demographic factors and carer burden. The variance in help-seeking behaviour and current support from GRC and GRF was analysed through a multiple regression analysis.

2.2.4 Procedure

Specialist nurses identified possible participants and invited them to participate in the study, providing them with an information sheet and a paper version of the survey that was

returned to the researcher in the post (Appendix D). All participants were also able to access the survey in an online version powered by Survey Monkey, which could be accessed via clicking on a link that was advertised on various internet platforms. The survey took approximately 20 minutes to complete. Paper versions of the survey were entered into Survey Monkey by a member of the research team, and all data was downloaded from Survey Monkey and stored on a network drive that was only accessible by the researcher. All data was anonymised.

2.2.5 Power Calculation

An a priori power calculation was undertaken using SPSS to determine number of participants required to undertake the proposed hierarchical regression (Appendix E). The power calculation was made to detect at least a medium effect.

2.3 Results

2.3.1 Demographics

Sixty eight participants were recruited to the study, of whom 59 completed the survey online and 9 completed a paper version. Participants were aged between 18 and 87 years ($M = 52.47$ years, $SD = 13.32$), indicating that respondents were broadly within middle age range. Table 3 gives a summary of the characteristics of the participants. Although there was variation in the amount of hours participants worked, it is evident that the majority were not working full time (less than 40 hours per week). Respondents reported low levels of professional and informal support for themselves with a mean of 2.4 minutes/week, with the majority of respondents reporting no professional or informal support.

Table 3

Sociodemographic characteristics of the sample

Participant Characteristics	<i>M (SD)</i>	<i>n</i>
Length of time spent supporting/caring for someone with MS (years)	10.51 (7.27)	68
Length of relationship (years)	23.28 (12.73)	65
Number of children	1.64 (1.36)	64
Time spent working (hours per week)	26.31 (19.98)	63
Professional care received for physical needs (hours per week)	3.03 (6.14)	58
Health professional care received (hours per week)	0.70 (1.88)	55
Psychological therapy/counselling/support group attendance (hours per week)	0.04 (0.16)	56

Table 4 provides information on the participants' place of residence, and it is apparent that the majority of participants were from the UK (36.2%). However, a substantial number of participants were from Channel Islands and Isle of Man (14.5%), and also New Zealand (13%), where their MS Society enthusiastically advertised the study.

Table 4

Participants' place of residence

Country	Frequency (%)
Australia	4 (5.8)
Channel Islands and Isle of Man	13 (18.7)
Ireland	4 (5.8)
Netherlands	2 (2.9)
New Zealand	9 (13.0)
South Africa	2 (2.9)
UK	25 (36.2)
USA	7 (10.6)

Note. *n* = 66, due to missing data.

2.3.2 Self-Report Measures

Table 5 provides the means for the questionnaire measures (and subscales) included in the survey. B-ZBI scores indicated a mean burden score of 17.72 ($SD = 9.46$), and mMOS-SS scores indicated a mean social support score of 21.61 ($SD = 7.90$). Respondents indicated mean Instrumental support and Emotional support scores of 11.20 ($SD = 4.99$) and 11.03 ($SD = 4.39$), respectively. The mean level of perceived help-seeking was 39.74 ($SD = 7.37$). Participants indicated a mean GRC score of 50.43 ($SD = 12.27$), and of the GRC subscales, the highest scores came from Restrictive Emotionality ($M = 13.19$, $SD = 4.62$) and Conflict Between Work and Family ($M = 13.46$, $SD = 4.62$). On the measure of gender flexibility, responses on the PAQ indicated similar scores on masculine traits (Instrumentality; $M = 19.79$, $SD = 5.36$) and feminine traits (Expressivity; $M = 20.54$, $SD = 5.37$).

Table 5
Summary of means for scores on the questionnaire measures

Measure	<i>M (SD)</i>	<i>n</i>
GRCS-SF	50.43 (12.27)	67
GRCS – Success, Power, and Competition	11.00 (4.19)	67
GRCS – Restrictive Emotionality	13.19 (4.62)	67
GRCS – Restrictive Affectionate Behaviour Between Men	12.81 (5.23)	67
GRCS – Conflict Between Work and Family Relations	13.46 (4.62)	67
B-ZBI	17.72 (9.46)	67
mMOS-SS	21.61 (7.90)	66
mMOS-SS – Instrumental	11.20 (4.99)	66
mMOS-SS – Emotional	11.03 (4.39)	66
WSHQ	39.74 (7.37)	68
PAQ	56.55 (10.18)	67
PAQ – Expressivity	20.54 (5.37)	67
PAQ – Instrumentality	19.79 (5.36)	67

Note. GRCS – SF = Gender Role Conflict Scale – Short Form; B-ZBI = Brief Zarit Burden Interview; mMOS-SS = Eight item modified Medical Outcome Study Social Support Survey; WSHQ = Willingness to Seek Help Questionnaire; PAQ = Personality Attributes Questionnaire.

2.3.3 Correlations

Due to the relatively small sample size and the number of independent variables it was necessary to constrain the number of predictors in the regression analysis. Therefore, Pearson correlation coefficients two-tailed tests were computed between all predictor variables (demographic variables and questionnaire measures) with the critical alpha level set at 0.01 to control for Type 1 error (see Table 6 for a summary of significant correlations, and Appendix F for the full correlation table).

Not unexpected, significant correlations were noted between age, years in relationship, and years care ($r = 0.53, p < .001$; $r = 0.63, p < .01$, respectively). Significant negative correlations emerged between age and time spent working ($r = -0.45, p < .001$), length of relationship and time spent working ($r = -0.38, p < .01$), and length of time spent caring and time spent working ($r = -0.38, p < .01$). The older the respondent, the more years in a relationship and providing care was related to reducing the number of hours worked.

Of the other predictors, only GRC presented significant correlations, being positively correlated with carer burden ($r = 0.61, p < .001$), such that higher levels of GRC were related to higher levels of burden. It was also noted that GRC was positively (although more weakly) correlated with number of children ($r = 0.32, p < .05$).

Table 6

Summary of significant correlations between variables

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	
1. Age	—	.53 ***	.63 ***	.28 *	-.45 ***								-.35 **			-.30 *								.86 ***		
2. Length of time spent caring(years)		—	.51 ***		-.38 **				-.33 **				-.27 *											.81 ***		
3. Length of relationship			—	.27 *	-.38 **								-.28 *											.75 ***	.32 *	
4. Number of children				—					.32 *	.31 *															.81 ***	
5. Time spent working					—								.44 ***											-.67 ***	.29 *	
6. Professional care for physical needs pwMS						—										-.27 *										.86 ***
7. Health professional care pwMS							—																			.81 ***
8. Psychological therapy/Informal support								—																		-.52 ***
9. GRCS-SF									—	.71 ***	.69 ***	.63 ***	.61 ***	.40 ***												
10. GRCS – SPC										—	.46 ***		.31 *	.33 **												-.29 *
11. GRCS – RE											—			.44 ***												-.35 **
12. GRCS – RABBM												—														
13. GRCS – CBWFR													—	.36 **												-.43 **
14. B-ZBI														—	-.27 *											-.27 *

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	
15. mMOS-SS															—	.84 ***	.92 ***									
16. mMOS-SS Instrumental																—	.66 ***									
17. mMOS-SS Emotional																	—	.27 *								
18. WSHQ																		—	.31 *	.31 *		.26 *				
19. PAQ																			—	.67 ***	.91 ***	.41 ***				
20. PAQ – Expressivity																				—	.49 ***	-.28 *			-.34 *	
21. PAQ – Instrumentality																					—	.30 *				
22. PAQ – Androgyny																						—				
23. Factor - Relationship																							—			
24. Factor- Work - Children																								—		
25. Factor - Physical support																									—	

Note. *p < .05, ** p < .01, ***p < .001.

2.3.4 Regression Analysis

Prior to performing regression analyses, primary component analysis (PCA) was conducted on the demographic factors to reduce the number of predictor variables in the regression models. PCA resulted in three factors, one pertaining to relationship variables, one that related to work and children variables, and a factor of support-related variables. PCA was also conducted on the gender variables but this did not clearly provide factors that were significantly fewer than the component subscales of GRC and the PAQ (Appendix G).

Prior to testing, data was screened for outliers using both Mahalanobis and Cook's distance. Analysis indicated the need to remove three participants' data. Tests of normality and homoscedasticity were met. As two separate regression analyses were undertaken a Bonferroni correction was set at $p < .025$.

2.3.4.1 Help-seeking. Table 7 displays the results of a hierarchical multiple regression analysis conducted to test the hypothesis that gender constructs predict attitudes to help-seeking (Appendix H). The predictor mMOS-SS was entered into the first step as theoretically this may be considered a predictor of help-seeking. Perception of social support predicted attitudes towards help-seeking, $\beta = .23, p = .017$. The addition of gender constructs did not significantly increase the explanatory power of the regression; however, when the predictors PAQ – Expressivity and GRCS – RABBM were added the model still retained significance ($F(3, 59) = 3.335, p = .025$). Therefore the hypothesis that gender constructs significantly predict attitudes to help-seeking was not supported.

Table 7

Summary of hierarchical multiple regression analysis predicting attitudes to help-seeking

		<i>b</i>	<i>SEb</i>	β
<i>Step 1</i>				
	Constant	35.48	2.11	
	mMOS-SS	0.23	0.09	.30*
<i>Step 2</i>				
	Constant	30.63	3.55	
	mMOS-SS	0.22	0.09	.28*
	PAQ – Expressivity	0.25	0.15	.20
<i>Step 3</i>				
	Constant	33.00	4.30	
	mMOS-SS	0.21	0.09	.27*
	PAQ – Expressivity	0.23	0.15	.19
	GRCS – RABBM	-0.14	0.14	-.12
<i>Step 4</i>				
	Constant	33.85	4.87	
	mMOS-SS	0.21	0.09	.28*
	PAQ – Expressivity	0.22	0.15	.18
	GRCS – RABBM	-0.13	0.14	-.11
	GRCS – CBWFR	-0.06	0.16	-.05
<i>Step 5</i>				
	Constant	34.57	6.82	
	mMOS-SS	0.21	0.10	.27*
	PAQ – Expressivity	0.21	0.18	.17
	GRCS – RABBM	-0.12	0.15	-.11
	GRCS – CBWFR	-0.06	0.16	-.05
	GRCS – RE	-0.03	0.20	-.02
<i>Step 6</i>				
	Constant	33.22	6.82	
	mMOS-SS	0.25	0.10	.32*
	PAQ – Expressivity	0.25	0.18	.20
	GRCS – RABBM	-0.09	0.15	-.08
	GRCS – CBWFR	-0.01	0.17	-.00
	GRCS – RE	0.10	0.22	.08
	GRCS – SPC	-0.30	0.21	-.21
<i>Step 7</i>				
	Constant	32.29	6.83	
	mMOS-SS	0.25	0.10	.32*
	PAQ – Expressivity	0.12	0.21	.10
	GRCS – RABBM	-0.10	0.15	-.09
	GRCS – CBWFR	0.01	0.16	.01
	GRCS – RE	0.09	0.22	.07
	GRCS – SPC	-0.38	0.22	-.26

PAQ – Instrumentality	0.23	0.18	.19
<i>Note.</i> $R^2 = .09$ for Step 1, $\Delta R^2 = .04$ for Step 2 ($p = .097$), $\Delta R^2 = .01$ for Step 3 ($p = .330$), $\Delta R^2 = .00$ for Step 4 ($p = .705$), $\Delta R^2 = .00$ for Step 5 ($p = .881$), $\Delta R^2 = .03$ for Step 6 ($p = .162$), $\Delta R^2 = .02$ for Step 7 ($p = .209$). * $p < .05$.			

2.3.4.2 Carer burden. Table 8 displays the results of a hierarchical multiple regression analysis conducted to test the hypothesis that gender constructs explain significant variance in carer burden, as measured by the B-ZBI (Appendix I). To be parsimonious with predictor variables, the factor Work-Children was selected as a known predictor of burden in addition to the four subscales from the GRCS and two subscales of the PAQ. The results from the regression analysis indicate that the final model explained 36.5% of the variance in burden ($R^2 = 0.365$, $F(1, 44) = 3.033$, $p = .013$). The effect size was large, $F^2 = 0.57$, although the adjusted R^2 was less (adjusted $R^2 = 0.244$), suggesting possible over fit in the final model. The predictors GRCS – RE, GRCS – CBWF, and PAQ – Expressivity were significant predictors of carer burden at $p < .05$; however, only GRC – RE was significant at the level set for the Bonferroni correction ($\beta = 1.12$, $p = .002$) ($p < .025$). Against expectations, the factor Work-Children did not significantly predict burden. Therefore the hypothesis that gender constructs would significantly explain variance in carer burden in comparison to known predictors was met.

Table 8
Summary of hierarchical multiple regression analysis predicting burden

	<i>b</i>	<i>SEb</i>	β
<i>Step 1</i>			
Constant	17.59	1.36	
Work-Children	1.01	1.44	.11
<i>Step 2</i>			
Constant	20.54	5.89	
Work-Children	0.86	1.48	.09
PAQ – Expressivity	-0.15	0.29	-.08

<i>Step 3</i>			
Constant	22.12	6.60	
Work-Children	0.95	1.51	.10
PAQ – Expressivity	-0.06	0.33	-.03
PAQ – Instrumentality	-0.17	0.31	-.10
<i>Step 4</i>			
Constant	10.64	8.27	
Work-Children	0.05	1.50	.01
PAQ – Expressivity	-0.04	0.32	-.02
PAQ – Instrumentality	-.0.08	0.30	-.04
GRCS – CBWFR	0.69	0.32	.037
<i>Step 5</i>			
Constant	7.62	9.72	
Work-Children	-0.00	1.52	.00
PAQ – Expressivity	0.02	0.33	.10
PAQ – Instrumentality	-0.10	0.30	-.06
GRCS – CBWFR	0.69	0.32	.34*
GRCS – RABBM	0.17	0.28	.10
<i>Step 6</i>			
Constant	-18.87	11.29	
Work-Children	0.64	1.34	.07
PAQ – Expressivity	0.82	0.37	.45*
PAQ – Instrumentality	-0.30	0.27	-.17
GRCS – CBWFR	0.65	0.28	.32*
GRCS – RABBM	0.09	0.25	.05
GRCS – RE	1.20	0.34	.62**
<i>Step 7</i>			
Constant	-19.27	11.34	
Work-Children	0.36	1.38	.04
PAQ – Expressivity	0.85	0.37	.46*
PAQ – Instrumentality	-0.38	0.29	-.22
GRCS – CBWFR	0.59	0.29	.29
GRCS – RABBM	0.08	0.25	.04
GRCS – RE	1.13	0.35	.58**
GRCS – SPC	0.30	0.35	.14

Note. $R^2 = .01$ for Step 1, $\Delta R^2 = .01$ for Step 2 ($p = .609$), $\Delta R^2 = .01$ for Step 3 ($p = .588$), $\Delta R^2 = .10$ for Step 4 ($p = .037$), $\Delta R^2 = .01$ for Step 5 ($p = .549$), $\Delta R^2 = .22$ for Step 6 ($p = .001$), $\Delta R^2 = .01$ for Step 7 ($p = .400$). * $p < .05$, ** $p < .01$.

2.3.5 Path Analysis

Although not predicted formally in the hypotheses, it was thought valid to examine the relationships between social support and carer burden and the influence of GRC subscales (as indicated in regression) and the PAQ – Expressivity subscale, which was the measure of gender flexibility. The relationship between social support and burden has previously been demonstrated in models of carer coping (Kniepmann, 2012; Pearlin et al., 1990).

Data was subject to multiple imputation (five imputations) and bootstrapped (200 iterations) to provide confidence intervals. Tests indicated a good model fit (Appendix J), CMIN = 1.583 $p = .453$, GFI = .998, Bollen-Stine bootstrap = .428.

The model demonstrated several significant direct effects (Table 9) and no significant indirect effects.

Table 9

Direct effects of path analysis model (p values at 95% confidence interval)

	GRCS – CBWFR	GRCS – RE	PAQ – Expressivity	mMOS-SS	B-ZBI
B-ZBI	.007	.013	.012	.018	...
WSHQ013	.007	.757

Therefore, the model (see Figure 4) provides evidence for demonstrating how burden can be predicted by a combination of gender constructs, and attitudes to help-seeking can be predicted by perceptions of social support and the measure of gender flexibility (PAQ – Expressivity), but not directly by carer burden.

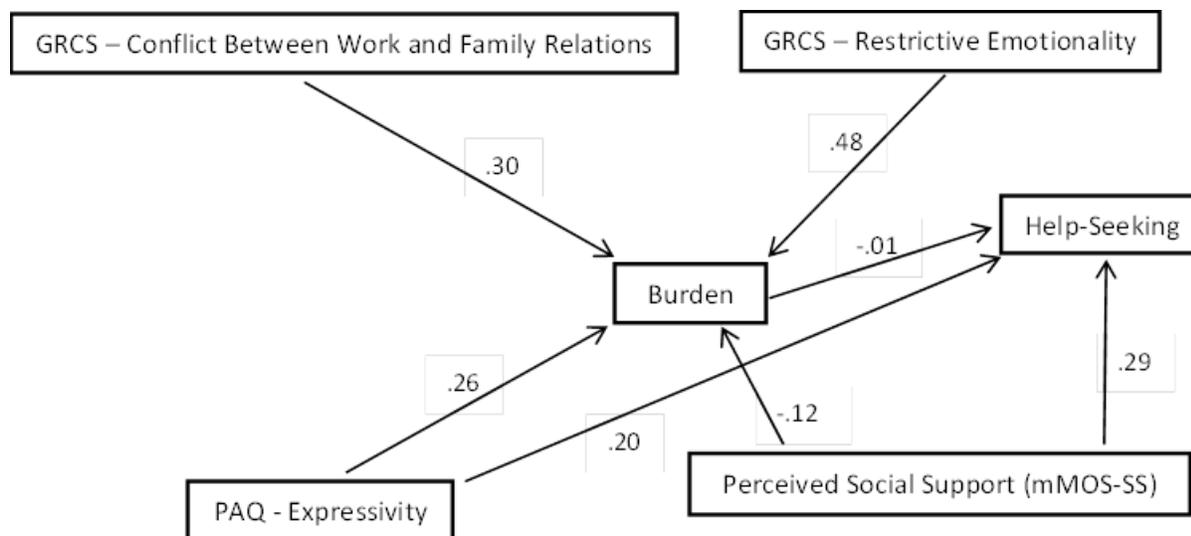


Figure 4. Path analysis of direct effects of gender constructs upon caring constructs (standardised beta weights).

Note. Covariances were removed as they were not significant. See Appendix I for full SPSS AMOS output.

2.4 Discussion

2.4.1 Attitudes towards Help-Seeking

Pearlin et al's. (1981) stress process model highlights how carers may ameliorate the effects of caring through application of coping styles and engaging resources, specifically social supports. Evidence indicates that men are reluctant to seek help and it was hypothesised that it was the need to 'live-up to' cultural masculine ideals that may be a barrier to help-seeking.

In this sample perceptions of social support were predictive of attitudes towards help-seeking. Although gender constructs did not significantly predict attitudes to help-seeking, there is evidence for their importance in MICs seeking support for themselves.

2.4.2 Social Support and Help-Seeking

Perceptions of enhanced social support predicted more positive attitudes to help-seeking; if you perceive support it is unsurprising that you may feel more able to ask for help. Of interest

in the current study was MICs perceptions of social support being lower than those reported in studies of the general population (Gómez-Campelo et al., 2014; Moser et al., 2012) which, as will be discussed, has impacts on not just attitudes but also practical levels of support.

Results indicated that MICs not only perceived relatively low levels of social support but also in practice received rather meagre levels of professional support for themselves. Sibley et al.'s. (2012) survey noted that MICs reported little difficulty in accessing support. However, demographic information suggests that the current study comprised a younger sample than that of Sibley et al.'s. (2012) (52 years and 60 years, respectively), and so this may have implications in terms of the respondents not having time to incorporate self-care into their already busy lives.

The finding that MICs reported low levels of perceived emotional support is consistent with previous research which has concluded that MICs are more likely to report lowered quality of life in comparison to female counterparts due to their perceived lower levels of social support (Lee et al., 2015).

Reduced social support is a common adverse effect of caregiving and can lead to feelings of social isolation (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). Research has demonstrated that male caregivers are at a much greater risk of social isolation than female carers once they reduce their engagement in activities such as employment and social activities (Neri et al., 2012). Although not central to the current investigation, it was noted there was a positive relationship between hours worked and perceived social support, perhaps suggesting that men receive emotional support through workplace relationships. For men who are restricted in other social outlets, work should be seen as offering positive social benefits and services should strive to recognise this and to support men in remaining in work. Liu et al. (2017) noted a similar

effect among a sample of 120 informal carers of people with Alzheimer's disease, suggesting that balancing of roles was a mediating variable in regulating carer burden.

2.4.3 Gender Role Conflict and Help-Seeking

GRC did not demonstrate a predictive relationship with help-seeking in the current study, contradictory to the majority of studies (O'Neil, 2008). MICs demonstrated a lower willingness to seek help in regard to their own well-being when compared to the general population. Similarly, Segal, Coolidge, Mincic, and O'Riley (2005) compared younger and older male adults on the WSHQ ($M = 51.3$ and $M = 50.3$, respectively), and both groups demonstrated more positive attitudes towards seeking psychological help than the current sample of MICs ($M = 38.1$). Thus, MICs may have poorer attitudes to help-seeking than the general population, despite the fact they are at greater risk of developing mental health problems. Examination of the self-reported behaviour of hours of personal psychological and informal support in the current sample indicated a substantial difference with the general population. In the current sample, the average number of hours per week of psychological support received was negligible. In addition to concerns about being able to access appropriate psychological support, there are other possible barriers to MICs engaging in psychological self-care including informal support.

Pedersen and Vogel (2007) have theorised that self-stigma is a mediating variable between GRC and attitudes to self-help seeking. Self-stigma has been conceptualised as the negative effect help-seeking has upon one's self-concept, and reducing stigma is prioritised above the suffering of emotional pain (Miller, 1985). Within the context of caring, consideration needs to be given to appearance of coping as a possible variable; the need for MICs to keep up an appearance of coping so as not to emotionally burden the individual with MS and other family members. This has been clinically observed and reported in the qualitative literature (Appleton et

al., in press). MICs are thus potentially cutting themselves off from sources of informal support, especially from their partners, through the gender related beliefs which form an appearance of coping; stoicism and the need to protect others from emotional distress.

MICs scores on the Success, Power and Competition (SPC) subscale of the GRCS were weakly correlated with levels of support for the individual with MS. This may suggest that MICs who perceive difficulty in fulfilling masculine ideals of success may be more likely to seek professional care for their partner. Such a finding supports the characterisation of the male carer who struggles with the gendered role of caregiving, and seeks help to offload these tasks (Brown & Chen, 2008). As Hanlon (2012) argues, men tend to approach caregiving in a more task-orientated manner, considering the instrumental and practical aspects of caring that can be outsourced. This finding can be understood by recognising the context of this study and the tools used. The WSHQ is commonly used to measure attitudes towards seeking help for oneself; however, in the context of caring it may also be interpreted as seeking help for the person for whom one is caring.

2.4.4 Gender Role Flexibility

GRF, as measured by the PAQ – Expressivity subscale, did not predict attitudes towards help-seeking behaviour. However, the Expressivity subscale was weakly correlated to attitudes towards seeking help, and similar findings have been reported in the general male population (Ang, Lim, Tan, & Yau, 2004). One may conceptualise the Expressivity subscale as an indication of the ability to utilise skills and qualities that are traditionally conceptualised as being female gendered (Cheng, 2005). Cheng (2005) posits that this is a form of gender flexibility and supports the ‘Knowing How’ hypothesis (Lazarus & Folkman, 1984) and the ‘Goodness of Fit’ hypothesis (Forsythe & Compass, 1987). These hypotheses refer to the ability to behave in ways

that are appropriate to the situation. In this study this can be considered being behaviourally flexible and not tied to hegemonic gender roles. Therefore, it may be beneficial to consider gender flexibility as a component coping flexibility (Cheung, Lau, & Chan, 2014). Furthermore, one can conceptualise the forces of gender constructs as having a balance of effects on help-seeking, or hindering and facilitating factors as Brown, Chen, Mitchell, and Province (2007) have termed in their model of carer coping (Table 10).

Table 10
Hindering and facilitating in help-seeking

Hindering	Facilitating
Appearance of coping	Expressiveness/Femininity (PAQ) Competition and Success (GRC)

2.4.5 Burden and Gender Constructs

Gender constructs predicted burden, and explained the variance in burden when compared to the previously observed factor of Work and Family. The CBWFR subscale of the GRCS was a significant predictor of burden scores. This finding can be conceptualised as an internalisation of gender conflict stresses adding to carer burden. MICs perceptions of caring demands are significantly influenced by the degree with which they feel they are not living up to the hegemonic masculine ideal, within Pearlin’s model this is a secondary stressor (Bai et al., 2017).

In the current study it was the RE and CBWFR subscales that significantly predicted variance in burden. However Baker, Robertson, and Connelly (2010) note in their study that the RABBM subscale of the GRCS was a significant variable in determining variance in strain scores, implying that men who have problems with affectionate behaviour between men report increased burden. This in turn has implications for avoiding emotional support from male friends

and family, which was a suggestion previously made in relation to men's reluctance to engage in psychological therapy with male therapists (Good & Wood, 1995). The difference between the studies may be explained by the use of a younger sample in the current study in contrast to the older sample utilised by Baker et al. (2010), who were no longer in paid employment and balance of career and family might be less pertinent. In the context of this study, the RE subscale is best understood as another component in the need to give an appearance of coping to preclude emotional burden on others.

The current finding that age was not correlated with GRC in MICs contradicts the findings of Vogel, Heimerdinger-Edwards, Hammer, and Hubbard (2011), whose analysis of a community sample of over 4000 men revealed that adherence to dominant masculine ideologies appeared to decline with age. Theodore and Lloyd (2000) have argued that these age-related changes are associated with the need to achieve and manage family life. Therefore as men age they more readily accept the role of carer as expectations of masculinity change, with an emphasis more on social networks and lifestyle and emphasising their role as a partner/husband (Ribeiro, Paul, & Nogueira, 2007). It is unclear why no significant relationship was evidenced between age and GRC in the current sample; however, it is important to note that in comparison to other MICs caring for spouses with Alzheimer's disease and Parkinson's disease, the current sample was significantly younger. This middle aged group of MICs may be exhibiting other forms of masculinity - a new caring masculine ideology that is becoming more dominant in Western societies (Elliott, 2016). This view states that although the hegemonic ideal of masculinity may still be the most honoured, other forms of masculinity develop within a society and become acceptable to identify with: this has been particularly noted in younger men and their adoption and acceptance of caring parental roles over the last few decades (Goldscheider,

Bernhardt, & Lappegård, 2015). Adoption of alternative views of masculinity may partly off-set some of the negative effects of traditional masculinity.

The effect of GRC increasing carer burden is balanced by GRF (PAQ – Expressivity subscale), further supporting the argument that the application of a flexible coping predisposition reduces burden. Therefore it is possible to consider a modified stress process model in which burden is influenced by gender role constructs and social support, which have an influence upon attitudes to help-seeking (Figure 5). Such a model is partially supported by the path analysis model developed from the current data with the addition of a new unobserved variable referred to as Appearance of Coping.

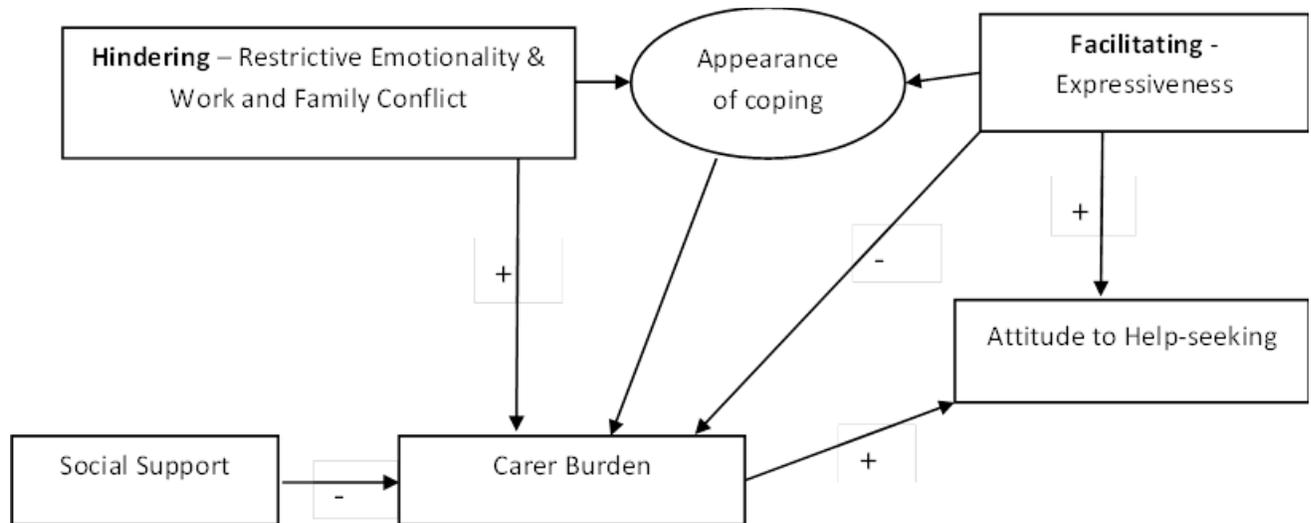


Figure 5. Model of the effects of gender constructs in carer coping.

2.4.6 Conclusion

MICs of pwMS can be considered an at risk group who are vulnerable to poor mental health. Both GRC and GRF play significant factors in predicting and explaining variance in carer burden. Although regression analysis did not indicate gender constructs directly predict attitudes

to help-seeking, other measures provided evidence that MICs are generally poor at accessing personal support and may be influenced by gender factors. These are important findings building upon previous carer coping research, but more importantly they provide a nuanced view of the factors that affect MICs coping and provide services with insights into how to provide more tailored services to engage this population.

2.4.7 Limitations

2.4.7.1 Response bias. O'Rourke et al. (1996) report a bias in response to measures of perceived burden, and instead suggest it is more a measure of burden that is willingly reported. This bias can be viewed as a defence mechanism against judgement by self and others regarding state of coping, and therefore it can also be seen as further evidence that MICs struggle to conform with hegemonic masculinity and the need to appear in control and coping at all times. The finding that GRC and burden are positively correlated is explained by Baker et al. (2010), that men who report greater GRC will have greater burden as this is in fact a way of asserting that they are masculine and are struggling to do the feminine work of caring.

2.4.7.2 Recruitment bias. A substantial proportion of participants (42%) were recruited via the internet (Facebook and Twitter). Although this method has been criticised for producing an unrepresentative sample, empirical data and contemporary prevailing opinion suggests this method can provide a better and more diverse representation of the community (Gosling & Mason, 2015; Gosling, Vazire, Srivastava, & John, 2004; Thornton et al., 2016). In the current study, internet recruitment was international and so this may have mitigated, to some extent, biases of particular countries and provided more generalizable findings. However, it is important to note that all but two respondents were from Western English speaking countries with the

majority from commonwealth countries ($n = 48$), which share similar types of health services with free secondary health and social care.

In an effort to keep the questionnaire to a reasonable length, several demographic factors were also omitted that are known to affect help-seeking, for example education, which is known to have a positive impact on attitudes towards seeking psychological help (Calvo-Salguero, Garcia-Martinez, & Monteoliva, 2008; Hammer, Vogel, & Heimerdinger-Edwards, 2013). Finally, the sexuality of the couple was not identified and to date there have been no studies examining this and so it is unknown what effect this may have upon a couple's ability to cope.

2.4.7.3 Statistical analysis. Examining the data through regression analysis presented some difficulties as the sample size may have been considered relatively small. To mitigate against being underpowered, confirmatory factor analysis was used to produce new aggregate variables. This may have lost some possible smaller effects from the original variables, however only a larger sample size would be able to overcome this. In the final analysis observed power was adequate in the regression analyses, meaning the findings could be interpreted with confidence.

2.4.8 Future Research and Clinical Implications

This is the first study to document the effect of gender constructs and adherence to a hegemonic masculinity on help-seeking and carer burden in MICs. Although it focused on MICs of pwMS, it is not unreasonable to speculate that aspects of gender constructs may play a part in carer coping in MICs of people with other neurodegenerative diseases, such as Huntington's disease, who similarly have to cope with a severe and unpredictable disease process that often begins in middle age. Further, the population of MICs caring for partners with cancer is a larger

population that would have similar characteristics to the current sample and merits further investigation.

Future research pertinent to service development should consider how attitudes to help-seeking are affected by the availability of services. Investigation is required to assess if educational and therapeutic interventions can substantially effect attitudes to gender roles and change help-seeking behaviour, as has been shown in the general male help-seeking literature (Hammer & Vogel, 2010; Vogel, Wester, Hammer, & Downing-Matibag, 2014).

Screening and proactive interventions are recommended for providing services to MICs, as clinicians will commonly subscribe to the view that MICs invariably do not seek help until times of crisis (Milligan & Morbey, 2016). Clinicians could develop informational outreach programs and single-session groups in which men can experience what it is like to have psychological and peer support, thereby dispelling preconceived ideas and attenuating the potential anxiety that these men may experience if they needed services in the future, and such small-scale efforts can be effective (Navaie, 2011). Furthermore, this could be stratified by age of the MIC and their partner's stage of the disease process.

Services addressing gender constructs impact upon carer burden may contribute to reduced prevalence of mental health problems and enhanced quality of life. A possible avenue of intervention would be for MICs to develop a greater understanding of the constraints of traditional masculinity, and the effects of adherence upon them and their relationships (Kahn, 2009; Wahto & Swift, 2016). In this way, men can move towards a caring masculinity (Elliot, 2016), and be able to embrace and recognise the rewards of caring - “‘responsible’, ‘competent’, ‘proud’, ‘challenged’, ‘joy’, ‘fantastic’, ‘happy’, ‘brilliant’, and wanted...” (Hanlon, 2012, p. 137).

Skills that enable MICs to develop a more flexible attitude to how they approach care for others and themselves is a promising area for clinical development. If gender flexibility is reconceptualised as a coping flexibility, as advocated by Cheng et al. (2014), it may provide another possible intervention. Cheng et al. (2014) argue it is not simply learning more skills that are of value but the appropriate deployment of those skills, sensitive to the situational context. A critical component of coping flexibility is acceptance, a skill used when the external factors of problems are uncontrollable. This appears consistent with Pakenham and Samios' (2013) findings on couples' adjustment to coping with MS, that acceptance from one spouse has a positive relationship with coping by the other partner. Acceptance-based therapeutic interventions, such as Acceptance and Commitment Therapy, may thus help develop unique interventions for MICs.

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Section 3.0: Reflective Critique

Word Count: 1,920

3.1 Origins of the Study

During initial discussions with my supervisor around putting a plan together for my doctoral portfolio I was intrigued by the challenge of undertaking an ethnographic meta-synthesis and following this up with a qualitative study, but it was suggested by my supervisor that I balance this with a piece of empirical research. I wished to combine my doctoral research with my clinical work as a neuropsychologist and my longstanding research interest in family coping within the context of disabilities. I was aware of the research in older MICs of people with Alzheimer's disease and Parkinson's disease, but there appeared to be a gap in the literature regarding younger MICs. Clinically, I regularly work with couples where the female partner has MS, and so it seemed a good opportunity to focus my study on MICs of pwMS.

3.2 Meta-synthesis

I was curious about how a couple cope and adapt their relationship when one partner has MS, and so this became the basis for my meta-synthesis. I opted to utilise the Noblit and Hare (1988) approach to undertake the meta-synthesis and chose to use the Cochrane Review Guidelines (2011), which suggest the use of both translational and line-of argument elements of synthesis.

My initial attempts in developing the line-of-argument synthesis were influenced by my clinical work, and were much more closely aligned with Dixon-Wood et al's. (2006) concepts of critical interpretative synthesis. This produced a model (Appendix K) that heavily relied on the ideas of Hughes et al. (2013), specifically about rejecting or embracing the role of carer, and concepts of acceptance from Acceptance and Commitment Therapy. I have found this model useful in my clinical work for formulating and educating couples about their coping and how they may approach current and future problems. However, this line-of-argument failed to fully

encapsulate elements of the context and so failed to fulfil Nobilit and Hare's (1988) concept of line-of-argument, meaning it was rejected in favour of the model presented in my portfolio.

3.3 Empirical Research

The findings from the meta-synthesis indicated that MICs were quite unrepresented in the literature, and this piqued my interest further. At this point, my supervisor suggested I look at issues around concepts of masculinity and whether this affects the caring experience. I found the process of establishing my research question quite difficult, and made multiple iterations to it before it was finalised. Initially, I tried to combine too many concepts into my research, particularly I thought the literature around gender flexibility could be linked with the concept of psychological flexibility, but I came to the realisation this required a study of its own and could not be incorporated into my research. After thoroughly reviewing the literature around carer coping, including the models of Lazarus and Folkman (1984), and the factors and contexts affecting coping, the work on male help-seeking was most pertinent for MICs, and so this became the focus of my research. It tied with my clinical work with men caring for their partners across a range of long-term neurological conditions, and I relished the opportunity to put my clinical hunches to the empirical test.

3.4 Ethical Process

At the outset, I did not think I would encounter many ethical difficulties with my project - the study was not invasive, it had a high degree of anonymity, and had minimal possible impact upon the researcher. However, it was the sheer number of ethics committees I was required to submit to that became rather problematic and labour-intensive. As I work outside of the UK NHS, I had to submit to the local ethics committee as well as the university ethics committee. I also wanted to enlist the help of MS nurses in the other crown dependencies of Jersey and the

Isle of Man to widen my recruitment, but this process was complicated by the fact that each area has its own health service, ethics committee, and data protection laws (although mostly based on UK law) and so had particular stipulations regarding the handling and storage of data. In order to further expand my recruitment I also wanted to access the UK MS Nurse Network and this meant I had to submit to NHS Research Ethics Committees (REC), something I wanted to avoid having to do due to preconceptions of the difficulty of this process. This posed some interesting challenges as:

1. I was not based in the UK
2. I did not have one particular site of recruitment
3. I required University sponsorship

My experience of acquiring NHS REC and HRA approval is best described as a Kafkaesque bureaucratic nightmare. Within the UK, each country required that its own stipulations be met and then each site also (rather unnecessarily) had duplicate scrutiny from its Research and Development office, meaning the whole process took the best part of 6 months!

3.5 Recruitment Strategy and Bias

My naivety in running a larger scale project than I had done before became starkly apparent to me when recruitment of online participants was worryingly slow. I was lulled into a false sense of optimism by looking at recruitment for other online studies that utilised websites such as FindParticipants.com and Prolific.ac, which appeared to be able to rapidly recruit participants. However, I failed to consider the very specific nature of the participants I was hoping to recruit, which meant that rapid recruitment using the aforementioned channels was not going to be possible. After several weeks, I realised I was not going to complete recruitment by my planned date and I suffered a sense of ‘is this me?’, but was reassured:

Recruiting participants is a challenge for many health, medical and psychosocial research projects. Participant recruitment can often be an expensive and time consuming process, complicated by the fact that some traditional methods of recruitment, such as mail and phone recruitment have become more difficult and expensive in recent decades. (Thornton et al., 2016, p. 72).

My initial recruitment strategy was to advertise my research on UK, American, Irish, and Australian MS organisation websites. However, I received very few responses using this method and on closer inspection it became apparent why – current research studies could only be accessed by navigating through several webpages before then being confronted by a bewildering number of studies to choose from, and so only the most motivated participants were likely to be recruited.

My second strategy was a more proactive internet recruitment campaign through the use of Facebook, Twitter, online forums, and Google AdWords. This aspect of the research became fascinating as I had to quickly develop skills in social media promotion, but also employ skills in data analysis and simple experimental design. There has been little published in this area as most previous literature focuses on large epidemiological studies (Thornton et al., 2016).

Collecting data alongside a pharmacological trial may have been a far more effective recruitment strategy, but was something I realised too far into my project as I looked enviously at the study by McKenzie et al. (2015) who followed this strategy and recruited over 1000 participants.

The traditional recruitment method, through the use of specialist MS nurses, has an inherent bias in that the person with MS is already currently receiving some form of support.

This seemed an inevitable and unavoidable bias; however, there did not appear to be any significant differences between nurse-recruited and internet-recruited respondents on most of the measures collected (Appendix L).

An unmeasured bias, and a possible explanation for the relatively difficult recruitment, is the context in which participants were living. When the demands of care, support, and work are high, participating in a 15 minute survey may feel like an onerous task and therefore those under the greatest carer burden may not have responded.

Recruitment issues aside, I received some feedback from participants in person. Several indicated that they thought the questions were strange, and on further questioning it appeared this feedback was based on items from the GRCS-SF, with two asking me if the questionnaire was about homosexuality. This highlights issues around using questionnaires which use language that may make participants uncomfortable, but where the researcher is constrained by the need to test particular theoretical concepts and does not have the resource to develop their own versions of the test. The test was also constructed in the 1970's and, perhaps as with many psychometric tests, an update of the language used needs to be considered.

These personal contacts with participants provided personally poignant moments that I felt grounded me back in the meaningfulness of my research. One participant contacted me through Facebook and thanked me for my research and sent me a link to his video. In watching the video, he eloquently explains the effect of caring for his wife, listing the impact it has had on him and the family. With particular poignancy he says "I have become emasculated" (Gainsworthy, 2017); in a nutshell he summarises the basis of my research. Watching the video had a significant emotional impact upon me and has provided me with motivation during the inevitably difficult times one experiences conducting research.

3.6 Statistical Analysis

Due to the sample size, I was constantly aware of the risk of my study being underpowered, and so this required me to think carefully about how to undertake regression analyses. I endeavoured to be parsimonious with the variables I entered into the regression analyses and focused on the variables that previous research suggested would be of importance, which meant my study was sufficiently powered. In spite of my small sample size, I also considered it important to examine other relationships between social support and burden as my clinical intuition and the literature suggested significant relationships may exist between these variables, and this led to the use of path analysis and the development of a model to explain the relationships between gender constructs and MICs caring constructs.

The focus of my research was the attitudes of participants', but they were also asked to report on actual levels of support they received. Initially I thought I would be able to contrast perceptions and attitudes against reality, but this comparison proved difficult as it was impossible to compare whether obstacles to support were attitudinal or due to the nature of the health and social care systems available.

3.7 Future Research

The use of path analysis modelling allowed a different exploration of the data and it is hoped this may provide a stepping stone to future research, which could take several directions in terms of providing a more comprehensive model of coping and help-seeking in MIC. This may include examining the role of appearance of coping as a variable or examining social context, as it is likely that friends and family notice MICs struggling and then suggest seeking professional help, and whether this has a different effect on looking for personal support. Further qualitative

research needs to be undertaken to explore if real tensions exist between attitudes and actually asking for support.

3.8 Personal Reflections

As I finish this research, I am entering the second half (or final act!) of my career in clinical psychology. Undertaking the PsyD has been in addition to my clinical work, and has been repeatedly questioned by colleagues as it has no particular benefits for grading or remuneration. However, completing this challenging project has enriched my clinical work. My ability to be informed by theory and develop my own theories has significantly improved the level of satisfaction I have in my clinical work, and the effectiveness of my interventions with clients and consultation with colleagues.

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Section 4.0: Service Evaluation

Audit of psychological screening and psychological care of oncology patients and the evaluation of standardised screening protocol with breast cancer patients

Word Count: 6,838

Executive Summary

Over the last 15 years the psychological care provided to oncology patients has come under greater scrutiny, and with it a growing recognition of the prevalence of psychological distress in oncology patients (Carlson, Waller, & Mitchell, 2012). In response to concerns about the psychological well-being of oncology patients, the National Institute for Health and Care Excellence (NICE) issued a guideline outlining a tiered system of psychological care that forms the basis for this service evaluation (NICE, 2004). The aim of the current service evaluation was twofold:

1. To audit current methods of identifying psychological distress and psychological care pathways for oncology patients.
2. To evaluate the use of a battery of standardised screening instruments for identifying psychological distress with breast cancer patients.

The audit of current services involved:

1. A retrospective audit of patient notes.
2. Administering questionnaires to determine nurses' knowledge of identifying psychological distress and current referral pathways.
3. An audit of referrals of oncology patients to mental health services.

The evaluation of screening instruments involved:

1. The breast nurse administering the screening instrument to patients during routine consultations for a 12-week period.
2. Interviews with the breast nurse and patients to gather their experiences of using the screening instruments.

Results from the audit indicated:

1. Nurses have a high level of knowledge of psychological symptoms associated with common mental health disorders such as anxiety and depression.
2. There is no systematic screening of psychological distress or referral process for patients identified.

Results from the screening trial indicated:

1. The majority of patients indicated some psychological distress but only a small minority required referral for psychological intervention.
2. The breast nurse and patients found the use of screening tools positively added to their care.

Recommendations for developing a tiered model of psychological care for oncology patients locally include:

1. Training nurses in administering psychological distress screening instruments.
2. Making the screening of psychological distress a routine part of consultations by all oncology staff at all stages of treatment.
3. Training specialist and consultant nurses' in brief cognitive behavioural therapy (CBT) that can then be used within routine consultations.
4. Developing a clear referral pathway in consultation with mental health services.
5. Conducting an annual audit of the psychological care for oncology patients.

4.1 Introduction

4.1.1 Distress in Cancer Patients

Over recent years, distress in cancer patients has been recognised as the “sixth vital sign” in cancer care (Carlson et al., p. 1161). Distress is a term defined by the National Comprehensive Cancer Network (NCCN) as “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope with cancer...” (Holland et al., 2007, p. 450). The term distress was chosen as it has less perceived stigma than diagnostic terms of anxiety or depression. The effects of cancer and its treatment range from anxiety and depression to problems with memory and social skills, which can all contribute negatively to a patient’s quality of life (Macmillan Cancer Support, 2009). The overall prevalence of distress in cancer patients has been estimated 35.1% (Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001). In the UK a study conducted by Macmillan Cancer Support found that 75% of cancer patients experience anxiety and almost 50% experience depression (Cardy et al., 2006). Studies show varying rates of distress in cancer patients depending on the type of cancer and the stage of treatment (Zabora et al., 2001). Although there is a high rate of psychological distress in cancer, research has also shown there is a distinction between normal grief and adjustment reactions to cancer, and those who develop severe levels of distress (Moorey, 2013).

Given the high prevalence of psychological distress, it is surprising that research has found many cancer patients with emotional problems do not seek help. A study conducted by Macmillan Cancer Support (2009) found that only 60% of 442 cancer patients struggling with emotional problems sought help. A possible reason for this is the physical difficulties and effects of the cancer hiding any parallel emotional strain they are experiencing (Carlson et al., 2004).

Alternatively, cancer patients may see their unhappiness as a necessary consequence of their diagnosis but not recognise it as depression (Macmillan Cancer Support, 2009).

4.1.2 Guidelines

NICE and the Department of Health published guidelines in the UK recommending that all patients should be psychologically assessed at systematic points throughout their cancer journey. These assessments should be at the time of diagnosis, during treatment episodes, at the end of treatment, and at the time of recurrence (NICE, 2004).

The guidelines make recommendations about service configuration for the provision of psychological support (see Figure 6). The four-tiered model suggests that patients with milder forms of distress should be supported by the professionals working directly with them, particularly nurses, and patients presenting with more severe levels of distress should be supported by specialist mental health providers. The NICE guidance notes that this model should not only be provided within specialist oncology units but across cancer pathways including in primary care. The model also emphasises the autonomy and agency of the patient, recognising that “It is also essential that health and social care professionals empower and equip patients to recognise and manage their own psychological needs.” (NICE, 2004, p. 77). There is recognition that patients will use their own support networks, both informal and formal, to develop their own repertoire of self-management techniques.

Recommended model of professional psychological assessment and support

Level	Group	Assessment	Intervention
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
3	Trained and accredited professionals	Assessed for psychological distress and diagnosis of some psychopathology	Couselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)

Self help and informal support

Figure 6. Recommended four-tier model of psychological assessment and support (NICE, 2004).

A similar approach has been taken in both Australia (Turner, 2015) and by the NCCN in the United States whose clinical practice guidelines stress the need to routinely screen and treat distress (NCCN, 2013). The NCCN guidelines recommend using the Distress Thermometer as a brief screening tool for distress, and studies have found this to be an effective tool for identifying a distress that is acceptable to patients and clinicians. The Distress Thermometer consists of a picture of a thermometer on which the patient is asked to rate their distress, and a list of problems for the patient to indicate which areas they are struggling with the most.

4.1.2.1 Difficulties with screening. Despite the high prevalence of psychological distress and these clear guidelines, studies have found that screening for psychological distress does not take place frequently in clinical settings. For example, one study found that of 226 health professionals working with cancer patients, only 5.9% used any type of screening tool to assess distress as they prefer using their own clinical judgement (Mitchell, Kaar, Coggan, & Herdman, 2008). This being said, a recent observational study investigated how often emotional issues were discussed during consultations in light of the guideline changes, and it was found that these discussions took place in only 27% of consultations (Taylor et al., 2011). This throws into question the risk of relying on clinical judgement to assess distress without the prompt of a screening tool or standardised protocol.

4.1.2.2 Use of screening. The utility of psychological screening tools for this population has been the centre of debate; cancer professionals query its practicality and efficacy in busy, clinical settings. Mitchell et al. (2008) identified several reasons why cancer clinicians do not use screening tools or discuss emotional distress in patients, with the most commonly reported barriers being a perceived lack of time (57.8%), lack of training (16.9%), and low personal abilities and confidence in the skills required (13.3%). A further hypothesized barrier to psychological screening is the fear that it will lead to an increase in the referrals to psychological services and overwhelm them (Carlson et al., 2012; Lynch, Goodhart, Saunders, & O'Connor, 2011); however, this hypothesis has been disputed by research showing that use of the Distress Thermometer did not lead to an increase in referrals for psychological support (Lynch et al., 2011).

High numbers of cancer patients refuse formal psychological support, even when their distress levels are above the cut-off. For example, Graves et al. (2007) reported in their study that

61.6% of lung cancer patients were experiencing clinically significant levels of distress but fewer than 25% expressed a desire for help with their symptoms. This finding is echoed in studies with breast cancer patients where only 40% of women were willing to accept psychological support (Graves et al., 2007; Scholten, Weinländer, Krainer, Frischenschlager, & Zielinski, 2001).

Even after taking the various sides of the debate into account, the systematic screening of distress in cancer patients is firmly set out in the clinical guidelines, and it will also help to promote equal access to psychological support and so ensuring patients are not overlooked.

4.1.3 Local Clinical Context

The Channel Islands have never formed part of the British National Health Service (NHS), and primary care services are provided on a 'fee for service' basis by private family practitioners, whilst secondary care is provided under contract (Payne, Jarrett, Jeffs, & Brown, 2001).

A number of studies have examined the patient's perspective when travelling from rural to urban areas for radiation cancer treatment (Fitch et al., 2005). North American studies have generally found a correlation between travel distance and treatment outcome, adherence, social support, and alienation. In an English sample, a clear relationship between take-up of radiotherapy and travel time to the nearest radiotherapy hospital has been documented (Jones et al., 2008). When travel time for radiotherapy is over three hours, there appears a significant increase in psychological problems and a reduction in treatment adherence. There are very few direct studies examining psycho-social adaption and treatment compliance among UK island communities. Of those that have reported on it, the evidence is mixed. For example, Payne et al. (2001) found few differences in terms of patient satisfaction and perception of social support

between local patients in Southampton and island-based patients who received chemotherapy and/or radiotherapy in Southampton.

4.1.3.1 Local figures. Locally, there are 7 multi-disciplinary oncology teams: breast, gastro-intestinal, gynaecological, head and neck, lung and thoracic, urological, and skin. Figure 7 shows the number of patients diagnosed with each of these cancers between 2012 and 2014.

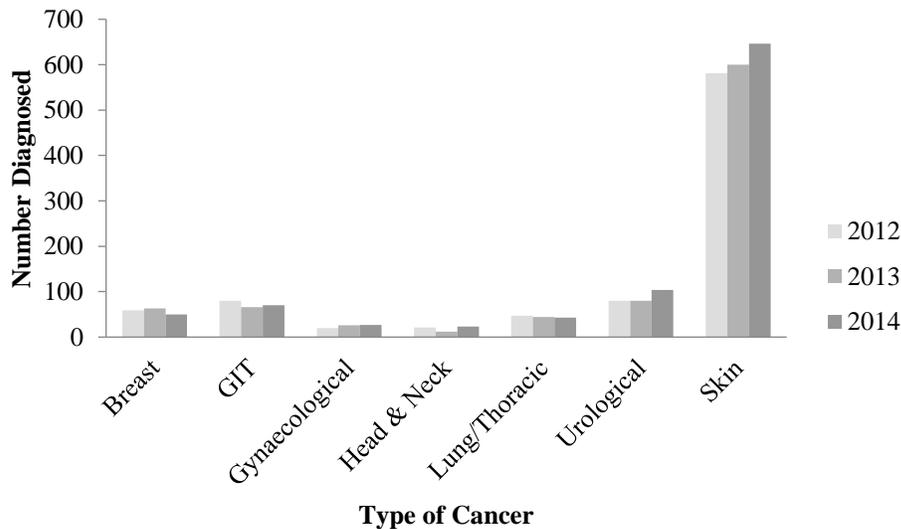


Figure 7. Number of people diagnosed with each cancer type in 2012, 2013, and 2014.

More specifically, the multi-disciplinary breast unit team is made up of a consultant pathologist, consultant radiologist, two consultant oncologists, consultant breast surgeon, lymphodema nurse specialist, breast care nurse specialist, two mammographers, and three superintendent radiographers.

4.1.3.2 Off-island figures. Table 11 shows the total number of oncology patients sent off-island to Southampton General Hospital for treatment in 2014 and the first half of 2015, and also the number of these who were breast cancer patients.

Table 11
Number of patients sent to Southampton General Hospital

Year	All cancer patients	Breast cancer patients (%)
2014	197	27 (13.71)
2015 (January-July)	133	16 (12.03)

4.1.4 Rationale and Aims

There is a strong need locally to ensure services are adhering to the best practice guidelines. Every year, approximately 60 residents are diagnosed with breast cancer and begin receiving treatment. Given the statistics, it is highly likely that at least some of these patients are experiencing psychological distress that may be negatively impacting on their quality of life, their relationships, and their recovery (Cardy et al., 2006). The principal aim of this clinical audit was to investigate psychological screening within the breast unit at the local hospital. It also forms part of a wider project to create a screening protocol and an established tiered pathway for assessing and supporting psychological distress in cancer patients. This seems crucial in not only ensuring that best practice guidelines are being followed but also that patients on the island are receiving the crucial support they need.

The first aim of the audit was to review past and current screening for psychological distress and the subsequent support offered in patients within the oncology service. This included carrying out an assessment of nurse knowledge and experience about mental health disorders and screening, with the aim of identifying any training needs and potential barriers to using screening tools locally. Nurses' current knowledge and understanding of the referral process for patients that are experiencing psychological distress was also to be assessed.

The second aim of the audit was to evaluate the utility and acceptability of implementing a routine screening process during patient consultations with a specialist breast nurse through the

use of semi-structured telephone interviews to gain qualitative information about patients' views of the screening tools and their use in consultations.

Looking to the future, it is hoped that this audit will aid in mapping out a psychological screening process and tiered referral pathway for use within the local oncology service.

4.2 Method

4.2.1 Ethical considerations

Prior to commencing the audit, ethical considerations were highlighted by the author and oncology nurses. Of most concern was that after identifying patients with distress there would be appropriate resources available to support them. To this end, an interim referral pathway was developed with mental health services. Further ethical considerations were also discussed with the chairman of the local ethics committee who advised that the audit and subsequent pilot study did not require an application to the local ethics committee. It was further recognised by the local audit officer that the project fulfilled criteria for a service audit.

4.2.2 Adult Mental Health Referral Audit

Over a period of eight weeks, psychologists within local adult mental health services collected data on oncology patients referred to their service. This included the client's oncology diagnosis, oncology treatment and stage of treatment, and reason for referral. Following weekly team meetings in which new referrals were discussed, the assistant psychologist entered the relevant data into an Excel spreadsheet that was then forwarded to the researchers at the end of the eight week period.

4.2.3 File Review

As previously mentioned, one of the aims of this audit was to see what screening had been undertaken and what support had been provided in the near past for oncology patients in the breast unit experiencing psychological distress. In order to do this, 20 patient files and 30 patient files were selected at random from the breast unit and general oncology unit, respectively. The files selected were of patients who could be at any stage of treatment, from having been recently diagnosed and not yet started treatment through to those who had finished treatment. The assistant psychologist used the NICE (2004) guidelines on screening for psychological distress as a structure for the file review, and recorded any other psychological distress that was mentioned in the patient files. The NCCN's definition of distress (Holland et al., 2007) was used as the criteria for interpreting psychological distress.

4.2.4 Oncology Nurse Knowledge and Experience

As previous research has identified specialist nurses confidence and knowledge as a potential barrier to psychological screening, a tool was developed to identify their experience and training in recognising psychological distress (Appendix M). The first section took symptoms from the GAD-7 (Spitzer, Kroenke, Williams, & Lowe, 2006) and PHQ-9 (Kroenke, Spitzer, & Williams, 2001), and asked nurses to identify which symptoms they would associate with the relevant disorder. The other questions comprised of self-rated competency questions on a 10-point Likert Scale and short answer questions to identify current screening procedures. In addition to this self-report tool, a number of nurses informed the assistant psychologist that they encounter many patients who they think are presenting as psychologically distressed but do not have the time to offer additional support and are not fully aware of the referral processes they should follow if they thought this was an appropriate course of action.

This prompted the compilation of a few short questions for all the oncology nurses to complete that specifically addressed their knowledge of the local referral process (Appendix N). The assistant psychologist collected and analysed this data using brief thematic analysis.

4.2.5 Implementing Screening Tools

The second part of this audit was to introduce validated screening tools for psychological distress into routine clinical practice. The specialist breast nurse began doing this in her consultations with patients at various stages of treatment. The following tools were used for screening in consultations as they are used by the local Improving Access to Psychological Therapies (IAPT) service or are recommended specifically for cancer patients (see Appendix O).

The PHQ-9 (Kroenke et al., 2001) is a 9-item measure taken from the original 3-page Patient Health Questionnaire that is used to screen for the presence and severity of depression symptoms. This measure is self-administered and, despite being half the length of many other measures of depression, it still shows comparable specificity and sensitivity (Kroenke & Spitzer, 2002).

The GAD-7 (Spitzer et al., 2006) is a brief 7- item measure to assess the presence and severity of anxiety symptoms and can be useful in measuring change across time. It asks the patient to rate the anxiety they have been experiencing over the past two weeks. This measure is administered to all patients at every session within the IAPT services in the UK to provide a comprehensive picture of change in symptoms over time (National IAPT Programme Team, 2011).

The Distress Thermometer is a very brief tool in which the patient is asked to rate how much distress they have been experiencing in the past week on a scale from “0” (No Distress) to “10” (Extreme Distress). In addition to this, patients are asked to indicate any areas on the

“Problem List” in which they have been experiencing distress over the past week. The list is comprised of a range of problem areas including physical, practical, emotional, and familial. This tool is the main measure recommended by the NCCN (NCCN, 2013).

The breast nurse was instructed to use these screening instruments for a 12-week trial period. The assistant psychologist scored the measures and entered the data onto a database in preparation for analyses to investigate the number of patients that fall within the different severity thresholds for anxiety and depression.

4.2.6 Patient Telephone Interviews: Acceptability of Screening Measures

Acceptability of screening tools is of paramount importance for the patients. Although following NICE guidelines (2004) and adhering to best clinical practice is extremely important, this needs to be done in a way that is acceptable for patients. Therefore, it was decided that patients who had experienced the screening protocol would be contacted and asked to provide their thoughts. Due to the sensitive nature of the topic, it was agreed that brief semi-structured telephone interviews would be the most appropriate method to use (see Appendix P). The breast care nurse personally contacted patients who were seen for the screening procedure and informed them about the interview and gained verbal consent. The names and contact numbers for the patients who consented were given to the assistant psychologist who contacted them to carry out the brief semi-structured telephone interview. It was stressed to patients on the phone that the interview was purely to ask about the procedure of the screening and that they were not being asked to divulge any personal experiences or feelings.

4.3 Results

4.3.1 Adult Mental Health Referrals

Oncology referrals to both the primary and secondary psychological therapies teams were monitored over an eight week period. In that time, one referral was made. This suggests a relatively low rate of referrals if this sampling period is representative of the rest of the year, and there were no factors to suggest otherwise.

4.3.2 File Review

4.3.2.1 Breast unit. Of the 20 files audited, 13 mentioned psychological distress in the notes, which was described in various terms including “anxious”, “upset”, “emotional”, “unhappy” and “depressed”. It was indicated in 13/20 cases that “psychological support” was offered or provided, as noted by a tick box response in an admission form. However, in only three cases were specific psychological care plans indicated, and on two occasions these indicated referral to psychology. “No distress” was noted in 4/20 cases (Figure 8).

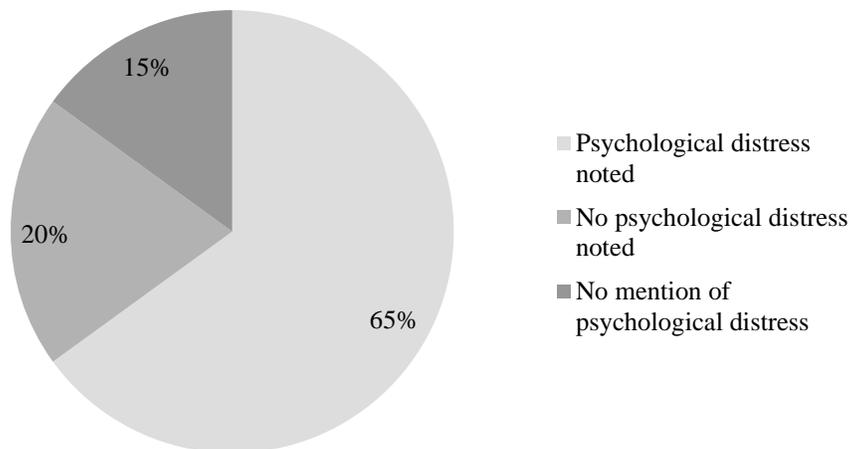


Figure 8. Percentage of cases reporting psychological distress within the breast unit file review.

4.3.2.2 General oncology unit. Of the 30 files audited, 16 made explicit mention of issues of psychological distress and in 14 cases there was no note of distress (Figure 9). In three cases where distress was noted, it was also identified that the patient had been prescribed psychiatric medication. In two cases the CanMove programme (an exercise referral programme designed for oncology patients) was mentioned and its beneficial effects on psychological well-being. No reference was made of referral to specialist psychological treatments.

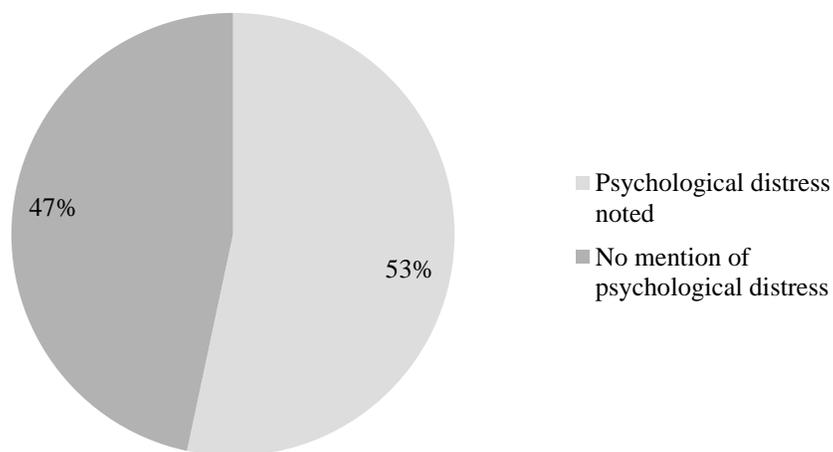


Figure 9. Percentage of cases reporting psychological distress within the general oncology unit file review.

In neither the breast unit nor general oncology unit files was there evidence of standardised screens of psychological distress being administered. Therefore there are no measures of the intensity and chronicity of the distress.

4.3.3 Oncology Nurse Knowledge and Experience

A questionnaire was designed to assess nurses' knowledge of common mental health disorders and their confidence in dealing with psychological problems. This was completed by eight nurses, five from the general oncology unit and three from the breast unit.

All the nurses exhibited good knowledge of the common symptoms of anxiety and depression, and were clearly able to state how they would assess these through interview with the patient and their family and observation whilst undergoing treatment. All respondents indicated that they frequently assess patients' mental well-being, usually at each visit; however, this is through interview and observation rather than using a standardised screening assessment at specific points during treatment. All the nurses demonstrated a good understanding of the behavioural symptoms of anxiety and depression and were able to express these clearly in their responses to the question "In what ways would you notice if someone was suffering from psychological distress e.g. if they were feeling anxious or depressed?"

Only the specialist nurse had undergone further training in assessing and treating psychological distress and this was reflected in responses to questions regarding knowledge of the assessment of other mental health difficulties such as drug and alcohol issues, personality disorders, and psychosis.

All the nurses reported a moderate level of confidence in their knowledge of psychological and support services and referral processes. This result may have been skewed somewhat as one respondent indicated they had only recently moved to the island.

Nurses' experience of referral pathways for patients with significant psychological distress yielded some interesting insights into the barriers to psychological care within local oncology services. In response to the question addressing the current referral procedure, there

appeared to be a wide range of different responses from requesting GP's to make referrals to consulting with a clinical psychologist directly. Confusion about the referral process was highlighted as the major barrier to making referrals, while other barriers included the view that mental health services are too busy, and patients would find it difficult to be referred to the mental health services due to perceived stigma that exists locally. These difficulties were reflected in that none of the four respondents had made a referral for psychological distress within the last three months.

4.3.4 Implementation of Screening Tools

The breast unit was identified as a suitable area to trial the use of standardised screening assessments, in part due to the specialist nurse already having had additional training in using screening assessments and brief CBT. The nurse was to administer the screening assessments (PHQ-9, GAD-7, and Distress Thermometer) during routine appointments, which could be at any stage of the patient's treatment.

The trial period lasted 12 weeks. Meetings between the clinical psychologist, assistant psychologist and specialist nurse were held weekly, and the specialist nurse was able to report on the use of the standardised assessments and outcomes leading from these assessments. It was at these meetings that patients identified with high levels of distress could be discussed and a psychological care plan developed if necessary, which aided in forming the overall final tiered referral pathway.

Over the 12 week trial period, 15 patients were screened. Of these, seven patients were post-treatment, three were still undergoing active treatment, and five were newly diagnosed. The majority of patients indicated at least a mild level of anxiety, and two patients indicated severe levels of anxiety. A similar pattern was noted in responses to the PHQ-9, with nine patients

reporting at least mild levels of depressive symptomatology, and three patients indicating severe levels of depression.

Scores on the Distress Thermometer reflected similar levels of distress, but as a tool it provided a greater insight into the wider range of areas that caused distress for the patients; Figure 10 displays the four most common problems. Interestingly, three out of the four areas (fears, worry, and sadness) fall under the “Emotional Problems” subsection, highlighting the importance of considering this type of problem in consultations and throughout treatment.

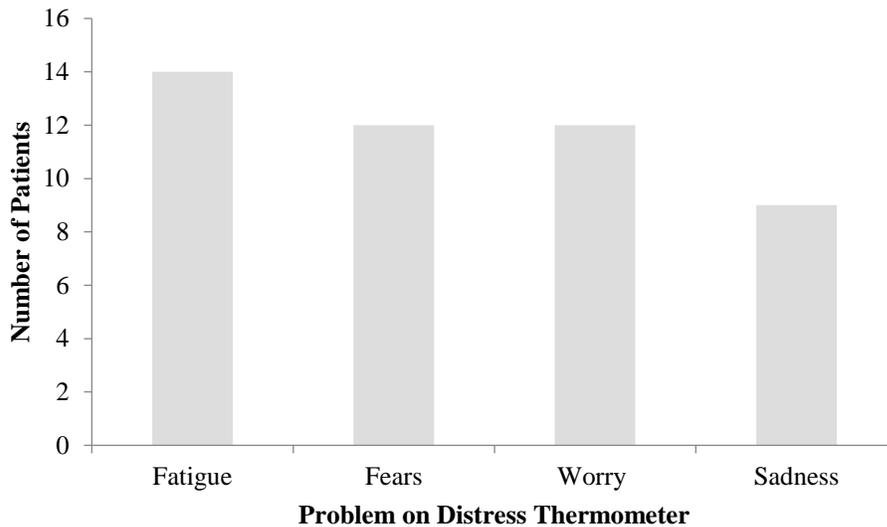


Figure 10. Four most common problems reported by patients on the Distress Thermometer.

The representativeness of this sample may be criticised as it included almost exclusively patients who were post-treatment, and research has highlighted this as a particularly difficult transition period in cancer survivorship (Zabora et al., 2001). Nevertheless, even within this group the level of distress is significant and covers a large proportion of the patients. Due to the small numbers of patients who had just been diagnosed or were undergoing treatment, it is

difficult to make meaningful generalisations about psychological distress that would be representative of a larger sample of patients.

4.3.4.1 Specialist nurse experience of administering the screening assessment. The specialist nurse reported that administering the screening tools provided a more balanced focus to her consultations with patients, with more time spent discussing and exploring psychosocial issues rather than physical symptoms and medical procedures. Preconceived conceptions about the length of time to administer the self-report measures and how they may interfere with the patient-nurse relationship were, in practice, unfounded. The specialist nurse reported that she felt the self-report measures were not a barrier to rapport building but instead helped in developing a more holistic relationship with the patient.

4.3.5 Patient Telephone Interviews: Acceptability of Screening Measures

Eight patients agreed to take part in a telephone interview; however, due to various reasons such as currently being in treatment, only five interviews took place. All five patients stated they found the screening measures easy to understand and thought they took an acceptable amount of time to complete during the consultation. When asked about their initial reaction when presented with the screening measures in their consultation, all five patients stated that they were happy to fill them in with one patient stating they thought it was “good practice for people to periodically do”. Furthermore, although one patient said she would not have discussed psychological distress if not prompted by the measures, the remaining four patients said they were very open people but the measures are a “good way to start that kind of conversation and ease you into talking about those issues”. When asked for any further comments on the process, one patient said she had been experiencing distress but did not realise until then how normal this was for someone in her position and that she could discuss it with the consultant breast nurse

who is able to offer support. Another patient at this stage in the interview commented that, although the consultation was useful for her, she was at the end of treatment and would have liked to have been offered this service while her treatment was taking place - “from the start to the end of treatment your emotions change a lot and you need that 1:1 psychological support throughout.” Another interesting comment was that the process was helpful, but it was felt this was due to the fact that the questionnaires were administered as a dialogue between the patient and the breast nurse and not just a pen and paper exercise; this comment was echoed by another patient. Finally, all the women who were contacted for the telephone interview felt that the screening process added to the excellent support they were or currently are being offered by the breast nurse and other nurses, and so they felt comfortable talking about any issues they may be facing.

4.4 Discussion

4.4.1 File Review and Nurses Knowledge of Psychological Distress

The audit of patient files in both the breast unit and general oncology unit indicated that staff frequently recorded psychological distress in clinical notes. However, this appeared to be completed in an ad hoc way, with no clear system of reporting levels of distress, and no description of the type of support or intervention given. In cases where distress was noted, there were few examples of referral to psychological services or for pharmacological interventions. Therefore, it did not appear that the standards for psychological screening and intervention as set out by NICE (2004) are being consistently attained. Why might this be occurring? At the time of audit there appeared to be several barriers.

Firstly, nurses' confidence in screening, assessing, and treating psychological distress appeared to be rather low, as evidenced by their responses in the questionnaire they completed. Interestingly, in responses about assessing distress, the nurses indicated there was a breadth of knowledge in understanding behavioural and emotional signs of distress. Langewitz et al. (2010) suggest that nurses' lack of confidence in discussing psychosocial distress may stop them from discussing psychological matters with their patients. As such, the focus of consultations becomes more medically and physically-based. The challenge is to achieve a balance between these elements and so provide a more patient-centred consultation. They note in their study that consultations moved more towards discussing psychosocial issues as a result of oncology nurses attending communication training.

Training can help to overcome these issues around a lack of confidence and knowledge. In a study that surveyed 26 inpatient oncology nurses on their educational needs in providing psychosocial care, results indicated the following areas required attention: communication skills, knowing how to approach sensitive topics, and clinical guidelines for distress and use of screening tools (Chen & Raingruber, 2014). These areas are consistent with the current audit and suggest a lack of training as a barrier to providing excellent psychosocial care.

Further training will enable the specialist oncology nurses to move from tier 1 of the four-tiered model of psychological care (NICE, 2004) to tier 2, where they are able to provide screening and some brief psychological interventions. Examples of the effectiveness of this type of training has been demonstrated through the training of palliative care nurses in CBT (Mannix et al., 2006; Moorey et al., 2009). In the study by Mannix et al. (2006), 20 palliative care clinicians were trained for 12 days in CBT techniques, with half the group receiving ongoing training. Findings demonstrated that providing relatively brief CBT training, supported by

supervision, produced significant improvements in professionals' ability to recognise emotional distress and provide appropriate interventions to reduce distress. Ongoing supervision was critical in the maintenance of the acquired skills, as recommended by NICE (2004).

Improved knowledge of psychological distress is likely to lead to an increase in referrals for treatment (Moorey, 2013). Currently, the lack of a clear referral pathway acts as another significant barrier to dealing with patients' distress, and this was reflected in both the nurses responses in the questionnaire and the audit of files and referrals to mental health services. The course of action following a positive distress screen will depend on the specific identified needs of the patient, but it could involve a stepped-care approach that ranges from group-based psychoeducation for patients with mild to moderate distress, to structured individual therapy for those with more severe levels of distress (Mitchell, 2013).

A final point to note is that training can have the benefit of reducing burnout in nurses. By providing them with a better understanding of psychological distress and equipping them with skills in order for them to better help their patients, it is possible that nurses may adopt a more positive attitude towards their patients difficulties and so experience fewer feelings of hopelessness and frustration that can contribute to feeling burnt out (Ewers, Bradshaw, McGovern, & Ewers, 2002).

4.4.2 Implementation of Screening Tools in the Breast Unit

Implementing a screening protocol in the breast unit revealed there was a significant level of psychological distress among the majority of patients who were screened, with two cases requiring a referral to specialist services. Although the proportions and level of distress reported here are consistent with findings from other studies (Cardy et al., 2006), the timing and duration

of our screening meant that most patients were at the end of their treatment and so this sample might not provide an accurate representation of local levels of psychological distress.

One of the greatest barriers to providing excellent psychosocial care is the failure to link treatment to screening result (Mitchell, 2013). In his systematic review of 24 studies, Mitchell (2013) argues that it is the provision of sufficient aftercare that is the most significant barrier to implementing successful and effective routine screening - “Without addressing aftercare, systematic adoption of distress screening in clinical practice is probably not worthwhile”. A randomised controlled trial implemented by McLachlan et al. (2001) provides evidence for the importance of providing aftercare. In this trial, patients with a positive distress screen received individualised feedback and a formulated management plan. Results indicated a significant reduction in depressive symptoms compared to those patients who just received screening alone. It appears that the opportunity to develop a management plan is critical as frontline staff who were only able to administer screening did little to influence distress (Braeken et al., 2011; Hollingworth et al., 2013).

Patients who participated in the screening at the breast unit indicated it was a broadly acceptable experience and very few negative comments were made, which reflects what has been reported in the literature that screening for distress does not cause distress (Moorey, 2013).

How services address psychological screening and the treatment of psychological distress has been a cause of much debate (Mitchell, 2013; Salmon, Clark, McGrath, & Fisher, 2014). Salmon et al. (2014, p.265) argue that future developments in psychological screening must move away from a diagnostic model of care and towards a public health model as “deciding whether a patient has psychological needs, and how these should be met, is too complex to be reduced to a simple screen for distress.” In this way “normal” distress, which can present in a

variety of ways, can be taken into account more readily and a greater sensitivity can be given to patients needs in addressing their distress, which may not always include formal psychological interventions. This also highlights the need for patient involvement in the development of screening and psychological care programs (Carlson et al., 2012).

There is no one-size-fits-all screening model that will work for every oncology service (Turner, 2015); however, there are underlying principles in several international guidelines including those of the US, Canada, Australia, and UK that have been summarised by Coleman, Hession and Connolly (2011) (Figure 11). These principles provide a framework for developing local policies and pathways to ensure excellent and effective psychosocial care is provided.

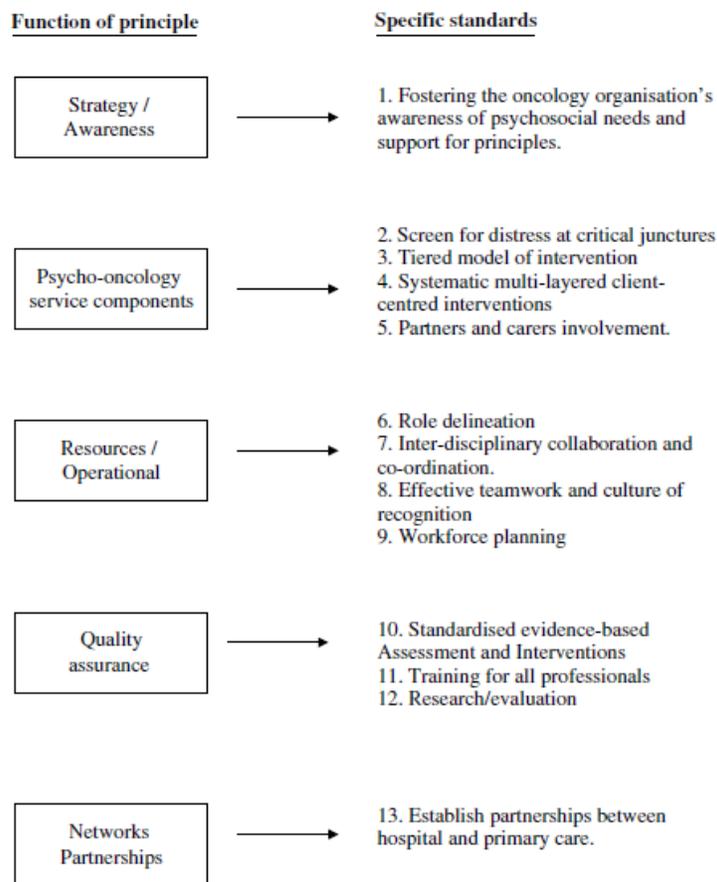


Figure 11. Summary of principles from psycho-oncology guidelines (Coleman et al., 2011).

4.4.3 Critique of Audit

The main criticism of the current audit and trial of implementing psychological distress screening is the low number of patients that were involved and the restricted period of time over which it was carried out, which raises doubts about the generalizability of some of the findings. Furthermore, this trial is limited by our sample consisting only of breast cancer patients and so caution must be taken if applying the findings to other areas of oncology. Nevertheless, overall the results were concordant with the literature on psychological distress in oncology patients and therefore it is valid to make recommendations from the current audit and trial.

4.4.4. Recommendations

Following this project, the following actions are recommended:

1. To develop a model and pathway of psychosocial care including screening, interventions, and referral across all local oncology services. This should be developed in conjunction with patients and families, GPs, and the mental health service (Appendix Q).
2. To provide tiered training for staff in the knowledge of distress screening, psychological interventions, and referral options. This should be dependent on staff grade and include consultants, nurses, and allied health professionals.
3. To carry out an annual audit of psychological screening use, referrals, and patient experience of psychosocial care.

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Appendix A – Summary of CASP Appraisal

Paper	Clear statement of aims	Appropriate methodology	Research design appropriate	Recruitment strategy appropriate	Data collected addressed research issue	Relationship between researcher and participants adequately considered	Ethical issues considered	Data analysis sufficiently rigorous	Clear statement of findings	How valuable is the research
Cheung & Hocking (2004a)	✓	✓	✓	✓	✓	×	×	✓	✓	Key
Courts et al. (2005)	✓	✓	✓	✓	✓	×	×	✓	✓	Key
Starks et al. (2010)	✓	✓	✓	✓	✓	×	×	✓	✓	Key
Boeije et al. (2003)	✓	✓	✓	✓	✓	✓	×	✓	✓	Satisfactory
Boland et al. (2012)	✓	✓	✓	✓	✓	×	✓	✓	✓	Key
Esmail et al. (2010)	✓	✓	✓	✓	✓	×	×	✓	✓	Satisfactory
Boeije & Van Doorne-Huiskes (2003)	✓	✓	✓	✓	✓	×	×	✓	✓	Satisfactory
McKeown et al. (2004)	✓	✓	✓	✓	✓	✓	✓	✓	✓	Satisfactory

Hughes et al. (2013)	✓	✓	✓	✓	✓	×	✓	✓	✓	Satisfactory
Mutch (2010)	✓	✓	✓	✓	✓	×	✓	✓	✓	Satisfactory
Heward et al. (2011)	✓	✓	✓	✓	✓	×	✓	✓	✓	Key
Esmail et al. (2007)	✓	✓	✓	✓	✓	×	×	✓	✓	Satisfactory
Heward et al. (2006)	✓	✓	✓	✓	✓	×	✓	✓	✓	Satisfactory
Cheung & Hocking (2004b)	✓	✓	✓	✓	✓	×	✓	✓	✓	Satisfactory
Hainsworth (1996)	✓	✓	✓	✓	✓	×	✓	✓	✓	Satisfactory
DesRosier et al. (1992)	✓	✓	×	✓	✓	×	×	×	✓	Satisfactory
Blank & Finlayson (2007)	✓	✓	✓	✓	✓	×	✓	✓	✓	Irrelevant
Chen & Habermann (2013)	✓	✓	✓	✓	✓	×	×	✓	✓	Irrelevant
McCurry (2013)	✓	✓	✓	✓	✓	✓	✓	✓	✓	Satisfactory
Rollero (2016)	✓	✓	✓	✓	✓	×	✓	✓	✓	Satisfactory

Appendix B – Summary of Papers Included in the Meta-synthesis

Study	Research Aims	Theoretical Framework	Population	Methodology	Analysis	Ethical Considerations	Reflexivity
Cheung & Hocking (2004a), Australia	To explore how spousal carers of people with MS interpreted their lived experience with their partner, the way in which they assigned meanings to their being in such a situation, and the skills and knowledge they have developed to live with their situation. To gain an understanding of carers' interpretation of their apparent losses.	Interpretative phenomenological analysis	<i>N</i> = 10 6 males 4 females 40 - 60 years	Unstructured in-depth interviews	Hermeneutic analysis	Informed consent was obtained	None
Courts et al. (2005), USA	To investigate the experiences of persons whose spouses have MS.	Not reported	<i>N</i> = 12 8 males (31 - 67 years) 4 females (50 - 65 years) Caucasian	Two focus groups	Thematic analysis	Informed consent was obtained	None
Starks et al. (2010), USA	To examine how couples adapt to the challenges of MS and to identify possible	Not reported	<i>N</i> = 8 couples (16 people) Partner with MS - 6 females 2 males	Survey and semi-structured interviews	Thematic analysis	Informed consent was obtained	None

Boeije & Van Doorne-Huiskes (2003), Netherlands	risk factors for relational stress. To examine how spouses experience caregiving when predominantly motivated by a sense of duty and address whether any differences between female and male caregivers can be detected.	Interpretative	40-69 years N = 13 8 males 5 females 48 - 75 years	Semi-structured interviews	Constant comparative analysis	None	Yes
Boland et al. (2012), New Zealand	To explore what to expect about how people cope as a couple.	Interpretative phenomenological analysis	N = 14 People with MS - 4 females 3 males 35 - 75 years Significant other - 3 females 4 males 43 - 74 years 12 New Zealand Europeans 2 British	Semi-structured interviews	Thematic analysis	Ethical approval obtained	None
Esmail et al. (2010), Canada	To understand the impact of MS on couples' sexual relationships when the male partner was diagnosed with MS during the relationship.	Phenomenological approach	N = 4 Heterosexual couples with male partner diagnosed with MS 18 - 60 years	In-depth semi-structured interviews	Thematic analysis	None	None

Boeije et al. (2003), Netherlands & Belgium	To examine how commitment is established between people who have become dependent on care as a result of MS and their spouses, and what their roles are in the maintenance of the caregiving role when total care is provided. To contribute to the knowledge of family care in mostly middle-aged and elderly couples.	Not reported	<i>N</i> = 17 couples Caregivers – 10 males 7 females 39 - 77 years People with MS - 7 males 10 females 44 - 78 years	Interviews loosely structured around open questions	Constant comparative analysis	None	None
McKeown et al. (2004), Northern Ireland	To gain an understanding of the experiences of a group of caregivers of people with MS.	Phenomenological approach	<i>N</i> = 16 caregivers 11 females 6 males 18 - 66 years	Four focus groups	Interpretive analysis	Ethical approval obtained	None
Hughes et al. (2013), UK	To draw on data from a qualitative research study that examined the experiences of family members and friends of pwMS to explore how they interpret the label 'carer'.	Not reported	<i>N</i> = 48 19 males 29 females 17 - 75 years Range of ethnic backgrounds	Narrative interviews	Thematic analysis	Informed consent was obtained	Yes

Mutch (2010), UK	To gain a deeper understanding of the experiences of the partner living with and caring for a spouse disabled by multiple sclerosis.	Not reported	<i>N</i> = 8 spouses 4 females (62-74 years) 4 males (50-70 years)	Interview using a semi-structured questionnaire	Thematic analysis	Informed consent was obtained	None
Heward et al. (2011), UK	To explore the psychological, emotional and identity issues faced by partners of pwMS and how they cope in unpredictable situations they are often faced with.	Grounded theory	<i>N</i> = 9 partners	Semi-structured interview	Microanalysis, constant comparative analysis, Selective coding	Ethical approval was obtained	None
Esmail et al. (2007), Canada	To investigate the personal 'lived experience' of couples in which the female partner is diagnosed with MS, and more specifically the impact of disability on sexuality.	Hermeneutic phenomenological approach	<i>N</i> = 6 couples (female partner diagnosed with MS) 32 - 58 years	In-depth semi-structured interview with each individual	Interpretative thematic analysis	None	None
Heward et al. (2006), UK	To explore the occupational impact of being a partner of someone with MS.	Constructionist grounded theory	<i>N</i> = 9 4 female 5 male	In-depth semi-structured interview	Constant comparative analysis	Ethical approval was obtained	None

Cheung & Hocking (2004b), Australia	To explore the challenges and demands encountered by spousal carers for people with MS.	Hermeneutic phenomenology	<i>N</i> = 10 6 males 4 females 40 – 60 years	Unstructured in-depth interviews	Hermeneutic analysis	Informed consent was obtained	Yes
Hainsworth (1996), USA	To explore the presence of chronic sorrow in spousal caregivers of people with MS.	None reported	<i>N</i> = 10 5 males 5 females 50 – 70 years	Interview questionnaire using Burke/NCRC Chronic Sorrow Questionnaire (Caregiver Version)	Selective coding	None	None
DesRosier et al. (1992), US	To describe social support in the everyday experience of wives caring for their husbands who have MS.	None reported	<i>N</i> = 8 females 41 – 58 years	Focus groups	Constant comparative analysis	None	None
Blank & Finlayson (2007)	To explore the impact of MS on the lives of couples living with the disease and their coping strategies.	Not reported	<i>N</i> = 4 2 females 2 males (two couples)	Semi-structured interviews	Thematic analysis	Ethical approval was obtained	None
Chen & Habermann (2013), USA	To explore how couples living with MS approach planning for health changes together.	Not reported	<i>N</i> = 10 couples 42 – 75 years Spouse with MS - 7 females 3 males Mean age 58 years	In-depth semi-structured interviews	Thematic analysis	None	None

McCurry (2013)	To explore decision making by informal caregivers of pwMS.	Not reported	<i>N</i> = 6 48 – 76 years 3 males 3 females	In-depth semi-structured interviews	Thematic content analysis	Ethical approval was obtained	Yes
Rollero (2016), Italy	To explore the experience of male care-givers living with a partner with MS.	Grounded theory approach	<i>N</i> = 24 men-husbands or partners 37 – 68 years	In-depth semi-structured interviews	Thematic analysis	Ethical approval was obtained	None

Appendix C – Ethical Approval

Jersey Health and Social Services Department Research Ethics Committee Approval Letter

Health and Social Services Department
Research Ethics Committee,
General Hospital, Gloucester Street
St Helier, Jersey, JE1 3QS



4th July 2017

Private & Confidential

[REDACTED]
Clinical Neuropsychologist
Adult Community Services
Princess Elizabeth Hospital
Rue Mignot, St Andrews
Guernsey GY6 8TW

Our ref: MJ/MT/LC

Dear [REDACTED]

Project: The effect of gender identity on help seeking and social support in male carers of people with multiple sclerosis

Thank you for submitting your research application form and accompanying information to the HSSD Research Ethics Committee. This was reviewed at our meeting on 22nd June 2017.

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion is granted for the above research pending the Committee's following recommendations.

- For Jersey participants, a paper survey version is used.
- The States of Jersey do not approve the use of Survey Monkey and therefore the HSSD Research Ethics Committee cannot approve use of it. That States of Jersey recommend the use of SmartSurvey.co.uk
- For Jersey participants, responses should go to a gov.gg address. The States of Jersey do not approve the use of personal email addresses for work purposes and therefore the HSSD Research Ethics Committee cannot approve use of it.

While the HSSD Research Committee grants a favourable opinion, you will require permission from Dr Howard Gibson to recruit participants and carry out the research.

I would like to convey the Committee's best wishes for the success of this project. The Committee would be really interested in hearing the outcome of your research.

Yours sincerely

A handwritten signature in blue ink that reads "Maureen Turner".

pp **Maureen Turner,**
Secretary of the HSSD Research Ethics Committee
Lay member (Chaplain)

direct dial: +44 (0)1534 442377
email: ma.turner@health.gov.je

NOTE: Approval of the HSSD Research Ethics Committee is valid for 3 years from date of this letter

Guernsey HSC Ethics Committee Approval Letter



IJG/CS.4

Le Vauquiedor Office
Rue Mignot
St Andrew
Guernsey
GY6 8TW
+44 (1481) 725241
www.gov.gg

Our Ref:
Your Ref:

██████████
Clinical Neuropsychologist
Adult Community Services

16 June 2017

Dear ██████████

THE EFFECT OF GENDER IDENTITY ON HELP SEEKING AND SOCIAL SUPPORT IN MALE CARERS OF PEOPLE WITH MULTIPLE SCLEROSIS

Thank you for attending the Ethics Committee meeting on Thursday 23 March 2017 to discuss your application for the above research project. At the meeting, the following documents were reviewed by the Ethics Committee:

- a) Proforma Ethics Application: Principal Researcher ██████████
- b) Research Proposal.

Members of the Committee were pleased to have had an opportunity to meet you, to hear your summary of the proposed project and to ask questions.

At the meeting, the Ethics Committee agreed to approve the proposed study, subject to clarification of points as discussed, as follows:

- i) including information on how participants could access support if completing the survey caused any emotional distress;
- ii) including sufficient participant information on-line at the start of the survey;
- iii) referring to study data being retained in accordance with the HSC policy on the Retention and Destruction of Information (G102).

On 31 March 2017, Emily Barrasin provided Ian Gaudion, Executive Assistant (Committees), with revised documentation for your research proposal and he has confirmed that the changes made have addressed the matters raised by the Ethics Committee.

On 31 May 2017, you emailed me and Ian Gaudion advising that you wished to make a small change to the project in respect of recruitment, so that paper versions of the survey, information sheet and consent form could be handed out by MS specialist nurses directly to patients. Your email was accompanied electronic versions of the survey, together with a combined information sheet / consent form. On behalf of the Ethics Committee and using Chair's action, I confirmed by email on 2 June 2017 that this change was acceptable and would be noted on a subsequent meeting agenda for information.

Therefore, on behalf of the Committee, I am pleased to formally confirm that full approval is granted for your research study.

In order to track progress of approved studies, the Ethics Committee would be grateful if you could provide regular progress reports for the project (at least annually) and / or a final report following its completion. This should be forwarded to: Ian Gaudion, Executive Assistant (Committees), The Office of the Committee for Health & Social Care, Le Vauquiedor Office, Rue Mignot, St Andrew, GY6 8TW.

The Committee and I wish you every success with your project.

Yours sincerely



Dr Tracey McClean
Chairman, Ethics Committee

University of Leicester Ethics Committee Approval Letter



University Ethics Sub-Committee for Psychology

06/04/2017

Ethics Reference: 11126-da179-neuroscience,psychologyandbehaviour

TO:

Name of Researcher Applicant: [REDACTED]

Department: Psychology

Research Project Title: The effect of gender identity on help-seeking and social support in male carers of people with multiple sclerosis.

Dear [REDACTED]

RE: Ethics review of Research Study application

The University Ethics Sub-Committee for Psychology has reviewed and discussed the above application.

1. Ethical opinion

The Sub-Committee grants ethical approval to the above research project on the basis described in the application form and supporting documentation, subject to the conditions specified below.

2. Summary of ethics review discussion

The Committee noted the following issues:
Seems OK

3. General conditions of the ethical approval

The ethics approval is subject to the following general conditions being met prior to the start of the project:

As the Principal Investigator, you are expected to deliver the research project in accordance with the University's policies and procedures, which includes the University's Research Code of Conduct and the University's Research Ethics Policy.

If relevant, management permission or approval (gate keeper role) must be obtained from host organisation prior to the start of the study at the site concerned.

4. Reporting requirements after ethical approval

You are expected to notify the Sub-Committee about:

- Significant amendments to the project
- Serious breaches of the protocol
- Annual progress reports
- Notifying the end of the study

5. Use of application information

Details from your ethics application will be stored on the University Ethics Online System. With your permission, the Sub-Committee may wish to use parts of the application in an anonymised format for training or sharing best practice. Please let me know if you do not want the application details to be used in this manner.

Best wishes for the success of this research project.

Yours sincerely,

Prof. Panos Vostanis
Chair

North of Scotland Research Ethics Committee Favourable Opinion on Further Information Letter

North of Scotland Research Ethics Committee (1)

Summerfield House
2 Eday Road
Aberdeen
AB15 8RE

Telephone: 01224 558458
Facsimile: 01224 558609
Email: nosres@nhs.net



Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

10 November 2017

██████████
Princess Elizabeth Hospital
ST MARTINS
Guernsey
GY6 8TW

Dear ██████████

Study title: The effect of gender identity on help seeking and social support in male family members of people with multiple sclerosis.
REC reference: 17/NS/0111
Protocol number: 0629
IRAS project ID: 231942

Thank you for your e-submission of 10 November 2017, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University Insurance]	1	28 July 2017
IRAS Application Form	231942/114 6280/37/87 4	02 October 2017
IRAS Checklist XML [Checklist 10.11.2017]		10 November 2017
Letter from sponsor [Indemnity letter - signed by Sue Banbury]		28 September 2017
Letters of invitation to participant [Study advert]	1	21 September 2017
Participant consent form	1	18 October 2017
Participant information sheet (PIS) [Participant IS comments]	v.2	08 November 2017
Research protocol or project proposal	1	08 August 2017
Summary CV for Chief Investigator (CI) [REDACTED]	1	18 October 2017
Summary CV for student [REDACTED]	1	18 October 2017
Summary CV for supervisor (student research) [Noelle Robertson]	1	18 October 2017
Validated questionnaire [Questionnaire]	1	18 October 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/NS/0111	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



Professor Nigel R Webster
Chair

Enclosures: "After ethical review – guidance for researchers" SL-AR2

Copy to: Dr Diane Delahooke
Ms Carolyn Maloney, University Hospitals of Leicester

Submission No 64/2017 from LREC to Department of Health and Social Care

**Submission No 64/2017 from LREC
to Department of Health and Social Care**

LREC Project application

<u>Applicant</u>	<u>Name</u>	[REDACTED]
	<u>e-mail</u>	[REDACTED]
<u>Title of Project</u>		<u>The effect of gender identity on help seeking and social support in male carers of people with multiple sclerosis</u>
<u>Date considered by Committee</u>		19 July 2017 & 16 August 2017
<u>Recommendation</u>		Approval
<u>Conditions (if any)</u>		Amendments shown and agreed in his letter of 3 rd August must be incorporated. We would request to see the results of this research.
<u>Comment</u>		
<u>Documents attached</u>		Full documents

Submitted by Derek M Legg, Secretary to LREC dated 16 August 2017

DHSC Decision

Approved

Comments: none

Signed:  Date: 23 August 2017
Dr Malcolm Couch, Chief Executive Officer
Department of Health and Social Care

Letter of NHS Health Research Authority Approval



Health Research Authority

██████████
Princess Elizabeth Hospital
St Martins
Guernsey
GY6 8TW

Email: hra.approval@nhs.net

20 November 2017

Dear ██████████

Letter of HRA Approval

Study title:	The effect of gender identity on help seeking and social support in male family members of people with multiple sclerosis.
IRAS project ID:	231942
Protocol number:	0629
REC reference:	17/NS/0111
Sponsor	University of Leicester

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

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It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from the [HRA website](#).

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through [IRAS](#).

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the [HRA website](#).

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HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details on the [HRA website](#).

Your IRAS project ID is **231942**. Please quote this on all correspondence.

Yours sincerely

Juliana Araujo

Assessor

Email: hra.approval@nhs.net

*Copy to: Sponsor Representative: Dr Diane Delahooke, University of Leicester
Lead NHS R&D Office Representative: Ms Carolyn Maloney, University Hospitals
of Leicester NHS Trust*

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Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University Insurance]	1	28 July 2017
HRA Schedule of Events [HRA Schedule of Events (Reviewed)]	1.0	20 November 2017
HRA Statement of Activities [HRA Statement of Activities (Reviewed)]	1.0	20 November 2017
IRAS Application Form	231942/114 6280/37/87 4	02 October 2017
Letter from sponsor [Indemnity letter - signed by Sue Banbury]		28 September 2017
Letters of invitation to participant [Study advert]	1	21 September 2017
Participant consent form	1	18 October 2017
Participant information sheet (PIS) [Participant IS comments]	v.2	08 November 2017
Research protocol or project proposal	1	08 August 2017
Summary CV for Chief Investigator (CI) [REDACTED]	1	18 October 2017
Summary CV for student [REDACTED]	1	18 October 2017
Summary CV for supervisor (student research) [Noelle Robertson]	1	18 October 2017
Validated questionnaire [Questionnaire]	1	18 October 2017
231942 17 NS 0111 PRS Favourable Opinion on Further Information Letter 10.11.2017.pdf		10 November 2017
231942 17 NS 0111 Researcher's responses to Validation Findings 18.10.2017.pdf		20 October 2017
231942 17-NS-0111 VUC - Email Request - 17.10.2017.pdf		10 October 2017
231942 17 NS 0111 PRS Application Valid Letter 20.10.2017.pdf		20 October 2017
231942 17 NS 0111 PRS Provisional Opinion Letter 31.10.2017.pdf		31 October 2017

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Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.*

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Dr Diane Delahooke
 Tel: 0116 223 1660/ 373 6410
 Email: uolsponsor@le.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	Multiple NHS organisations will be involved in this study. Only the University Hospitals of Leicester NHS Trust has confirmed involvement as a Participant Identification Centre at this date.
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The Statement of Activities will form the agreement between the sponsor and the participating NHS organisations. The Schedule of Events was submitted.

Section	HRA Assessment Criteria	Compliant with Standards	Comments
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No funding application was made for the study.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	NHS Research Ethics Committee favourable opinion was confirmed by the North of Scotland Research Ethics Committee on 10 November 2017.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

<i>This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.</i>
<p>This is a multi-site study undertaking the same research activities; there is therefore one research type.</p> <p>Some participants may also be recruited outside the NHS. HRA approval does not cover activity outside the NHS. Before recruiting outside the NHS the research team must follow the procedures and governance arrangements of responsible organisations.</p> <p>The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.</p> <p>If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.</p>

Confirmation of Capacity and Capability

<i>This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.</i>
<p>Participating NHS organisations in England will be expected to formally confirm their capacity and capability to host this research.</p> <ul style="list-style-type: none"> • Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the <i>Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)</i> section of this appendix. • The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

<i>This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).</i>
<p>No Local Collaborator or Principal Investigator will be expected.</p> <p>GCP training is <u>not</u> a generic training expectation, in line with the HRA/MHRA statement on training</p>

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[expectations.](#)

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

HR Good Practice Resource requirements are not applicable, as no research activities will take place in areas where healthcare is delivered.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix D – Information Sheet, Consent Form, and Survey



Help-Seeking and Social Support in Husbands/Partners/Spouses & other male significant others of people with Multiple Sclerosis

1. Information & Consent

Name of the institution responsible for the study: University of Leicester.

IRAS number: 231942

Researcher: [REDACTED] Clinical Neuropsychologist.

This research is asking male family members (husband/partner/son/father) and significant others of people with multiple sclerosis (MS) to complete a series of online questionnaires investigating levels of social support, carer burden, willingness to seek help and attributes related to gender role.

If you decide to complete this survey, you will be required to complete it in one sitting, which means you cannot save your responses half way through and come back to it later to complete. It should take approximately 20- 30 minutes to complete and your time is greatly appreciated.

Your responses will be anonymous and no identifiable information will be included in any reports that are produced with the results of this survey. The responses will be stored securely on a computer that only the research team has access to and all data will be destroyed after 7 years. Should you wish to withdraw at any time, you have every right to do so and will need to contact the researchers to request this.

By choosing to complete this survey and submit your results, you are agreeing to the terms above and consenting to your anonymous data to be used in a research report. You are also confirming that you are a male family member or significant other of a person with MS.

Should you wish to do so, you can choose to provide your contact details in the form of an email address to be entered into a draw to win one of four £50/\$50 Amazon vouchers.

If completing this survey causes you any emotional distress, please contact your GP to talk through support options that may be available to you.

We thank you again for your time taken to complete this survey. Should you wish to complete the questionnaires in written form, please contact the researchers and this can be arranged.

Contact Details:

Please email [REDACTED] if you have any other questions or require further information.

If you have any complaints or concerns please contact Noelle Robertson, Academic Supervisor,
Leicester University nr6@leicester.ac.uk

1. How old are you?

2. What country do you live in? e.g. Australia/ Guernsey/ UK

3. How long have you been supporting/caring for someone with MS? (partner/spouse/parent/child)

4. How long have you been in a relationship with the above person with MS?

5. If you have children, how many children do you have?

6. If you have children, how old are they?

7. How many hours a week do you work?

8. How many hours of professional care for support with physical needs do you receive?

9. How many hours of professional support (GP, Consultant, and other health professionals) do you receive?

10. How many hours do you spend attending psychological therapy/counselling/support groups?

11. Please read the following statements and indicate the extent to which you agree with them by selecting the corresponding circle next to the statement.

	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
Affection with other men makes me tense	<input type="radio"/>					
Talking (about my feelings) during sexual relations is difficult for me	<input type="radio"/>					
I have difficulty expressing my emotional needs to my partner	<input type="radio"/>					
Men who touch other men make me uncomfortable	<input type="radio"/>					
Finding time to relax is difficult for me	<input type="radio"/>					
I have difficulty expressing my tender feelings	<input type="radio"/>					
Hugging other men is difficult for me	<input type="radio"/>					
Winning is a measure of my value and personal worth	<input type="radio"/>					
My needs to work or study keep me from my family or leisure more than I would like	<input type="radio"/>					
I strive to be more successful than others	<input type="radio"/>					
I do not like to show my emotions to other people	<input type="radio"/>					

	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
My work or school often disrupts other parts of my life (home, health, leisure, etc)	<input type="radio"/>					
Being very personal with other men makes me feel uncomfortable	<input type="radio"/>					
Being smarter or physically stronger than other men is important to me	<input type="radio"/>					
Overwork and stress, caused by a need to achieve on the job or in school, affects/hurts my life	<input type="radio"/>					
I like to feel superior to other people	<input type="radio"/>					

12. How often do you feel...

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
that because of the time you spend with your relative that you don't have enough time for yourself?	<input type="radio"/>				
stressed between caring for your relative and trying to meet other responsibilities (work/family)?	<input type="radio"/>				
angry when you are around your relative?	<input type="radio"/>				
that your relative currently affects your relationship with family members or friends in a negative way?	<input type="radio"/>				
strained when you are around your relative?	<input type="radio"/>				
that your health has suffered because of your involvement with your relative?	<input type="radio"/>				
that you don't have as much privacy as you would like because of your relative?	<input type="radio"/>				
that your social life has suffered because you are caring for your relative?	<input type="radio"/>				
that you have lost control of your life since your relative's illness?	<input type="radio"/>				
uncertain about what to do about your relative?	<input type="radio"/>				
you should be doing more for your relative?	<input type="radio"/>				
you could do a better job in caring for your relative?	<input type="radio"/>				

13. If you needed it, how often is someone available...

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
to help you if you were confined to bed?	<input type="radio"/>				
to take you to the doctor if you need it?	<input type="radio"/>				
to prepare your meals if you are unable to do it yourself?	<input type="radio"/>				
to help with daily chores if you were sick?	<input type="radio"/>				
to have a good time with?	<input type="radio"/>				
to turn to for suggestions about how to deal with a personal problem?	<input type="radio"/>				
who understands your problems?	<input type="radio"/>				
to love and make you feel wanted?	<input type="radio"/>				

14. Please read the following statements and indicate the extent to which you identify with them by selecting the corresponding circle next to the statement.

	Do not identify with statement at all	Do not identify with statement	Identify with statement	Identify completely with statement
If I were afraid of heights, I would try to conceal this from my friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
No conflict in our marriage could be so severe that my partner and I could not solve it on our own	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were a problem to develop in my sex life, I would either need to solve it alone or to live with it, because I would not be able to discuss it with anyone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If, for whatever reason, I were to have prolonged difficulty walking, I would do whatever possible to avoid asking help from anyone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Do not identify with statement at all	Do not identify with statement	Identify with statement	Identify completely with statement
When something breaks down in my home, I usually persist in trying to fix it myself, even when it is difficult and I am wasting time and money	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I were suddenly afraid to go out in the street, I believe I could overcome without help from anyone else	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If a serious problem were to arise in my marriage, I would be willing to talk about it with a professional, or with a friend or relative, but in any case I would not keep it to myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexual problems are a difficult topic to talk about, but if I were to have such a problem I would use the services of an expert	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I ever have difficulty seeing, I will try to arrange my life so no one will notice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I were to lose control and hurt my child in a moment of anger, I would need to make sure that no one would know about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discovering unexpectedly that my spouse was hitting my child too hard would lead me to seek out someone who could intervene as quickly as possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were my spouse to suggest that we go to a family therapist, I would take the position that we are able to solve our own problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Do not identify with statement at all	Do not identify with statement	Identify with statement	Identify completely with statement
I believe that a time of mourning for a loved one would be a time when I would need other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If both legs were to be broken in an accident, I would prefer to stay home for a few months rather than be pushed around in a wheelchair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some problems are so distressing that they cannot be managed alone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I were to develop an irrational fear of the dark and I were concerned that it might affect my child, I would seek out a person who could help me overcome my fear	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
At the funeral of a loved one, I would do all I could do to appear strong and not show any weakness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I had a chronic illness, such as diabetes, I would seek out persons who could offer me guidance in addition to the medical treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If a member of my family were to become mentally ill, I would hope for contact with an expert who could advise me in how I might be of help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I thought I had a problem of excessive drinking, I could discuss it with persons who might be able to help me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Problems of sexual dysfunction would cause me to seek outside help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Do not identify with statement at all	Do not identify with statement	Identify with statement	Identify completely with statement
During a period of bereavement for a loved one, I would allow friends and relatives to take over some of the tasks for which I am usually responsible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Becoming addicted to drugs is the kind of situation that would cause me to place my fate in the hands of an expert	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If, in the course of medical treatment for a physical ailment, I were to experience serious anxiety, I would ask the doctor to treat the anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I am ever depressed, I will seek out the appropriate person to tell about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. The items below inquire about what kind of person you think you are. Each item consists of a PAIR of characteristics, with the letters A-E in between. For example:

Not at all artistic A.....B.....C.....D.....E Very artistic

Each pair describes contradictory characteristics - that is, you cannot be both at the same time, such as very artistic and not at all artistic.

The letters form a scale between the two extremes. You are to chose a letter which describes where YOU fall on the scale. For example, if you think that you have no artistic ability, you would choose A. If you think that you are pretty good, you might choose D. If you are only medium, you might choose C, and so forth.

	A	B	C	D	E
Not at all aggressive - Very aggressive	<input type="radio"/>				
Not at all independent - Very independent	<input type="radio"/>				
Not at all emotional - Very emotional	<input type="radio"/>				
Very submissive - Very dominant	<input type="radio"/>				

	A	B	C	D	E
Not at all excitable in a major crisis - Very excitable in a major crisis	<input type="radio"/>				
Very passive - Very active	<input type="radio"/>				
Not at all able to devote - Able to devote self completely to others self completely to others	<input type="radio"/>				
Very rough - Very gentle	<input type="radio"/>				
Not at all helpful to others - Very helpful to others	<input type="radio"/>				
Not at all competitive - Very competitive	<input type="radio"/>				
Very home oriented - Very worldly	<input type="radio"/>				
Not at all kind - Very kind	<input type="radio"/>				
Indifferent to others' approval - Highly needful of others' approval	<input type="radio"/>				
Feelings not easily hurt - Feelings easily hurt	<input type="radio"/>				
Not at all aware of feelings of others - Very aware of feelings of others	<input type="radio"/>				
Can make decisions easily - Has difficulty making decisions	<input type="radio"/>				
Gives up very easily - Never gives up easily	<input type="radio"/>				
Never cries - Cries very easily	<input type="radio"/>				
Not at all self-confident - Very self-confident	<input type="radio"/>				
Feels very inferior - Feels very superior	<input type="radio"/>				

	A	B	C	D	E
Not at all understanding of others - Very understanding of others	<input type="radio"/>				
Very cold in relations with others - Very warm in relations with others	<input type="radio"/>				
Very little need for security - Very strong need for security	<input type="radio"/>				
Goes to pieces under pressure - Stands up well under pressure	<input type="radio"/>				

16. If you wish, you can leave an email address/telephone number below to be entered into a draw to win one of four £50/\$50 Amazon vouchers. This is completely optional.

Thank you again for taking the time to complete this survey, it is greatly appreciated.

If you feel completing this survey has caused you any emotional distress and you are concerned, please contact your GP to talk through the support that may be available to you in your area.

Appendix E – Power Calculations

G*Power 3.1.9.2

Tests – Linear multiple regression: Fixed model, R^2 increase

Analysis: A priori: Compute required sample size

Input: Effect size f^2 = 0.20

α err prob = 0.05

Power ($1-\beta$ err prob) = 0.8

Number of tested predictors = 6

Total number of predictors = 6

Output: Noncentrality parameter λ = 15.0000000

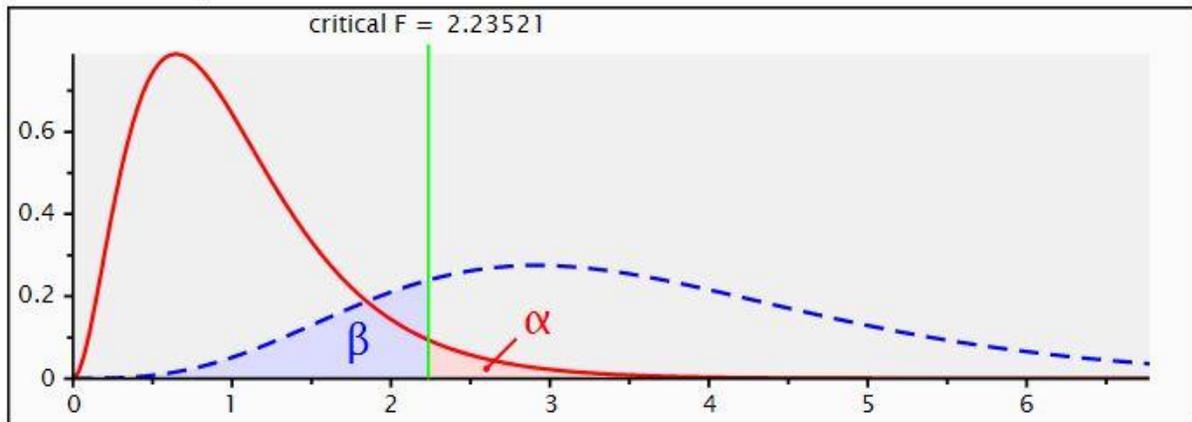
Critical F = 2.2352104

Numerator df = 6

Denominator df = 68

Total sample size = 75

Actual power = 0.8023187



Appendix F – Correlation Analysis SPSS Output

Correlations		Gender Role Conflict Scale Short Form	GRCS - Success, Power & Competition	GRCS - Restrictive Emotionality	GRCS - Restrictive Affectionate Behaviour Between Men	GRCS - Conflict Between Work and Family Relations	Zarit Burden Interview	Eight item modified Medical Outcome Study Social Support Survey	mMOS-SS Instrumental	mMOS-SS Emotional	Willingness to Seek Help Questionnaire	Personality Attributes Questionnaire	PAQ - Expressivity	PAQ - Instrumentality	PAQ - Androgyny	GRC3
Gender Role Conflict Scale Short Form	Pearson Correlation	1	.699**	.672**	.633**	.621**	.390**	-0.084	0.007	-0.132	.264*	-0.114	-.341**	0.020	0.111	.954**
	Sig. (2-tailed)		0.000	0.000	0.000	0.000	0.001	0.514	0.959	0.302	0.035	0.369	0.006	0.878	0.381	0.000
	N	64	64	64	64	64	64	63	63	63	64	64	64	64	64	64
GRCS - Success, Power & Competition	Pearson Correlation	.699**	1	.431**	0.188	.312*	.326**	0.146	0.213	0.139	0.139	0.106	-0.071	0.201	0.076	.453**
	Sig. (2-tailed)	0.000		0.000	0.136	0.012	0.009	0.255	0.093	0.277	0.272	0.407	0.579	0.111	0.549	0.000
	N	64	64	64	64	64	64	63	63	63	64	64	64	64	64	64
GRCS - Restrictive Emotionality	Pearson Correlation	.672**	.431**	1	0.186	0.186	.443**	-0.226	-0.067	-0.234	0.000	-.293*	-.458**	-0.152	0.049	.662**
	Sig. (2-tailed)	0.000	0.000		0.141	0.141	0.000	0.075	0.601	0.064	1.000	0.019	0.000	0.232	0.698	0.000
	N	64	64	64	64	64	64	63	63	63	64	64	64	64	64	64
GRCS - Restrictive Affectionate Behaviour Between Men	Pearson Correlation	.633**	0.188	0.186	1	0.157	-0.027	-0.125	-0.099	-0.180	.298*	-0.046	-0.192	0.039	0.078	.705**
	Sig. (2-tailed)	0.000	0.136	0.141		0.215	0.833	0.330	0.441	0.159	0.017	0.719	0.129	0.758	0.538	0.000
	N	64	64	64	64	64	64	63	63	63	64	64	64	64	64	64
GRCS - Conflict Between Work and Family Relations	Pearson Correlation	.621**	.312*	0.186	0.157	1	.332**	0.023	0.025	-0.029	0.213	-0.049	-0.151	-0.022	0.080	.645**
	Sig. (2-tailed)	0.000	0.012	0.141	0.215		0.007	0.857	0.844	0.820	0.092	0.701	0.235	0.865	0.371	0.000
	N	64	64	64	64	64	64	63	63	63	64	64	64	64	64	64
Zarit Burden Interview	Pearson Correlation	.390**	.326**	.443**	-0.027	.332**	1	-0.238	-0.157	-0.238	0.132	-0.093	-0.056	-0.038	-0.108	.351**
	Sig. (2-tailed)	0.001	0.009	0.000	0.833	0.007		0.060	0.218	0.061	0.298	0.467	0.658	0.767	0.698	0.004
	N	64	64	64	64	64	64	63	63	63	64	64	64	64	64	64
Eight item modified Medical Outcome Study Social Support Survey	Pearson Correlation	-0.084	0.146	-0.226	-0.125	0.023	-0.238	1	.849**	.921**	0.116	0.098	0.142	0.020	0.037	-0.163
	Sig. (2-tailed)	0.514	0.255	0.075	0.330	0.857	0.060		0.000	0.000	0.365	0.443	0.267	0.875	0.772	0.201
	N	63	63	63	63	63	63	63	63	63	63	63	63	63	63	63
mMOS-SS Instrumental	Pearson Correlation	0.007	0.213	-0.067	-0.099	0.025	-0.157	.849**	1	.657**	-0.054	0.078	0.081	-0.028	0.115	-0.073
	Sig. (2-tailed)	0.959	0.093	0.601	0.441	0.844	0.218	0.000		0.000	0.676	0.543	0.528	0.831	0.371	0.568
	N	63	63	63	63	63	63	63	63	63	63	63	63	63	63	63
mMOS-SS Emotional	Pearson Correlation	-0.132	0.139	-0.234	-0.180	-0.029	-0.238	.921**	.657**	1	0.165	0.112	0.189	0.050	-0.020	-0.221
	Sig. (2-tailed)	0.302	0.277	0.064	0.159	0.820	0.061	0.000	0.000		0.195	0.381	0.138	0.696	0.878	0.081
	N	63	63	63	63	63	63	63	63	63	63	63	63	63	63	63
Willingness to Seek Help Questionnaire	Pearson Correlation	.264*	0.139	0.000	.298*	0.213	0.132	0.116	-0.054	0.165	1	-0.004	-0.122	0.020	0.095	.262*
	Sig. (2-tailed)	0.035	0.272	1.000	0.017	0.092	0.298	0.365	0.676	0.195		0.976	0.337	0.876	0.457	0.036
	N	64	64	64	64	64	64	63	63	63	64	64	64	64	64	64
Personality Attributes Questionnaire	Pearson Correlation	-0.114	0.106	-.293*	-0.046	-0.049	-0.093	0.098	0.078	0.112	-0.004	1	.607**	.899**	.466**	-0.186
	Sig. (2-tailed)	0.369	0.407	0.019	0.719	0.701	0.467	0.443	0.543	0.381	0.976		0.000	0.000	0.000	0.141
	N	64	64	64	64	64	64	63	63	63	64	64	64	64	64	64
PAQ - Expressivity	Pearson Correlation	-.341**	-0.071	-.458**	-0.192	-0.151	-0.056	0.142	0.081	0.189	-0.122	.607**	1	.419**	-.304*	-.392**
	Sig. (2-tailed)	0.006	0.579	0.000	0.129	0.235	0.658	0.267	0.528	0.138	0.337	0.000		0.001	0.015	0.001
	N	64	64	64	64	64	64	63	63	63	64	64	64	64	64	64
PAQ - Instrumentality	Pearson Correlation	0.020	0.201	-0.152	0.039	-0.022	-0.038	0.020	-0.028	0.050	0.020	.899**	.419**	1	.341**	-0.061
	Sig. (2-tailed)	0.878	0.111	0.232	0.758	0.865	0.767	0.875	0.831	0.696	0.876	0.000	0.001		0.006	0.635
	N	64	64	64	64	64	64	63	63	63	64	64	64	64	64	64
PAQ - Androgyny	Pearson Correlation	0.111	0.076	0.049	0.078	0.080	-0.108	0.037	0.115	-0.020	0.095	.466**	-.304*	.341**	1	0.103
	Sig. (2-tailed)	0.381	0.549	0.698	0.538	0.532	0.396	0.772	0.371	0.878	0.457	0.000	0.015	0.006		0.416
	N	64	64	64	64	64	64	63	63	63	64	64	64	64	64	64
GRC3	Pearson Correlation	.954**	.453**	.662**	.705**	.645**	.351**	-0.163	-0.073	-0.221	.262*	-0.186	-.392**	-0.061	0.103	1
	Sig. (2-tailed)	0.000	0.000	0.000	0.000	0.000	0.004	0.201	0.568	0.081	0.036	0.141	0.001	0.635	0.416	
	N	64	64	64	64	64	64	63	63	63	64	64	64	64	64	64

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

Appendix G – Principal Component Analysis SPSS Output

KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.660
Bartlett's Test of Sphericity	Approx. Chi-Square	76.454
	df	28
	Sig.	.000

Communalities

	Initial	Extraction
Age	1.000	.765
Years_caring	1.000	.658
Years_relationship	1.000	.691
Number_children	1.000	.684
Hours_work	1.000	.570
Hours_professional_support_physical_needs	1.000	.728
Hours_professional_support	1.000	.719
Hours_therapy_counseling_supportgroup	1.000	.408

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	% of			% of			% of		
	Total	Variance	Cumulative %	Total	Variance	Cumulative %	Total	Variance	Cumulative %
1	2.638	32.979	32.979	2.638	32.979	32.979	2.533	31.668	31.668
2	1.540	19.250	52.228	1.540	19.250	52.228	1.568	19.594	51.263
3	1.046	13.076	65.304	1.046	13.076	65.304	1.123	14.041	65.304
4	.921	11.518	76.822						
5	.632	7.900	84.722						
6	.547	6.835	91.557						
7	.384	4.804	96.361						
8	.291	3.639	100.000						

Extraction Method: Principal Component Analysis.

Component Matrix^a

	Component		
	1	2	3
Age	.832	-.133	.237
Years_caring	.785	-.143	.147
Years_relationship	.821	.121	.050
Number_children	.212	.763	.239
Hours_work	-.692	.272	.130
Hours_professional_s	.226	.309	-.763
upport_physical_needs			
Hours_professional_s	.158	.830	-.066
upport			
Hours_therapy_coun	-.237	.216	.553
selling_supportgroup			

Extraction Method: Principal Component Analysis.
a. 3 components extracted.

Rotated Component Matrix^a

	Component		
	1	2	3
Age	.872	.036	-.058
Years_caring	.811	.009	.019
Years_relationship	.776	.265	.137
Number_children	.108	.808	-.141
Hours_work	-.690	.160	-.262
Hours_professional_s	.004	.267	.811
upport_physical_needs			
Hours_professional_s	-.018	.834	.148
upport			
Hours_therapy_coun	-.156	.225	-.577
selling_supportgroup			

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser
Normalization.^a

a. Rotation converged in 4 iterations.

Component Transformation Matrix

Component	1	2	3
1	.961	.172	.218
2	-.188	.980	.059
3	.203	.098	-.974

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

Appendix H – Regression Analysis SPSS Output: Help-Seeking

Model Summary^h

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.300 ^a	.090	.075	5.71124	.090	6.027	1	61	.017
2	.362 ^b	.131	.102	5.62711	.041	2.838	1	60	.097
3	.381 ^c	.145	.102	5.62876	.014	.965	1	59	.330
4	.384 ^d	.147	.088	5.67003	.002	.144	1	58	.705
5	.384 ^e	.147	.073	5.71841	.000	.023	1	57	.881
6	.421 ^f	.177	.089	5.66851	.030	2.008	1	56	.162
7	.448 ^g	.200	.099	5.63760	.023	1.616	1	55	.209

a. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey

b. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey, PAQ - Expressivity

c. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey, PAQ - Expressivity, GRCS - Restrictive Affectionate Behaviour Between Men

d. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey, PAQ - Expressivity, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS - Conflict Between Work and Family Relations

e. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey, PAQ - Expressivity, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS - Conflict Between Work and Family Relations, GRCS -Restrictive Emotionality

f. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey, PAQ - Expressivity, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS - Conflict Between Work and Family Relations, GRCS -Restrictive Emotionality, GRCS - Success, Power & Competition

g. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey, PAQ - Expressivity, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS - Conflict Between Work and Family Relations, GRCS -Restrictive Emotionality, GRCS - Success, Power & Competition, PAQ - Instrumentality

h. Dependent Variable: Willingness to Seek Help Questionnaire

ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	196.602	1	196.602	6.027	.017 ^b
	Residual	1989.716	61	32.618		
	Total	2186.317	62			
2	Regression	286.459	2	143.229	4.523	.015 ^c
	Residual	1899.859	60	31.664		
	Total	2186.317	62			
3	Regression	317.027	3	105.676	3.335	.025 ^d
	Residual	1869.291	59	31.683		
	Total	2186.317	62			
4	Regression	321.664	4	80.416	2.501	.052 ^e
	Residual	1864.654	58	32.149		
	Total	2186.317	62			
5	Regression	322.408	5	64.482	1.972	.097 ^f
	Residual	1863.909	57	32.700		
	Total	2186.317	62			
6	Regression	386.928	6	64.488	2.007	.080 ^g
	Residual	1799.390	56	32.132		
	Total	2186.317	62			
7	Regression	438.277	7	62.611	1.970	.076 ^h
	Residual	1748.040	55	31.783		
	Total	2186.317	62			

a. Dependent Variable: Willingness to Seek Help Questionnaire

b. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey

c. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey, PAQ - Expressivity

d. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey, PAQ - Expressivity, GRCS - Restrictive Affectionate Behaviour Between Men

e. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey, PAQ - Expressivity, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS - Conflict Between Work and Family Relations

f. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey, PAQ - Expressivity, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS - Conflict Between Work and Family Relations, GRCS -Restrictive Emotionality

g. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey, PAQ - Expressivity, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS - Conflict Between Work and Family Relations, GRCS -Restrictive Emotionality, GRCS - Success, Power & Competition

h. Predictors: (Constant), Eight item modified Medical Outcome Study Social Support Survey, PAQ - Expressivity, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS - Conflict Between Work and Family Relations, GRCS -Restrictive Emotionality, GRCS - Success, Power & Competition, PAQ - Instrumentality

Coefficients^a

Model		Unstandardized		Standardize	t	Sig.
		B	Std. Error	d Coefficients Beta		
1	(Constant)	35.481	2.109		16.820	.000
	Eight item modified Medical Outcome Study Social Support Survey	.231	.094	.300	2.455	.017
2	(Constant)	30.629	3.552		8.624	.000
	Eight item modified Medical Outcome Study Social Support Survey	.217	.093	.282	2.331	.023
	PAQ - Expressivity	.250	.148	.204	1.685	.097
3	(Constant)	33.003	4.297		7.681	.000
	Eight item modified Medical Outcome Study Social Support Survey	.210	.093	.273	2.255	.028
	PAQ - Expressivity	.228	.150	.185	1.517	.135
	GRCS - Restrictive Affectionate Behaviour Between Men	-.136	.139	-.120	-.982	.330
4	(Constant)	33.853	4.873		6.947	.000

	Eight item modified Medical Outcome Study Social Support Survey	.212	.094	.275	2.252	.028
	PAQ - Expressivity	.220	.153	.179	1.436	.156
	GRCS - Restrictive Affectionate Behaviour Between Men	-.128	.141	-.113	-.904	.370
	GRCS - Conflict Between Work and Family Relations	-.061	.160	-.047	-.380	.705
<u>5</u>	(Constant)	34.566	6.817		5.070	.000
	Eight item modified Medical Outcome Study Social Support Survey	.207	.099	.270	2.100	.040
	PAQ - Expressivity	.205	.182	.167	1.128	.264
	GRCS - Restrictive Affectionate Behaviour Between Men	-.124	.145	-.109	-.850	.399
	GRCS - Conflict Between Work and Family Relations	-.059	.161	-.046	-.365	.717
	GRCS -Restrictive Emotionality	-.031	.204	-.024	-.151	.881
<u>6</u>	(Constant)	33.221	6.824		4.868	.000

	Eight item modified Medical Outcome Study Social Support Survey	.246	.102	.319	2.418	.019
	PAQ - Expressivity	.246	.182	.201	1.350	.182
	GRCS - Restrictive Affectionate Behaviour Between Men	-.087	.146	-.077	-.597	.553
	GRCS - Conflict Between Work and Family Relations	-.005	.165	-.004	-.028	.978
	GRCS -Restrictive Emotionality	.101	.223	.078	.453	.652
	GRCS - Success, Power & Competition	-.297	.210	-.206	-1.417	.162
<u>7</u>	(Constant)	32.292	6.826		4.731	.000
	Eight item modified Medical Outcome Study Social Support Survey	.245	.101	.318	2.426	.019
	PAQ - Expressivity	.121	.207	.098	.585	.561
	GRCS - Restrictive Affectionate Behaviour Between Men	-.098	.146	-.086	-.670	.506

GRCS - Conflict Between Work and Family Relations	.008	.164	.006	.046	.963
GRCS -Restrictive Emotionality	.086	.222	.066	.389	.699
GRCS - Success, Power & Competition	-.376	.218	-.261	-1.729	.089
PAQ - Instrumentality	.225	.177	.187	1.271	.209

a. Dependent Variable: Willingness to Seek Help Questionnaire

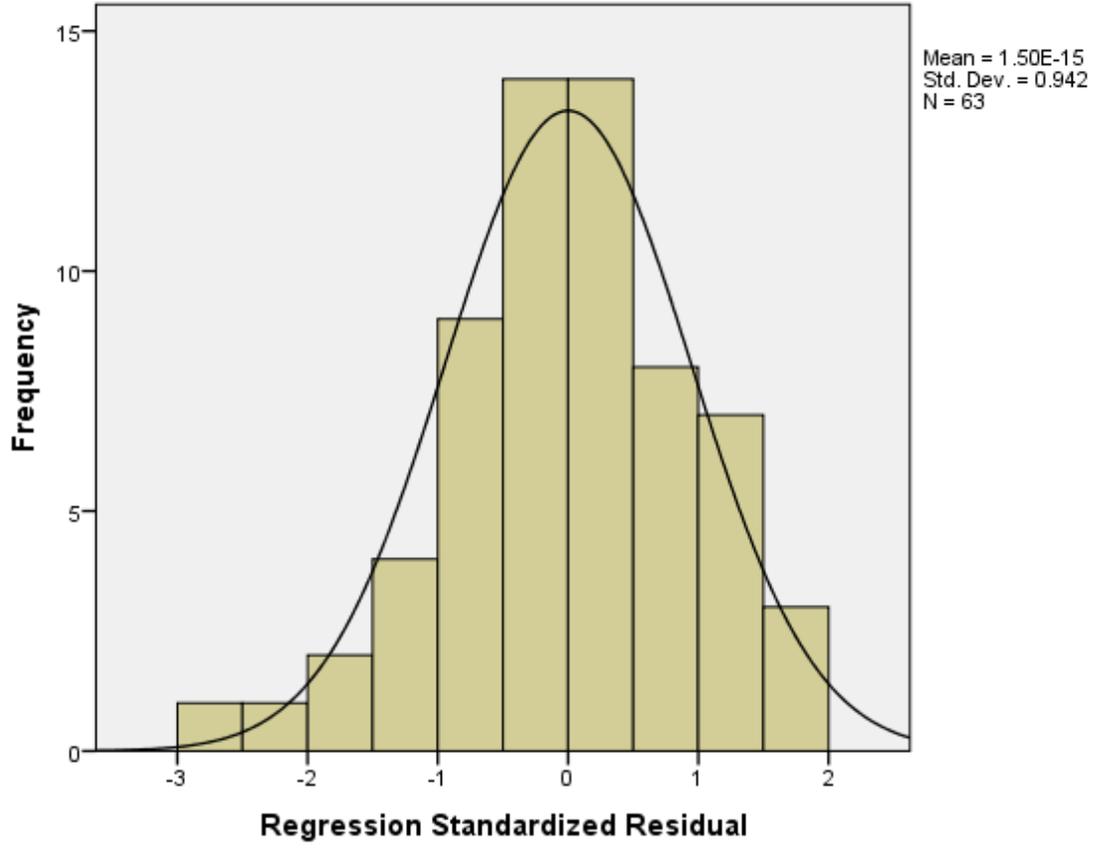
Residuals Statistics^a

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	33.7379	47.0255	40.3492	2.65876	63
Residual	-14.32439	11.26469	.00000	5.30982	63
Std. Predicted Value	-2.487	2.511	.000	1.000	63
Std. Residual	-2.541	1.998	.000	.942	63

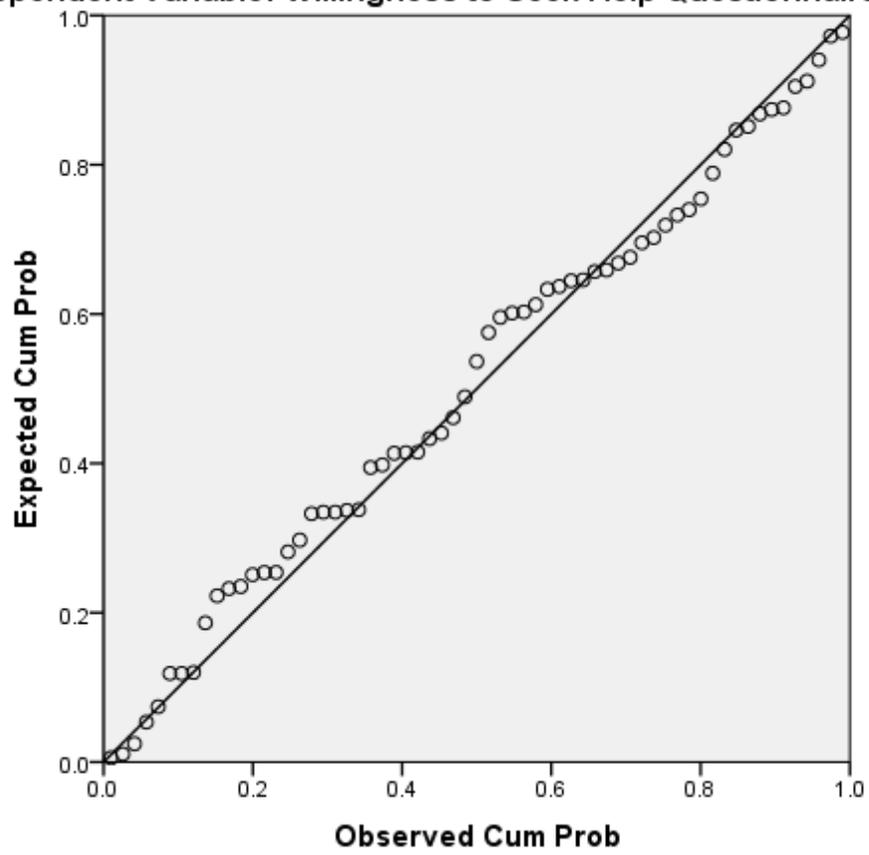
a. Dependent Variable: Willingness to Seek Help Questionnaire

Histogram

Dependent Variable: Willingness to Seek Help Questionnaire

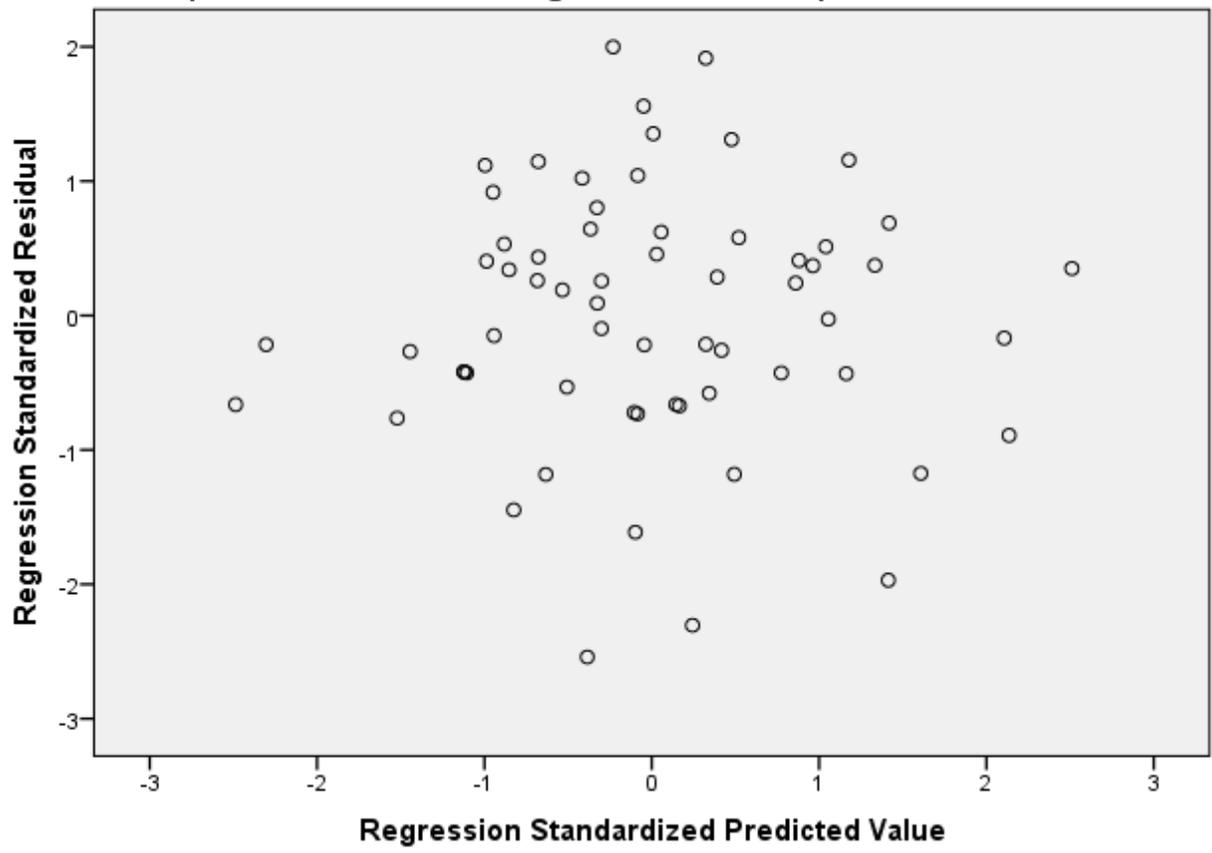


Normal P-P Plot of Regression Standardized Residual
Dependent Variable: Willingness to Seek Help Questionnaire



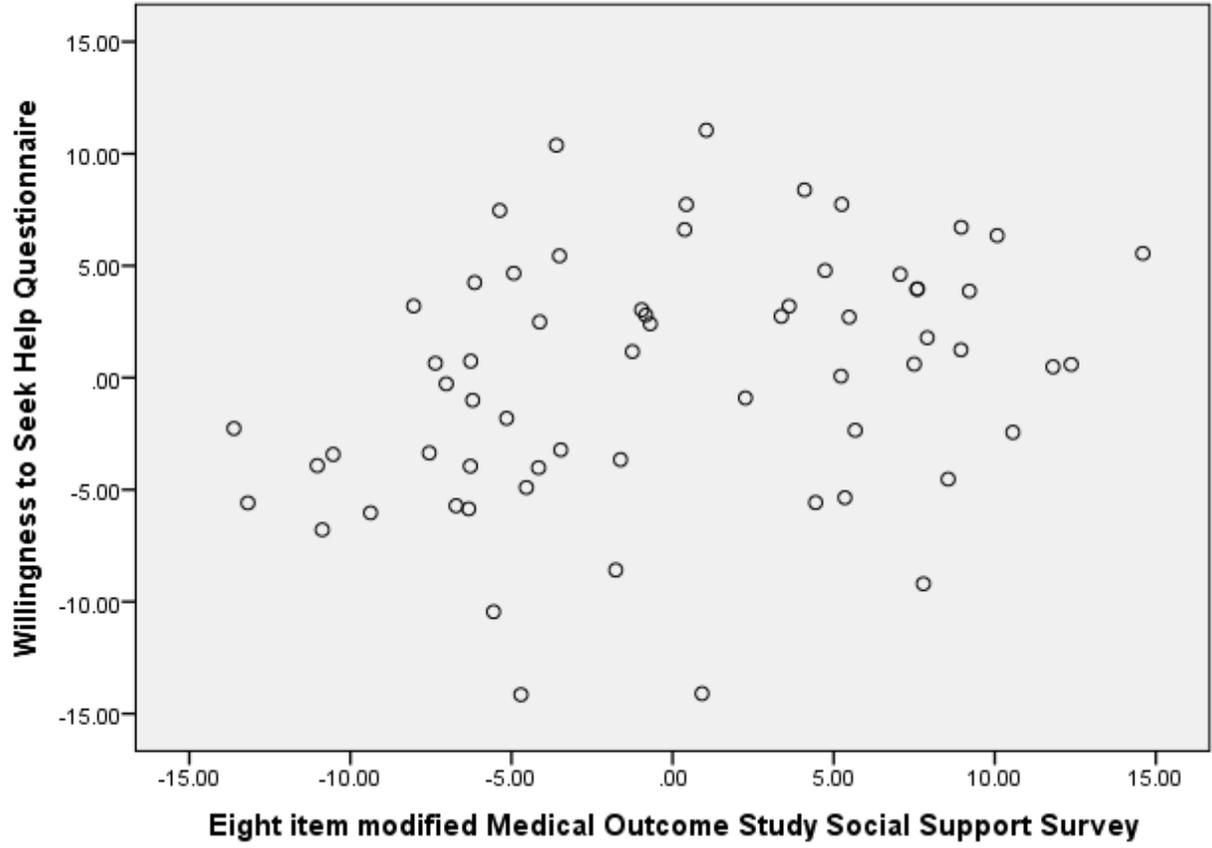
Scatterplot

Dependent Variable: Willingness to Seek Help Questionnaire



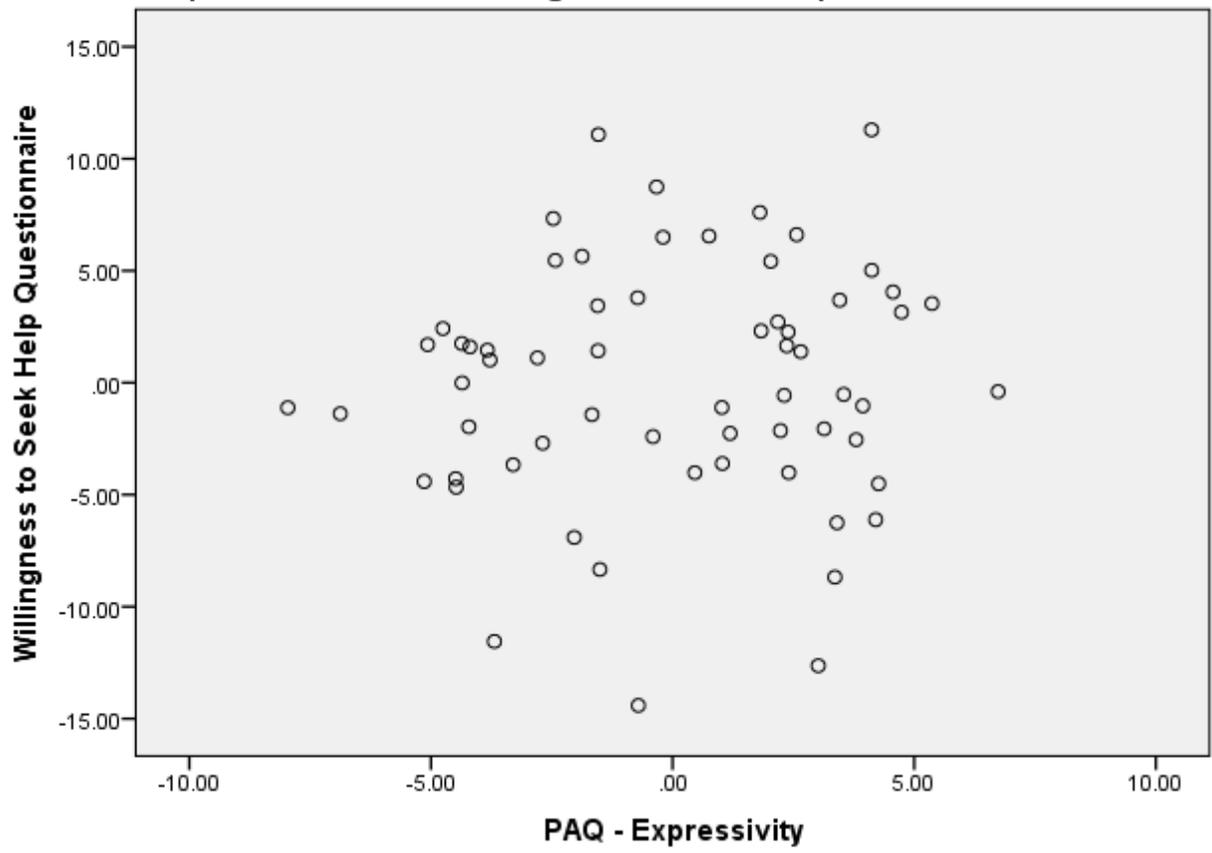
Partial Regression Plot

Dependent Variable: Willingness to Seek Help Questionnaire



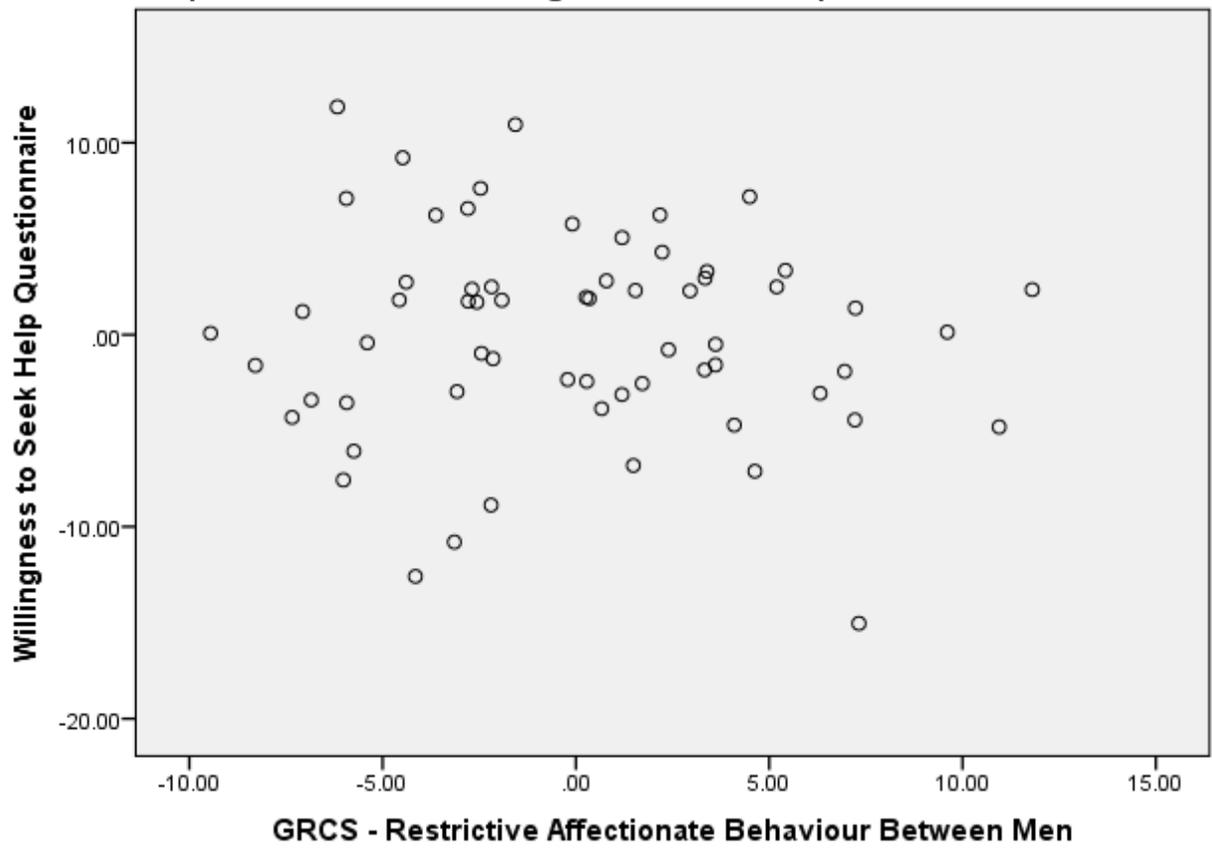
Partial Regression Plot

Dependent Variable: Willingness to Seek Help Questionnaire



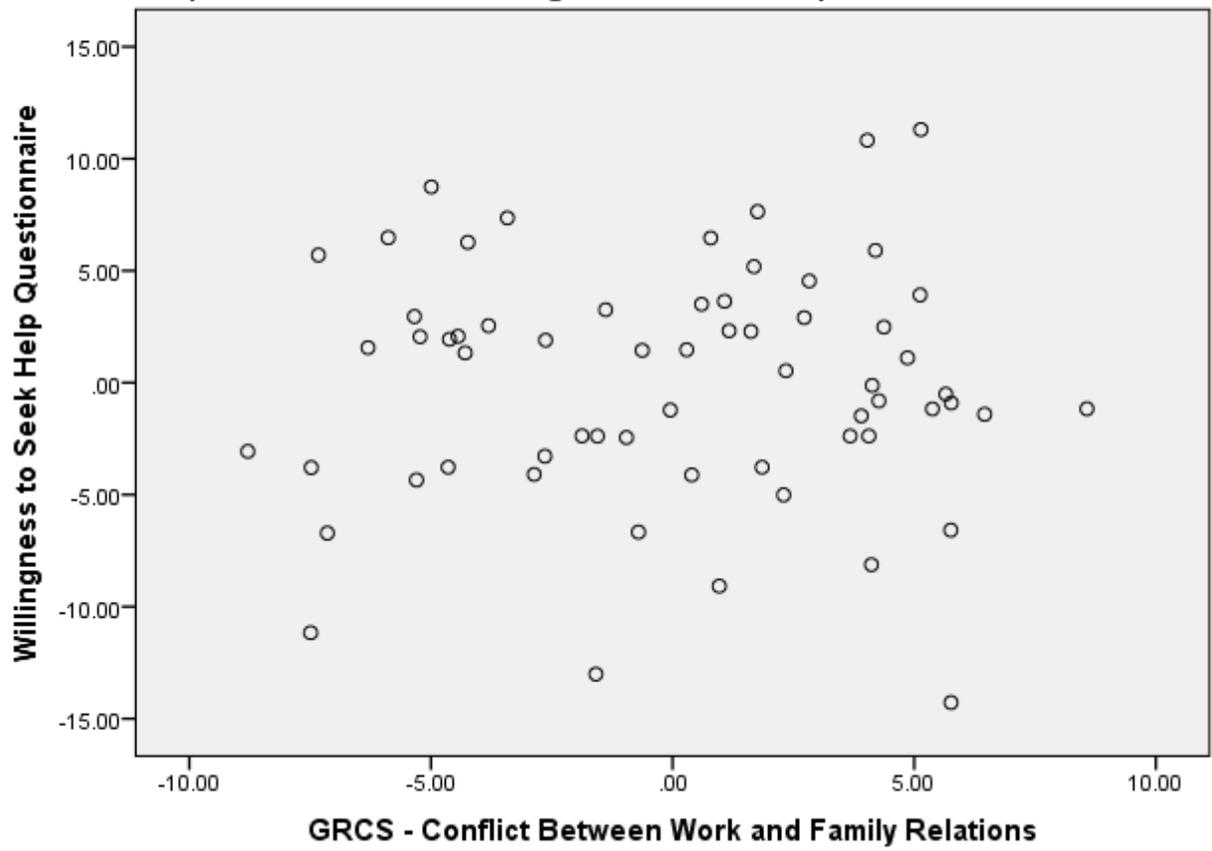
Partial Regression Plot

Dependent Variable: Willingness to Seek Help Questionnaire



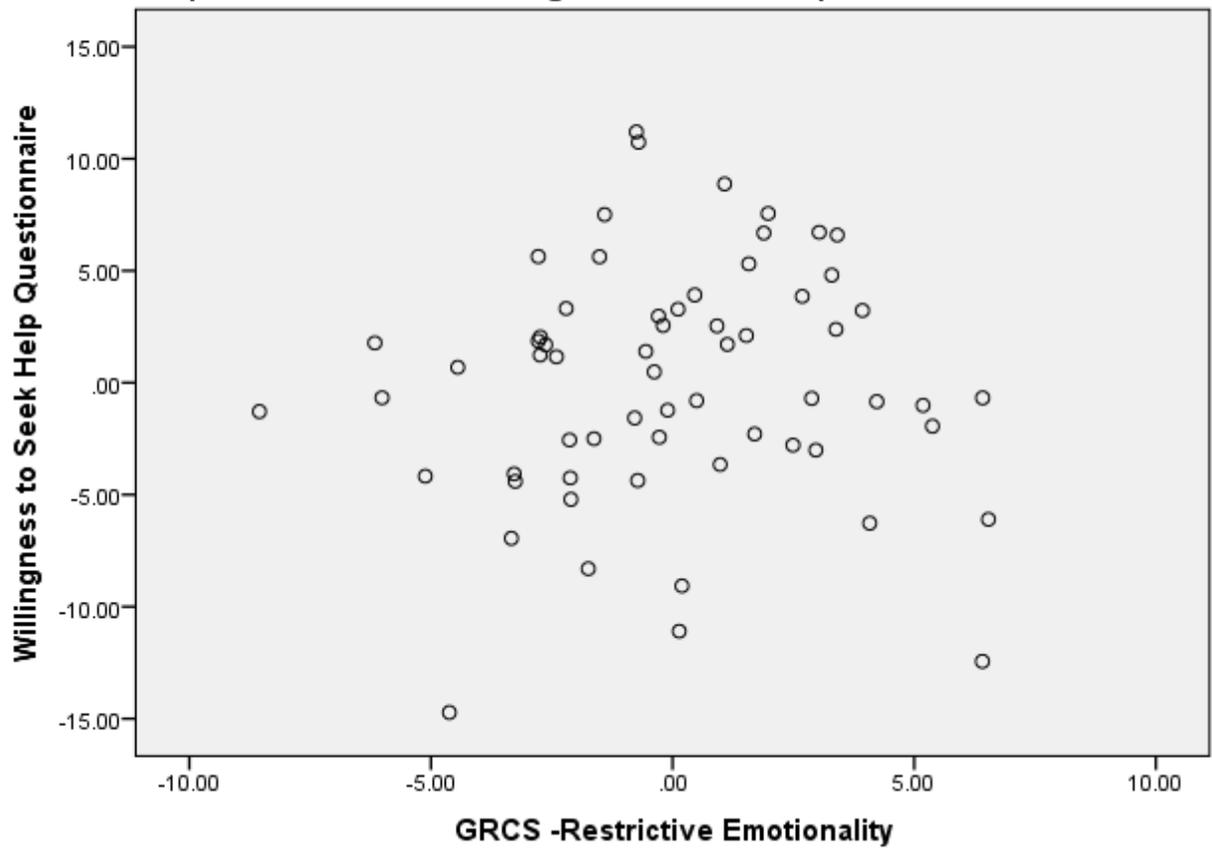
Partial Regression Plot

Dependent Variable: Willingness to Seek Help Questionnaire



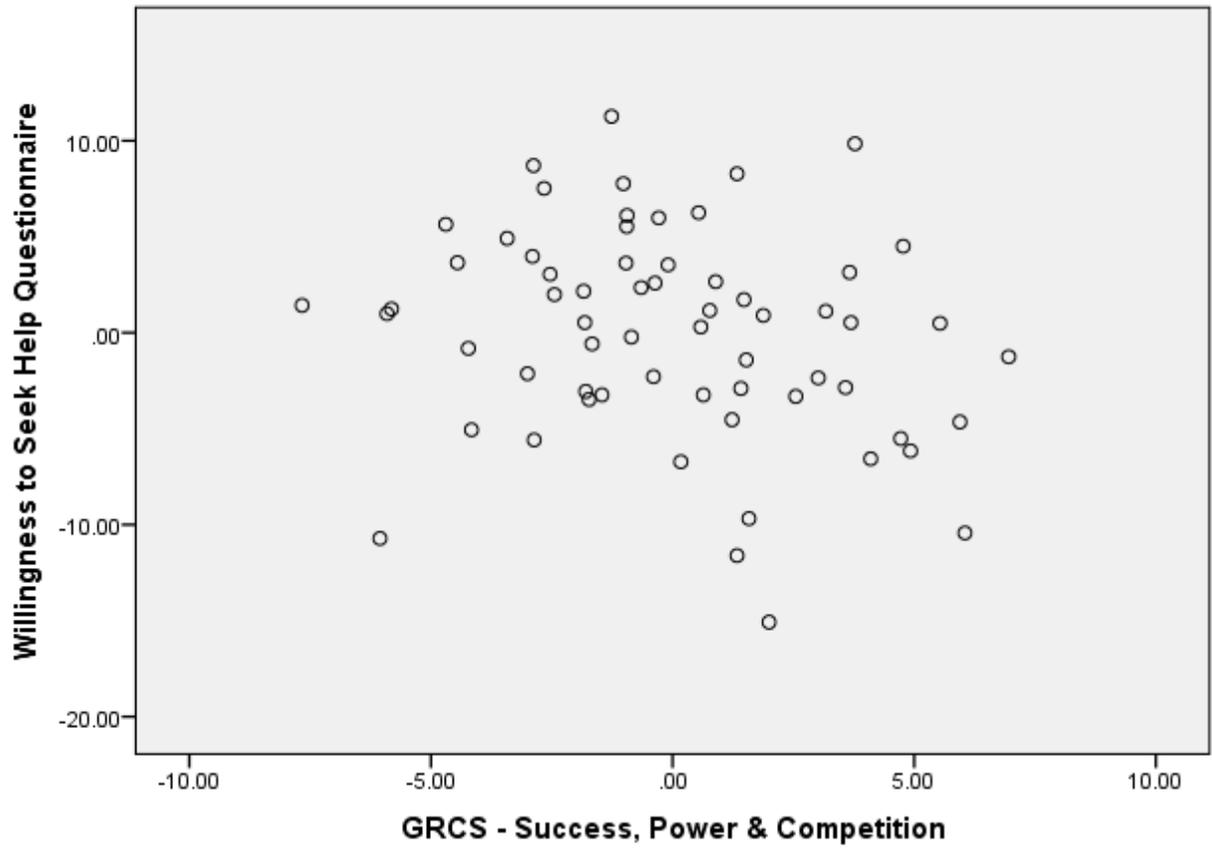
Partial Regression Plot

Dependent Variable: Willingness to Seek Help Questionnaire



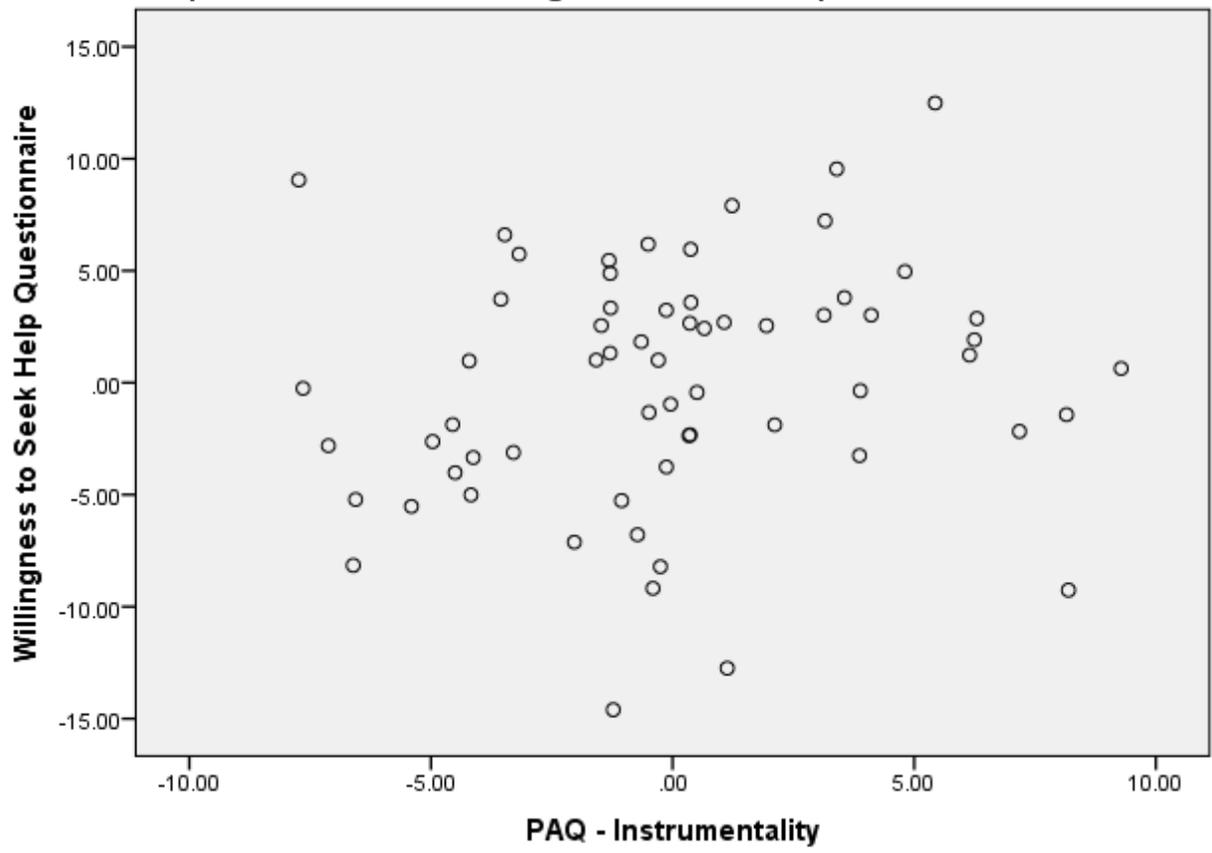
Partial Regression Plot

Dependent Variable: Willingness to Seek Help Questionnaire



Partial Regression Plot

Dependent Variable: Willingness to Seek Help Questionnaire



Appendix I – Regression Analysis SPSS Output: Burden

Model Summary^h

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.107 ^a	.011	-.012	9.11684	.011	.494	1	43	.486
2	.133 ^b	.018	-.029	9.19565	.006	.266	1	42	.609
3	.157 ^c	.025	-.047	9.27348	.007	.298	1	41	.588
4	.355 ^d	.126	.039	8.88604	.102	4.653	1	40	.037
5	.367 ^e	.134	.023	8.95744	.008	.365	1	39	.549
6	.593 ^f	.352	.250	7.85076	.218	12.770	1	38	.001
7	.604 ^g	.365	.244	7.87922	.012	.726	1	37	.400

a. Predictors: (Constant), Work-Children

b. Predictors: (Constant), Work-Children, PAQ - Expressivity

c. Predictors: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality

d. Predictors: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality, GRCS - Conflict Between Work and Family Relations

e. Predictors: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality, GRCS - Conflict Between Work and Family Relations, GRCS - Restrictive Affectionate Behaviour Between Men

f. Predictors: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality, GRCS - Conflict Between Work and Family Relations, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS -Restrictive Emotionality

g. Predictors: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality, GRCS - Conflict Between Work and Family Relations, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS -Restrictive Emotionality, GRCS - Success, Power & Competition

h. Dependent Variable: Zarit Burden Interview

ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	41.087	1	41.087	.494	.486 ^b
	Residual	3574.024	43	83.117		
	Total	3615.111	44			
2	Regression	63.590	2	31.795	.376	.689 ^c
	Residual	3551.521	42	84.560		
	Total	3615.111	44			
3	Regression	89.213	3	29.738	.346	.792 ^d
	Residual	3525.898	41	85.998		
	Total	3615.111	44			
4	Regression	456.640	4	114.160	1.446	.237 ^e
	Residual	3158.471	40	78.962		
	Total	3615.111	44			
5	Regression	485.918	5	97.184	1.211	.322 ^f
	Residual	3129.193	39	80.236		
	Total	3615.111	44			
6	Regression	1273.005	6	212.168	3.442	.008 ^g
	Residual	2342.106	38	61.634		
	Total	3615.111	44			
7	Regression	1318.073	7	188.296	3.033	.013 ^h
	Residual	2297.038	37	62.082		
	Total	3615.111	44			

a. Dependent Variable: Zarit Burden Interview

b. Predictors: (Constant), Work-Children

c. Predictors: (Constant), Work-Children, PAQ - Expressivity

d. Predictors: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality

e. Predictors: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality, GRCS - Conflict Between Work and Family Relations

f. Predictors: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality, GRCS - Conflict Between Work and Family Relations, GRCS - Restrictive Affectionate Behaviour Between Men

g. Predictors: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality, GRCS - Conflict Between Work and Family Relations, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS -Restrictive Emotionality

h. Predictors: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality, GRCS - Conflict Between Work and Family Relations, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS -Restrictive Emotionality, GRCS - Success, Power & Competition

Coefficients^a

Model		Unstandardized		Standardize	t	Sig.
		B	Std. Error	d Coefficients Beta		
1	(Constant)	17.589	1.360		12.934	.000
	Work-Children	1.014	1.442	.107	.703	.486
2	(Constant)	20.542	5.887		3.489	.001
	Work-Children	.862	1.484	.091	.581	.564
	PAQ - Expressivity	-.147	.285	-.080	-.516	.609
3	(Constant)	22.119	6.602		3.350	.002
	Work-Children	.948	1.505	.100	.630	.532
	PAQ - Expressivity	-.060	.329	-.033	-.183	.856
	PAQ - Instrumentality	-.167	.306	-.096	-.546	.588
4	(Constant)	10.635	8.268		1.286	.206
	Work-Children	.045	1.502	.005	.030	.976
	PAQ - Expressivity	-.044	.315	-.024	-.138	.891
	PAQ - Instrumentality	-.076	.297	-.044	-.257	.798
	GRCS - Conflict Between Work and Family Relations	.690	.320	.338	2.157	.037
5	(Constant)	7.615	9.719		.783	.438
	Work-Children	-.002	1.516	.000	-.001	.999
	PAQ - Expressivity	.019	.334	.010	.057	.955
	PAQ - Instrumentality	-.096	.301	-.055	-.319	.752

	GRCS - Conflict Between Work and Family Relations	.692	.323	.339	2.146	.038
	GRCS - Restrictive Affectionate Behaviour Between Men	.169	.280	.095	.604	.549
<u>6</u>	(Constant)	-18.867	11.291		-1.671	.103
	Work-Children	.636	1.341	.067	.474	.638
	PAQ - Expressivity	.816	.368	.446	2.217	.033
	PAQ - Instrumentality	-.297	.270	-.171	-1.101	.278
	GRCS - Conflict Between Work and Family Relations	.653	.283	.320	2.308	.027
	GRCS - Restrictive Affectionate Behaviour Between Men	.088	.247	.050	.358	.723
	GRCS -Restrictive Emotionality	1.197	.335	.617	3.574	.001
<u>7</u>	(Constant)	-19.267	11.341		-1.699	.098
	Work-Children	.360	1.384	.038	.260	.796
	PAQ - Expressivity	.848	.371	.464	2.284	.028
	PAQ - Instrumentality	-.382	.288	-.220	-1.324	.194
	GRCS - Conflict Between Work and Family Relations	.594	.292	.291	2.029	.050

GRCS - Restrictive Affectionate Behaviour Between Men	.077	.248	.044	.312	.757
GRCS -Restrictive Emotionality	1.126	.347	.580	3.249	.002
GRCS - Success, Power & Competition	.299	.351	.136	.852	.400

a. Dependent Variable: Zarit Burden Interview

Excluded Variables^a

Model		Beta In	t	Sig.	Partial Correlation	Collinearity Statistics Tolerance
1	PAQ - Expressivity	-.080 ^b	-.516	.609	-.079	.961
	PAQ - Instrumentality	-.112 ^b	-.734	.467	-.113	1.000
	GRCS - Conflict Between Work and Family Relations	.349 ^b	2.312	.026	.336	.918
	GRCS - Restrictive Affectionate Behaviour Between Men	.097 ^b	.633	.530	.097	.986
	GRCS -Restrictive Emotionality	.404 ^b	2.882	.006	.406	.998
	GRCS - Success, Power & Competition	.271 ^b	1.733	.091	.258	.900
	2	PAQ - Instrumentality	-.096 ^c	-.546	.588	-.085
GRCS - Conflict Between Work and Family Relations		.344 ^c	2.242	.030	.330	.907
GRCS - Restrictive Affectionate Behaviour Between Men		.081 ^c	.497	.622	.077	.900
GRCS -Restrictive Emotionality		.585 ^c	3.310	.002	.459	.605
GRCS - Success, Power & Competition		.264 ^c	1.649	.107	.249	.875
3		GRCS - Conflict Between Work and Family Relations	.338 ^d	2.157	.037	.323
	GRCS - Restrictive Affectionate Behaviour Between Men	.092 ^d	.557	.581	.088	.889
	GRCS -Restrictive Emotionality	.638 ^d	3.562	.001	.491	.577

	GRCS - Success, Power & Competition	.340 ^d	1.994	.053	.301	.763
4	GRCS - Restrictive Affectionate Behaviour Between Men	.095 ^e	.604	.549	.096	.888
	GRCS -Restrictive Emotionality	.623 ^e	3.663	.001	.506	.576
	GRCS - Success, Power & Competition	.268 ^e	1.565	.126	.243	.719
5	GRCS -Restrictive Emotionality	.617 ^f	3.574	.001	.502	.571
	GRCS - Success, Power & Competition	.262 ^f	1.509	.140	.238	.715
6	GRCS - Success, Power & Competition	.136 ^g	.852	.400	.139	.673

a. Dependent Variable: Zarit Burden Interview

b. Predictors in the Model: (Constant), Work-Children

c. Predictors in the Model: (Constant), Work-Children, PAQ - Expressivity

d. Predictors in the Model: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality

e. Predictors in the Model: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality, GRCS - Conflict Between Work and Family Relations

f. Predictors in the Model: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality, GRCS - Conflict Between Work and Family Relations, GRCS - Restrictive Affectionate Behaviour Between Men

g. Predictors in the Model: (Constant), Work-Children, PAQ - Expressivity, PAQ - Instrumentality, GRCS - Conflict Between Work and Family Relations, GRCS - Restrictive Affectionate Behaviour Between Men, GRCS -Restrictive Emotionality

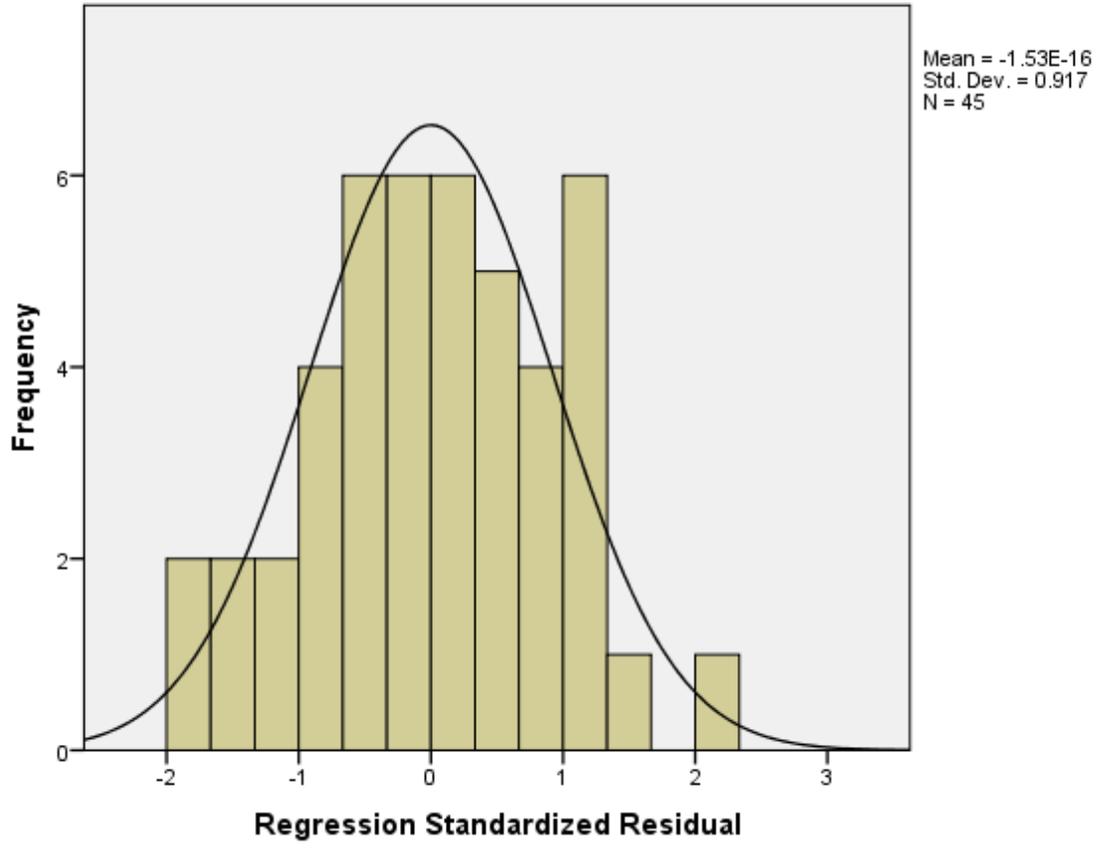
Residuals Statistics^a

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	5.6932	25.8986	17.5556	5.47323	45
Residual	-15.08889	16.23779	.00000	7.22533	45
Std. Predicted Value	-2.167	1.524	.000	1.000	45
Std. Residual	-1.915	2.061	.000	.917	45

a. Dependent Variable: Zarit Burden Interview

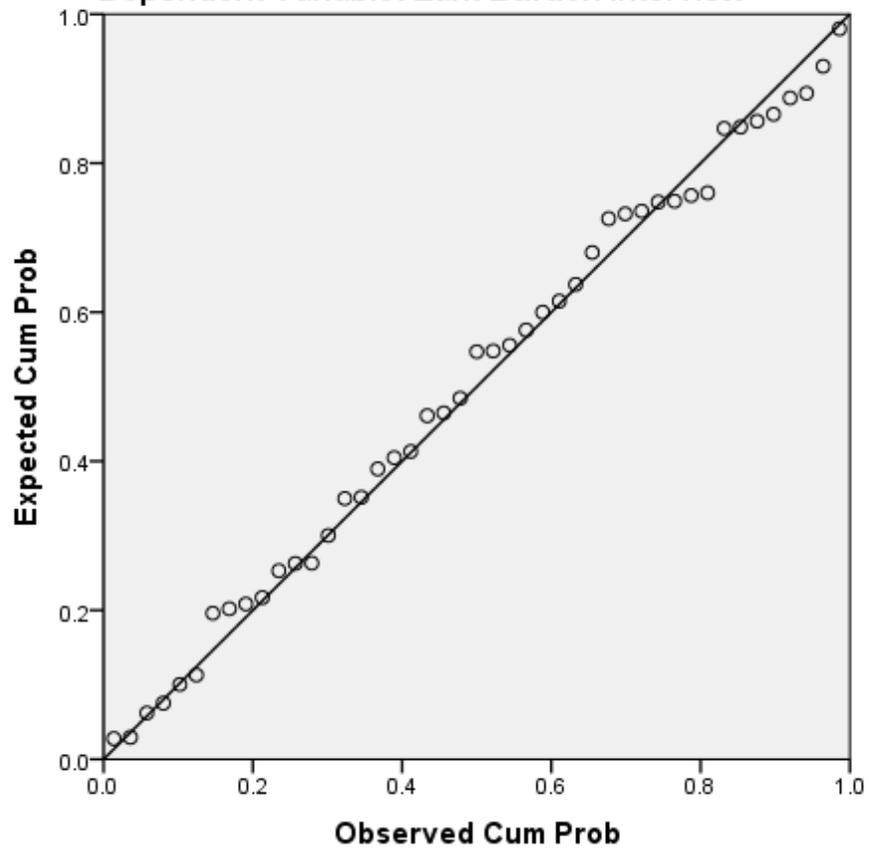
Histogram

Dependent Variable: Zarit Burden Interview



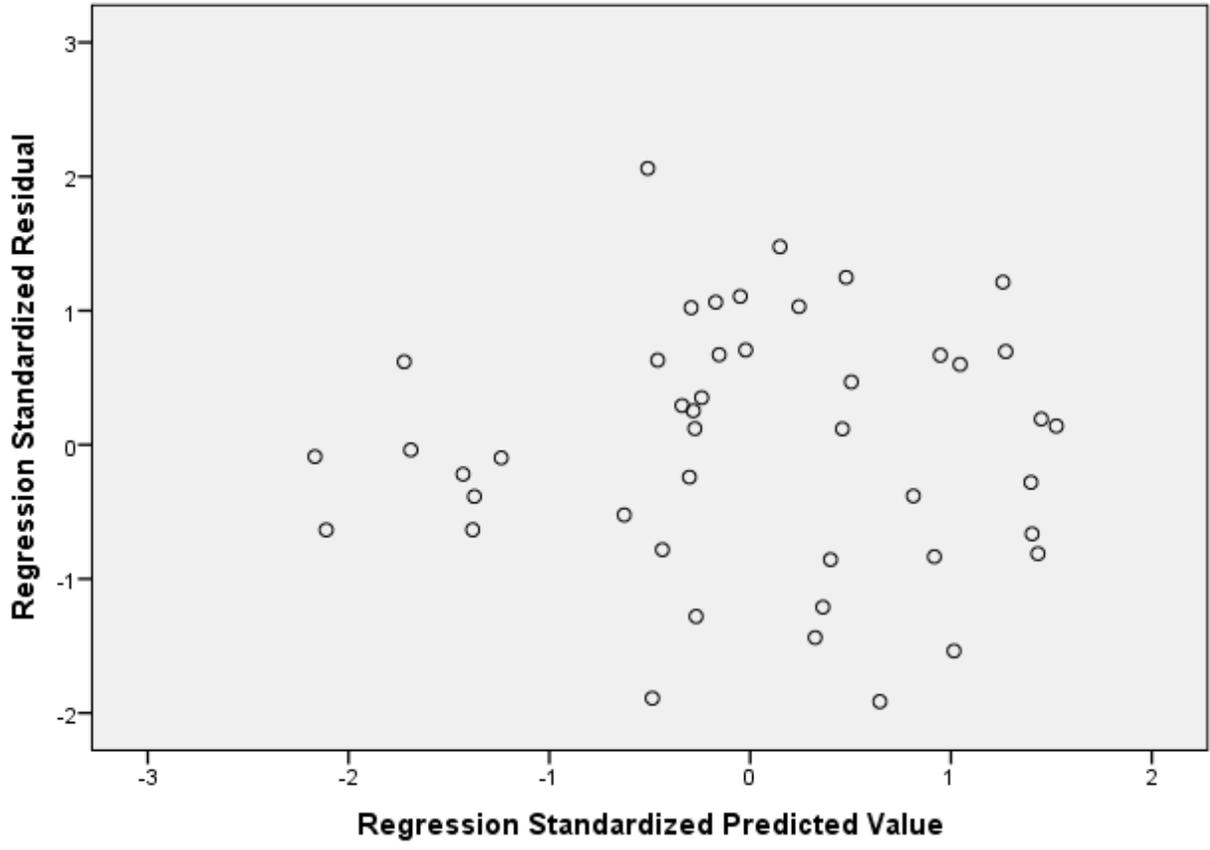
Normal P-P Plot of Regression Standardized Residual

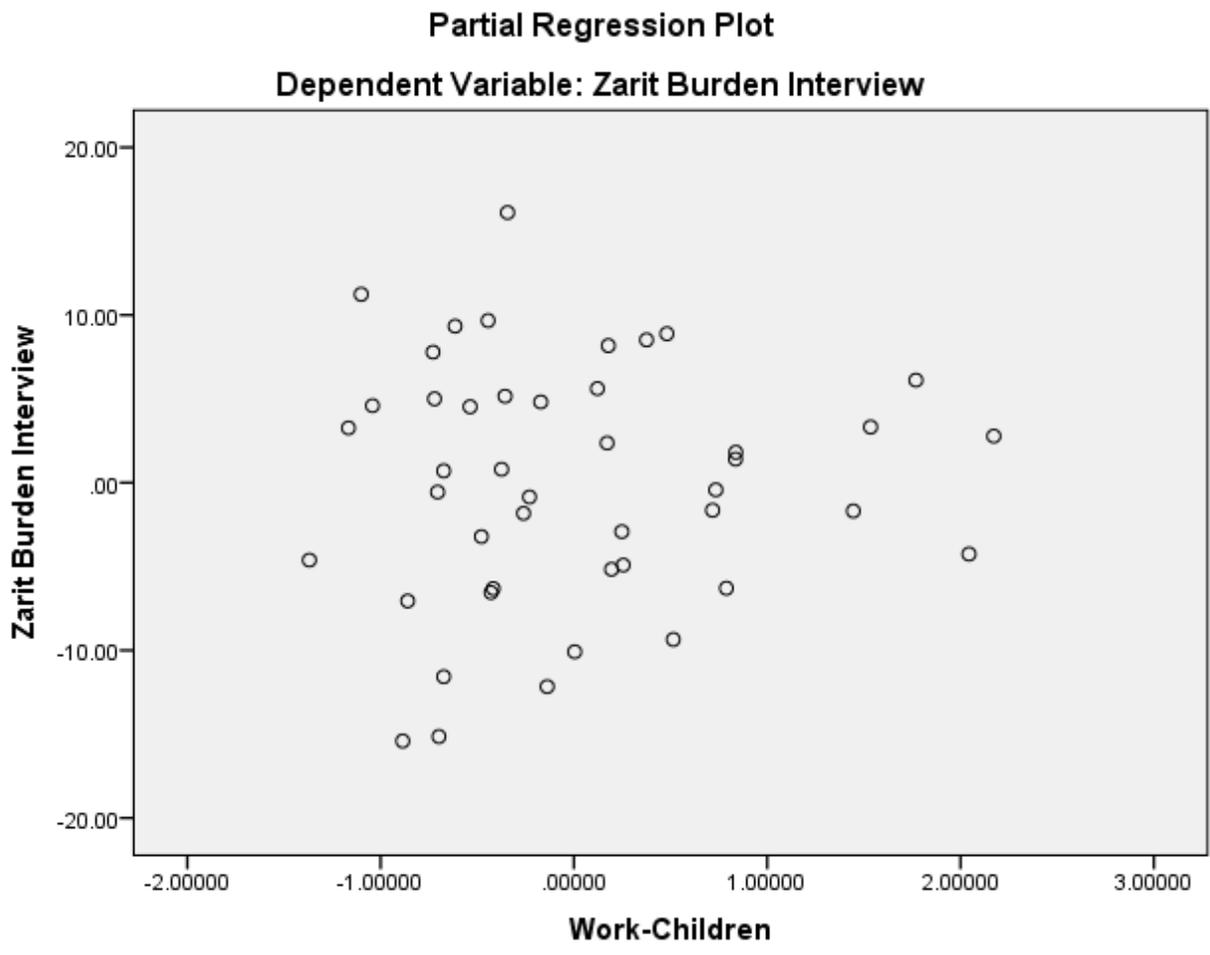
Dependent Variable: Zarit Burden Interview



Scatterplot

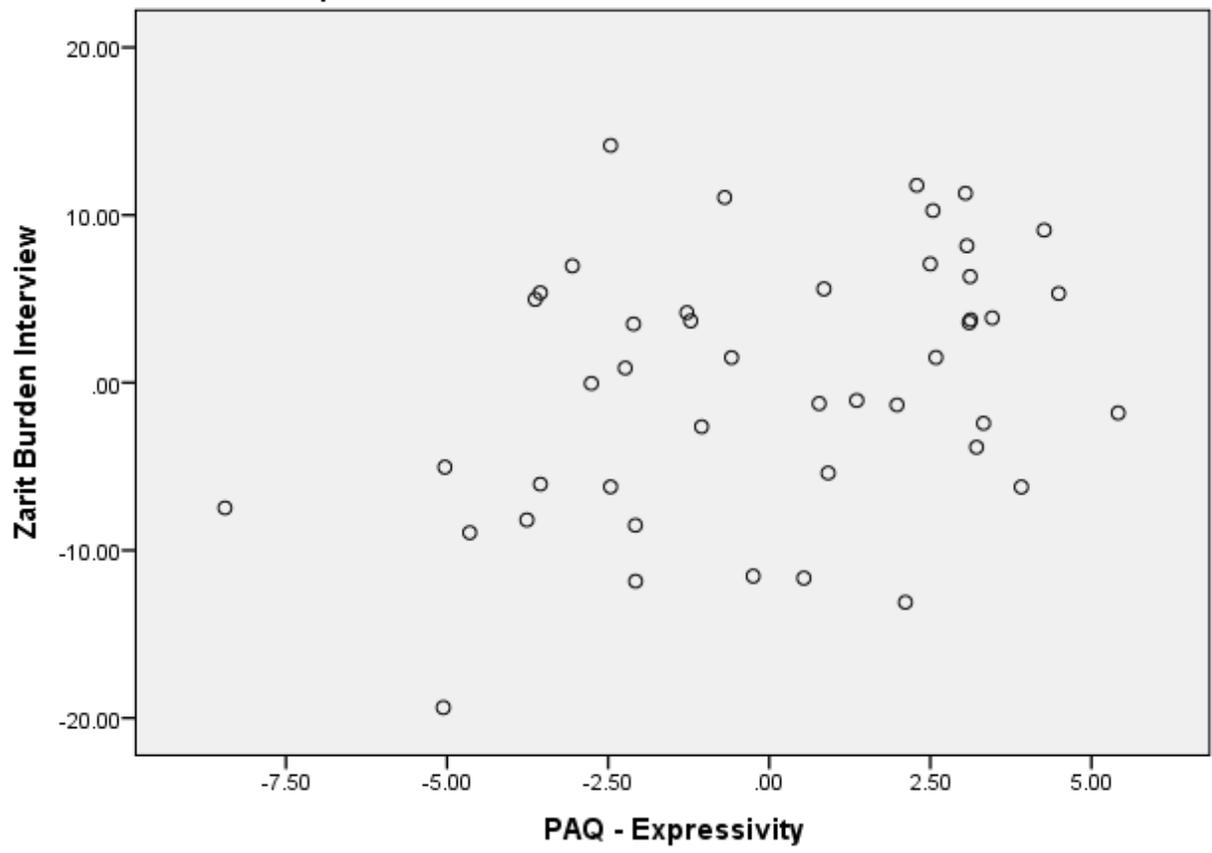
Dependent Variable: Zarit Burden Interview





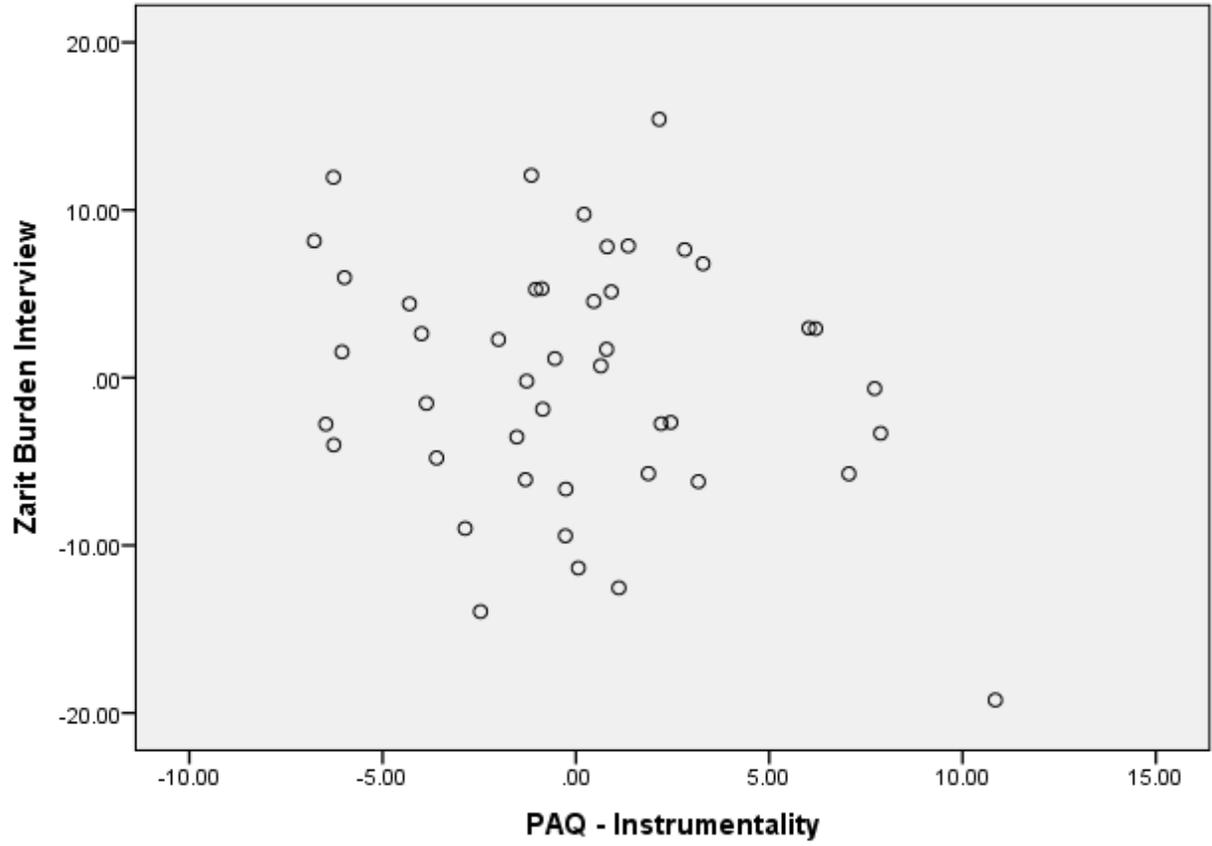
Partial Regression Plot

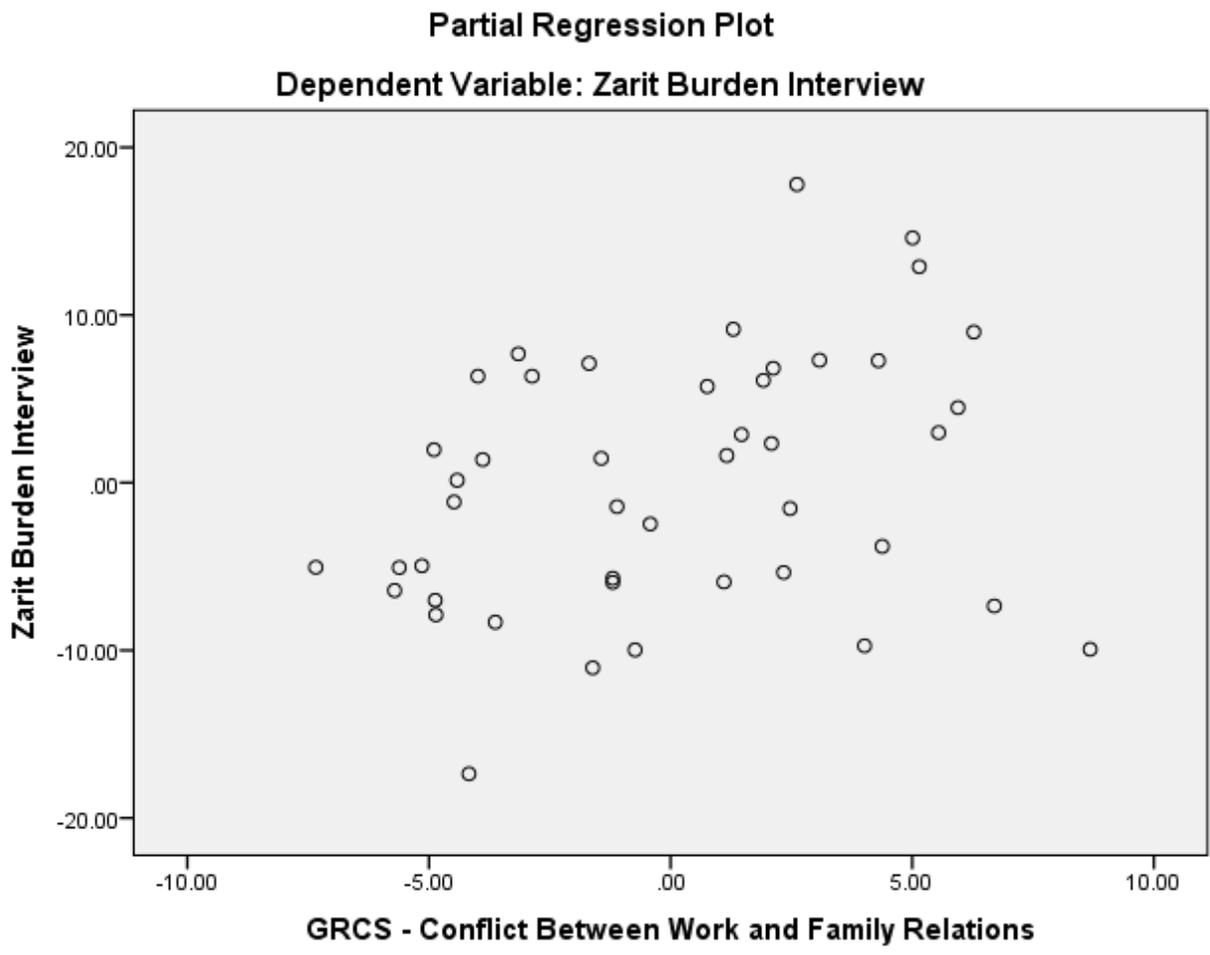
Dependent Variable: Zarit Burden Interview

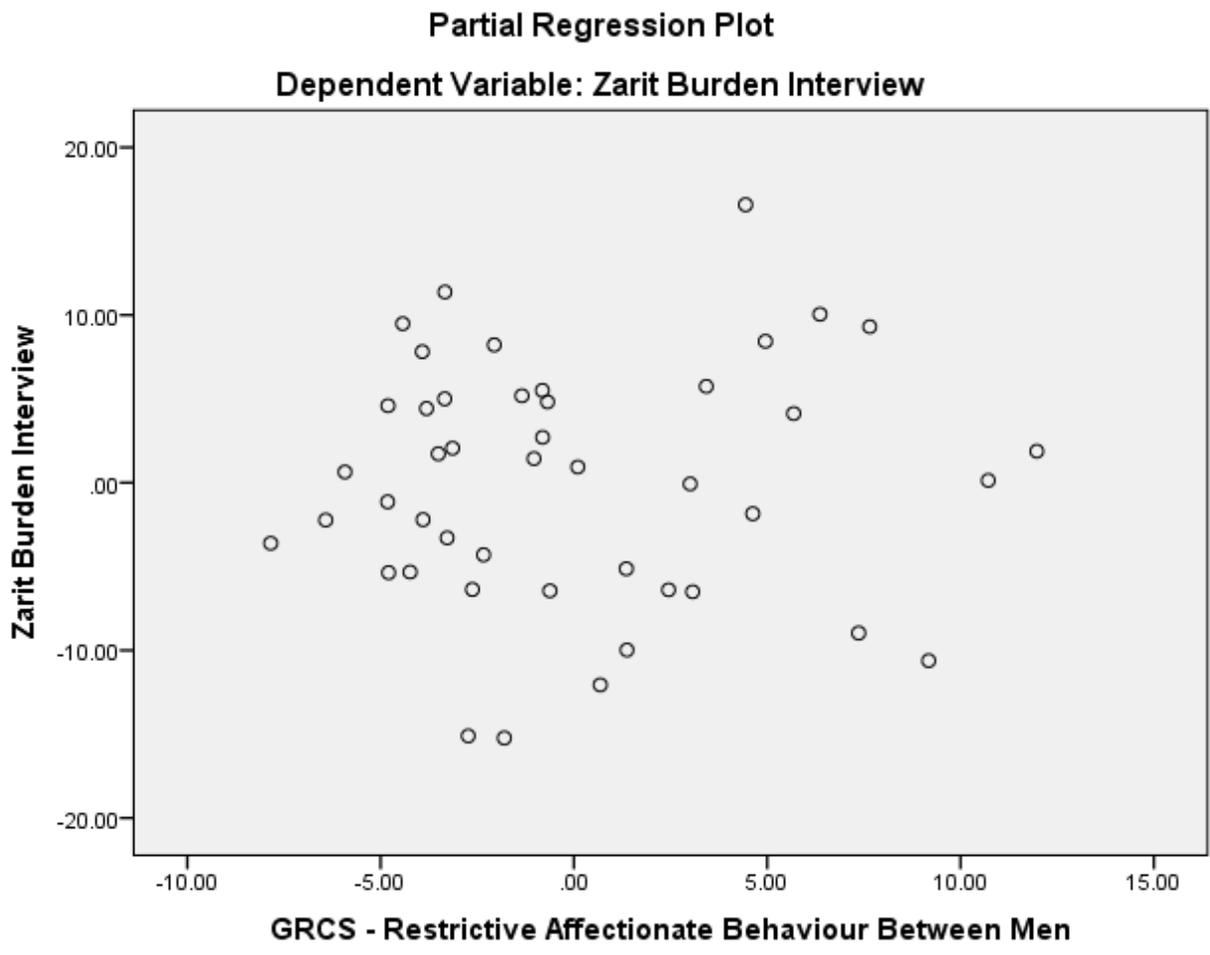


Partial Regression Plot

Dependent Variable: Zarit Burden Interview

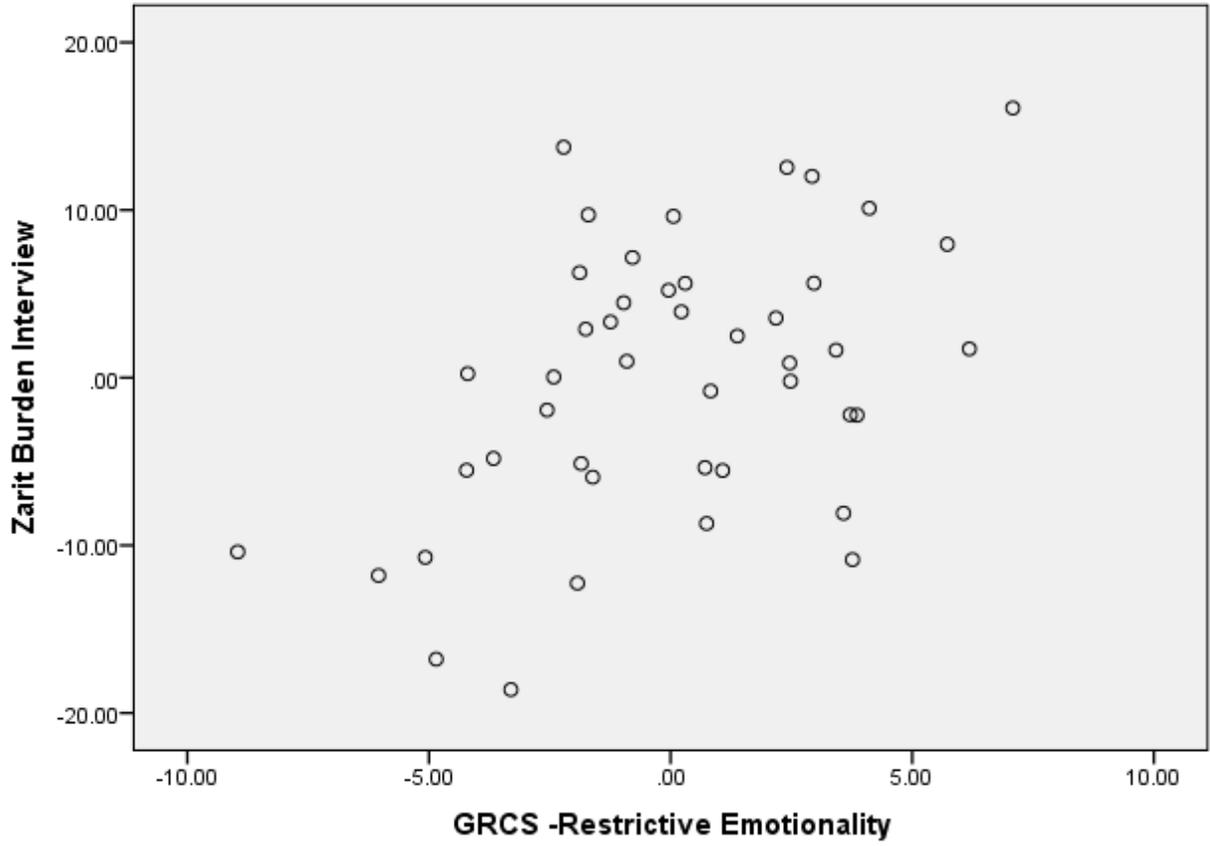






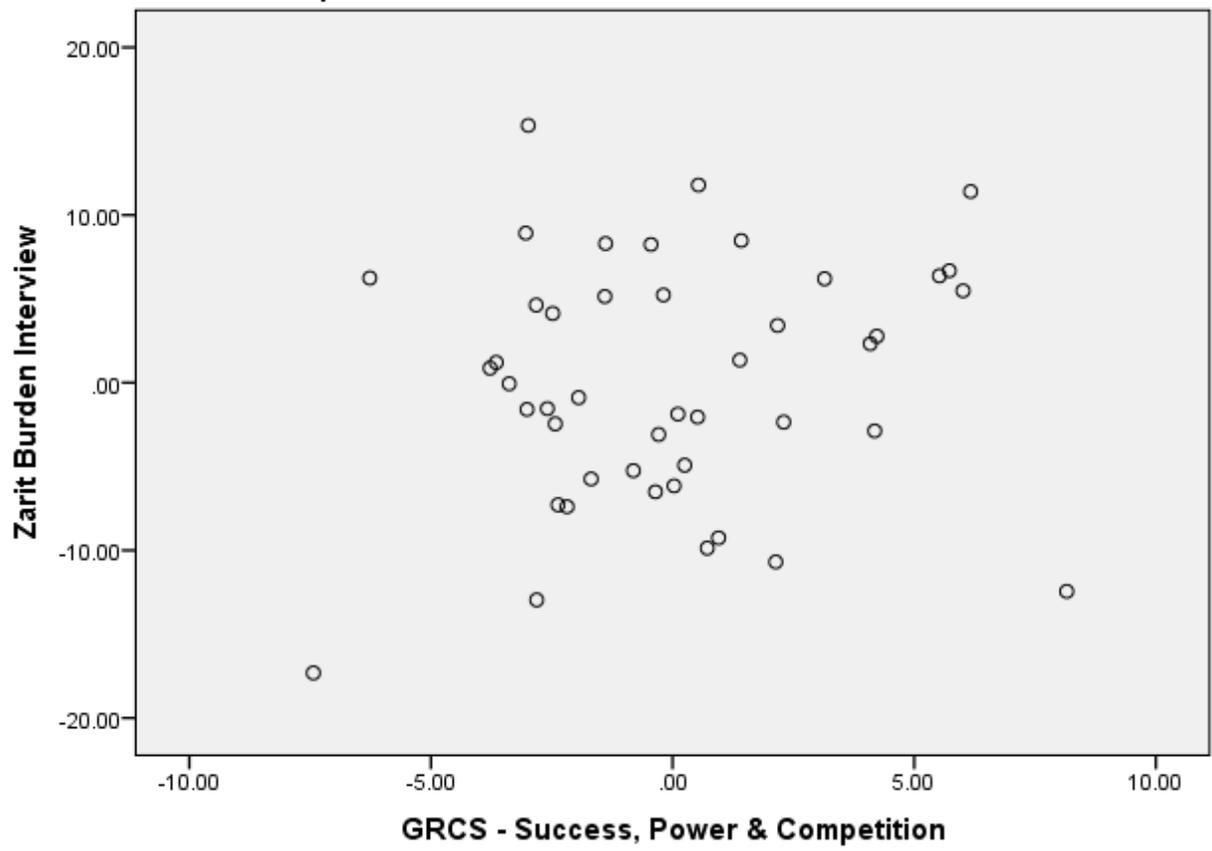
Partial Regression Plot

Dependent Variable: Zarit Burden Interview



Partial Regression Plot

Dependent Variable: Zarit Burden Interview



Appendix J – Path Analysis

Model Fit Summary

CMIN

Model	NPAR	CMIN	DF	P	CMIN/DF
Default model	19	1.583	2	.453	.792
Saturated model	21	.000	0		
Independence model	6	324.592	15	.000	21.639

RMR, GFI

Model	RMR	GFI	AGFI	PGFI
Default model	.298	.998	.983	.095
Saturated model	.000	1.000		
Independence model	8.110	.750	.650	.536

Baseline Comparisons

Model	NFI Delta1	RFI rho1	IFI Delta2	TLI rho2	CFI
Default model	.995	.963	1.001	1.010	1.000
Saturated model	1.000		1.000		1.000
Independence model	.000	.000	.000	.000	.000

Parsimony-Adjusted Measures

Model	PRATIO	PNFI	PCFI
Default model	.133	.133	.133
Saturated model	.000	.000	.000
Independence model	1.000	.000	.000

NCP

Model	NCP	LO 90	HI 90
Default model	.000	.000	6.838
Saturated model	.000	.000	.000

Model	NCP	LO 90	HI 90
Independence model	309.592	254.677	371.935

FMIN

Model	FMIN	F0	LO 90	HI 90
Default model	.005	.000	.000	.021
Saturated model	.000	.000	.000	.000
Independence model	1.018	.971	.798	1.166

RMSEA

Model	RMSEA	LO 90	HI 90	PCLOSE
Default model	.000	.000	.104	.679
Independence model	.254	.231	.279	.000

AIC

Model	AIC	BCC	BIC	CAIC
Default model	39.583	40.436	111.181	130.181
Saturated model	42.000	42.942	121.135	142.135
Independence model	336.592	336.861	359.202	365.202

ECVI

Model	ECVI	LO 90	HI 90	MECVI
Default model	.124	.125	.147	.127
Saturated model	.132	.132	.132	.135
Independence model	1.055	.883	1.251	1.056

HOELTER

Model	HOELTER .05	HOELTER .01
Default model	1208	1856
Independence model	25	31

Estimates (Group number 1 - Default model)

Scalar Estimates (Group number 1 - Default model)

Maximum Likelihood Estimates

Regression Weights: (Group number 1 - Default model)

	Estimate	S.E.	C.R.	P	Label
B_ZBI <--- GRCS_RE	.993	.121	8.231	***	
B_ZBI <--- mMOS_SS	-.145	.058	-2.483	.013	
B_ZBI <--- PAQ_Exp	.506	.110	4.610	***	
B_ZBI <--- GRCS_CBWFR	.604	.096	6.306	***	
WSHQ <--- B_ZBI	-.008	.035	-.241	.810	
WSHQ <--- PAQ_Exp	.251	.066	3.787	***	
WSHQ <--- mMOS_SS	.224	.042	5.386	***	

Standardized Regression Weights: (Group number 1 - Default model)

	Estimate
B_ZBI <--- GRCS_RE	.482
B_ZBI <--- mMOS_SS	-.121
B_ZBI <--- PAQ_Exp	.259
B_ZBI <--- GRCS_CBWFR	.299
WSHQ <--- B_ZBI	-.013
WSHQ <--- PAQ_Exp	.198
WSHQ <--- mMOS_SS	.289

Covariances: (Group number 1 - Default model)

	Estimate	S.E.	C.R.	P	Label
mMOS_SS <--> PAQ_Exp	3.267	2.078	1.572	.116	
PAQ_Exp <--> GRCS_RE	-11.853	1.371	-8.645	***	
mMOS_SS <--> GRCS_RE	-10.020	2.037	-4.919	***	
PAQ_Exp <--> GRCS_CBWFR	-3.512	1.238	-2.836	.005	
mMOS_SS <--> GRCS_CBWFR	.843	1.996	.422	.673	
GRCS_RE <--> GRCS_CBWFR	3.199	1.171	2.732	.006	

Correlations: (Group number 1 - Default model)

	Estimate
mMOS_SS <--> PAQ_Exp	.088
PAQ_Exp <--> GRCS_RE	-.553
mMOS_SS <--> GRCS_RE	-.287

	Estimate
PAQ_Exp <--> GRCS_CBWFR	-.161
mMOS_SS <--> GRCS_CBWFR	.024
GRCS_RE <--> GRCS_CBWFR	.155

Variances: (Group number 1 - Default model)

	Estimate	S.E.	C.R.	P	Label
mMOS_SS	60.336	4.777	12.629	***	
PAQ_Exp	22.647	1.793	12.629	***	
GRCS_RE	20.272	1.605	12.629	***	
GRCS_CBWFR	21.060	1.668	12.629	***	
e3	59.452	4.707	12.629	***	
e2	31.352	2.482	12.629	***	

Matrices (Group number 1 - Default model)

Total Effects (Group number 1 - Default model)

	GRCS_CBWFR	GRCS_RE	PAQ_Exp	mMOS_SS	B_ZBI
B_ZBI	.604	.993	.506	-.145	.000
WSHQ	-.005	-.008	.247	.225	-.008

Standardized Total Effects (Group number 1 - Default model)

	GRCS_CBWFR	GRCS_RE	PAQ_Exp	mMOS_SS	B_ZBI
B_ZBI	.299	.482	.259	-.121	.000
WSHQ	-.004	-.006	.195	.291	-.013

Direct Effects (Group number 1 - Default model)

	GRCS_CBWFR	GRCS_RE	PAQ_Exp	mMOS_SS	B_ZBI
B_ZBI	.604	.993	.506	-.145	.000
WSHQ	.000	.000	.251	.224	-.008

Standardized Direct Effects (Group number 1 - Default model)

	GRCS_CBWFR	GRCS_RE	PAQ_Exp	mMOS_SS	B_ZBI
B_ZBI	.299	.482	.259	-.121	.000
WSHQ	.000	.000	.198	.289	-.013

Indirect Effects (Group number 1 - Default model)

	GRCS_CBWFR	GRCS_RE	PAQ_Exp	mMOS_SS	B_ZBI
B_ZBI	.000	.000	.000	.000	.000
WSHQ	-.005	-.008	-.004	.001	.000

Standardized Indirect Effects (Group number 1 - Default model)

	GRCS_CBWFR	GRCS_RE	PAQ_Exp	mMOS_SS	B_ZBI
B_ZBI	.000	.000	.000	.000	.000
WSHQ	-.004	-.006	-.003	.002	.000

Bollen-Stine Bootstrap (Default model)

The model fit better in 115 bootstrap samples.

It fit about equally well in 0 bootstrap samples.

It fit worse or failed to fit in 85 bootstrap samples.

Testing the null hypothesis that the model is correct, Bollen-Stine bootstrap p = .428

Standardized Direct Effects (Group number 1 - Default model)

Standardized Direct Effects - Lower Bounds (BC) (Group number 1 - Default model)

	GRCS_CBWFR	GRCS_RE	PAQ_Exp	mMOS_SS	B_ZBI
B_ZBI	.231	.363	.156	-.233	.000
WSHQ	.000	.000	.115	.193	-.119

Standardized Direct Effects - Upper Bounds (BC) (Group number 1 - Default model)

	GRCS_CBWFR	GRCS_RE	PAQ_Exp	mMOS_SS	B_ZBI
B_ZBI	.389	.579	.352	-.022	.000
WSHQ	.000	.000	.277	.390	.076

Standardized Direct Effects - Two Tailed Significance (BC) (Group number 1 - Default model)

	GRCS_CBWFR	GRCS_RE	PAQ_Exp	mMOS_SS	B_ZBI
B_ZBI	.007	.013	.012	.018	...
WSHQ013	.007	.757

Standardized Indirect Effects (Group number 1 - Default model)

Standardized Indirect Effects - Lower Bounds (BC) (Group number 1 - Default model)

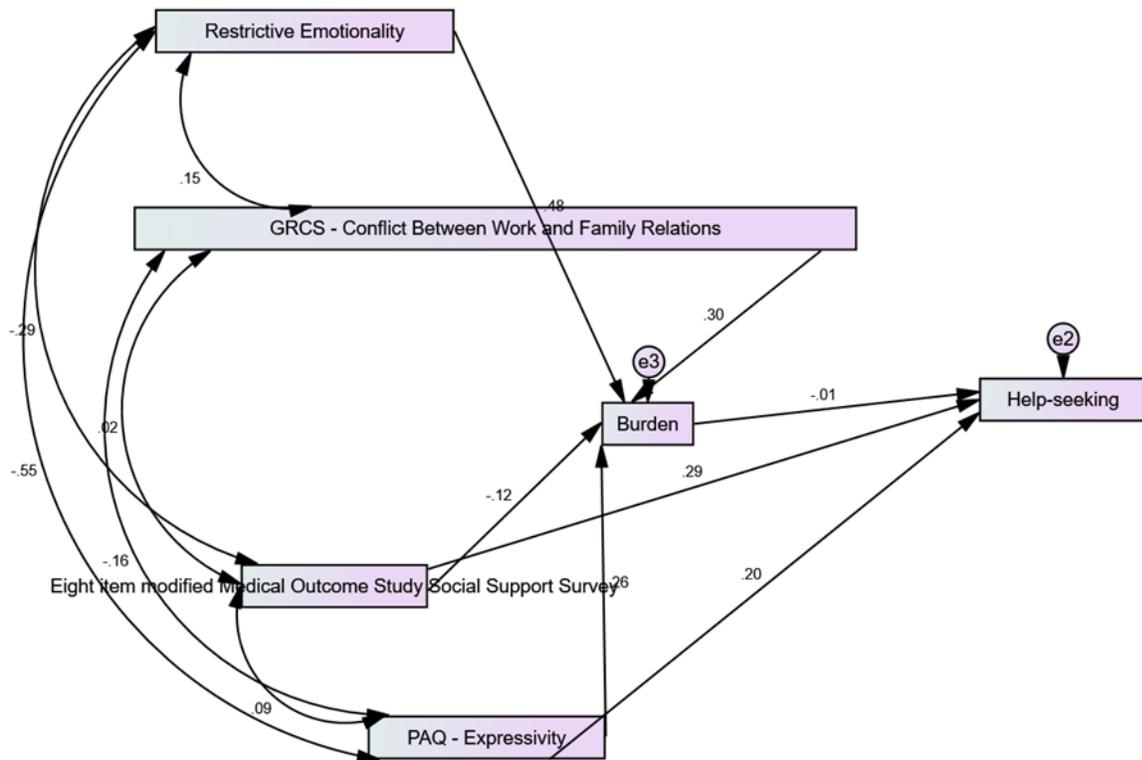
	GRCS_CBWFR	GRCS_RE	PAQ_Exp	mMOS_SS	B_ZBI
B_ZBI	.000	.000	.000	.000	.000
WSHQ	-.038	-.057	-.029	-.008	.000

Standardized Indirect Effects - Upper Bounds (BC) (Group number 1 - Default model)

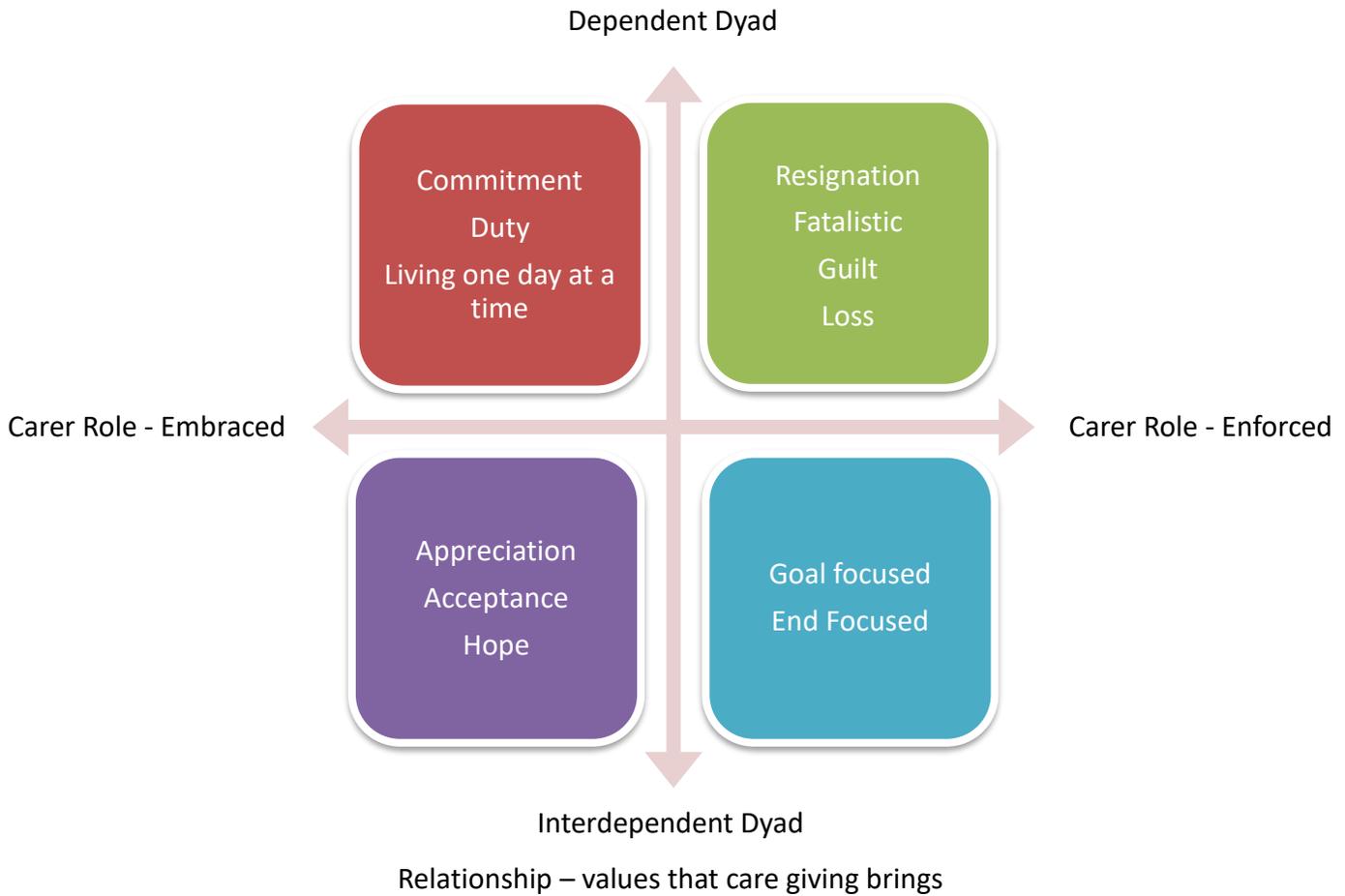
	GRCS_CBWFR	GRCS_RE	PAQ_Exp	mMOS_SS	B_ZBI
B_ZBI	.000	.000	.000	.000	.000
WSHQ	.023	.035	.020	.024	.000

Standardized Indirect Effects - Two Tailed Significance (BC) (Group number 1 - Default model)

	GRCS_CBWFR	GRCS_RE	PAQ_Exp	mMOS_SS	B_ZBI
B_ZBI
WSHQ	.719	.701	.720	.673	...



Appendix K – Carer Experience Synthesis



Further Investigation

Risk factors – children, level of disability, cognitive disability, and personality?

Barriers to change

Role of services – help people move to the 'good'
Communication

Appendix L – T-Test SPSS Output: Recruitment

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Age	Equal variances assumed	2.099	.152	-2.765	63	.007	-8.46681	3.06320	-14.59013	-2.34750
	Equal variances not assumed			-2.873	62.090	.006	-8.46681	2.94822	-14.36206	-2.57556
Years_caring	Equal variances assumed	.050	.824	-1.923	63	.059	-3.50370	1.82247	-7.14562	.13821
	Equal variances not assumed			-1.917	55.566	.060	-3.50370	1.82775	-7.16576	.15835
Years_relationship	Equal variances assumed	.000	.983	-.107	60	.916	-.35784	3.35855	-7.07593	6.36025
	Equal variances not assumed			-.108	54.348	.914	-.35784	3.30651	-6.98602	6.27034
Number_children	Equal variances assumed	.714	.401	-.207	59	.836	-.07363	.35513	-.78423	.63698
	Equal variances not assumed			-.212	57.661	.833	-.07363	.34725	-.76882	.62157
Hours_work	Equal variances assumed	.019	.890	-.379	59	.706	-1.98255	5.22740	-12.44256	8.47747
	Equal variances not assumed			-.378	48.502	.707	-1.98255	5.25173	-12.53903	8.57394
Hours_professional_support_physical_needs	Equal variances assumed	1.921	.171	-.301	54	.764	-.51738	1.71669	-3.95913	2.92437
	Equal variances not assumed			-.278	33.637	.782	-.51738	1.85913	-4.29710	3.26234
Hours_professional_support	Equal variances assumed	12.904	.001	-2.003	50	.051	-.72888	.36389	-1.45977	.00201
	Equal variances not assumed			-1.730	24.113	.096	-.72888	.42124	-1.59805	.14029
Hours_therapy_counselling_supportgroup	Equal variances assumed	1.396	.243	-.551	51	.584	-.02418	.04392	-.11235	.06399
	Equal variances not assumed			-.477	25.308	.637	-.02418	.05064	-.12842	.08006
Gender Role Conflict Scale Short Form	Equal variances assumed	1.703	.197	.873	62	.386	2.73482	3.13092	-3.52381	8.99345
	Equal variances not assumed			.925	61.674	.358	2.73482	2.95541	-3.17358	8.64321
GRCS - Success, Power & Competition	Equal variances assumed	.552	.460	.805	62	.424	.84008	1.04325	-1.24535	2.92552
	Equal variances not assumed			.825	58.156	.412	.84008	1.01769	-1.19692	2.87708
GRCS-Restrictive Emotionality	Equal variances assumed	3.347	.072	2.348	62	.022	2.61943	1.11575	.38909	4.84978
	Equal variances not assumed			2.504	61.931	.015	2.61943	1.04611	.52824	4.71062
GRCS - Restrictive Affectionate Behaviour Between Men	Equal variances assumed	1.659	.203	-1.242	62	.219	-1.64575	1.32532	-4.29503	1.00353
	Equal variances not assumed			-1.196	46.612	.238	-1.64575	1.37587	-4.41426	1.12276
GRCS - Conflict Between Work and Family Relations	Equal variances assumed	.032	.858	.780	62	.438	.92105	1.18091	-1.43956	3.28166
	Equal variances not assumed			.770	51.528	.445	.92105	1.19546	-1.47834	3.32044
Zarit Burden Interview	Equal variances assumed	.359	.551	.774	62	.442	1.85020	2.38987	-2.92708	6.62748
	Equal variances not assumed			.794	58.133	.431	1.85020	2.33166	-2.81690	6.51730
Eight item modified Medical Outcome Study Social Support Survey	Equal variances assumed	.229	.634	.743	61	.460	1.47193	1.98180	-2.49092	5.43479
	Equal variances not assumed			.759	57.785	.451	1.47193	1.93866	-2.40903	5.35289
mMOS-SS Instrumental	Equal variances assumed	1.902	.173	.605	61	.548	.72349	1.19660	-1.66926	3.11625
	Equal variances not assumed			.636	60.705	.527	.72349	1.13843	-1.55316	3.00014
mMOS-SS Emotional	Equal variances assumed	.002	.962	.698	61	.488	.77339	1.10741	-1.44101	2.98778
	Equal variances not assumed			.713	57.662	.479	.77339	1.08418	-1.39711	2.94389
Willingness to Seek Help Questionnaire	Equal variances assumed	.813	.371	2.335	62	.023	3.48583	1.49261	.50215	6.46951
	Equal variances not assumed			2.412	59.202	.019	3.48583	1.44549	.59362	6.37804
Personality Attributes Questionnaire	Equal variances assumed	.891	.349	.035	62	.972	.08300	2.39154	-4.69763	4.86362
	Equal variances not assumed			.033	46.065	.974	.08300	2.48984	-4.92859	5.09459
PAQ - Expressivity	Equal variances assumed	.083	.774	-1.587	62	.117	-1.91498	1.20632	-4.32639	.49643
	Equal variances not assumed			-1.574	52.289	.121	-1.91498	1.21639	-4.35553	.52557
PAQ - Instrumentality	Equal variances assumed	.380	.540	.230	62	.819	.28947	1.25680	-2.22283	2.80177
	Equal variances not assumed			.223	47.943	.824	.28947	1.29581	-2.31601	2.89496

Appendix M – Nurse Knowledge and Experience Questionnaire

Psychological Consequences of Cancer

A) *Recognising psychological distress*

Which of these symptoms would suggest someone is suffering from anxiety (please circle):

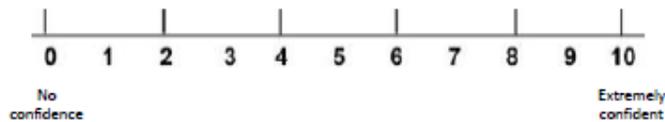
- Feeling tense/wound up
- Worrying thoughts
- Feeling frightened
- Not being able to relax/sit at ease
- Sudden feelings of panic
- Feeling restless
- All of the above

Which of these symptoms would suggest someone is suffering from depression (please circle):

- Doesn't enjoy the things they used to enjoy
- Doesn't laugh or see the funny side of things
- Doesn't feel cheerful
- Feels slowed down
- Lost interest in appearance
- Doesn't enjoy a good book/radio/TV programme
- All of the above

B) *Differentiating between mild, moderate and severe levels of psychological distress*

How confident do you feel differentiating between a patient who is experiencing mild, moderate and severe levels of psychological distress (please circle your answer)?

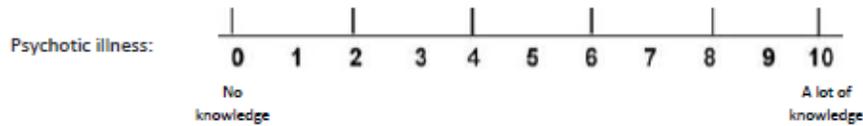
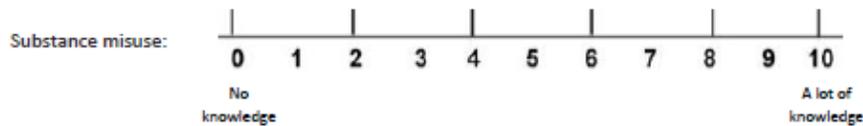
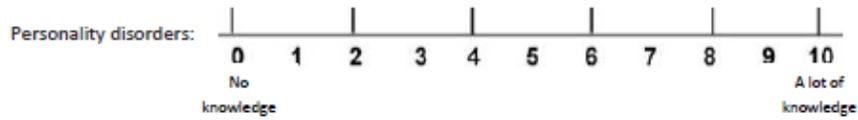


Have you received any formal training on how to recognise the level of psychological distress someone is experiencing?

Yes No

C) Other mental health problems

Please rate how much knowledge you have regarding the following disorders:

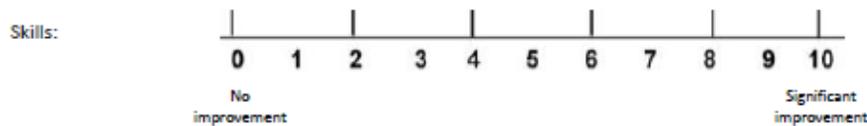
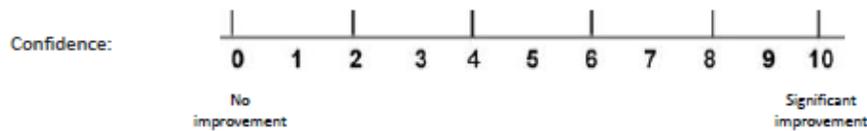
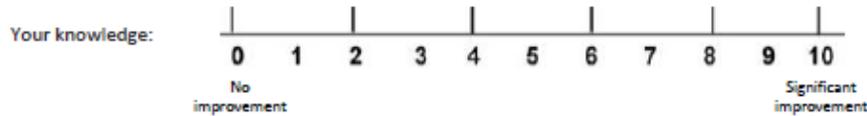


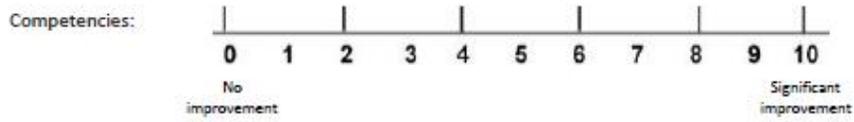
D) Training

Have you received any training regarding how to avoid causing psychological harm to patients?

Yes No

If yes, please rate to what extent the training improved each of the following factors in avoiding causing psychological harm to patients:





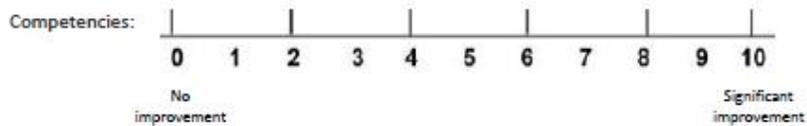
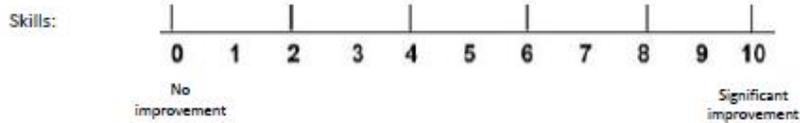
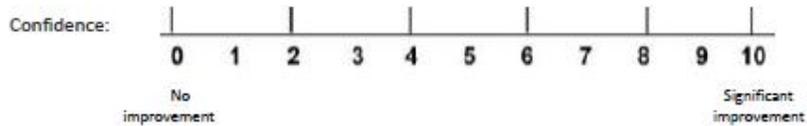
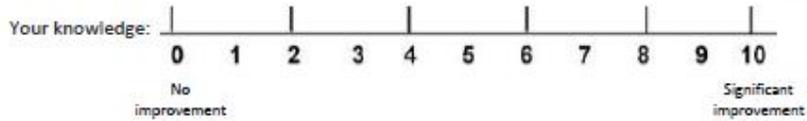
Have you received any training for screening for psychological distress?

Yes No

If yes:

a) What type of training did you receive e.g. 1 day course, conference?

b) Please rate how this course improved each of the following factors in screening for psychological distress:



E) Screening for psychological distress

How would you assess whether someone is suffering with anxiety/ the severity that someone is suffering with anxiety:

- Interview with the patient
- Interview with family/carers
- Patient questionnaire
- Observation
- All of the above
- We don't
- Other

How would you assess whether someone is suffering with depression/ the severity that someone is suffering with depression:

- Interview with the patient
- Interview with family/carers
- Patient questionnaire
- Observation
- All of the above
- We don't
- Other

At present do you use a psychological screening assessment for patients?

- Yes Please state which assessment you use.....
- No

If you answered yes to the previous question, do you administrate the assessment at :

- The time of diagnosis
- Referral
- Initial appointment
- Middle of treatment
- End of treatment
- Follow up (after discharge)
- Every session

If at present you screen for psychological distress, does your screening tool assess the following factors regarding the impact of cancer on the patient's:

- Daily life: Yes No
- Mood: Yes No
- Family relationships (including sexual relationships): Yes No
- Work: Yes No

What would you do if you identified that a patient was suffering with anxiety/depression?

- Offer help through our service
- Refer to another service e.g. mental health services, GP, counselling services
- Wait to see if the patient improved over time
- No follow up

If someone is not offered any help or referred on, are they followed up in the future in regards to how they are feeling?

- Yes
- No

How often do you monitor a patient's psychological state by talking to the patient?

- Never
- A few times
- Often
- Very often
- Every session

How often do you monitor a patient's psychological state by observing the patient?

- Never
- A few times
- Often
- Very often
- Every session

How often do you monitor a patient's psychological state by talking to their carers/partners/friends/significant others?

- Never
- A few times
- Often
- Very often
- Every session

In what ways would you notice if someone was suffering from psychological distress e.g. if they were feeling anxious or depressed:

.....

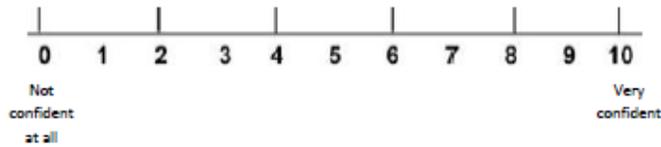
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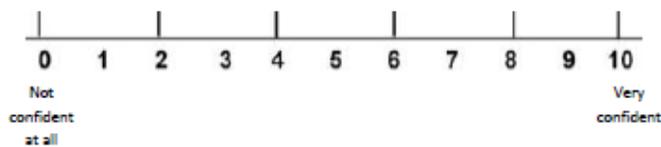
F) Competency and confidence

Please circle the number on the rating scale which applies to you:

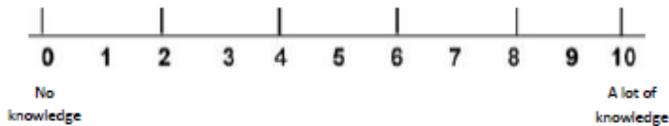
How confident are you at identifying whether a patient is anxious?



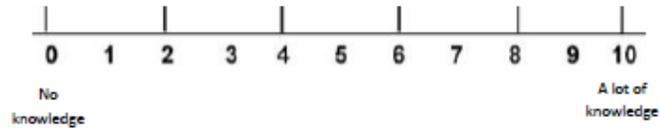
How confident are you at identifying whether a patient is depressed?



How much knowledge do you have about anxiety?

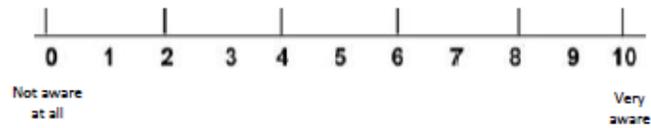


How much knowledge do you have about depression?

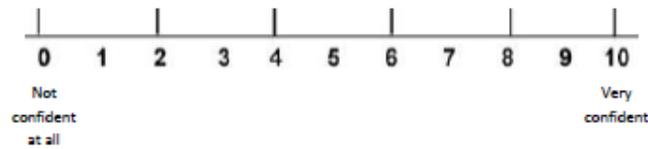


G) Referral to other specialist mental health services

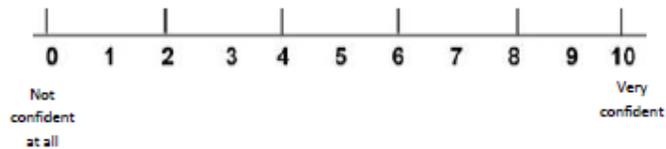
How aware are you of the services available to help an individual who is anxious/depressed?



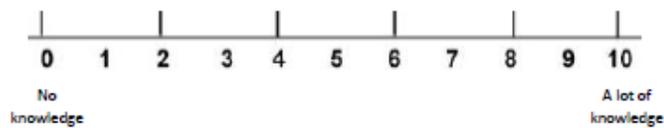
How confident are you at addressing patient's psychological needs?



How confident are you at referring patients on for psychological therapy/counselling?



How much knowledge do you have regarding the affects of cancer on psychological wellbeing?



Appendix N – Referral Process Questionnaire

Referring a patient in psychological distress to mental health services – Short Questionnaire

- To your knowledge, what is the process for referring a patient in psychological distress to mental health services?

.....
.....
.....
.....
.....

- What are the barriers you see in referring patients to mental health services?

.....
.....
.....
.....
.....

- Have you made any referrals to mental health services in the last 3 months?

.....
.....
.....
.....
.....

- What services are available for your patients that are in psychological distress?

.....
.....
.....
.....
.....

- Do you have any other comments about the referral process?

.....
.....
.....
.....
.....
.....

PHQ-9

Over the last 2 weeks, how often have you been bothered by any of the following problems?

(Use "✓" to indicate your answer)

	Not all	at Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things.....	0	1	2	3
2. Feeling down, depressed, or hopeless.....	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much.....	0	1	2	3
4. Feeling tired or having little energy.....	0	1	2	3
5. Poor appetite or overeating.....	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down.....	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television.....	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual.....	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way.....	0	1	2	3

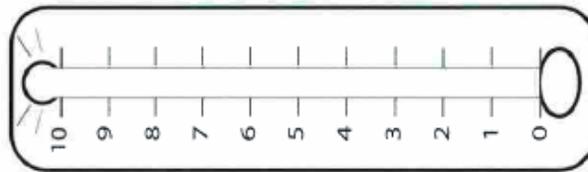
Column totals ___ + ___ + ___ + ___

= Total Score _____

NCCN Distress Thermometer for Patients

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.



Extreme distress

No distress

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

- | YES | NO | Practical Problems | YES | NO | Physical Problems |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Child care | <input type="checkbox"/> | <input type="checkbox"/> | Appearance |
| <input type="checkbox"/> | <input type="checkbox"/> | Housing | <input type="checkbox"/> | <input type="checkbox"/> | Bathing/dressing |
| <input type="checkbox"/> | <input type="checkbox"/> | Insurance/financial | <input type="checkbox"/> | <input type="checkbox"/> | Breathing |
| <input type="checkbox"/> | <input type="checkbox"/> | Transportation | <input type="checkbox"/> | <input type="checkbox"/> | Changes in urination |
| <input type="checkbox"/> | <input type="checkbox"/> | Work/school | <input type="checkbox"/> | <input type="checkbox"/> | Constipation |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment decisions | <input type="checkbox"/> | <input type="checkbox"/> | Diarrhea |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Eating |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Fatigue |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Feeling Swollen |
| <input type="checkbox"/> | <input type="checkbox"/> | Family Problems | <input type="checkbox"/> | <input type="checkbox"/> | Fevers |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with children | <input type="checkbox"/> | <input type="checkbox"/> | Getting around |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with partner | <input type="checkbox"/> | <input type="checkbox"/> | Indigestion |
| <input type="checkbox"/> | <input type="checkbox"/> | Ability to have children | <input type="checkbox"/> | <input type="checkbox"/> | Memory/concentration |
| <input type="checkbox"/> | <input type="checkbox"/> | Family health issues | <input type="checkbox"/> | <input type="checkbox"/> | Mouth sores |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Nausea |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Nose dry/congested |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Pain |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Sexual |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Skin dry/itchy |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Sleep |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Substance abuse |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Tingling in hands/feet |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | |

Other Problems: _____

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) are a statement of evidence and consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult the NCCN Guidelines® is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network® (NCCN®) makes no representations or warranties of any kind regarding their content, use, or application, and disclaims any responsibility for their application or use in any way. The NCCN Guidelines are copyrighted by National Comprehensive Cancer Network®. All rights reserved. The NCCN Guidelines and the illustrations herein may not be reproduced in any form without the express written permission of NCCN, ©2013.

Appendix P – Breast Unit Patient Telephone Interview

Breast Unit Patient Telephone Interview

1. What was your initial thought when [REDACTED] explained you would be going through some psychological screening measures in your consultation? (anxiety, relief, fear)
2. Did you find the measures useful in the consultation to help you express the distress you may be experiencing?
3. Did you feel confident that if you did disclose any distress you were experiencing that appropriate support would be offered?
4. Would you have thought to discuss psychological-related issues and distress with [REDACTED] if you had not had the prompt of the screening tools?
5. Did you find the screening measures easy to understand? (Yes with help from [REDACTED]?)
6. In terms of the three different measures used, were any of them more relevant and acceptable than the others?
7. If asked to fill in the measures again at a future consultation, would you be willing to do so?
8. Did you feel using these measures lasted an acceptable amount of time during the consultation? (Did it not leave you with time to discuss other things?)
 - a. If you didn't, do you feel it would be useful to work through these at various times throughout your treatment journey?
9. Do you have any other comments or recommendations on this screening process?

Appendix Q – Psychological Screening Pathway for Local Oncology Services

