Exploring the day-to-day support needs and coping strategies of mothers with rheumatoid arthritis (RA)

Shannyn Meloncelli
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Shannyn Meloncelli
Bachelor of Arts (Communication)
Graduate Diploma in Education (Early Years)

Submitted in fulfilment of the requirements of the degree of
Master of Science

School of Health and Sport Sciences
Faculty of Science, Health, Education and Engineering
University of the Sunshine Coast
November 2016
Abstract

Rheumatoid arthritis (RA) is an autoimmune disease, whereby the body’s immune system attacks its own tissues. This chronic, systemic condition impacts the whole body, including organs, joints, respiratory and digestive systems. According to 2012 ABS self-reported data approximately 445,000 Australians (2% of the population) had RA with RA prevalence expected to rise 40% in Australia by 2032. RA onset commonly occurs between 35-64 years of age, potentially impacting women in their reproductive years. There is currently no cure for RA and treatment success is unpredictable despite improvements in early stage treatment over the last two decades. Little qualitative research in relation to how mothers with RA cope and their support needs has been undertaken. Some evidence exists that individual adaptive coping strategies, including accepting realistic standards, pacing activities and drawing in support are beneficial. There is also evidence that mothers connecting locally and online to share stories, practical strategies and parenting tips is a useful way for mothers with RA to gain peer support and useful information.

The aim of the research was to explore the day-to-day support needs and coping strategies of mothers with rheumatoid arthritis (RA). The research question asked: What are the day-to-day support needs and coping strategies of mothers with rheumatoid arthritis (RA)? This research was positioned within a social constructivist epistemology, the theoretical framework utilised was Skinner, Edge, Altman, and Sherwood (2003) and Skinner and Zimmer-Gembeck’s (2007) coping theories and the research methodology was a qualitative exploratory case study. A Facebook online survey (43 respondents) and in-depth semi-structured face-to-face interviews (four participants) were the methods used to collect and analyse qualitative data. Mothers with RA, 18 years and over, and living in Australia were the target population.

Overall results identified coping with the emotional, physical, socio-cultural and financial impacts of RA alongside a parenting role was an ongoing, challenging process for mothers and their families. Emotional support from family and friends with RA was identified as important as well as the need for more information regarding treatments, coping strategies and support services. Emotions such as guilt, acceptance, denial, happiness, frustration and sadness potentially impacted how participants coped. Participants’ utilisation of interrelated ‘families of coping’ such as ‘problem-solving’, ‘information-seeking’ and ‘self-reliance’ better enabled them to cope. Participants who felt emotionally supported and appropriately informed and educated to cope more independently were better equipped to seek support and cope which aligns with coping theory and previous research.
Overall research findings provide some evidence of the support needs and coping strategies of mothers with RA, which could potentially inform other mothers, their families, friends and health professionals on how to support mothers with RA to cope. These findings identified a need for more supportive and appropriate interventions matching the support needs of mothers. Additionally, ‘peer-to-peer information’ exchange regarding practical coping strategies was desired by mothers who wanted to hear other mothers’ stories of how they coped with parenting alongside managing the impacts of RA. Additionally, further research is needed exploring the usefulness of peer support to assist mothers with RA to develop coping strategies. To gain a more comprehensive understanding of the support needs of mothers with RA further research is needed particularly in naturalistic settings, such as mothers’ homes.
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<th>Full title</th>
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<tbody>
<tr>
<td>A&amp;OV</td>
<td>Arthritis and Osteoporosis Victoria</td>
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<tr>
<td>DMARDs</td>
<td>Disease-modifying anti-rheumatic drugs</td>
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<td>GP</td>
<td>General practitioner</td>
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<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<td>MS</td>
<td>Multiple sclerosis</td>
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<td>NSAIDs</td>
<td>Non-steroidal anti-inflammatory drugs</td>
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<td>OS</td>
<td>Osteoarthritis</td>
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<td>OT</td>
<td>Occupational therapy</td>
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<tr>
<td>PM</td>
<td>Personal message</td>
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<tr>
<td>RA</td>
<td>Rheumatoid arthritis</td>
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Acknowledgements

I would like to acknowledge Dr Jane Taylor and Dr Renee Barnes for their dedication in supervising this research project. I am eternally grateful for their commitment to get involved in the project, to believe it was possible and see it to completion. Thank you also to Dr Gail Crimmins for your mentorship early in the project. Most importantly thank you to the courageous, wise and generous mothers with rheumatoid arthritis (RA) who shared their stories for the purposes of this research. I believe your stories of how you cope and are supported to manage the impacts of RA alongside parenting will be valuable knowledge for other mothers with RA, their families and supporters and hopefully will inform future public health strategies.

I also wish to acknowledge the numerous other people who have supported me. Thank you to Maddy Thorpe and Blake Chapman for editing and formatting my thesis. Thank you also to everyone who has helped me to overcome the many hurdles faced to get to this point including the University of the Sunshine Coast (USC) Faculty of Science, Health, Education and Engineering (FOSHEE), USC School of Health and Sport Sciences and the USC Office of Research and Office of Engagement. I would also like to thank the two research clusters I am a member of, Inflame and CHI, and USC Student Support Services for the research grants received which enabled me to hire much needed editorial support. Additionally, thank you to MOVE Muscle, Bone and Joint Health (formerly Arthritis and Osteoporosis Victoria) for your support with the interview phase of the research.

To my parents, Denise and Michael, thank you for your selfless support and care, especially in looking after my precious little girls and keeping us well nourished, this project would not have been possible without you. I’m forever grateful and acknowledge the personal sacrifices you have made to support my dream. Thank you to my beautiful daughters, Amelie and Audrey, for being kind, wise and funny beyond your young years. You were the reason I started this research. You inspire me to be a better person every day.

To my support crew Danny, Nina, Abby, Nana, Kaz, Sharon, Janelle, Lea-anne, Robyn and Gail thank you. Especially to Kaz for all the countless hours of babysitting, laughs and the “you go woman!” pep talks. Also to our kindy and school teacher angels for your kindness and care for the little girls. Thank you all for believing in me especially on the days I couldn’t believe in myself! It meant a lot. To anyone I’ve forgotten please accept my apologies.
Statement of Originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the Thesis contains no material previously published or written by another person except where due reference is made in the Thesis itself.

Signed: [Signature]

Shannyn Meloncelli

Dated: 23 November 2016
Chapter 1: Introduction

1.1 Introduction

Rheumatoid arthritis (RA) is an autoimmune disease, whereby the body’s immune system attacks its own tissues. This chronic, systemic condition can affect people of all ages, and impacts the whole body, including organs, nerves, eyes, and the respiratory and digestive systems (Australian Institute of Health and Welfare, 2015a; Matteson, Cohen, & Conn, 1997; Robbins, Mehl, Holleran, & Kasle, 2011; Ryan, Hassell, Dawes, & Kendall, 2003). Joints are primarily affected, with painful swelling and stiffness (Arthritis Australia, 2015; Curtis, Groarke, Coughlan, & Gsel, 2004). There is currently no cure for RA, and an individual’s success through treatment and medication is unpredictable. Over the last two decades improvements have been made regarding early stage treatment of RA (Arthritis Australia, 2015). Accessing treatment early is imperative as significant joint deformities can occur in the first few years of disease activity (Arthritis Australia, 2015). The prevalence of RA is expected to rise by 40% in Australia by 2032 (Arthritis and Osteoporosis Victoria, 2013).

The onset of RA commonly occurs between 35-64 years of age, potentially impacting women in their reproductive and child caring years (Gordon & Hastings, 1997; MOVE muscle bone & joint health, 2016). Women account for five out of eight people affected by the disease according to Australian and overseas figures (Australian Institute of Health and Welfare, 2015b; Meade, Sharpe, Hallab, Aspanell, & Manolios, 2013; Mitton, Treharne, Hale, Williams, & Kitas, 2007; Østensen & Villiger, 2007; Symmons et al., 2002) and experience parenting related issues such as accessing appropriate post-natal care and parenting information (Ackerman, Jordan, Van Doornum, Ricardo, & Briggs, 2015; Chambers, Tutuncu, Johnson, & Jones, 2006; Signore, Spong, Krotoski, Shinowara, & Blackwell, 2011). However, limited research exists on how mothers with RA cope and what their support needs are. There is a need therefore to explore the support needs and coping strategies of mothers with RA, who still fulfil a parenting role (White, Mendoza, White, & Bond, 2009).

1.1.1 Rheumatoid Arthritis

According to self-reported data from the Australian Bureau of Statistics (ABS) National Health Survey (2011–12), approximately 445,000 Australians (2% of the population) reported having RA (Australian Bureau of Statistics, 2012). An RA diagnosis can cause increased emotional, physical and financial impacts for the individual and their family (Grant, 2001; Mitton et al., 2007). According to Arthritis Australia (2015) RA disease progression and severity varies from person to person. People with RA can experience pain, fatigue, disability and loss of mobility (Dickens & Creed, 2001; Meade et al., 2013). RA can be an
unpredictable disease, fluctuating between manageable levels and periods of exacerbations or ‘flares’ (Lutze & Archenholtz, 2007; Mitton et al., 2007; Plach, Stevens, & Moss, 2004). Flares can occur with little warning, and lead to pain, swelling and immobility, and can last for an undetermined period of time. These events cause further uncertainty for the individual and their family (Ryan et al., 2003).

The uncertain nature of RA can impact on many aspects of a person’s life, including undertaking domestic and professional tasks (Ramjeet, Smith, & Adams, 2008) and people may have to give up work due to the physical impacts of RA (Walsh, Blanchard, Kremer, & Blanchard, 1999). A paid working role can be a measure of a person’s worth in western society, and having to relinquish this role because of RA can cause financial, physical, social and emotional impacts and stressors (Abraido-Lanza, 2004; Allaire, Wolfe, Niu, Lavallée, & Michaud, 2005; Arvidsson, Bergman, Arvidsson, Fridlund, & Tops, 2011a; Hwang, Kim, & Jun, 2004; Katz, Pasch, & Wong, 2003; Mitton et al., 2007; Sinclair & Blackburn, 2008; Wolfe, Michaud, Choi, & Williams, 2005).

Parents with RA may also feel guilty at their perceived inability to consistently fulfil a parenting role (Barlow, Cullen, Foster, Harrison, & Wade, 1999; Kocher, 1994; Mitton et al., 2007). An RA diagnosis can disrupt social and professional relationships, and adversely affect a person’s self-worth (Coty & Wallston, 2008; Katz et al., 2003; Katz & Yelin, 2001; Lapsley et al., 2002; Mahat, 1997). Indeed, depression and anxiety are more common amongst people with RA, compared to the general population (Ang, Choi, Kroenke, & Wolfe, 2005; Archenholtz, Burckhardt, & Segesten, 1999; Barlow et al., 1999; Dickens, McGowan, Clark-Carter, & Creed, 2002; Kamwendo, Askenbom, & Wahlgren, 1999; Mitton et al., 2007; Rosemann et al., 2007; Sale, Gignac, & Hawker, 2008; Sinclair & Blackburn, 2008).

Research has identified that emotional issues can adversely impact individuals and their ability to parent (Covic, Tyson, Spencer, & Howe, 2006; Evans & de Souza, 2008; Rolland, 1999; Sharpe, Sensky, & Allard, 2001), and people in constant pain and with chronic health issues are more likely to experience anxiety and/or depression and have lower self-esteem than the general population (Mitton et al., 2007; Treharne, Lyons, Booth, & Kitas, 2007). Two-thirds of people with arthritis report negative emotional impacts (Arthritis Australia, 2015).

Arthritis Australia (2015) recommends that people diagnosed with RA seek treatment from a rheumatologist in the early stages of the disease to reduce joint deformities. Common medications prescribed include non-steroidal anti-inflammatory drugs (NSAIDs), corticosteroid medicines or injections, disease-modifying anti-rheumatic drugs (DMARDs) and biological DMARDs (Arthritis Australia, 2015). Other medications, known as ‘first-line’ medicines, include paracetamol, codeine, and non-steroidal anti-inflammatories, and are
used to treat symptoms such as pain and swelling (Arthritis Australia, 2015). Furthermore, it is recommended that sufferers seek professional help to manage physical and emotional problems, become involved in social activities, exercise regularly, eat a balanced diet and seek social support (Arvidsson, Bergman, Arvidsson, Fridlund, & Tops, 2011b; Holman & Lorig, 1997; Vliet Vlieland, 2007). There is a need to tailor and deliver patient management programs to meet the needs of younger people, including mothers caring for children of all ages (Ackerman et al., 2015; Astin, Beckner, Soeken, Hochberg, & Berman, 2002; Dixon, Keefe, Scipio, Perri, & Abernethy, 2007). Ackerman et al. (2015) identified a need to address the specific needs and information relevant to younger women and mothers with RA, including physical, practical and emotional support services.

1.2 Research issue

Recent research has identified that RA can have a profound impact on women in their childbearing years. Meade et al. (2013) found that mothers with RA need to have their individual support needs identified to ensure they, and their families, receive appropriate physical and emotional support from health professionals. Ackerman et al. (2015) concurred, stating that mothers reported a lack of information regarding available support services and information for the post-partum ‘flare’, a period of possible increased pain and physical disability following the birth of a baby (Ackerman et al., 2015; de Man, Dolhain, van de Geijn, Willemsen, & Hazes, 2008).

Research involving mothers with RA identified a range of challenges and impacts, including physical fatigue, functional childcare issues with bathing and feeding, and psychosocial issues, such as irritability, stress, guilt and depression. These impacts, and subsequent increased physical, psychological, socio-cultural and financial burdens, not only affect an individual, but may also be experienced by their whole family. A chronic health condition, such as RA, can affect a mothers’ independence, sense of control over life events and coping ability (Chambers et al., 2006; Grant, 2001; Signore et al., 2011). The organisational and communication patterns of families that have a member with RA were analysed, and it was identified that families that developed supportive systems, normalising household functioning, despite the severity of the person’s RA symptoms, appeared to cope better (Whitley, Beck, & Rutkowski, 1999). Receiving appropriate and responsive support to cope with the impacts of RA was identified as important for adults and women with RA (Neville et al., 1999; Ryan, 1998).

As identified in other studies mothers with RA wanted to be seen as capable of coping independently and not as disabled or dependent on others for support (Mitton et al., 2007; Sinclair & Blackburn, 2008; Thomas, 1997). Mothers stated being labelled as dependent led
to fears for the future, a loss of independence and a lack of self-esteem (Mitton et al., 2007). One study regarding how women with RA cope identified that active, approach-oriented coping strategies, such as pacing oneself, delegating tasks and boundary-setting, led to positive feelings of self-efficacy and optimism. The establishment of these adaptive coping strategies can then lead to greater feelings of self-efficacy and a sense of control which is important in relation to chronic health issues such as RA which is currently incurable (Sinclair & Blackburn, 2008). Currently, there is limited research exploring the impacts of RA on mothers and families, particularly focusing on how RA directly impacts a mother’s ability to cope and her support needs throughout all stages of parenting.

1.3 Research significance

This research is significant as limited research exists regarding mothers self-identified coping strategies and support needs to manage the impacts of RA alongside a parenting role (White et al., 2009). As RA is currently incurable, identifying and exploring mothers’ successful self-identified coping strategies and their specific support needs is significant in helping inform other mothers with RA and people in their support network (Sinclair & Blackburn, 2008). As identified in previous studies, adaptive coping strategies are essential in managing a chronic health condition, such as RA, which is not only currently incurable but has unpredictable impacts that fluctuate in severity, causing pain, fatigue and loss of mobility (Mitton et al., 2007; Ryan et al., 2003; Sinclair & Blackburn, 2008). This unpredictability necessitates that mothers have contingency plans to continue to parent, despite the severity of their RA symptoms, and draw in support from people in their network to continue to care for themselves and their children.

Previous research has focused mainly on RA and pregnancy, with only limited information available regarding how RA impacts mothers throughout all stages of parenting (Ackerman et al., 2015). Ackerman et al’s (2015) study identified that women found it difficult to find information on pregnancy and parenting, including vital information on safe medications for use during this time. Additionally, the study identified a need for evidence-based information, enabling mothers to gain insights from the experiences of other mothers with RA. This current research, in exploring mothers’ stories, significantly contributes to knowledge regarding how mothers with RA cope and are supported during all stages of parenting, an area of current limited research.

1.4 Research overview

This research was positioned within a social constructivist epistemology and was guided by a qualitative exploratory case study methodology. Skinner et al (2003) and Skinner and
Zimmer-Gembeck (2007) *Hierarchical models of coping* was utilised as the theoretical framework (Figure 1). The aim of this research was to explore the day-to-day support needs and coping strategies of mothers with rheumatoid arthritis (RA), as identified by mothers themselves. In the first component of this qualitative research, an online survey (Method 1) consisting of three questions was posed to mothers with RA on two female-only Australian RA Facebook groups. Secondly, four mothers with RA from the Sunshine Coast, Queensland (Australia), were interviewed face-to-face (Method 2) to further explore their self-identified support needs and coping strategies. The knowledge generated from this research will be used to inform community-based public health strategies aimed at educating and informing mothers with RA to draw in support and cope with the impacts of RA alongside a parenting role.

Ethics approval was granted by the University of the Sunshine Coast Human Research Ethics Committee (Ethics Approval S/13/501) (Appendix 1).
Figure 1: Research design overview

1.5 Thesis structure

The purpose of this thesis is to report on the support needs and coping strategies of mothers with RA. This thesis consists of seven chapters: (1) introduction; (2) literature review; (3) research design; (4, 5) results (2 chapters); (6) discussion; and (7) conclusion and recommendations.

This chapter introduced the research study and provided an overall summary of rheumatoid arthritis (RA). Key issues faced by mothers with RA were introduced and the research significance was presented. An overview of the research design was also presented. The aim of Chapter Two was to review the literature related to the support needs and coping strategies of mothers with RA, and the impacts of living with RA alongside managing a
parenting role. The chapter concludes with an overview of the key issues identified in the review.

Chapter Three outlines the research design, including the research aim and research question, epistemology, theoretical framework, research methodology, research participants, recruitment strategy and data collection and analysis methods.

Chapters Four and Five present the research results in relation to the overall aim and research question. Chapter Four presents the results of the Facebook online survey (Method 1) with a focus on participants support needs. This chapter commences with a description of participants. Identified themes are then presented which include participants; 1) support network, 2) types of current support, 3) desired support, 4) initial coping strategies and longer term coping ‘resources’ and 5) emotions experienced. Results are then presented in relation to participants utilisation of the “support-seeking” ‘family of coping’ with participant statements presented under the ‘lower-order families’ of ‘instrumental aid’, ‘social-referencing’, ‘contact-seeking’ and ‘comfort-seeking’. This section is concluded with an exploration of ‘coping as an episodic process’ to identify the different factors influencing the development of coping strategies and longer term coping ‘resources’.

Chapter Five presents results of the semi-structured interviews (Method 2) which explored participants self-identified coping strategies. The aim of the interviews was to further explore the themes identified in Method 1. This chapter’s results focus on participants self-identified coping strategies, individual coping adaptations and coping ‘resources’ and day-to-day ‘support-seeking’ behaviours to manage the impacts of RA alongside a parenting role. A description of participants is presented followed by a presentation of results in three parts. Firstly, results are presented with participant statements, in relation to their “support-seeking” behaviours. Secondly, results are presented, also with participant statements, in relation to participants’ utilisation of interrelated ‘families of coping’. Lastly, results of participants coping outcomes, ‘resources’ and ‘liabilities’, are presented identifying participants individual adaptive coping strategies and longer term coping ‘resources’.

Chapter Six presents the discussion of the research results in relation to the relevant literature and theoretical framework. How the research results may contribute to future knowledge and understanding about how mothers seek support and develop coping strategies to manage the impacts of RA alongside a parenting role are discussed. The chapter concludes with a discussion of the implications for practice and future research, and the strengths and limitations of the study.

Chapter Seven presents the conclusion of the research and makes recommendations for future research, practice and policy.
The Appendices include: 1) Ethics approval; 2) *Hierarchal models of coping* (Skinner et al. 2003 and Skinner and Zimmer-Gembeck, 2007); 3) *Coping processes* model (Skinner and Zimmer-Gembeck, 2007); 4) Facebook online survey questions; 5) Participant information statements; 6) Participant questionnaire; 7) Research project information sheet (RPIS); 8) Recruitment press release; and 9) Participant consent form.

The following chapter presents a review of relevant literature to the research.
Chapter 2: Literature Review

2.1 Introduction

The aim of this chapter was to review the literature related to the research issue, specifically the support needs and coping strategies of mothers with rheumatoid arthritis (RA), and the impacts of living with RA alongside a parenting role. The review commences by exploring the various impacts of RA on mothers, followed by mothers support needs and coping strategies. The review then explores appropriate and responsive support received by mothers with RA as identified in the review studies. Findings are presented under the following three key themes and includes relevant research gaps: 1) the range of impacts affecting a mothers’ ability to cope (Section 2.4); 2) support needs and coping strategies of mothers (2.5); and 3) appropriate and responsive support for mothers (2.6). Limitations in the studies included in the review and limited sample diversity are outlined (Section 2.7). The literature review concludes with an overview of the research findings, key research gaps and future research directions. This section includes a reflection on the impacts of RA on mothers’ ability to parent with studies in the review identifying a need for more supportive interventions matching the support needs of mothers in order to assist them to develop independent adaptive coping strategies (Section 2.8).

2.2 Narrative literature review methodology

A narrative literature review methodology was adopted for this review. According to Green, Johnson, and Adams (2006), narrative reviews are used to synthesise chosen studies to present an overview of a problem or its management. In the case of this literature review, the aim was to synthesise current research relating to the range of impacts of RA on a mothers ability to cope, and to ascertain what is currently known regarding the support needs and coping strategies utilised by mothers to manage a parenting role alongside of managing the impacts of RA. Peer-reviewed qualitative and mixed-method research (from 1997 to 2015) was electronically searched via seven databases (Cinahl, Google Scholar, PubMed, PsycInfo, PsycNet, Scopus and Web of Knowledge).

The review was undertaken between 2012 and 2015, with a post hoc search between 2015 and 2016. Reference lists of studies were also searched. Key search terms used in multiple combinations included: parenting with rheumatoid arthritis, rheumatoid arthritis, mothers, women, coping, support, social support, mothers coping with parenting and rheumatoid arthritis, chronic health issues, and mothers with disabilities and self-efficacy.
**Inclusion criteria**

Due to the paucity of research relating to mothers with RA, the search scope was widened to include adults (>16 years) with RA and mothers and grandparents with other chronic health conditions in a parenting or child caring role. Other such conditions included autoimmune and musculoskeletal conditions, chronic back pain, migraines, mental health issues and multiple sclerosis (MS). The scope was limited to qualitative and mixed-method research to provide in-depth information. Quantitative research within mixed-method approaches deemed useful included, for example, survey research followed by interviews and focus groups.

**Exclusion criteria**

Quantitative research, clinical drug trials, research duplications and conference papers were excluded. Research relating to juveniles (under 16 years) and the elderly (65 years and over) with RA or other chronic health issues with no reference to domestic duties or caring for children were also excluded. Research published prior to 1997 (with the exception of research on coping) was excluded due to the lack of relevance to current patient treatment protocols; particularly for women with RA in their childbearing and caring years.

### 2.3 Search results

The initial primary search yielded a total of 111 studies. The studies were read in full to ensure the research met the inclusion criteria. Ninety studies were excluded, leaving 21 remaining after the exclusion criteria was applied. A secondary search of the reference lists of these 21 studies was subsequently conducted. Although an additional 19 studies were identified, they were all ultimately excluded for reasons such as the research provided limited relevance to parenting and coping strategies. A further nine studies were excluded following research team examination, leaving a total of 12 relevant studies (Figure 2). The findings from these studies were then organised into themes for the purpose of this review. Themes included: 1) the range of impacts affecting a mothers’ ability to cope; 2) support needs and coping strategies of mothers; and 3) appropriate and responsive support for mothers. The post hoc search undertaken between 2015 and 2016 yielded an additional three relevant studies, which were also included in this review.
Databases searched
Cinahl, Google Scholar
PsycInfo, PsycNet, Pubmed
Scopus, Web of Knowledge

Keywords
Parenting with rheumatoid arthritis, rheumatoid arthritis, mothers, women, coping, support, social support, mothers coping with parenting and rheumatoid arthritis, chronic health issues, mothers with disabilities, self-efficacy

21 studies identified for additional assessment

90 studies excluded

111 full text studies assessed for eligibility

Hand search conducted on 21 studies. Search yielded additional 19 studies

40 studies remain for additional assessment

All abstracts read. Studies read in full if deemed relevant. Further 19 studies excluded with reasons

Final 12 studies remained

21 studies were further examined with a further 9 studies excluded with reasons

Post Hoc Search
2015 - 2016
Databases Searched
Cinahl, Google Scholar, PsycInfo, PsycNet, Pubmed, Scopus, Web of Knowledge

Additional 3 studies added

Keywords
Parenting with rheumatoid arthritis, rheumatoid arthritis, mothers, women, coping, support, social support, mothers coping with parenting and rheumatoid arthritis, chronic health issues, mothers with disabilities, self-efficacy, coping theory, Lazarus and Folkman’s problem versus emotion focused coping

Total of 15 studies (included in the literature review)
(Abraido-Lanza, 2004; Ackerman et al., 2015; Barlow et al., 1999; Evans & de Souza, 2008; Grant, 2001; Kanzaki et al., 2004; Katz, Pasch, & Wong, 2003; Meade et al., 2013; Mitton et al., 2007; Prodinger et al., 2014; Ramjeet et al., 2008; Ryan et al., 2003; Sinclair & Blackburn, 2008; Thomas, 1997; Whitley et al., 1999)

Figure 2: Literature review search
2.4 Range of impacts affecting a mothers’ ability to cope

A range of physical, psychological, financial and socio-cultural impacts were identified as affecting mothers and their ability to cope with these impacts alongside a parenting role.

2.4.1 Physical impacts experienced by mothers with RA

Physical impacts experienced by mothers with RA included fatigue, pain and the loss of mobility due to joint issues, and an inability to carry out everyday tasks and cope with parenting alongside the impacts of RA (Barlow et al., 1999; Grant, 2001; Katz et al., 2003; Meade et al., 2013; Mitton et al., 2007; Poole, Willer, & Mendelson, 2009). Specifically, mothers had physical difficulties with buckling children into car seats, preparing meals and getting up and down off the floor to play (Poole et al., 2009). Physically keeping up with energetic children and managing laundry, grocery shopping and preparing meals was also problematic. A mixed-method study using surveys and focus groups to understand how arthritis impacts parenting ability found that fatigue, pain and physical restrictions impacted parenting with issues mainly with caring for babies and toddlers (Barlow et al., 1999).

However, almost half of the American mothers in another study reported physical parenting issues associated with RA irrespective of children’s age. The study, which asked 231 women with RA open and closed questions, assessed the disability level of women with RA in relation to parenting. Themes identified included: the unpredictability of RA symptoms and associated fatigue, problems associated with bathing and dressing children and transferring them into cots and car seats, and increased financial costs when domestic support and assistive devices were required due to functional disability Katz et al. (2003).

In an Austrian study one mother stated that she could not shop alone anymore as she couldn’t even lift a litre of milk. In this occupational therapy (OT) based study, seven women with RA were interviewed and observed as they identified how they managed domestic tasks, such as cleaning, grocery shopping and cooking. Mothers identified that they faced complex physical challenges regarding completing and coordinating everyday tasks, such as shopping or cooking. Family provided most assistance, with the availability of support influencing daily occupations, such as cooking, due to needing help with kitchen devices and lifting heavy pots. This study identified the need for therapists to individually assess their patients everyday domestic occupations and challenges to provide appropriate practical solutions (Prodinger, Shaw, Stamm, & Rudman, 2014).

In another qualitative study, 14 women’s written accounts of pre-parenting decisions and motherhood experiences in relation to managing RA were collated. A need was identified for support and information to be available for women with RA, and their families, so that they
may make informed decisions regarding health and family responsibilities. The research identified that having RA posed significant challenges for mothers, with parenting experiences often surrounded by fear and uncertainty. Uncertainty often related to the use of medication and the physical impacts of it on unborn and newborn babies (during pregnancy and breastfeeding) with the impact of RA disease activity if a mother remained un-medicated while breastfeeding. Mothers stated that their rheumatologists were their main source of information; however, they identified a need for more information on pregnancy, post-partum flares and parenting issues, and more comprehensive support regarding parenting decisions (Meade et al., 2013). A need for practical interventions, developed in coordination with other mothers, was identified as a means to enable greater control in managing the physical impacts of RA alongside a parenting role (Grant, 2001; Meade et al., 2013; Mitton et al., 2007).

2.4.2 Psychological impacts experienced by mothers with RA

The psychological impacts of RA on a mother were identified in the literature to cause a range of issues (Abraido-Lanza, 2004; Evans & de Souza, 2008; Grant, 2001; Kristiansen, Primdahl, Antoft, & Hørslev - Petersen, 2012; Mitton et al., 2007). Potentially causing feelings of disempowerment, guilt and resulting in significant life-long psychological implications (Mitton et al., 2007). This was especially true if children became caregivers to chronically unwell parents, causing feelings of guilt for mothers who perceived that they were unable to fulfil parental duties (Kristiansen et al., 2012).

Research identified that without appropriate support and understanding to manage the impacts of RA, mothers could struggle to parent. This could subsequently lead to depression, causing flow on impacts for families and long-term psychological implications for mothers. This qualitative study explored how mothers with arthritis (not RA exclusively) coped and the role of OT in their lives. Four mothers were interviewed, including two who had RA, and OT observations were utilised. The mothers’ occupational therapists (OT’s) were also interviewed, and case notes were explored. Themes identified included: practical and psychological parenting issues, OT experiences and level of available support. The study identified a need for individual psychological and practical interventions for mothers. The study also identified that the level of partner support significantly impacted a mother’s coping abilities (Grant, 2001).

Research into the family life of mothers with chronic pain was explored through undertaking interviews with sixteen mothers with chronic pain conditions and their children. The interviews were conducted in the family homes and examined families’ daily challenges, how they overcame challenges and the overall impacts of the mothers’ conditions. The study
identified that although the mothers’ chronic pain caused challenges, the situation provided opportunities for families to grow stronger. Additionally, chronic pain could make mothers and children vulnerable; however, they also developed individual and collective courage and strength in regards to coping and supporting one another (Evans and de Souza, 2008).

Structured interviews with 98 Latina women with arthritis who identified as being homemakers were undertaken to explore the role of social support in the mothers’ lives. It was identified that although some support was well-intentioned, it could still have a negative psychological impact on the recipient. For example, for these Latina mothers, physical support with housework was only deemed beneficial if it was their daughters helping, as this was within cultural norms. The study identified that support from outside the family, although well-intentioned, made the women feel like inadequate wives and mothers, and caused psychological impacts, such as feelings of guilt (Abraido-Lanza, 2004).

The motivation for a British study was in response to mothers with RA (patients at an RA clinic) identifying that they couldn’t cope with the extra motherhood responsibilities alongside the impacts of RA. Semi-structured face-to-face interviews were undertaken with seven of these women. A number of psychological impacts were identified, including mothers experiencing depression and guilt and ‘feeling robbed of motherhood’ (Mitton et al., 2007, p. 191); however, other mothers stated that they found inner strength managing with RA and parenthood. The study identified practical issues such as a lack of available information and support, which caused feelings of fear and uncertainty for some mothers.

In some of these studies, mothers and wives lamented not being emotionally and physically available to their families in the ways they wanted to be (Abraido-Lanza, 2004; Evans & de Souza, 2008; Mitton et al., 2007). Consequently, mothers experienced negative psychological impacts, such as feeling fearful and uncertain. It was found that future interventions need to be in consultation with mothers to aid with individual problem solving strategies to improve self-efficacy to reduce negative psychological impacts, such as depression, anxiety and feelings of social isolation (Ackerman et al., 2015; Grant, 2001; Meade et al., 2013; Sinclair & Blackburn, 2008).

2.4.3 Financial impacts experienced by mothers with RA

In addition to physical and psychological impacts, RA can cause financial impacts for mothers with RA (Evans and de Souza, 2008; Grant, 2001; Katz et al., 2003). One study assessed disability levels and parenting activity amongst women with RA identifying that mothers, who can be permanently disabled by RA, could have difficulty performing even basic parenting tasks. Consequently, domestic help may need to be sought, or assistive devices bought, including wheelchairs and stair-lifts, which can be costly. This can be a
double blow, impacting the family budget at a time when one or both parents may have to give up work to care for the family (Katz et al., 2003). Mothers and women identified that their pain conditions had an impact on their careers, with some having to give up work permanently (Evans & de Souza, 2008; Grant, 2001). One mother stated that she managed to work; however, it was at the expense of other areas of her life, as work consumed all of her energy. In the same study it was identified other flow-on impacts included increased parenting stress and the loss of self-esteem due to the added pressure of financial problems (Katz et al., 2003).

2.4.4 Socio-cultural impacts experienced by mothers with RA

Studies identified that mothers with RA and other chronic health issues also experienced socio-cultural impacts. Mothers identified a lack of support and understanding from friends, family and medical professionals in relation to living with RA and other disabilities. Common themes to emerge from these studies included social isolation, anger, frustration and a lack of support or inappropriate support received (Evans & de Souza, 2008; Grant, 2001; Katz et al., 2003; Meade et al., 2013; Thomas, 1997).

Semi-structured qualitative interviews with 17 disabled mothers identified that they faced social barriers regarding motherhood because of their disabilities. Issues identified included: receiving ‘unhelpful help’ with nurses taking over care of their babies without permission; judgement for taking ‘risks’ by having a baby, for example risking genetically passing on their disability; fears of being judged as an inadequate parent; and mothers experiencing distress at not meeting their own parenting expectations (Thomas, 1997).

Women felt that their pain conditions dominated their lives and gave them a sense of missing out. They further stated pain could dictate their attendance at social functions and had resulted in lost friendships due to a lack of understanding of their self-identified ‘invisible’ illnesses (Evans & de Souza, 2008). Chronic pain conditions can contribute to social isolation, and studies have identified a need for supportive interventions to address this (Evans & de Souza, 2008; Grant, 2001).

2.4.4.1 The collective impacts of RA on mothers

The physical, psychological, financial and socio-cultural impacts identified in this review add to the potential for mothers with chronic health issues to feel inadequate, fearful and dependent (Evans & de Souza, 2008; Grant, 2001; Meade et al., 2013; Mitton et al., 2007; Ryan et al., 2003; Thomas, 1997). A study examining women’s decision making processes relating to motherhood and living with RA, found that having RA significantly impacted a mothers decision making, adjustment and acceptance. However, it was further identified that
mothers with RA wanted to be seen as normal, not as disabled or dependent (Mitton et al., 2007; Thomas, 1997).

Feeling overly dependent on others for support can lead to issues, such as a perceived loss of independence, lack of self-esteem and fears for the future (Mitton et al., 2007). In a study exploring disabled mothers’ parenting experiences it was identified their experiences were marred by social barriers, with some mothers living in fear of being judged as inadequate, leaving them feeling vulnerable (Thomas, 1997). Mothers in other studies expressed similar fears and frustrations, especially when experiencing difficulties with basic parenting tasks, such as bathing and feeding children (Grant, 2001; Mitton et al., 2007).

In qualitative interviews 40 people with RA were questioned regarding control perceptions related to living with RA including the impact of social support and information provision. It was identified that social support can influence a person’s sense of control, with inappropriate support leaving the recipient feeling helpless. Themes identified included: staying involved in family activities to remain feeling in control, receiving ongoing support from family, and support needs being matched by support provision. Involving families and individuals in patient management plans allowed the person with RA to still feel in control, while also being supported (Ryan et al., 2003).

Ongoing physical and emotional support was described as being integral in coping with the impacts of RA alongside a parenting role. This support enabled mothers to care for children, maintain a house and function in general (Ryan et al., 2003). Additional support came from children helping with household chores or by family members being emotionally responsive, with mothers indicating that they appreciated this support (Evans & de Souza, 2008; Ryan et al., 2003). Mothers wanted to be seen as independent, normal mothers, not as disabled or dependent, and to be supported, through the involvement of family through appropriate strategies, to fulfil their parenting roles. Appropriate and responsive support, in consultation with the person with RA, was identified as being integral to the needs of adults and mothers living with RA (Mitton et al., 2007).

2.4.5 Research gaps: Range of impacts on a mothers’ ability to cope

Key research gaps relating to the impacts of RA and a mothers’ ability to cope were identified in the studies in this review. Despite the importance of a parenting role, limited research on how RA impacts mothers exists and in particular, the impact of maternal chronic pain and the socio-cultural impacts associated with RA (Barlow et al., 1999; Evans & de Souza, 2008; Sepa, Frodi, & Ludvigsson, 2004). The information needs of women with RA from research from the United Kingdom the United States of America was considered greatest (Fraenkel, Bogardus, Concato, & Felson, 2001; Neame, Hammond, & Deighton,
2005). Despite this, limited research exists on exploring and identifying what information is most needed by women with RA in their childbearing years (Ackerman et al., 2015). Limited research exists on how mothers with RA cope in regards to parenting with main issues of concern for mothers being RA disease activity, treatments, depression, anxiety and family stress (Meade et al., 2013). There is also limited research on the most appropriate interventions and supports to alleviate these impacts (Grant, 2001; Meade et al., 2013). Additional research on the emotional and physical support services available for mothers with RA is needed (Ackerman et al., 2015).

2.5 Support needs and coping strategies of mothers with RA

The support needs and coping strategies utilised by mothers to manage the physical, psychological, financial and socio-cultural impacts of RA were identified in the review. The importance of mothers with RA receiving support from various sources, including informational, emotional and physical support, to cope with the impacts of RA alongside a parenting role was also identified (Ackerman et al., 2015; Grant, 2001; Kanzaki, Makimoto, Takemura, & Ashida, 2004; Meade et al., 2013; Mitton et al., 2007; Ryan et al., 2003; Sinclair & Blackburn, 2008; Thomas, 1997).

A literature review examining the physical and psychological coping strategies and levels of adjustment of people living with RA was undertaken. In the review reference was made to Skinner et al. (2003) and Skinner and Zimmer-Gembeck (2007) coping theories. The authors firstly referred to Lazarus’ (1984) earlier coping theories, and then Skinner et al. (2003) and Skinner and Zimmer-Gembeck’s (2007) coping theories which were described as a ‘top-down hierarchical restructuring of coping, with a specific focus on coping strategies as the core building blocks’ (Ramjeet et al., 2008, p. 420).

A number of positive coping strategies have been identified that have provided mothers with a sense of control and self-efficacy in their lives. Nineteen women with RA were interviewed, examining their adaptive coping strategies in relation to managing the impacts of RA in a qualitative study. Themes identified in this study included: accepting role limitations, regaining control and strengthening courage. The authors also referred to Lazarus and Folkman’s Stress and Coping Model (1984), which informed some of Skinner et al. (2003) and Skinner and Zimmer-Gembeck’s (2007) coping theories (Sinclair & Blackburn, 2008). Other studies utilised models of health behaviour, such as the Health Belief Model (Rosenstock, 1974 in Ryan et al., 2003) and the Family Environment Scale Manual (Moos and Moos, 1981 in Whitley et al., 1999).
2.5.1 Mothers positive coping strategies and a sense of control

Mothers stated in various studies in the review that it was important for them to stay in control, particularly of parenting duties, with the support of others around them (Grant, 2001; Kanzaki et al., 2004; Ryan et al., 2003; Prodinger et al., 2014; Sinclair and Blackburn, 2008).

One mother with RA stated that it was important to remain in control of parenting duties, with her husband supporting her, but not taking over (Ryan et al., 2003). Perceived control over the impacts of RA can positively influence general well-being and a mother’s ability to parent (Grant, 2001). A Japanese study utilising qualitative and quantitative methods explored the implementation of an internet-based system, which the researchers developed for 12 women with RA to describe their daily experiences and coping abilities. Participants wrote frequent journal-like entries and submitted the data into the system over one month, with the researchers responding regularly. The researchers claimed the process enabled them to collect data on the participants fluctuating pain levels and resulting changing coping strategies throughout a given day. Women in the study stated that the process helped them to cope with RA, especially through receiving regular feedback from the researchers (Kanzaki et al., 2004).

Women with RA in another study identified that they reclaimed control of their lives by utilising different strategies at various times, including pacing activities, changing priorities, delegating tasks, being flexible and asking others for social support. The authors identified that as RA can cause losses, such as the loss of independence through not being able to work or complete physical tasks, people needed to develop coping strategies that enabled them to set goals and establish a sense of purpose and well-being (Sinclair & Blackburn, 2008).

Coping strategies that gave women with RA a sense of self-efficacy and psychological well-being included accepting realistic standards, gaining confidence from successes, acquiring optimism, finding meaning, and hoping for medical breakthroughs. These positive adaptive coping strategies that made accommodations to a woman’s current situation, such as pacing activities to conserve energy, were identified as enabling women to cope more effectively and gain a sense of purpose. One woman stated that it was important to accept that it was not a sign of weakness to accept help and support (Sinclair & Blackburn, 2008). One mother in another study stated that she planned her housework, and coped by taking breaks and also delegating tasks to her partner (Prodinger et al., 2014). Accepting that asking for support would help achieve tasks gave these mothers a greater sense of control over their own lives (Prodinger et al., 2014; Sinclair & Blackburn, 2008).
2.5.2 Mothers with RA experiencing a lack of support

A lack of support for mothers with RA was identified as causing a number of psychological and practical issues (Ackerman et al., 2015; Grant, 2001; Meade et al., 2013; Mitton et al., 2007; Thomas, 1997). In one study mothers identified that they lacked information on coping strategies and support services and needed more practical tips and strategies to cope with parenting. Also identified was a lack of information on medication safety, physical and emotional support services, and practical strategies. Mothers and women stated that they felt the needs of younger women with arthritis were not being met, in particular by arthritis organisations, and that the misleading perception remained that arthritis was an older person’s condition (Ackerman et al., 2015).

Mothers expressed feelings of being let down by a health system that failed to understand the unique needs of managing the impacts of RA alongside the demands of motherhood (Grant, 2001; Meade et al., 2013; Mitton et al., 2007; Thomas, 1997). It was identified a perceived inadequate level of support for disabled mothers existed, with mothers stating health workers often assumed care of their babies, without first consulting them, which made them feeling inadequate (Thomas, 1997).

One mother identified that she was left to cope alone with her previous baby, and felt she was better off learning to cope without support for her next baby too (Meade et al., 2013). In other research a mother ironically stated that she must have been the first woman with RA to be pregnant, considering the lack of supportive information available. She stated that she had done an untold number of Google searches and searched libraries, all to no avail, adding that her own doctors had to contact other doctors for advice, as they were unsure of the safety of RA medications during pregnancy (Ackerman et al., 2015).

One study outlined a mothers individual support needs should be identified, ensuring that they, and their families, receive appropriate physical and emotional support and information from health professionals, such as maternal health nurses, general practitioners, rheumatologists and OT’s. The study further identified health professionals’ need to be more understanding and supportive, helping women to make informed choices regarding RA and parenthood. A lack of information and support for mothers with RA has the potential to increase stress and anxiety levels and impact their ability to cope (Meade et al., 2013).

2.5.3 The support needs of mothers with RA

The literature in this review identified that receiving appropriate physical, psychological, informational and social supports can determine a mother’s level of coping and acceptance regarding RA and a parenting role (Ackerman et al., 2015; Grant, 2001; Meade et al., 2013). Additionally, it is imperative that support provided suits a woman’s individual needs in order
to be truly responsive and helpful (Mitton et al., 2007; Ryan et al., 2003). Responsive and supportive help can also influence how a mother copes. The women in Kanzaki et al. (2004) study reported that the simple act of having someone listen and acknowledge their issues and respond with concern made them feel less socially-isolated. The authors also identified that the use of Internet research relating to RA, to date, has mainly been quantitative, elucidating limited in-depth information about participants (Kanzaki et al., 2004).

Research utilising focus groups and telephone interviews identified a need for more support for mothers, particularly from rheumatologists, regarding treatment and medication decisions. The majority of mothers in the telephone interviews stated that their rheumatologist was their primary source of support; however, they also sourced information from other areas, such as online forums and social media (Ackerman et al., 2015). In other research the need to provide more comprehensive information for mothers with RA so that they could make informed choices regarding medications, general health and parenting choices was discussed (Meade et al., 2013). A lack of knowledge particularly regarding treatments often left mothers feeling uncertain and anxious (Ackerman et al., 2015; Meade et al., 2013).

A need for practical parenting tips and coping strategies was identified. Some mothers identified a need to connect with peer support services at a local level, or online through social media or via peer-support or mentoring programs that allowed women to share their stories. ‘Peer-to-peer information’ exchange regarding practical, functional and coping strategies was highly desired by research participants (Ackerman et al., 2015). Women with RA identified that it was beneficial and encouraging to talk with other women who understood their experiences and could identify with their challenges (Ackerman et al., 2015; Sinclair & Blackburn, 2008).

2.5.4 Research gaps: mothers support needs and coping strategies

This literature review identified gaps in relation to the support needs and coping strategies of mothers with RA. Limited qualitative research exists regarding how mothers with RA cope and their support needs (Grant, 2001; Meade et al., 2013; Mitton et al., 2007). There is a need for practical and psychosocial supportive interventions to understand the challenges mothers and their families’ experience, in order to better support them (Barlow et al., 1999; Grant, 2001; Mitton et al., 2007).

A need was identified for arthritis organisations to act as ‘resource hubs’, assisting in peer support facilitation through support groups and mentoring between mothers. A need was also identified for the facilitation of information exchanges between medical disciplines on issues, such as medications, to assist mothers and families to make crucial treatment
decisions (Ackerman et al., 2015). Studies identified that support and information for mothers with arthritis continues to be inadequate, with health professionals having limited knowledge on how to assist mothers with RA (Meade et al., 2013; Mitton et al., 2007). Women indicated that they felt uncertain about balancing disease management and child-rearing, as they received limited and conflicting information on the safety of treatments and medications (Chakravarty, 2011). RA-specific education for health professionals was further identified as a need, so that they could better support mothers to make medical decisions (Ackerman et al., 2015; Meade et al., 2013). Currently, limited supportive information exists to help mothers to fulfil a parenting role, with women reporting that they were sometimes discouraged by health professionals in regards to having children (Backman, Smith, Smith, Montie, & Suto, 2007; Vallido, Wilkes, Carter, & Jackson, 2010).

Studies in the review identified a need for practical tips and strategies to support mothers with RA. Research consistently identified a need for practical tips and strategies to manage day-to-day. More specifically, mothers identified a need for practical information regarding caring for children, such as with bathing, dressing and feeding, and utilising assistive devices for items such as car seats. Practical strategies on conserving energy and reducing fatigue were also desired (Ackerman et al., 2015; Sinclair & Blackburn, 2008).

Limitations of the studies in this review included a paucity of in-depth research into the day-to-day lives of mothers with RA, their coping strategies and their support needs. Little, to no, research exists involving observations in mothers’ homes exploring and recording their strategies. Future research exploring the challenges faced by mothers and their families, as well as their support needs and coping strategies is needed (Ackerman et al., 2015; Prodinger et al., 2014).

2.6 Appropriate and responsive support for mothers for RA

The review identified mothers need appropriate and responsive support to manage the unpredictable nature of RA which can cause family stress, possible family breakdowns, and marital problems (Revenson & Deborah Majerovitz, 1991; Ward & Paul Leigh, 1993). A mixed-method study analysed the cohesiveness and organisational and communication patterns of 15 families where a female member had RA. Women were purposively recruited to participate in the research, with all family members interviewed individually. It was identified that families that developed systems to normalise household operations, despite the issues surrounding RA, appeared to cope better. A number of participants stated that the family communicated well together, dividing tasks and supporting the member with RA when needed. The authors recommend social workers be involved in supportive interventions, and
all members of the household should be included, not just the member with RA (Whitley et al., 1999).

Appropriate support for mothers with RA can assist families to cope better, with emotional support from families contributing to more positive feelings in the person with RA (Abraido-Lanza, 2004; Whitley et al., 1999). Educating spouses on appropriate and responsive support that fulfils the mothers support needs may enable families to communicate better and support one another more effectively. One mother identified that it would be helpful to have more in-depth information outlining the impacts of RA and how family members can be supportive (Ackerman et al., 2015). Family members, themselves, may need support and education on how to appropriately help the person with RA and also be assisted to draw in external support to manage the demands of having a family member with RA (Whitley et al., 1999). Additionally, having ongoing support from family and remaining involved in family activities provided helpful support to members with RA (Ryan et al., 2003).

2.6.1 The positive impacts of a supportive spouse and family

A supportive spouse and family were identified in the literature as being beneficial to a mother’s coping abilities. In research on family cohesion and organisation where a female family member had RA it was identified that some families became stronger and closer in the process of dealing with the impacts of RA. One husband discussed how he and his wife worked together as a team to solve problems and issues associated with RA. Families who appropriately used active and passive coping strategies positively impacted the stability of the family unit. For example in the research 60% of the mothers identified they actively tried to maintain normalcy by attempting to undertake their regular daily activities (Whitley et al., 1999, p 91). The authors identified a need for families to communicate and recognise the need for external support to ensure a stable family environment irrespective of the impacts of RA. The organisational structure of the family was also identified as important with a need for all members to contribute. One daughter of a mother with RA stated that everyone in the family had their own designated chores (Whitley et al., 1999).

Alternatively, a critical or unsupportive spouse could have negative impacts on a mother’s ability to cope. Research identified that negative health outcomes were more likely in unsupportive interpersonal relationships. An unsupportive spouse could potentially impact a mother’s psychological and physical well-being. Mothers who felt that their partners were unsupportive identified that this impacted their parenting experience, while having a supportive spouse assisted mothers to cope better with RA symptoms alongside a parenting role (Grant, 2001).
The literature review identified the importance of ongoing, open and honest communication, which helped families to support one another. One participant stated that it took a lot of communication within the family to negotiate appropriate support to minimise the impacts of RA. The participant stated that they would let their family know when they wanted support, and their particular support needs, so that they didn’t feel so dependent. Other participants in the research stated that the whole family had to make adjustments and accept that the parent could no longer do some things. Some families found this adjustment difficult, with other participants stating that their families treated them like they were disabled, took their control away, or became overprotective, which negatively impacted on the participant’s feelings of self-worth (Ryan et al., 2003).

Appropriate support that meets the needs of mothers with RA is essential when they are also managing a parenting role. One mother stated that without the support of her family, she could not cope practically. Another mother stated that she delegated household tasks to her partner to manage (Prodinger et al., 2014). These examples strengthen the need for more comprehensive education for a mother with RA and her support network. Health professionals can actively support mothers and families by developing individualised, responsive interventions, which can positively impact on parenting experiences (Grant, 2001; Ryan et al., 2003). Supportive professional relationships with health providers can positively influence a person’s sense of control over their situation (Ryan et al., 2003). Other studies identified that support from health professionals and specialists was lacking, perhaps due to a lack of knowledge of RA, especially in relation to parenting issues (Barlow et al., 1999; Meade et al., 2013; Mitton et al., 2007).

The right level or type of support is important for a mother with a disability to develop positive feelings of self-efficacy (Thomas, 1997). Support that is not responsive to the needs of the recipient can do more harm than good, resulting in stress and possibly increased levels of depression and anxiety. Mothers need to feel in control and to be able to look after the family and house, and that support to assist with these things was vital for their sense of self-worth. Mothers stated that helping with daily household tasks assisted their sense of coping and increased their sense of control over their own lives (Ryan et al., 2003).

In research exploring beneficial support for Latina mothers with arthritis it was identified although outside support is often well-intended, it sometimes has negative psychological impacts for the recipient. For example, the receipt of non-familial assistance with housework had the potential to denigrate the woman’s self-esteem. However, if the support was provided by the recipients’ daughters, it was found to be highly beneficial, as this was within their cultural norms. The mothers in this study highly valued their homemaker role and took pride in looking after their homes and families. Staying within cultural norms allowed them to
retain their sense of pride and control over their situation, while also feeling supported. Appropriate support had the ability to bolster a mother’s sense of control over her situation and reduce negative feelings, such as an inability to cope, which could impact on her ability to parent (Abraido-Lanza, 2004).

Although this research pertained directly to a particular cultural group, other research identified commonalities regarding the support needs of mothers with chronic health issues and RA. For some, motherhood gave them strength and a sense of purpose (Del Fabro Smith, Suto, Chalmers, & Backman, 2011). However, other mothers stated that their mothering experience was riddled with feelings of guilt and shame at an inability to meet expectations (Vallido et al., 2010). Regardless of a mother’s cultural or sociocultural background, having a sense of control over her own life was identified as important in coping with the impacts of RA (Sinclair & Blackburn, 2008).

2.6.2 Research gaps: appropriate and responsive support for mothers with RA

Studies in the review identified that further research is needed to gather stories from mothers with RA, their families, and health professionals to ascertain mothers support needs to cope with RA alongside a parenting role (Abraido-Lanza, 2004; Evans & de Souza, 2008; Ryan et al., 2003). There is also a need to analyse the organisational and communication structures of families, and how they work together to manage the negative impacts of maternal RA (Whitley et al., 1999).

A need for supportive interventions to assist rheumatologists and other health professionals to become better educated to meet the support needs of mothers with RA and assist them on their parenting journeys was identified (Meade et al., 2013; Mitton et al., 2007). Coping strategies that enhanced quality of life were critical when dealing with chronic health issues, such as RA, which are currently incurable (Sinclair & Blackburn, 2008).

Future research needs to involve mothers with RA, directly, in developing supportive interventions to ensure that support is beneficial to individual needs (Prodinger et al., 2014; Sinclair & Blackburn, 2008). A need for arthritis organisations to facilitate supportive resources for mothers, including an online hub to access information and online peer support programs that allow mothers to share their stories, was identified. Additionally a need to raise awareness that RA affects younger women of reproductive age was also identified (Ackerman et al., 2015).

In-depth information regarding the lived experiences of mothers with RA is needed to assist mothers to cope, and for health professionals, families and the community to provide more appropriate and responsive support. Through education, mothers can be better supported.
and equipped to develop effective and adaptive coping strategies to manage the physical, psychological and psychosocial impacts of RA (Sinclair & Blackburn, 2008).

Future research needs to give mothers with RA a voice, allowing them to describe their challenges and express their support needs. This objective could be achieved by conducting further in-depth interviews with mothers in a naturalistic setting, such as their homes. Most previous studies conducted interviews in more artificial settings, such as rheumatology clinics. Some studies conducted family interviews in the participants’ homes, which can potentially elicit greater insight into the experiences of mothers and their families (Evans & de Souza, 2008; Whitley et al., 1999). Future support programs need to assist mothers with RA to have greater independence and self-efficacy over the negative impacts of RA while fulfilling a parenting role. Through undertaking research on how mothers cope day-to-day managing the impacts of RA alongside a parenting role, this information can then be used to educate other mothers in similar situations.

2.7 Limitations and limited sample diversity

A trend was identified in the studies in this review regarding a lack of demographic diversity in the sample cohort. One exception was Abraido-Lanza’s (2004) research, which explored the impacts of RA on Latina women, identifying specific cultural implications. The remaining research comprised similar sample groups; white, European, middle class, married, with above average education. Limited research focused on how more socially disadvantaged mothers with RA cope, such as single parents, low-income earners and indigenous people and migrants.

2.8 Conclusion

This review explored literature relevant to the day-to-day support needs and coping strategies of mothers with rheumatoid arthritis (RA). The coping strategies and support needs of adults and mothers managing other chronic health issues, not just RA, in relation to parenting was also explored. Three themes were identified in this review including: 1) the range of factors impacting a mothers’ ability to cope; 2) support needs and coping strategies of mothers; and 3) appropriate and responsive support for mothers. Physical, psychological, financial and socio-cultural impacts were identified which potentially affected a mother’s ability to manage the impacts of RA alongside a parenting role.

Three key research gaps were identified in the review including: 1) limited research on how RA impacts mothers, particularly the impact of maternal chronic pain and the physical, financial, psychological and socio-cultural impacts of RA (Barlow et al., 1999; Evans & de Souza, 2008; Sepa et al., 2004); 2) limited qualitative research on how mothers cope and
their support needs; and 3) a lack of qualitative research regarding self-identified coping strategies and mothers' support needs to cope with RA alongside a parenting role (Abraido-Lanza, 2004; Evans & de Souza, 2008; Ryan et al., 2003). Mothers sharing their stories was identified throughout this review as a comprehensive way to ascertain their effective coping strategies and support needs (Evans & de Souza, 2008; Meade et al., 2013).

Further research is needed to more comprehensively understand the impacts of RA on mothers, and their families, and to explore individual coping strategies and support needs (Ackerman et al., 2015; Prodinger et al., 2014). Studies in the review also identified a need for more supportive interventions matching the individual support needs of mothers. Appropriate support, assisting the development of independent adaptive coping strategies, potentially empowered mothers with a sense of self-efficacy. These adaptive coping strategies, including accepting realistic standards, gaining confidence from successes, pacing activities to conserve energy and drawing in support, were identified as beneficial (Sinclair & Blackburn, 2008). In addition studies identified ‘peer-to-peer information’ exchange on practical parenting tips and coping strategies were desired, with mothers stating that it was helpful to share stories about similar life situations (Ackerman et al., 2015; Sinclair & Blackburn, 2008). Further research is needed to explore the usefulness of peer support in helping mothers with RA to develop coping strategies.

Informational, emotional and physical supports from different sources, such as medical professionals and family and friends, was identified as beneficial. Rheumatologists, OT’s and family were identified as mothers’ most influential supporters; however, it was identified that these supporters sometimes lacked the knowledge to appropriately support mothers (Meade et al., 2013; Mitton et al., 2007). Further research interviewing people in a mothers support network, such as families and rheumatologists, could be useful to explore appropriate and responsive supportive interventions for mothers. Additionally, further qualitative research is needed to identify and explore mothers self-identified coping strategies and their support needs to cope with the impacts of RA alongside a parenting role.

The next chapter presents the research design of this study.
Chapter 3: Research Design

This chapter outlines the research design, including the research aim, research question, epistemology, theoretical framework, methodology, research participants, recruitment strategies, and data collection and analysis methods.

3.1 Research aim

To explore the day-to-day support needs and coping strategies of mothers with rheumatoid arthritis (RA).

3.2 Research question

What are the day-to-day support needs and coping strategies of mothers with RA?

3.3 Epistemology

This research was positioned within a social constructivist epistemology, which seeks to create meaning and understanding of participants' lives and cultural and historical backgrounds from varying, individual viewpoints, not constrained by narrow ideas, themes or limitations (Creswell, 2014; Crotty, 1998). A social constructivist approach was utilised to develop knowledge of the lives of mothers with RA through allowing them to discuss their support needs and coping strategies in their own words. This allowed the researcher unique insight into their day-to-day support needs, support-seeking behaviours and coping strategies (Crotty, 1998). Due to the unique, personal and in-depth nature of social constructivism, this epistemological approach was deemed relevant for the study in regards to the research question posed.

3.4 Theoretical framework

Skinner et al. (2003) and Skinner and Zimmer-Gembeck (2007) Hierarchical models of coping (Appendix 2) was utilised as the theoretical framework for exploring the support needs and coping strategies of mothers with RA.

3.4.1 The development of the coping theory 1984 - 2007

Early coping theorists Lazarus and Folkman described coping in their Stress and Coping Model (1984) as continuously changing cognitive and behavioural efforts to manage external and internal demands that a person views or ‘appraises’ to exceed their resources. The theorists proposed that people utilised two major coping styles: problem-focused coping and emotion-focused coping. Problem-focused coping includes active efforts to change a situation, such as developing practical strategies, whereas emotion-focused coping describes cognitive responses to stress, such as seeking emotional support.
In 2003, 100 cases of various coping strategies were critiqued to best identify coping category systems (Skinner et al., 2003). From these systems, a compendium of 400 ways of coping was compiled. They recommended that Lazarus and Folkman’s (1984) problem-versus emotion-focused coping theories no longer be utilised, in favour of ‘hierarchal systems of action types’. These hierarchal systems encompassed Skinner et al. (2003) Hierarchical models of coping (Appendix 2), involving ‘higher- and lower-order families of coping’ and ‘adaptive processes’. These ‘families of coping’ included 12 ‘higher-order coping families’: ‘problem solving, information-seeking, helplessness, escape, self-reliance, support-seeking, delegation, social isolation, accommodation, negotiation, submission, and opposition’. Within these ‘higher-order families’ exist ‘lower-order families’. For example, within the ‘support-seeking family’ the ‘lower-order families’ are ‘contact-seeking’, ‘comfort-seeking’, ‘instrumental aid’, and ‘social referencing’. Each of these ‘families of coping’ is then associated with an adaptive process. For example, the ‘adaptive process’ associated with ‘support-seeking’ is ‘coordinate reliance and social resources available’. ‘Families of coping’ are not mutually exclusive, and can be interrelated; for example, a person can utilise ‘problem solving’ concurrently with ‘support-seeking’ (Appendix 2).

Coping research has identified that how people deal with stress could reduce or amplify stressful events, and impact on emotional distress, short-term coping ability and long-term physical and mental health (Skinner & Zimmer-Gembeck, 2007). A more contemporary definition of coping is ‘action regulation under stress’, which outlines how people mobilise; manage behaviour, attention and cognition; or fail to do these things when under stress (Skinner & Zimmer-Gembeck, 2007). The authors state that adaptive coping requires a person to have a range of flexible emotions to respond to a situation. To demonstrate this, they developed the ‘dual-process models of coping’ (Skinner & Zimmer-Gembeck, 2007). Previously, Lazarus and Folkman (1984) outlined a similar process with ‘primary appraisal’ and ‘secondary appraisal’. Skinner and Zimmer-Gembeck’s (2007) ‘dual-process of coping’ involved a combination of stress reactions and action regulation, with the authors discussing emotion and emotional regulation in terms of ‘hot’ emotional responses (anger) and ‘cool’ cognitive systems (rational problem solving). Stress reactions were described as automatic responses, with the authors stating that stress may disrupt or overwhelm these regulatory processes. In addition, action regulation is a response to stress involving physiology, emotion, cognition and behaviour, and is described as a proactive coping process, enabling someone to cope more effectively (Skinner & Zimmer-Gembeck, 2007). Within this theory, coping is multidimensional, serving different functions concurrently, such as solving external issues, dealing with personal emotions or changing the environment to reduce stressors. Coping is also interrelated with behavioural, social and emotional factors; for example, a
person’s temperament may directly impact how they cope. Emotion regulation is described as an adaptive, episodic and interactional process of coping with elevated levels of emotions and internal or external demands (Skinner & Zimmer-Gembeck, 2007).

### 3.4.2 Skinner et al. (2003) and Skinner and Zimmer-Gembeck’s (2007) ‘support-seeking’ to cope

‘Support-seeking’ was identified by Skinner and Zimmer-Gembeck (2007) as one of the most effective ‘higher-order families of coping’. This ‘family of coping’ was employed as the theoretical basis to identify and explore how mothers with RA sought support, including where support was sought; the ‘domain’ (for example the domestic or work domain); the type of support sought (comfort, contact); how support was sought (verbal requests, expressions of distress); and the outcomes of ‘support-seeking’, such as the development of coping ‘resources’ or ‘liabilities’. Linked to the ‘support-seeking’ family is the ‘adaptive process’ (‘coordinate reliance and social resources available’), which was utilised to explore the relationship between a mother’s support network, her support resources and her coping outcomes and strategies.

The ‘support-seeking’ family was identified as the central most relevant ‘family of coping’ to this research. However, as Skinner et al. (2003) have noted, the ‘support-seeking’ family is not used in isolation, and is interrelated with other ‘families’, such as ‘problem solving’ and ‘emotion regulation’ (the latter of which is a lower-order category of the coping family ‘self-reliance’). Therefore, these other ‘families of coping’ were also utilised to inform data analysis.

### 3.4.3 Skinner et al. (2003) and Skinner and Zimmer-Gembeck’s (2007) three coping processes

To conceptualise coping across a person’s lifetime, Skinner and Zimmer-Gembeck (2007, p. 138) developed three coping processes: ‘coping as an adaptive process’ over developmental time (childhood to adulthood), ‘coping as an episodic process’ (across weeks and months) and ‘coping as an interactive process’ (occurring in real-time) (Appendix 3). ‘Coping as an adaptive process’ relates to the development of coping over a person’s entire lifetime, and can result in long term coping ‘competence’ (Skinner & Zimmer-Gembeck, 2007, p. 138). The last process, ‘coping as an interactional process’, identifies immediate exchanges between the person and the stressor (how a person copes). As the situation unfolds, a person makes ongoing ‘appraisals and reappraisals’, adjusting their coping response or making alternative ‘resolutions’. This is an interactional process, with responses interdependent on individual characteristics, such as behaviour, emotion and motivation under stress.
‘Coping as an episodic process’ is described by Skinner et al. (2003) and Skinner and Zimmer-Gembeck (2007) as how one copes with an internal or external stressor over days and months, and it was this middle process of the coping model that was utilised in the present research to explore mothers’ ‘support-seeking’ behaviours and coping outcomes. This process conceptualised interrelated factors, including ‘previous (coping) episodes’, ‘demands’, ‘social factors’, ‘individual factors’, coping ‘outcomes’ and the development of coping ‘resources’ and ‘liabilities’ (Appendix 3). Here, coping is described as a response to an internal or external (‘environmental or intrapsychic’) demand or stressful event, such as a flare of RA symptoms. Social factors (support), individual factors (emotion regulation) and the availability of social and individual resources influence a person’s coping responses (Skinner et al., 2003; Skinner & Zimmer-Gembeck, 2007). Depending on how a stressful event evolved, such as an RA flare, a mother could ‘accumulate’ short-term coping ‘resources’ or ‘liabilities’ (Skinner et al., 2003; Skinner & Zimmer-Gembeck, 2007). For example, if a mother sought support from a neighbour who proved helpful, the mother might call on that person again the next time support is needed. The elements of the ‘episodic coping process’ informed the exploration of how mothers utilised ‘support-seeking’ to cope, and if support contributed to the development of coping ‘resources’ or ‘liabilities’. How mothers sought support, their support network, the type of support sought, current support received (positive, appropriate, unsupportive or inappropriate), and future support needs were all explored in this research.

3.5 Methodology

3.5.1 Case study methodology

A qualitative exploratory case study methodology was utilised to explore the support needs and coping strategies of mothers with RA. Researchers preferentially use case studies to explore ‘how’ or ‘why’ questions when they have limited control over events, and when the focus is on real-life context (Yin, 1994, p. 1). Case studies investigate situations where variables of interest outweigh various data points (Yin, 1994, p. 13 in Yin, 1999, p. 1211). According to Ragin (1999) a case-oriented research approach makes sense of a relatively small number of cases, due to their theoretical or substantive significance. This research utilised a case study approach to explore the everyday lives of mothers with RA and their self-identified support needs and coping strategies, as these questions had the potential to reveal a number of different results amongst a relatively small cohort of mothers. This is significant, as this approach has not previously been undertaken in studies on mothers with RA.
A qualitative case study approach was used previously by Grant (2001) to gain greater insight into the lives of mothers with arthritis and the role of occupational therapy (OT) in their treatment. Data collection methods included observations of OT sessions, interviews with mothers and their occupational therapists (OTs) and analysis of OT session notes. Four mothers and two OTs were included in the research. The case study approach, according to the researcher, afforded greater insight into the experiences of the four mothers, including parenting issues. As a result of the research, recommendations for future OT practice included developing mothers’ individual problem solving strategies and implementing appropriate physical and practical interventions (Grant, 2001).

According to Yin (1999), ‘the invaluable feature of the case study method is the ability to “discover” while in the process of doing the research’ (p. 1216). The primary researcher, as a mother with RA, was able to continuously discover and collect data as a cultural insider. As such, the researcher was afforded a more in-depth understanding of cultural meanings and was able to develop deeper relationships with others in similar life situations, which possibly assisted data collection. As relationships and trust with participants builds over time, positive interactions can result. However, the potential for bias needs to be acknowledged and accounted for in the research process, with rigorous data analysis techniques implemented to address this (Whitehead, 2002).

Case studies rely on multiple data collection methods that may include, but are not limited to, surveys, observations, interviews and physical artefacts, with surveys specifically noted as a valuable data collection method (Yin, 1999). The strength in conducting interviews is that they are ‘targeted and focus directly on the case study topic’ (p. 1218).

### 3.6 Methods

Two methods were utilised to collect and analyse qualitative data from participants for this research. Firstly, a Facebook online survey was administered, and secondly, semi-structured face-to-face interviews were conducted.

#### 3.6.1 Research participants

Mothers aged 18 years and over, living in Australia, and diagnosed with RA were the target population for this research. Additionally, potential participants had to be willing to be interviewed.
3.6.2 Method 1: Facebook online survey

3.6.2.1 Data collection

The purpose of the qualitative Facebook online survey (Appendix 4) was to inform the main research aim of exploring mothers’ support needs and coping strategies. The survey, which consisted of three questions, was posted concurrently on two RA Facebook groups from July to November 2013. The three questions were designed to explore and identify 1) members within a mothers support network and how they assisted the mother to cope; 2) suggested helpful information and support (intellectual/emotional/physical) at diagnosis; and 3) different emotions experienced when coping with RA.

The survey was developed based on topic-specific dialogue previously (informally) discussed on the RA Facebook groups’ pages (as the researcher, who is a mother with RA, had already been a member of these groups). Future research directions and research gaps identified in the literature review also informed the survey. Research in the literature review identified a need for mothers' self-identified coping and practical strategies (Ackerman et al., 2015). This motivated the inclusion of questions in the survey regarding mothers' support needs, including informational and physical support, people in a mother's support network, various coping strategies, and, lastly, emotions experienced from diagnosis.

Facebook, as the world's largest global social networking site, represents an important virtual space for people with shared interests or life stories to communicate and seek support (Burbary, 2011). More specifically, research has identified that Facebook groups provide supportive forums for people with chronic illness (Burroughs, 2014; Gaysynsky, Romansky-Poulin, & Arpadi, 2015; Maloney-Krichmar & Preece, 2005). Conducting an online survey via Facebook that explored the support needs and coping strategies of mothers with RA was deemed appropriate, especially as a method for capturing a wider audience with ease.

Facebook group members responded to survey questions within a discussion ‘thread’ or by personal message (PM) to the researcher. Members were informed that they could respond to the questions or choose to not engage with the research process. The Facebook groups utilised were ‘closed groups’, so non-members were unable to view content. Women who were not mothers did respond; however, only mothers’ responses were recorded. According to Creswell (2014), the collation of computer messages can be an unobtrusive way for participants to share their personal reality. Details on data collection and analysis, and a one page summary was provided for members to read as a conclusion to the online survey.
3.6.2.2 Recruitment

The Facebook groups surveyed included R.A.G.S (Rheumatoid Arthritis Girl's) (100 Australian and overseas members as of July 2013) and Rheumatoid Arthritis Australia (Female) (RAA) (500 Australian and overseas members as of July 2013). These Facebook groups were selected as the researcher had already developed relationships with members, enabling the collection of richer, more in-depth data.

Prior to commencing the online survey, two messages (Appendix 5) were 'pinned' (displayed) on the RA Facebook group pages by the administrators, as requested by the researcher. The purpose of this was to outline the details of the online survey and inform participants of their rights (confidentiality, complaints) regarding the research process. Discussions on the Facebook pages between group members and the researcher followed regarding the research process and overall aim. Members were encouraged to discuss questions or issues with the researcher via the Facebook group pages or PM.

3.6.2.3 Data analysis

Data collected via the online survey was analysed using thematic analysis, applying Skinner et al. (2003) and Skinner and Zimmer-Gembeck (2007) coping theories, and utilising research team examination. Thematic analysis is described by Braun and Clarke (2006) as a method of analysing data to identify patterns or themes. Firstly, mothers’ significant statements were extracted, copied into a table in a word document, and statements were then de-identified and names replaced with a number. Data was then organised and coded into themes. Research team examination was utilised, enabling more in-depth thematic analysis. Data was sorted and coded using Skinner et al. (2003) and Skinner and Zimmer-Gembeck (2007) ‘higher-order support-seeking families’, with findings presented using the ‘lower-order families’ of ‘comfort-seeking’, ‘contact-seeking’, ‘social referencing’ and ‘instrumental aid’ to represent the support mothers received or were seeking. Due to the volume of responses and issues with contacting members, member checking was deemed inappropriate.

3.6.3 Method 2: Semi-structured interviews

3.6.3.1 Data collection

The purpose of the semi-structured face-to-face interviews was to collect rich, in-depth qualitative data relating to mothers’ support needs and coping strategies. Four mothers with RA were individually interviewed for 20-30 minutes. This allowed participants to freely discuss their coping strategies and support needs and the impacts of RA alongside of
managing a parenting role. Themes formulated from the Facebook online survey (Method 1) were used to guide the collection of qualitative data during the interview process.

Participants were contacted by phone to organise interview times. Due to research restrictions, all participants needed to be interviewed on the same day, which eliminated one mother, who was unavailable. Participant demographic data was gathered through a participant questionnaire (Appendix 6), informal phone calls, texts and email exchanges with the researcher prior to the interview. Participants identified topics of importance to them, including the impacts of RA, parenting issues and support needs and coping strategies utilised.

Participants were informed throughout the recruitment and interview process, and via a Research Project Information Sheet (RPIS) (Appendix 7), that they could openly discuss their experiences as a mother with RA in relation to how they cope and are supported. Two researchers where present at the time of the interviews, with one researcher taking the lead as the sole interviewer. Immediately prior to the interviews, participants were able to engage in informal conversation with the researchers to clarify any issues that they may have had with the interview process. When undertaking open-ended conversational interviews, it is imperative that participants' perspectives are heard, and interviews remain unstructured with limited researcher interjection (Crotty, 1998). Following the research methodology of Grant (2001) study, semi-structured conversational interviews were conducted with mothers with RA in this current research. As with Grant’s (2001) study, participants in this research were given a research framework prior to the interviews, which included a number of questions. Informal conversational interviews in this study and Grant’s (2001) study enabled in-depth insights into the life experiences of mothers with RA. The interviewer only interjected to clarify participant statements or to direct participants back to the research topic. Towards the end of the interviews some participants were prompted to provide additional information if the interviewer felt further clarification was needed regarding the details of specific coping strategies.

Full audio-visual interviews were transcribed by a professional transcription service in preparation for data analysis. Participants were then sent their interview transcripts to read, provide feedback and request changes if they felt their opinions had been incorrectly represented, in-line with the methodology used by Mitton et al. (2007). Ultimately, all participants were satisfied with how their data was represented.

3.6.3.2 Recruitment

Participants were recruited in 2014 via local media exposure from radio interviews with ABC Coast FM, recruitment information on the University of the Sunshine Coast (USC) and
Arthritis and Osteoporosis Victoria websites, and through the researcher’s personal contacts. Mothers with RA contacted the researcher to express an interest in participating via email, Facebook PM and USC and ABC Coast FM, directly. Purposive sampling was utilised to identify and recruit suitable participants in relation to the in-depth information that they could provide to address the research aim: *Exploring the day-to-day support needs and coping strategies of mothers with rheumatoid arthritis (RA)*. This method has been utilised previously to recruit participants who the researcher believed would provide ‘information-rich’ research cases (Patton, 2002, p. 230). Creswell (2014) states purposefully recruiting participants allows the researcher to select people who will best assist them to evaluate the research question.

Purposive sampling via email and phone correspondence identified mothers with RA who could articulate their support needs and coping strategies to manage the impacts of RA alongside a parenting role. Potential participants were asked a series of questions in an informal manner to ascertain their suitability for inclusion in the research. This included asking them to detail their current coping and practical strategies and to explain how they drew in support to manage the impacts of RA alongside a parenting role. Participants who could readily describe a range of strategies to positively cope were identified as potential participants. Potential participants were also asked if they were comfortable being filmed while articulating their stories. One mother was very comfortable talking about her support needs and coping strategies but was not comfortable being filmed, which deemed her ineligible. The main aim of filming the mothers’ interviews was to enable the sharing of these stories with other mothers with RA and the wider community. On completion of the filming and editing process, mothers’ stories were then uploaded to the Arthritis and Osteoporosis Victoria’s website and YouTube for public viewing. On conclusion of this purposive sampling and recruitment process, four mothers with RA from the Sunshine Coast, Queensland (Australia) were recruited to participate in the semi-structured face-to-face interviews. A consent form was provided to all participants prior to the interviews (Appendix 9).

### 3.6.3.3 Data analysis

Thematic analysis was utilised to analyse the interview data. This process analyses, records and identifies repeated patterns of meaning and identifies and analyses data free from pre-determined theories or themes (Braun & Clarke, 2006). This method of analysis also enables connections to be made between statements of various interviewees, centred on the topics in the interview guide, as well as identifying emerging unanticipated themes (Guest, Namey, & Mitchell, 2012). For the present research, a four step analysis process was employed (Figure 3).
Step 1 involved the data being individually hand coded in relation to Skinner et al. (2003) and Skinner and Zimmer-Gembeck’s (2007) ‘support-seeking’ coping theories (Figure 3, Step 1). It was not the intention to use predetermined codes; however, some anticipated codes were used. A similar approach was utilised in Greene, Choudhry, Kilabuk, and Shrank (2011) research on diabetes patient management, where broad themes were introduced prior to thematic analysis. Broad themes identified prior to thematic analysis in this research included support needs, ‘support-seeking’ behaviours, coping strategies and practical strategies used.

In Step 2 (Figure 3), research team examination was used to discuss patterns and themes, and individual interpretations were employed to address and improve the trustworthiness of the findings (Lincoln & Guba, 1985). While the theme names individually chosen amongst researchers were not always identical, many of the ideas converged. The team discussed any differing interpretations, and final analyses were mutually agreed upon. While the ultimate goal of using more than one investigator in the qualitative analysis of data is not, and should not be, replicability, the discussion related to the analysis contributes to its credibility (Lincoln & Guba, 1985). In Step 3 (Figure 3), the process of Step 1 was repeated, but this time as a research team, as opposed to individually; themes were identified in relation to interrelated ‘families of coping’, including; ‘information-seeking’, ‘self-reliance’ and ‘problem solving’ (Skinner et al., 2003; Skinner & Zimmer-Gembeck, 2007). In Step 4 (Figure 3), the final step in the analysis process, participant statements were presented under all themes relating to ‘families of coping’, including ‘support-seeking’, ‘problem solving’, ‘information-seeking’ and ‘self-reliance’.

Figure 3: Diagrammatic representation of the semi-structured interview data analysis process
3.7 Potential for bias

Research team data examination was undertaken, with the primary researcher consulting with the team to discuss findings. The potential for bias was acknowledged by the researcher, who declared her position as a mother with RA. Research team examination was utilised throughout the research process to ensure that the personal experiences of the primary researcher did not impact on the exploration of other mothers’ support needs and coping strategies.

3.8 Conclusion

The purpose of this chapter was to outline the research design. This research study was positioned within a social constructivist epistemology, and guided by Skinner et al. (2003) and Skinner and Zimmer-Gembeck’s (2007) Hierarchical models of coping. A qualitative exploratory case study methodology was utilised, with the primary researcher positioned as a cultural insider as a mother with RA. Data was collected through two methods: a qualitative Facebook online survey and semi-structured face-to-face interviews. Thematic analysis was used to analyse all data collected. Strategies to ensure the quality of the research, such as research team examination and identifying potential researcher bias, were also employed.

The following chapter presents the results of the first study (Method 1), the Facebook online survey.
Chapter 4: Facebook online survey results

This chapter presents the results of the Facebook online survey, with a focus on participants’ overall support needs. The results identified the impact of participants having a support network and receiving various supports (emotional, physical, and informational) and the influence of support on participants’ ability to cope. The aim of the survey was to explore the support needs and coping strategies, as well as the longer-term coping ‘resources’ of participants managing the impacts of rheumatoid arthritis (RA) alongside a parenting role. The role of support-seeking is explored in relation to whether support enables participants to cope more effectively and develop longer-term coping ‘resources’.

This chapter commences with a description of participants (Section 4.1). Results are then presented in two sections. Results commence (Section 4.2) with participant statements regarding support needs for coping with the impacts of RA alongside a parenting role. Five themes were identified, including 1) support network, 2) types of current support, 3) desired support, 4) initial coping strategies and longer-term coping ‘resources’, and 5) emotions experienced. Results are then presented (Section 4.3) in relation to participants utilisation of the ‘support-seeking’ ‘family of coping’, with participant statements presented under the ‘lower-order families’ of ‘instrumental aid’, ‘social-referencing’, ‘contact-seeking’ and ‘comfort-seeking’. This chapter is concluded (Section 4.4) with an exploration of ‘coping as an episodic process’ to identify the different factors influencing the development of coping strategies and longer-term coping ‘resources’.

4.1 Description of participants

Forty-three participants with RA responded to three questions posed on two RA Facebook groups. The majority of participants responded in the discussion ‘thread’, although four participants (ID29, ID30, ID31 and ID34) responded via personal message (PM). All participants were mothers aged between 25 and 60 years, with the majority having one or two children, aged from newborn to 18 years. Most participants were partnered; however, some were single parents. Participants were geographically located in urban and rural areas all over Australia. Some participants were engaged in work outside the home and most were regular daily Facebook users.
4.2 Mothers support needs to cope with the impacts of RA

Results are presented under five themes (Table 1 – page 47), including participants 1) support network (family and non-family), 2) types of current support, 3) desired support, 4) initial coping strategies and 5) emotions experienced.

In exploring participants’ individual support needs, coping strategies and current experiences managing the impacts of RA alongside a parenting role, in-depth information relating to their life experiences was gathered. Results relate to the overall research by exploring and presenting a relationship between the support needs of participants, how these needs are fulfilled, or not fulfilled, and by whom. Following the presentation of support needs, the coping strategies utilised by participants and their longer-term coping ‘resources’ in relation to Skinner and Zimmer-Gembeck’s (2007) coping theories are then presented. Additionally, participants coping ‘resources’ and ‘liabilities’ are explored in further detail in Section 4.3.2, and later in Chapter 5 (Section 5.3).

4.2.1 Identifying people in mothers’ support networks

Participants stated that having supportive people in their network helped them to cope better emotionally and physically with the impacts of RA, which, consequently, enabled them to more effectively develop adaptive coping strategies and ‘resources’. Supporters were divided into two categories; family and non-family. Some participants stated that they received different types of support from various people. For example, primary supporters, such as husbands, provided practical and emotional support, while secondary supporters, such as neighbours and friends with RA, provided moral, esteem and emotional support.

Family support came from husbands (16), parents (4), siblings (2), children (2) and other family (1). Husbands were identified as the most integral primary supporters, providing different types of support, including emotional and physical. This support was identified as a source of reliable, unconditional support for most participants. ‘Support-seeking’ from husbands, in particular, became a supportive coping strategy utilised by a number of participants on a daily basis.

“I think our husbands/partners are the only ones that are the rock we rely on” (ID18)

In contrast, three participants stated that they received limited support from their extended families, and two stated they received limited support from their spouses.

“I have had very little family support and my (ex) fiancé and I broke up mostly over my illness…” (ID21)
“Eventually my husband as well. He took a while to be convinced that I didn’t cause this myself and flare ups were not self-inflicted” (ID24)

“…hubby sometimes is & sometimes isn’t lol” (ID28)

Participants who stated that they had limited family support discussed how support from friends helped them cope.

Non-family support came from online RA Facebook group friends (7) who were identified as the next most important supporters after husbands (16). The understanding, empathetic and emotional support participants received from RA Facebook group friends was identified as highly valuable in assisting participants to cope with the impacts of RA.

“Having this group of Raggies here is also a fantastic support as each and every one of us can completely understand what we are each going through” (ID25)

Other supporters included rheumatologists (5), myself (manage alone) (2), other health professionals (1), surgeon (1), general practitioner (GP) (1), colleagues (1), employer (1), non-RA friends (1), neighbour (1), and school mums (1).

Community support from a neighbour (1) and school mums (1) was also identified as fulfilling an important support need for participants.

“Well I live away from family and am a true single parent without the luxury of every second weekend off. I virtually have no support so I would have to say other school mums via the great school community to which our small primary has. They see when I’m having a bad pain day and offer to take my child to or from school…” (ID05)

Health professional support was provided by rheumatologist’s (5), GP’s (1) and a surgeon (1). One participant stated her rheumatologist had young children and empathised with her situation.

“My rheumatologist. He really seems to “get it”. He has young kids like me and truly empathises” (ID04)

Friends without RA were mentioned by one participant, but not as providing integral support.

“My friends try to support me, but honestly, they have no idea what this disease is doing to me, and so struggle to empathise or support me in the way I need” (ID16)

Participants stated that support that was understanding, sympathetic and reliable was valued. Being able to reach out and ‘seek support’ that was reliable, appropriate and responsive was identified as important to participants.
4.2.2 Current support received by mothers with RA

Various people in participants’ support networks were identified as offering different support at varied times. The types of support received included informational, physical (dressing, etc), practical/domestic, moral, esteem, and emotional. Parents (4), siblings (2), children (2) and other family (1) were identified as providing different types and levels of support at various times.

“My sister is great for emotional support & husband for physical support & help”
(ID15)

“…my workmate and I just swap sympathy on bad days, share what’s happening with each of our rheumy’s etc…” (ID26)

Husbands were relied upon particularly for emotional and physical/practical support, with many participants stating that they would struggle to cope without their husbands support.

“My very supportive hubby. Opening jars and medicine bottles ggrrrr, carrying heavy things, doing the shopping and most of the housework, it/when we go camping/travelling, he packs everything. Doing up my shoes etc the list goes on…”
(ID07)

“Again it’s been my husband as my strength through this. His love is what I am grateful for everyday” (ID16)

Non-family support was identified as important, and this came predominantly from RA Facebook group friends. These friends were identified as meeting a range of support needs, including informational, emotional and esteem support, and sharing medical and general news. Empathy and understanding from RA Facebook group friends was also important, with participants stating that this support made them feel less socially isolated.

Having a supportive, understanding friend to chat to via online RA Facebook groups was a valued form of support.

“… knowing that these beautiful women who truly understand what it’s like are just on the other side of the computer screen with all their wisdom, compassion and kind words is enough to get me through some of those tough days” (ID01)

The words participants used to describe the impact of current positive support from family and non-family supporters included: understanding, compassion, supportive, strength, sympathy and empathy. Support that helped participants cope with the negative emotions and impacts of RA enabled participants to develop their own individual coping strategies. For
example, some participants stated that an effective coping strategy for them was to chat to an RA Facebook group friend who could personally relate to, and understand, their situation.

4.2.3 Support desired by mothers with RA

A lack of information and support on the mental, emotional and physical impacts of RA alongside a parenting role was identified as an issue for participants. Additional informational support, particularly regarding medical treatments, was desired by participants. One participant sought information on being a disabled parent, but was frustrated at the lack of available information.

“I have found tons of assistance for those caring for a disabled BABY, but nothing for mothers with illnesses needing assistance caring for a healthy baby” (ID34)

Four participants identified a need for more information on supportive services, including local and online support groups.

“…connections with RAGS or YWASG (Young Women’s Arthritis Support Group), people who understand and have been there” (ID08)

Participants discussed a need for people to understand and empathise with their situation, not necessarily to solve their RA-related issues. Two participants desired more education on the physical, emotional and mental impacts of RA, while another two stated that information on managing their medical team and medications would be useful. Concerns about the physical and emotional impacts of RA were expressed by one participant, with a need identified for more in-depth medical information.

“More information on long term effects and what RA does to your body without treatment. Also all of the issues you go through mentally. No one warns you about how to cope mentally when you’re in physical hell every day... It would also be great for the Dr to set you up with a local support group. I only started to think about getting more medical help (physio, acupuncture, remedial etc etc) after reading a book from a similar woman. I also think it would be great if our Drs could explain what relationship we then need to set up with our GPs and other Drs” (ID05)

Two participants wanted an informative, easy-to-read pamphlet (or information in another format) explaining RA, treatment options and how to educate family about RA. Counselling at diagnosis to assist with coping strategies and associated mental health problems was suggested by another.

“A succinct, informative, easy to read pamphlet explaining the disease, the treatments, and how to deal when loved ones react badly/don’t believe…” (ID06)
Additional information on the long term physical impacts of RA with and without treatment, coping mentally with physical pain, treatment options, support groups and establishing relationships with health professionals were all desired. Participants stated that a lack of informational and emotional support made them feel isolated, scared and alone. Informational support assisting participants to develop adaptive coping strategies to manage the emotional and physical impacts of RA was highly desired.

4.2.4 Mothers’ initial coping strategies and longer-term coping ‘resources’

Most participants could readily describe the coping strategies that they utilised to manage the impacts of RA alongside parenting. A number of initial coping strategies identified included 1) information-seeking, 2) goal setting, 3) ‘venting’ with RA friends on Facebook, 3) finding new ways to be happy (new hobbies and experiences), 4) allowing yourself to express different emotions, 5) coping mentally with physical pain, and 6) embracing moments when you can manage.

In addition to identifying coping strategies and longer-term coping ‘resources’, participants also expressed various emotions experienced in managing the impacts of RA. These emotions included denial and acceptance of an RA diagnosis, and a need was identified for more emotional support to cope with the impacts of RA.

One participant reported that denial was one of her main coping strategies.

“I’m not anywhere near acceptance yet. More and more I realise I am actually still in denial! I’m guessing by the lack of responses that this is a common thing” (ID01)

Accepting an RA diagnosis was also discussed, with one participant outlining her coping strategies and ‘resources’ since being diagnosed.

“I was diagnosed at 18 and I’m now 28 and have one year left of my Master’s degree! So I've definitely come a long way from someone who couldn't walk themselves to the toilet or brush her hair. I'm not sure exactly why or when I accepted it but once I did, it was years though, dropping in and out of denial and acceptance, I worked out strategies to get things done (even if it was the long way to do it!) and plans/goals for the future. I'm currently in a flare but can seem to cope better now than I once did. I think it's when you look back at all the hurdles you've crossed and know that things do get better.... Eventually lol” (ID33)

This participant described how accepting her RA diagnosis better enabled her to cope and continue to set life goals.

Participants discussed the process of acceptance of an RA diagnosis in the discussion ‘thread’ and via PM. One participant provided in-depth insight, via PM, regarding how she
coped, stating that embracing the moments when she had energy and the pain was manageable was important for her process of acceptance.

“Accepting is also finding NEW things that give us happiness as a result of this change in lifestyle--reading, painting, cinema, better communication with our partners, and support from our friends. Accepting is ALSO knowing that times of pain and sadness are ok too. Allow yourself to be sad sometimes, to be angry if you are in pain, to be frustrated by those who do not support you. That’s ok, you’re not weak for feeling that way, don’t feel guilty or defeated. But also let those moments pass when they are finished, don’t hold onto them. Allow the next day to come and accept whatever it is. You’re going to be in pain, pain demands to be felt, but allow happiness to be felt just as strongly” (ID31)

Coping strategies and ‘resources’ identified included enjoying new hobbies, better communication with partners and seeking support from family and friends. Participants stated that these strategies helped them to manage the impacts of RA, such as pain and feelings of anger and frustration.

4.2.5 Mothers’ emotions and the impact of ‘support-seeking’ and coping strategies and ‘resources’

The reported emotions experienced while managing the impacts of RA alongside a parenting role included denial, acceptance, anger, frustration, sadness, social isolation, guilt and happiness. Exploring the emotions expressed and emotional impacts experienced by participants also enabled in-depth knowledge of their consequent support needs to cope. As identified by survey results, appropriate, inappropriate or a total lack of support had the potential to positively or negatively impact participants’ feelings of anger, frustration and isolation. Additionally, participants stated that a lack of informational support could also leave them feeling scared, isolated and/or unsupported.

When participants’ support needs were met with understanding, empathy and compassion, they demonstrated being able to better manage the impacts of RA. Support enabled participants to generally feel better and more in control. Acceptance of an RA diagnosis and expressing, not suppressing, emotions were identified as effective coping strategies.

“Firstly, I want to state that accepting pain is by no means trivialising it or pretending that it doesn’t exist. It does. And no amount of Zen thinking or pretty music is going to magically let you ignore the pain. Secondly, accepting chronic pain doesn’t mean that you will no longer have moments of frustration or anger, or sadness. You will. But that is part of it, you accept that part too--having a hard moment or night or day is not the same as breaking a diet or something. You are not failing by breaking down
sometimes, it's not a sign that you aren't 'strong enough' or have a 'low pain tolerance’” (ID30)

For another participant, accepting her RA diagnosis meant letting go of her previous life and learning to manage living with RA.

“Accepting chronic pain to me is accepting all of it. Letting go of the life you are simultaneously living…once you are diagnosed it is like we split into two lives…the one where a chronic illness has taken over, and the other life…where we never got the disease…where we continued our career, … wake up at 6am and go for a run… stay out at a social gathering without a worry about how tired we are or how much our joints are starting to swell. By holding onto this life as if it were still there, means we are constantly bitter at the life we have now. The one with all these limitations. The one where we aren't the person we wanted to be” (ID31)

This participant stated that by hanging onto her life before RA, she was also hanging onto negative feelings, such as bitterness.

So ACCEPTING chronic illness, is letting go of this imaginary life, and with that we can let go of the anger… This doesn't mean your life right now is any less beautiful or valued or deprived of any less happiness. Accepting the times that we feel energy and manageable pain and embracing these moments with gratefulness …knowing that we can participate with our loved ones and do some of the things we enjoy …” (ID31)

Adapting and learning coping strategies to manage an RA diagnosis assisted this participant to let go of previous life expectations.

Guilt was also expressed by two participants over perceived sacrifices family members made to support them.

“Mum and hubby…by putting their lives/careers and family plans on hold” (ID01)

“However, on a day to day basis my husband is my angel, I do not know what I would do without him. The struggle I have is with the guilt that he has to more than is fair” (ID20)

A lack of knowledge, information and medical support caused one participant to feel disappointed and alone.

“…I went to a doctor nearby and he told me that's not enough information to know that it's RA... I asked for referral to a Rheumy he refused…I spoke to the doctor in Adelaide and she said no more tests are needed you need to see a Rheumatologist
to see if you need other treatment. I asked for a referral cause I feel really bad and I don't want to wait she said no rush come see me when you get home next week. I thought great! They did seem really cold towards me as if they could not care less .I'm very disappointed…I'm alone without my family, right now I've gone to bed to try and relax after doing some light work . So yeah I think there's a lot of support missing” (ID02)

Another participant received daily support from RA Facebook groups.

“The inspiration I get and the hope from this page helps me with the daily living and when I feel down, I come on and have a whine and I feel better. There needs to be support and information on what we can do, who can help and the services we can receive” (ID04)

Connections with RA Facebook group friends inspired some participants, while giving others a chance to express their feelings.

Emotional support was identified as being a valuable form of support. Four participants discussed a need for more support, information and education on the physical, emotional and mental impacts of RA.

“I think that it would be extremely beneficial for anyone that is diagnosed with a chronic or terminal illness for it to be standard procedure for them to be instantly referred for counselling for assistance with coping strategies and also for the grieving process that we go through…” (ID01)

A lack of information regarding maternal RA and pregnancy left one participant feeling scared, particularly due to her doctors’ lack of knowledge.

“I have, like you did, researched into the help available and have been dealing with my OB and rheumy throughout my pregnancy. High risk tertiary care had definitely been a blessing as opposed to general primary care, but there are still huge gaps of knowledge that my team of doctors have. Which makes it very scary/intimidating when your specialists have less of a grasp on things than you do!” (ID34)

The emotions experienced by participants included grief, guilt, fear, bitterness, gratefulness, inspiration and happiness. It was identified through survey results that participants that were able to express their emotions, and have these expressions met with a form of support, were better enabled to cope.
Table 1: Descriptive findings of support, coping and emotions experienced by mothers with rheumatoid arthritis (RA)

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<th>Main themes</th>
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<td><strong>Desired support</strong></td>
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Shannyn Meloncelli

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4.3 Mothers utilising ‘support-seeking’ to develop coping strategies

This section explores participants ‘support-seeking’ behaviours and presents them in relation to Skinner and Zimmer-Gembeck’s (2007) coping theories. This process is significant, as it presents an in-depth analysis of the ‘support-seeking’ behaviours of participants in relation to managing RA alongside a parenting role. Findings are presented, with supporting participant statements, under the ‘support-seeking’ ‘lower-order families’ of ‘instrumental aid’, ‘social referencing’, ‘contact-seeking’ and ‘comfort-seeking’, in relation to participants support needs, support-seeking behaviours and initial coping strategies.

4.3.1 ‘Support-seeking’

A lack of information and support regarding the mental, emotional and physical impacts of RA were identified as contributing to participants’ feelings of social isolation, anger and frustration. Future support needs relating to ‘instrumental aid’ were identified, including a need for information on local and online support groups (4), education on the physical, emotional and mental impacts of RA (2), and information on managing a medical team (2). Support was also deemed necessary in relation to further information on treatment and medications for RA. Additionally, counselling at diagnosis to assist with coping strategies, anxiety and depression was suggested (1). The need for information on, and access to, physical support in the home was only mentioned by two participants, who stated that their husbands managed most of the physical domestic tasks.

Concerns were identified regarding the physical and emotional impacts of an RA diagnosis alongside a need for more in-depth medical information. A lack of ‘instrumental aid’ through education and support was identified by two participants.

“But if I had info from start I could have been better educated and in turn educate my dad better who is the only one that really doesn’t get it but eight years on he’s getting there, lol” (ID08)

“…I felt that I didn’t have enough information about the medication and the side effects and options…my dr didn’t say anything only wrote the scripts…regarding emotional support I didn’t realise just how much of an effect it would have on my whole life - what plans can I make for the future…when the meds make me drowsy and stupid how do I maintain my job - what are the side effects of the drugs verses the disease all of that…” (ID06)

A lack of medical support and information caused issues for another participant.

“Being told my actual diagnosis!!...my first Rheumy was very old school and just told me I had arthritis gave me a script for a disease modifier and just told me to come...”
One pregnant participant discussed how a lack of RA-specific knowledge amongst her medical team regarding safe treatments for her and her unborn baby caused her fear and anxiety. She also felt that she lacked information on practical strategies to cope with a baby alongside managing RA associated pain, fatigue and loss of mobility.

A lack of supportive information was initially an issue for this participant, who expressed feelings of frustration, something also identified by other participants. Over time, she sought more ‘instrumental aid’ and engaged in ‘social referencing’ and ‘contact-seeking’ from various sources, such as other RA Facebook group friends, to gain information and develop her own adaptive coping strategies.

This participant, who was initially anxious, scared and overwhelmed, sought support from other participants with RA through ‘bids and appeals’ and ‘verbal and other requests’ in the ‘social media domain’. Consequently, through the process of ‘support-seeking’, she developed adaptive coping strategies and longer-term coping ‘resources’ to manage parenting alongside the impacts of RA.

Accepting the diagnosis of RA and learning to cope longer-term was discussed amongst participants within the survey, identifying a need for supportive information for newly-diagnosed participants. This information, or ‘instrumental aid’, included a need for strategies on managing the long term physical impacts of RA with and without treatment, coping mentally with physical pain, treatment options, sourcing support groups, and establishing relationships with health professionals.

The need for connections and ‘social-referencing’ with other women with RA was identified in the results. Seven participants stated that online RA friends were the most important support category, with only husbands (16) ranking higher. Participants outlined how support and understanding from other women with RA helped reduce feelings of isolation.

‘Social-referencing’ gave participants the sense that they had support and understanding from others who were experiencing similar life situations.

“…there’s always an understanding ear on this website (RAGS)” (ID24)

“…all the great girls on RAGS, Thanks heaps XXX” (ID22)

“…the RAGS girls…” (ID23)
“my wonderful RA friends too…So many people have been inspirational especially from this group…” (ID13)

Other women with RA were identified as providing ‘comfort’ and were a source of support and inspiration for participants with RA.

“Yep these FB pages are great I would feel very isolated if I couldn’t chat” (ID02)

“…luckily I was able to have a chat to *name* who helped me out heaps!!” (ID06)

“There is NO support other than from here (Facebook group), if it wasn’t for this page and others like it I think I would curl up into a ball” (ID04)

This support was evident when one participant stated that she managed alone, due to an unsupportive family.

“No one! I do it all by myself. My family are in denial I reckon!” (ID12)

RA Facebook members responded with sympathy and support.

“That’s so tough for you (*name*) and I’m so sorry to hear that” (ID13)

It was identified in a pregnant participant’s statement that she was struggling to cope with a number of issues, including pain, fatigue and a lack of information and support. Yet, she continued seeking support from other participants via RA Facebook groups. This ‘social referencing’ allowed her to gather support, gain confidence and develop individual adaptive coping and practical strategies.

“As you’ve probably seen from my RAGS posts, I’m still struggling through pregnancy and have little hope for any assistance after birth. I would love to chat (and happy to participate if you would like to include for your research), about your journey and where mine has taken me so far” (ID34)

This participant recognised the possibility of developing post-partum depression (PPD) and sought support to cope with this.

“I will definitely be lodging this with Arthritis Victoria as I do not think there is enough information or support for women in our situation. I feel like I might suffer PPD if I get to a point where I feel like a failure as a mum not being able to care for my own baby” (ID34)

Through utilising ‘social-referencing’ this participant was able to ‘seek support’ and, eventually, share her newly-developed coping strategies with other women via the RA Facebook group, continuing the cycle of ‘social referencing’ support.
“Getting into a bit of a routine and have even thought of some great makeshift baby care equipment! I can’t get up, sit down or walk around with bubs as I need my hands to support myself (to get up etc or to use my walking sticks to get around) So we’ve bought a hairdressers trolley on wheels (with makeshift high sides rigged up) so I can pop bubs in when I’m done feeding and then get myself up, roll her to her crib using the trolley to support me, then pop her in the crib. It’s been a godsend!” (ID34)

Different people were identified in participants support network, with participants engaging in ‘contact-seeking’ with various supporters for numerous reasons. Support from friends and neighbours was sought when family wasn’t available. While some participants described unsupportive contact with specialists, others stated that health professionals, including rheumatologist’s (5), GP’s (1) and a surgeon (1), were integral in their support network.

“My biggest supports have been my health professionals” (ID04)

“I think the best support has come from my doctors. My rheumy is quite simply amazing. Every decision regarding my treatment was made by me, with him clearly explaining all the options” (ID02)

Remaining in control of important decisions and having ‘contact support’ from specialists was important for some participants.

‘Contact support’ came from a neighbour for another participant.

“I had a neighbour, she’s just moved, who was also really supportive, more morally than physical support. In saying that she helped me with my son when he was very little and still is very involved with him. At times she was my lifeline” (ID04)

A work colleague (1) and employer (1) were also identified as providing support.

“…my boss has been great at being understanding and helping me to understand what chronic pain is really all about…” (ID06)

Other friends (without RA) were identified in the results; however, not for providing support, and social isolation was identified as an issue for some participants.

“I haven’t really told many friends as they have enough going on in their own lives, I’m more of a recluse these days” (ID15)

‘Contact-seeking’ with a variety of people in the community (neighbours, specialists), in different domains (home, medical, social), was identified as integral in providing additional support outside of participants primary supports, such as from husbands.

‘Comfort-seeking’ and feeling emotionally-supported was identified as important by participants in their coping strategies. Having an understanding friend to communicate with
through RA Facebook groups was identified as a way for participants to feel comforted and supported, as they knew that others in the group could empathise and relate to their situation.

“The friends I have made who also have RA are my biggest support. They seem to be the only people who understand just what I am going through and I value their understanding and support” (ID11)

One participant said that it was her family who gave her the most comfort and strength to cope with the emotional impacts of RA.

“My family gives me the strength to pick myself up and keep on going even when it all seems too hard. My husband has never once made me feel that my RA is just my problem and my daughter aged 2 already shows amazing compassion for others because of what she has seen me go through” (ID29)

Some participants expressed gratitude in regards to family support, while also lamenting the negative impact RA had on family life.

“The actual day to day support comes down to my long-suffering husband who has had to shelve some of his life plans because of my health” (ID02)

“I have the most wonderful husband for who nothing is too much trouble” (ID25)

“Definitely my husband, he goes out of his way to make things easier for me without me having to ask. He’s amazing” (ID03)

“100% it’s my husband” (ID20)

“My hubby. He washes, cooks, does groceries, picks up meds, takes big boy to preschool…” (ID19)

The need for more emotional support for participants with RA emerged from the results.

4.3.2 The process of developing coping strategies and ‘resources’ for mothers

Emotional support from family, particularly husbands, was identified as important for participants to feel their support needs were being met. Empathetic and understanding support from RA Facebook group friends was also valued. The impacts of RA and emotions experienced by participants influenced ‘support-seeking’, and in some cases, the development of adaptive coping ‘resources’. In particular, participants who expressed how they were feeling (such as through RA Facebook groups) and had these emotional expressions met with support, expressed that they felt better supported and, thus, more able to cope with RA and a parenting role.
A link between factors such as participants’ support networks, current coping strategies, the emotions experienced and the development of coping ‘resources’ was identified. This process is described in coping theory as ‘coping as an episodic process’, with elements in the coping cycle influencing eventual coping ‘outcomes’. For example, the interrelationship of ‘previous episodes’ (how did the participant previously cope), with previous ‘demands’ and ‘appraisals’, is influenced by ‘individual factors’ (personality) and ‘social factors’ (availability of support). This, in-turn, then influences coping outcomes, ‘resources’ or ‘liabilities’ (Skinner and Zimmer-Gembeck, 2007, p 138).

As an example of this coping cycle, a pregnant participant in this research stated that she lacked vital information to cope with the impacts of RA alongside parenting, which left her feeling angry, scared and intimidated. This motivated her to engage in ‘support-seeking’ through a variety of methods (‘social referencing’, ‘instrumental aid’, ‘proximity-seeking’, ‘verbal requests’, ‘bids and appeals’, and sometimes, ‘expressions of distress’) and in different domains (medical, social). Through ‘support-seeking’, she received support via ‘social referencing’, ‘comfort support’ and ‘instrumental aid’. Consequently, she received information and support, which assisted her to develop her own individual coping strategies and coping ‘outcomes’.

This participant then utilised these coping ‘resources’ to manage the impacts of RA alongside a parenting role once her baby arrived. Factors such as ‘previous (coping) episodes’, current ‘demands’, ‘social factors’ and ‘individual factors’ are also relevant in understanding how people cope and their consequent coping ‘outcomes’. For this participant, her ‘support-seeking’ influenced the development of coping strategies and ‘resources’ in response to an internal and/or external demand (‘intrapsychic or environmental’), with the demand being RA, pregnancy and motherhood. The influence of social factors (‘support’), individual factors (‘emotion regulation’) and the availability of social and individual resources influenced the development of eventual longer-term coping ‘resources’ (Skinner & Zimmer-Gembeck, 2007). Exploring the emotional impacts of RA, as experienced by participants, is relevant to the exploration of their ‘support needs’ and coping strategies, as these factors potentially impact how participants engage in ‘support-seeking’ and the consequent development of longer-term coping ‘resources’.

4.4 Conclusion

This chapter presented the qualitative results of the Facebook online survey. Results reported on participants’ life experiences in regards to how they managed the impacts of RA alongside a parenting role and how they engaged in ‘support-seeking’ to cope. The overall results showed how emotional and informational support were important in assisting
participating mothers with RA to cope. Three key themes emerged from results, including 1) emotional support from family, and particularly husbands, was identified as important; 2) participants felt that the understanding, kind and empathetic support shared amongst RA Facebook group friends, utilising ‘social-referencing’, helped them to develop coping strategies and ‘resources’; and 3) the need for more information and ‘instrumental aid’ regarding treatments and medications, coping strategies and support services was identified. The results also identified that a lack of support, particularly emotional and informational support, sometimes led to participants feeling isolated, angry, frustrated and not able to manage the impacts of RA alongside a parenting role.

The results of this research provided insight into the lives of participants, including the presence of people in participants’ support networks, the current support being received, desired support needs, initial coping strategies and emotions experienced. Most participants experienced emotional impacts of RA that potentially influenced their coping strategies and longer-term coping ‘resources’. Seeking support, particularly emotional and informational, was identified as integral in helping participants to cope with the disease. Desirable emotional support included empathy, sympathy, kindness, compassion, care, understanding and general concern, and enabled participants to feel better supported. Participants stated that this support made them feel ‘better’, ‘inspired’ and ‘supported’, which potentially enabled them to develop adaptive coping strategies and longer-term ‘resources’.

Additionally, informational support was identified as important in helping participants feel in control of making their own decisions surrounding issues, such as treatment options. Physical and emotional support was identified as important in assisting participants to develop individual adaptive coping strategies or ‘resources’ to cope with the impacts of RA. Additionally, ‘instrumental aid’ to gather information from specialists in regards to medical treatments was also sought. These ‘support-seeking’ strategies enabled participants to draw people into their support network to assist in developing coping strategies and accumulate longer-term coping ‘resources’.

The following chapter presents results of the semi-structured interviews (data collection Method 2), which also examines the support needs and self-identified coping strategies of mothers with RA. Chapter Five further explores the themes identified in this chapter to provide a deeper understanding of the relationship between the impacts of RA, including emotional impacts, participants support needs and their coping strategies. The chapter predominately explores the self-identified coping strategies employed by four participants, which are then presented in relation to Skinner and Zimmer-Gembeck’s (2007) interrelated ‘families of coping’. These include ‘support-seeking’, ‘problem-solving’, ‘information-seeking’ and ‘self-reliance’, along with their ‘lower-order families’. The results of the interviews build
on the results of the survey by exploring in more depth the relationship between mothers support needs, their support-seeking behaviours, current support received and the emotional impacts of RA and how this influences/enables their subsequent coping strategies or ‘resources’. The overall aim of the interviews is to further explore the support needs of participants with RA and delve more deeply into their self-identified day-to-day coping strategies.
Chapter 5: Semi-structured interview results

The previous chapter presented the results of the online survey, which reported on participants’ experiences managing the impacts of rheumatoid arthritis (RA) alongside a parenting role. Results firstly identified participants’ support network, current support, desired support, initial coping strategies and emotions experienced. Additionally, participants ‘support-seeking’ behaviours and consequent coping outcomes (‘liabilities’ and ‘resources’) in relation to ‘coping as an episodic process’ were identified. This process identified factors potentially leading to the development of participants’ individual adaptive coping strategies and longer-term coping ‘resources’.

This chapter presents in-depth results of the semi-structured interviews, which explored participants’ self-identified coping strategies. The aim of the interviews was to further explore the themes identified in the Facebook online survey relating to mothers’ day-to-day support needs and coping strategies. How participants with RA coped, if and how their support needs were met and their consequent coping strategies and ‘resources’ are explored. The results of this chapter focus predominately on participants self-identified coping strategies, individual coping adaptations and their day-to-day support-seeking behaviours to manage the impacts of RA alongside a parenting role.

A description of the participants is presented (Section 5.1), followed by the study results. Results are presented in two parts. Firstly, results are presented, with supporting statements, in relation to participants’ self-identified coping strategies and their ‘support-seeking’ behaviours to cope (Section 5.2). Secondly, results are presented, also with participant statements, in relation to participants’ utilisation of interrelated ‘families of coping’ (Section 5.2). Lastly, results of participants coping outcomes, ‘resources’ and ‘liabilities’, are presented (Section 5.3), identifying participants’ individual adaptive coping strategies and longer-term coping ‘resources’.

5.1 Description of participants

Four participants, all mothers with RA, aged between 33 and 46 years, participated in the semi-structured interviews. Three participants had two children and one had three children. All participants had children living at home at the time of their interview. Participants’ children were aged between newborn and 25 years. Three participants were employed outside of the home, and one was a full-time mother. All participants were residents of the Sunshine Coast, Queensland (Australia).
5.2 Mothers self-identified coping strategies

The results of the interviews identified that participants who utilised ‘support-seeking’, alongside interrelated ‘families of coping’ were better enabled to develop individual adaptive coping strategies and consequent longer-term coping ‘resources’. ‘Support-seeking’ was identified as a coping strategy utilised daily by participants in different ways to cope with the impacts of RA alongside a parenting role. Results are presented in this section in two parts: 1) the use of ‘support-seeking’ to cope, and 2) the use of interrelated ‘higher-order families’ of ‘problem-solving’, ‘information-seeking’ and ‘self-reliance’ and their ‘lower-order families’. The interrelationship of these ‘higher-order’ and ‘lower-order families’ is demonstrated in Figure 4.

5.2.1 ‘Support-seeking’ to enable the development of coping strategies and longer-term coping ‘resources’

The results in this section present participants ‘support-seeking’ behaviours, helping to enable the development of adaptive coping strategies and longer-term coping ‘resources’. Firstly, participant responses are presented under the four ‘support-seeking’ ‘lower-order families’ (‘contact-seeking’, ‘comfort-seeking’, ‘instrumental aid’ and ‘social referencing’). In relation to the coping theory, ‘support-seeking’ has been identified as the most commonly utilised ‘higher-order family of coping’, which makes this ‘family of coping’ highly relevant in exploring participants’ support needs and coping strategies. A number of key factors influence the ‘support-seeking’ process, including the ‘source of support’ (spouse, friends), ‘domain’ (area the support is sought; domestic, medical, academic), ‘kind of support sought’ (‘comfort’, ‘contact’, ‘social’, ‘instrumental aid’) and the ‘means of seeking support’ (‘expressions of distress’, ‘bids and appeals’, ‘social referencing’, ‘proximity-seeking’ and ‘verbal requests’) (Skinner and Zimmer-Gembeck, 2007, p 128). Results identified that ‘support-seeking’ was utilised by participants in various ways, for different purposes, and from a number of different supporters, which better enabled them to develop effective coping strategies to manage the impacts of RA.

5.2.1.1 Contact-seeking

Participants sought contact from husbands, children and work colleagues in the domestic and work domains via ‘social referencing’, ‘proximity-seeking’, ‘verbal requests’, ‘bids and appeals’, and in some cases, ‘expressions of distress’. Participants mainly engaged in ‘contact-seeking’ from children via ‘proximity-seeking’, which for some participants also provided ‘comfort support’. The majority of ‘contact-seeking’ was sought in the domestic domain. However, for one participant, ‘contact-seeking’ in the work domain via ‘proximity-
seeking’ and ‘social referencing’ with other women experiencing health issues fulfilled some of her support needs.

“A lot of the ladies I was teaching, they also had similar problems as myself so we could relate that way. So they didn’t mind the fact that I was joining them in the water, and they’d known me for a long time as well. So I had that support there at work” (ID01)

A coping strategy utilised by one participant was ‘contact-seeking’ via ‘proximity’ through watching movies and reading with her children. This participant stated that this enabled her to manage RA-associated fatigue while still being close to her children.

“Then make it a game, and when the kids think it’s a game you’re relaxing because they actually see mum’s relaxed. You can let that mask down and you don’t feel like it’s a chore sort of thing or a guilt trip because you’re in pain. They actually do enjoy just sitting with you and just quietly reading a book together, watching a DVD, still love the Disney classics. So those sort of things do help a great deal I’ve found” (ID02)

One participant engaged in ‘contact-seeking’ with her daughter in the domestic domain through ‘proximity-seeking’ and ‘verbal requests’. Her daughter could gauge how her mother was coping and then offer appropriate and responsive support.

“She’s seen it now, not badly, but she’s old enough to understand now over the past years how bad it can be for me and how, no I’m okay, I can do it; she knows when to gauge, she’s old enough to gauge and understand my emotions and she can see it in my body language, and how I’m talking, if I’m down in the dumps or not. She just gauges it on that” (ID04)

For this participant, having her daughter simply understand how she was feeling enabled her to feel supported.

“But lucky my daughter, she’ll be 11 this year, so she helps me and she kind of reads the signs that I’m not 100 percent and she’ll say I’ll make the lunches today. She doesn’t really say much about oh, is your arthritis playing up” (ID04)

Not only did this participant’s daughter fulfil an integral emotional ‘comfort support’ need, but she also provided ‘instrumental aid’ by making the lunches.

‘Contact-seeking’ was sought via ‘proximity-seeking’ from a participant’s husband, who she had been with since the age of sixteen.
“I guess I did go through a lot of emotional distress but having the support of my family, having the support of my partner who I’m married to now, and being quite a strong person I felt like I could get through this” (ID01)

“I got married to my partner who I had been seeing since I was sixteen, so it was a long time coming. But we sort of grew together and he’s always been a great support for me and all my stubborn ways and he seems to put up with me, so good luck to him” (ID01)

‘Contact-seeking’ through various methods, in different domains, enabled participants to successfully seek practical and emotional support to manage challenging tasks, such as food preparation. ‘Contact-seeking’ enabled one participant to cope better, as she worked with people who empathised with her situation. Having ‘contact-seeking’ support needs fulfilled was identified as enabling most participants to develop adaptive coping strategies and useful longer-term coping ‘resources’. Other participants identified that ‘contact-seeking’ helped fulfil an emotional support need, which was mostly fulfilled by husbands and children.

5.2.1.2 Comfort-seeking

‘Comfort-seeking’ was sought predominately in the domestic domain from husbands and children through ‘verbal requests’, ‘bids and appeals’, ‘proximity-seeking’, and to a lesser degree, ‘expressions of distress’.

“A hug is another fantastic thing. There’s nothing like having a hug from one of the loved ones, whether it’s your children, your husband, a friend that actually is very cathartic too just to make you feel that little bit better and a little less guilty. Because you’re trying so hard to get through this fatigue, thorough the pain, through all these different things this disease does to you” (ID02)

This participant discussed that the ‘comfort support’ she received from being close to her children via ‘proximity-seeking’ was a self-identified coping strategy that she utilised to feel better, both emotionally and physically.

“Activities for them wears them out as well and then you can all just lay under a doona on the floor, on the couch, cuddle time. The kids love the cuddles, you love the cuddle, and it’s therapeutic for yourself as well to just have that closeness” (ID02)

Husbands were also identified as providing ‘comfort support’. One participant stated that her RA diagnosis was initially difficult to accept, causing emotional distress. She sought ‘comfort support’ from her husband in the domestic domain through ‘verbal requests’ and ‘proximity-seeking’.
“So I guess thinking back, it was pretty hard to accept because I thought this is not going to last forever, it’s something that I can overcome, but it just kept getting worse and I wasn’t able to work properly. I was told by doctors and specialists that I wouldn’t be able to do my degree because what was going to happen to me in the future and I guess I did go through a lot of emotional distress but having the support of my family, having the support of my partner who I’m married to now, and being quite a strong person I felt like I could get through this” (ID01)

‘Seeking support’ from her husband, and drawing on her own emotional strength through ‘comfort-seeking’ and ‘self-reliance’ were coping strategies this participant utilised to manage the emotional and physical impacts of RA. This participant also sought ‘comfort’ from her sister, mostly through ‘proximity-seeking’ in the domestic domain. Other participants sought ‘comfort’ from their husbands in the domestic domain via ‘verbal requests’ and ‘expressions of distress’.

In contrast, one participant stated that her husband had not always provided ‘comfort support’, but was now becoming more supportive and involved in her treatment.

“As my husband is, he’s a beautiful man but when it comes to illness he’s not one for wanting to know about it…if I’d go to the doctors and see the specialist, I wouldn’t talk to him about it. He doesn’t know what medication I’m on… It’s only recently since the kids left home and we’ve hit this speed bump after 26 years of being together that he actually has come with me and found out…trying to walk in my shoes. Speaking to other residents who actually have rheumatoid and they’re in their 70’s and 80’s and seeing how degenerative it is…actually made him realise what’s ahead” (ID02)

It was comforting for this participant that her husband was now trying to understand her challenges in managing the impacts of RA alongside a parenting and working role.

“But I still feel guilty. Like yesterday, classic example, I was in a mad rush vacuuming the house and next thing my husband’s behind me going…put the vacuum down. I’m going no, I’m vacuuming, put the vacuum down, sort of standoff sort of thing. He took it off me and said just go and relax…so he’s understanding now that I do need to. He said don’t feel ashamed if you’re lying on the couch, if you need to sleep, sleep” (ID02)

The results identified that ‘comfort-seeking’ was predominately sought from husbands and children in the domestic domain. ‘Comfort support’ was identified as beneficial in assisting participants to manage pain, mobility issues, reduce feelings of guilt, and cope with emotional distress.
5.2.1.3 Instrumental aid

All four of the participants discussed the emotional and physical challenges they faced because of RA and the need to seek ‘instrumental aid’, particularly physical support, from family members and doctors in the domestic and medical domains.

“I’m a very active person so I found it really hard and to be honest, that was the moment that I sat down and felt like I gave up. I sat down and I waited for my knees to feel better. I waited for the medicine to work” (ID03)

“Sure, so I’ve had rheumatoid arthritis for around about six and a half years and it actually came on very strong when I first had it. Being very a very athletic person and being able to use my body in many strong ways, and then all of a sudden becoming quite crippled and yeah. It was very stressful; emotionally and physical” (ID01)

“I was diagnosed just after my 25th birthday. My daughter was three months old at the time and I didn’t know what was happening to my body. I couldn’t get off the toilet seat because my legs, my knees were in so much pain, couldn’t grip on anything, couldn’t squeeze anything to open a bottle or a kettle or the gas cover in the car” (ID04)

“I can’t garden anymore. That was one of my passions, is to garden. That breaks my heart” (ID02)

The results identified that all participants’ experienced emotional distress due to the physical impacts and losses associated with RA. Being unable to undertake physical exercise, domestic chores and gardening caused distress for these participants. Coping strategies evolved mostly in the domestic domain to manage these challenges, with adaptations made to manage tasks, such as preparing food. These coping strategies and ‘resources’ were necessary for participants to maintain a level of independence and continue to undertake tasks, despite the physical impacts of RA.

Once again, support from husbands and children was integral for participants. Husbands and children were identified in the results as providing the majority of the ‘instrumental aid’ support in the domestic domain. Three participants utilised ‘verbal requests’ and ‘bids and appeals’ to seek ‘instrumental aid’ with household tasks and self-care routines. Two participants outlined the importance of seeking ‘instrumental aid’ to cope.

“Ask for help and take help when it’s offered” (ID04)

“The stairs at home, just perseverance and letting my husband run on those days that it’s not so easy. The kids are really good at going up and down stairs too, so just because I couldn’t do that day, doesn’t mean that somebody else couldn’t do it for
me. As much as I promote being able to do everything for yourself, I think it's good to teach your children to help out too” (ID03)

Part of developing effective adaptive coping strategies for these participants was knowing when and how to seek support, and from whom.

One participant's daughter and husband helped her with self-care and food preparation, fulfilling an ‘instrumental aid' need, when the physical impacts of RA made it difficult for her to undertake these tasks.

“My daughter has to help me do my hair sometimes, I can't grab onto the hair tie to tie my hair up. My husband, I often have to wait until he gets home to cut vegetables and what not because I'm just not capable of doing it, sometimes my hands play up. My knees played up recently, that stops me from exercising and doing those sorts of things; running around with the kids as often as I would like to” (ID04)

This participant stated that ‘seeking support' to manage was an integral part of her day-to-day coping strategies.

‘Instrumental aid' in the form of physical support via 'bids and appeals' in the domestic domain was important for one participant, who relied upon her family to help when RA impacted her mobility.

“By the end of the day I might not even be able to get out of the car when I get home, I can't actually physically get out of the car, I have to be helped out of the car” (ID02)

This participant also sought ‘instrumental aid' via 'bids and appeals' from a family day-care provider in the social domain to care for her youngest child so that she could rest.

“With younger ones, if you can have a day care mum. I had that with [daughter] and that was fabulous with the nightshifts because I had a couple of hours where I could just get two hours of a nap or go for a walk, relax, get rid of some of the pain and then start again. Then right, go and pick her up from day care, get [son] from school, and get dinner going, get everything into place and bedtime, then it's your time to just relax and just try and calm down” (ID02)

Two participants sought ‘instrumental aid' from doctors in the medical domain via ‘verbal requests' and ‘bids and appeals'. One participant stated that the support she received from her specialist helped her understand more about RA.

“I put on a little bit of weight and it was really, it was a really hard time for me. After I went back to see my specialist, they've changed, and I saw Dr [name], she was just
amazing and she was just like oh, you only had a baby, you’re alright. She really helped me understand that this wasn’t the end of the world” (ID03)

One participant sought ‘instrumental aid’ in the work domain through ‘proximity-seeking’ and ‘social referencing’.

“In terms of strategies for coping I was always a water baby so the water was somewhere that I felt my body could be used the best so I started getting back into my swimming. I was actually an aqua aerobics instructor for many years so instead of teaching out of the water, I started teaching in the water. So I taught in the water with RA for probably four years, but by the end of it I was feeling a lot better anyway so I could teach back out of the water” (ID01)

Swimming became a vital ‘instrumental aid’ activity assisting this participant to continue to work and exercise, irrespective of RA-associated mobility issues. As this participant’s health and mobility improved, she re-adapted her practices to teach out of the water again.

‘Support-seeking’ in this example helped the participant to adapt her work/exercise routines in response to her physical abilities and mobility issues.

Participants were practical in their responses regarding seeking ‘instrumental aid’, stating that it was essential to ‘seek support’ to cope. It was identified in the results that all four participants needed ‘instrumental aid’ in various domains, via a variety of methods, due to the physical impacts of RA. This support included assistance with self-care routines, domestic chores and employment tasks, and was utilised to manage RA-related impacts that could arise unexpectedly, such as joint swelling leading to a loss of mobility.

5.2.1.4 Social referencing

Participants sought ‘social referencing’ support in the social, medical and domestic domains from people with RA and other chronic health conditions, specialists, work colleagues and family. Support was sought via ‘verbal and other requests’, ‘proximity-seeking’ and ‘social referencing’.

This form of ‘support-seeking’ resulted in coping ‘resources’ for some participants and coping ‘liabilities’ for others. The results identified that two participants received support in the work domain through ‘proximity-seeking’ and ‘social referencing’. One participant worked in a retirement village and sought ‘social referencing’ support from the elderly residents.

“So the hot bath or just jammie day actually helps me get through the pain barrier of it, and just the deep breathing and sucking it up buttercup, as I say to myself. Come on, just keep going. I’ve learnt to have a high pain threshold. Seeing some of these women at the village I work at, and the pain they’re in, they’re amazing women
because their threshold is just unbelievable. They’ve got to the stage now, they don’t even tell their husbands when they’re in pain and they might have broken a bone or a joint or something like that, because they’ve lived with it for so long” (ID02)

Through ‘social referencing’ with elderly residents, this participant utilised ‘sucking up’ the pain as a coping strategy. This approach may be described as a coping ‘liability’, as it is more aligned to ‘escape’ (another ‘higher-order family of coping’) than ‘emotion regulation’, which is a ‘lower-order family’ of ‘self-reliance’.

“But it’s just interesting talking to people from a different generation, or generations, about it and then my own journey as well, walking through it. The only people who I’ve spoken to about RA is the people I work with, these women who I look after” (ID02)

This participant gained ‘social referencing’ support from these residents through ‘proximity-seeking’ and ‘listening’ to their advice, which helped develop more adaptive coping strategies.

“...from a lovely resident I have at the village who has rheumatoid, she says darling, don’t worry about it. She said it will get done tomorrow, don’t worry about it today. Just run the broom over the floor, don’t worry about the vacuum. Straighten the bed, don’t worry about it, that sort of thing. So now I take that to heart instead of doing hospital corners and polishing everything to a shine, I’ve just learnt, I’m slowly learning. I haven’t learnt, but I’m slowly learning” (ID02)

This form of ‘social referencing’ enabled the participant to develop longer-term coping ‘resources’, as through listening to the elderly resident’s advice, she adapted her everyday domestic practices to set more achievable standards.

Another example of ‘social referencing’ via ‘proximity’ in the work domain involved a participant who taught aqua aerobics to women who also had health issues.

“I was actually an aqua aerobics instructor for many years so instead of teaching out of the water, I started teaching in the water. So I taught in the water with RA for probably four years, but by the end of it I was feeling a lot better anyway so I could teach back out of the water” (ID01)

‘Social referencing’ enabled the participant to adapt her work practices through having the support of her students in the work domain. Engaging in ‘social referencing’ via ‘proximity-seeking’ with people with positive stories in the social domain supported another participant to develop coping ‘resources’. 
“Whereas I once said I can’t, I know that I can, it just takes practice. It takes perseverance and I’m chasing all my kids around, my three beautiful children, beautiful boys so I have to be active. So yeah, my life is not full of negative rheumatoid arthritis stories anymore. I hear people tell me lots of positive arthritis stories; how they can wear high heels ... It’s just there is no end to the possibilities you can do, you just have to believe in yourself and know that it’s a journey, but it will come good” (ID03)

The utilisation of ‘social referencing’ potentially influenced the development of individual coping strategies and subsequent coping ‘resources’ or ‘liabilities’ in participants (Skinner and Zimmer-Gembeck, 2007).

5.2.2 Utilising interrelated ‘families of coping’ to develop coping strategies and ‘resources’

Results identified that ‘support-seeking’ was not utilised by participants in isolation. Interrelated ‘families of coping’ and their ‘lower-order families’ were also used to assist participants to develop individual adaptive coping strategies and ‘resources’. These ‘families of coping’ (and their ‘lower-order families) included 1) ‘information-seeking’ (‘reading’, ‘observation’, ‘asking others’); 2) ‘self-reliance’ (‘emotion regulation’, ‘behaviour regulation’); and 3) ‘problem solving’ (‘strategising’, ‘planning’).

5.2.2.1 ‘Information-seeking’ and ‘self-reliance’

Results identified that ‘support-seeking’, ‘information-seeking’ and ‘self-reliance’ were closely interrelated ‘higher-order families of coping’. Additionally, ‘support-seeking’ and ‘self-reliance’ enabled people to ‘coordinate reliance and social resources available’, which is a key element in successfully ‘seeking support’ in subsequent coping ‘episodes’ (Skinner and Zimmer-Gembeck, 2007). Participants engaged in ‘information-seeking’ mostly in regards to healthcare, diet and exercise via ‘reading and asking others’. Information was also sought from consulting medical specialists, talking to others with RA and other chronic health conditions, reading books and through searching online.

One participant utilised ‘information-seeking’, alongside ‘support-seeking’, to educate herself on using alternative medicine to manage RA symptoms. The participant wanted to avoid traditional RA medications, as she wanted to become pregnant, and was concerned about the impact of medications on her body. As a result, she sought information predominately through ‘reading and asking others’.

“One of the major motivations for me not to be taking any medication that were actually recommended to me was the fact that I wanted to have children. I did a little
bit of research about what was in those medications, and being a young female that was always quite into looking after my body, I just wasn’t comfortable with taking anything. So that gave me a lot of strength to drive in the natural path and that’s where I started reading a few books and taking charge of my own research and my own understanding of rheumatoid arthritis. So I read a book that was about the raw diet. I’ve now spoken to many, many people that do recommend it and many, many people who don’t recommend it and they all have their reasons for why they do and why they don’t. But at the time it seemed right for me” (ID01)

This participant’s ‘information-seeking’ was closely interrelated with ‘self-reliance’, particularly ‘emotion and behaviour regulation’. ‘Information-seeking’, relating mostly to diet and exercise, was a form of ‘behaviour regulation’ utilised to naturally manage RA symptoms. These strategies formed accumulated coping ‘resources’, giving this participant a sense of control and self-efficacy over her situation. This participant integrated ‘support-seeking’ with ‘information-seeking’ and ‘self-reliance’ to develop regularly utilised coping strategies and coping ‘resources’.

Alternatively, another participant engaged in ‘information-seeking’ from a traditional specialist via verbal requests.

“So I was surprised when I realised we were away and I thought this is the arthritis, it’s come back. So I sought advice, went and got into the specialists again and obviously I’m back on medication” (ID04)

Although these participants took different approaches to treating and managing RA symptoms, their ‘information-seeking’ and ‘support-seeking’ approaches and consequent coping outcomes were similar.

‘Information-seeking’ was utilised by one participant in regards to a healthy lifestyle through ‘reading and asking others’. She utilised ‘self-reliance’ (‘behaviour regulation’), advocating taking responsibility for your own medical treatment.

“So the take home message that I really want to give to everyone out there in the same sort of position as me is take control of your own life and take control of your own research in regards to rheumatoid arthritis… Everyone’s going to have a different experience, but I believe we need to just take information from everyone and mould it into what best fits for us. … don’t just think that there’s only one answer, and what works for me doesn’t mean that it’s going to work for you” (ID01)

Utilising interrelated ‘families of coping’ through ‘support-seeking’ (husband and sister) ‘information-seeking’ (diet and exercise) and ‘self-reliance’ (taking control) enabled this
participant to have a sense of self-efficacy and control over the impacts of RA. Consequently, this assisted with ‘emotion regulation’, resulting in the participant developing adaptive coping ‘resources’, such as diet management and knowing when and where to engage in ‘support-seeking’. The ‘lower-order families’ of ‘information-seeking’, ‘reading’ and ‘asking others’, were utilised by this participant to educate herself on managing RA symptoms naturally. ‘Self-reliance’ and the ‘lower-order families’ of ‘behaviour regulation’ and ‘emotion regulation’ were also utilised.

“I do believe the mind plays a big role in this as well…and don’t believe that this is the end and this is who you are. Because it’s not who you are, and don’t let it take over your life” (ID01)

Maintaining a positive, ‘self-reliant’ mindset helped this participant to focus on ‘information-seeking’ to improve her diet and well-being and take control of her own health through self-education.

The results identified that a second participant had a similar approach to ‘self-reliance’ and ‘emotion and behaviour regulation’.

“One of the things that I did to keep me positive was to get back into exercise. I joined a gym and I went and tried all the classes and found out it was really hard to do most of it. But as soon as I said that I could do it, and I made allowances, it was fine. I did yoga when we had to do all the kneeling things and that, I stood there; I just did my thing” (ID03)

‘Behaviour regulation’, through ‘proximity to others’ assisted this participant to get re-involved in exercise, which she stated made her feel more positive (‘emotion regulation’).

Results identified one other participant who utilised ‘self-reliance’ (‘emotion regulation’ and ‘emotion expression’) through strategies like expressing emotion and exercising.

“But I’m keeping hold of that inner child. That is the main thing I’d say is hang onto your inner child and if you have to cry, cry, because you’ve got to let it out” (ID02)

Exercise also helped another participant feel more ‘self-reliant’.

“Don’t give up on yourself, and don’t say I can’t. Just go and try. There’s plenty, like the gym for instance, there’s plenty of people who go to the gym who can’t do yoga, can’t do all the things that they’re doing. I love Zumba, Zumba is awesome. I can do everything, I can get down and do all those things on my knees” (ID03)

Exercise was a form of ‘behaviour and emotional regulation’ enabling participants to gain a sense of ‘self-reliance’ to individually, and with support, manage the emotional and physical
impacts of RA. Participants gained a sense of self-efficacy in achieving physical and
domestic tasks.

‘Self-reliance’ through ‘behaviour regulation’ was identified in the results as helping
participants to adapt in the domestic domain.

“Utensils I think is a big thing, in the kitchen, that’s huge. I didn’t really realise how
much I did adapt until I had to actually think about it” (ID04)

This participant was also studying to become a teacher. She described how through ‘self-
reliance’ and ‘information-seeking’, she was able to achieve personal goals.

“I went back to work in 2011 when it came back, when the arthritis came back. So I
was full time for two years and then I decided I wanted to study teaching. So now I
work three days a week, study two. More like study four because study doesn’t stop
on Saturday or Sunday…I think once you take something on board, you don’t realise
how much time you’ve actually got to do other things until you take something on and
you just make it happen. Sometimes you just have to make it happen otherwise no
one else is going to make it happen for you, only you can make it happen” (ID04)

Coping strategies utilised by this participant, such as using adapted kitchen utensils and
organising her study and work schedule, were identified. ‘Self-reliance’ through ‘behaviour
regulation’ was identified to be interrelated with ‘problem solving’ for two participants. One
participant discussed how she managed fatigue, while still working and exercising.

“If I feel tired now I’ll lay down and rest. Whereas I used to be able to, I’d run two
hours a day, I’d do a night shift, go running for two hours,… I can’t run anymore, so I
walk. If I get really stressed out I put on really loud music and just let it all out by
cleaning or walking, headphones in blaring and that sort of thing” (ID02)

This participant also utilised strategies such as watching movies, listening to music and
breathing techniques to ‘regulate her behaviour and emotions’.

“I just take a deep breath, go outside, chill and say it’s not the children’s fault, it’s
something wrong with me. So then I’d just try and take a step back. Then if I felt too
much, I’d say to the kids let’s watch a movie” (ID02)

“At work it’s wonderful at night because the residents are at home. So if I’m cleaning,
I can have my music up. There’s a couple of residents who might come in, they have
a giggle and sort of say here she goes again. But that is the way I cope is through
music” (ID02)
‘Problem solving’

Participants utilised ‘problem solving’ through ‘planning’ and ‘strategising’ in the domestic and work domains to manage the impacts of RA. Changing jobs and starting a business was necessary for one participant to cope with a working role.

“I’m a children’s entertainer and I do kids parties. So in between I’ve been doing all that as well. The hardest thing in that was having to sit down and play pass the parcel. Standing up’s fine, I can run around, I’m a circus entertainer, I put that aside. I hired everyone else to do the circus still so I’m slowly getting back into that now” (ID03)

“Don’t give up on yourself, and don’t say I can’t. Just go and try” (ID03)

Through ‘problem solving’, the participant found solutions to not being able to sit down on the ground and not being able to do circus tricks by ‘support-seeking’ and hiring someone to assist.

‘Problem solving’ in the domestic domain was also utilised via ‘strategising’ and ‘instrumental action’ by another participant.

“So one of the practical adaptations I took on with my little girl when my flare up came quite bad again in my wrists and hands around eight months, was how I was carrying her. Obviously I couldn’t use the strength of my hands and wrists to do a lot of the things. So I rely a lot on my forearms in how I carried her. In a way, I looked at it as a good thing though, not as a bad thing, because it was better for my posture. I used to hold her in front of me and I used to hold her with my forearms, so she was never on my hips. So I guess I tried to look at it as a positive thing rather than a negative thing” (ID01)

Interrelated ‘families of coping’, including ‘support-seeking’ and ‘self-reliance’, were previously utilised by this participant. She then utilised coping ‘resources’ alongside ‘problem solving’ by figuring out alternative ways to carry her baby to remain ‘self-reliant’.

She also used ‘emotion regulation’ by remaining focused on her abilities, and the positive impacts on her posture, rather than focusing on her physical deficits.

“So I still have a good time and there’s still a life to be lived and don’t ever think that you need to give up and that it’s all over. Just because there’s a few things that you can’t do that you could do. Because I guess its human nature, we want to look at what we can’t do. But in the end let’s start looking at what we can do and then build on getting back some of those things that we can’t do because you never know what can happen…But it is life and life’s not meant to be easy and I guess it’s challenges
that pop up here and there that we need to just get through and enjoy what we’ve got” (ID01)

When the participant became pregnant with her first child, she utilised ‘problem solving’ to re-introduce foods that she had previously eliminated from her diet. ‘Problem solving’ was interrelated with ‘self-reliance’ (‘behaviour regulation’) to independently manage her RA symptoms.

“So before I had [child] I was still doing my raw type food…When I fell pregnant with Mia I was feeling so fantastic that I started trying to eat a few things just to see what happened, and nothing happened. So it was just amazing, I could eat all these foods again, but staying eating healthy obviously because that’s my motto. So I enjoyed my pregnancy with Mia and then after I had Mia everything was great as well. I was doing running and I hadn’t been running for a long time. I was doing all these yoga moves I wasn’t able to do prior. So it was just fantastic. I thought wow, look I’ve got this range of movement back in my wrists and I’ve got strength that I haven’t had for a long time” (ID01)

The results identified that ‘problem solving’ and adapting domestic practices through ‘strategising’ and ‘planning’ allowed another participant to independently prepare food.

“I mean, we all find jars and things hard to open, but having grip pads to use and even, you can get arthritis tools that you have to squeeze but some days you just can’t squeeze some days your hands just aren’t working. Electric food processors are my best friend. The pulley chopping devices that you can get, I’ve got a couple of those, I love those. Things, utensils with big handles that I don’t have to do that finer motor grip, I can do a bigger hold on things. I find those extremely helpful” (ID04)

Participants utilised ‘problem solving’ and the ‘lower-order families’ of ‘strategising’, ‘instrumental action’ and ‘planning’ predominately in the work and domestic domains to adapt and manage the physical impacts of RA. One participant utilised ‘problem solving’ to naturally manage RA related joint inflammation.

“Okay. In regards to the turmeric, I started adding that to a lot of my foods when I found out it was a great anti-inflammatory. So I was putting it in my juices…put it in my egg meals and then I was putting it in everything, smoothies. It’s something now like if I have rice at home I’ll add a bit of turmeric powder in the rice” (ID01)

As inflammation can cause negative physical impacts for people with RA, particularly in regard to dexterity and mobility, finding natural ways to ‘problem solve’ via ‘instrumental action’ was effective for this participant. Participants utilised ‘self-reliance’, ‘information-
seeking’ and ‘problem solving’ in various combinations to develop coping strategies and coping ‘resources’, as identified in Figure 4.

5.3 Mothers’ coping strategies and longer-term outcomes: ‘resources’ and ‘liabilities’

The results of the interviews identified that through utilising interrelated ‘families of coping’, such as ‘support-seeking’, ‘information-seeking’, ‘self-reliance’ and ‘problem solving’, participants were enabled to develop adaptive coping strategies and longer-term coping ‘resources’. These self-identified coping strategies and ‘resources’ also assisted participants to have a greater sense of self-efficacy, managing the impacts of RA alongside a parenting role.

Alternatively, some ‘support-seeking’ behaviours, such as ‘social referencing’, led to coping ‘liabilities’ for some participants, resulting in issues like fatigue through the setting of unrealistic goals surrounding everyday tasks, which also led to emotional impacts for one participant.
5.3.1 Mothers' coping choices enabling the development of coping 'resources'

Interview results identified that participants utilised a number of different coping strategies from various 'families of coping'. These coping strategies included researching and implementing a healthy diet and exercise plan, studying to achieve a goal, listening to music and reading and taking a bath to relax. The main 'families of coping' utilised included 'support-seeking', 'information-seeking', 'problem solving' and 'self-reliance'. By utilising these 'families of coping', in various combinations, participants were better enabled to develop coping strategies and 'resources' to fulfil support needs. Participants sought support on different levels, which enabled the accumulation of longer-term coping 'resources' that could be utilised in subsequent coping 'episodes' as identified in 'coping as an episodic cycle' (Skinner & Zimmer-Gembeck, 2007).

The results of the interviews identified that developing longer-term coping 'resources' enabled participants to deal with various stressors associated with RA and a parenting role. For example, one participant identified that her husband was compassionate and attempted to be supportive.

“My husband’s fantastic, he’ll help whichever way he can, but sometimes it’s hard for him if I’m a bawling mess, it’s hard for him to understand the depth of it because you can’t actually see it per say. So I think he finds it difficult to understand the depth of it but he tries very hard and he’s very compassionate which I’m very lucky to have him”

(ID04)

The coping theory states when someone’s 'expressions of distress' are met with support, as was the case between this participant and her husband, the subject is more likely to engage in this type of 'support-seeking' in the future (Skinner & Zimmer-Gembeck, 2007). Consequently, the husband, in this case, was identified as a potential source of reliable support for this participant to utilise as a coping 'resource' in future episodes.

5.3.2 Mothers' coping choices that contribute to coping 'liabilities'

The results identified that for some participants, an over-dependence on some 'families of coping', such as 'self-reliance', could lead to the development of coping 'liabilities'.

“But when it gets too much, I put on a mask. Women are very, very good at using different masks for different scenarios…I could be covered in sweat and just aching, but I’ll just put a smile on regardless. Do what I have to do and just keep going through it” (ID02)
This participant utilised ‘escape’, which is identified as another ‘higher-order family of coping’. The participant self-identified as being overly ‘self-reliant’ in the past, which she recognised had been detrimental to her physical and emotional well-being.

“Don’t hold the emotions in because it just ends up a big volcano and eventually it’s going to explode and you don’t want that. I’ve done it myself and you harm yourself more than anyone else because you’re physically, mentally, psychologically, it’s just hurting yourself... But if you can just sort of do the little steps each day, it just helps. But just getting out for a small walk even, even if it’s just around the garden that’s enough just to get going” (ID02)

The results identified that this participant adapted over time to develop more appropriate adaptive coping strategies and ‘resources’.

“As I said, just let everything go, unlearning - it doesn’t have to be done then and there, it can be done a little bit later when you feel a little bit better to do it. But yourself is number one and you have to, for your sake and your family’s sake, but more for your own sanity, spiritually, everything; psychologically, psychically, that’s the main thing” (ID02)

5.3.3 Feelings of guilt, leading to ‘coping liabilities’

Three of the four participants discussed feelings of guilt associated with having RA and not being able to fulfil their own parenting expectations.

“When I have a flare up, as a mum, it’s difficult. I can’t make the children’s sandwiches or lunches, I find that hard because it’s my job, I see it as my job” (ID04)

Not being able to complete everyday tasks and engage in activities with her children caused frustration and guilt for this participant.

“My knees played up recently, that stops me from exercising and doing those sorts of things; running around with the kids as often as I would like to. I think it puts strain on the whole family. They don’t show it, but I feel guilty. I get the guilt’s” (ID04)

A participant, (ID02), who expressed the most guilt also engaged in limited ‘support-seeking’ and utilised ‘escape’ to cope. The majority of this participant’s guilt was associated with not being able to manage domestic chores, struggling to work outside of the home, and the negative impacts of RA affecting time spent with her children.

“Occasionally even now [child] will still get the Disney movies out and we’ll have a jammie day. I’m not ashamed to have that, but in the of my mind I’m feeling guilty, like I shouldn’t be doing that. But on the other hand, I think well I can’t go anymore
because then the black dog sneaks up on me and I think nup, I’ve got to rest, I just can’t go any further, I’ve hit a wall. That’s virtually what happens is you work and work and work and you’re trying to keep all the pieces of the family together, everything running smoothly, plus working and trying to juggle all these different aspects of your life and it just sometimes overwhelms you" (ID02)

The participant states that she feels overwhelmed by trying to manage the different areas of her life.

“But I felt guilty because the house wasn’t clean, if the house got messy. I’d feel guilty if the washing got behind or something like that. So I’d always make sure that I did all that first and then I’d rest. Even to this day now, even though we only have our 19-year-old daughter living with us, if I’m on the couch and I see my husband’s car come down the driveway from work, on my days off I jump off the couch because I feel guilty because I haven’t been in the garden” (ID02)

“That’s one of my biggest things, burdens I carry is a lot of guilt and that about it because I feel that I can’t do a lot of things I used to do. But I battle through it and I fight it. A lot of it’s up here, you’ve got to stay [unclear], but you’re entitled to have your pity parties, as I call them. If you feel like having a pity party, doesn’t matter where, just have it” (ID02)

Not being able to do all the things she used to do was a source of guilt for this participant.

Results identified that guilt for the three participants involved resentment at the physical limitations RA imposed on their ability to parent, work and manage a household.

5.4 Conclusion

This chapter presented the qualitative results of the semi-structured interviews (data collection Method 2). The study thoroughly explored participants’ day-to-day support needs and coping strategies, with a focus on exploring participants’ self-identified coping strategies and longer-term coping ‘resources’. Initially, the participants ‘support-seeking’ behaviours and the use of interrelated ‘families of coping’ in managing the impacts of RA alongside a parenting role were investigated. As with Chapter Four, a theoretical analysis of the results was undertaken, utilising coping theories developed by Skinner and Zimmer-Gembeck (2007). Additionally, the study provided an in-depth examination of the participants’ coping outcomes, ‘resources’ and ‘liabilities’.

Overall, the results identified that 1) family plays an important supportive role; 2) ‘support-seeking’ assisted the development of longer-term coping ‘resources’; 3) ‘support-seeking’ was interrelated with other ‘families of coping’, such as ‘problem-solving’, ‘information-
seeking’ and ‘self-reliance’; 4) ‘families of coping’, such as ‘support-seeking’ and ‘self-reliance’, were linked to the development of coping ‘resources’ and ‘liabilities’; and 5) different emotions, such as guilt, impacted on how participants engaged in ‘support-seeking’ and accumulated coping ‘resources’. Coping with the impacts of RA alongside a parenting role, as identified in the results, was an ongoing process, with participants utilising interrelated ‘families of coping’ at various times and in different combinations to cope with the emotional and physical impacts of RA.

The following chapter will present a discussion of the overall research findings.
Chapter 6: Discussion

In this chapter, the research results are discussed in relation to the literature. Discussion is also included on how the results may contribute to future knowledge and understanding regarding how mothers seek support and develop coping strategies and coping ‘resources’ to manage the impacts of rheumatoid arthritis (RA) alongside a parenting role.

6.1 Overview

This research utilised qualitative methods to generate in-depth information regarding the day-to-day support needs and self-identified coping strategies of mothers with RA. Coping theories were utilised to understand mothers’ support needs, ‘support-seeking’ behaviours and the impacts of RA. These theories provided the theoretical framework used to analyse the relationship between a participant’s supportive resources and whether support influences the development of individual coping strategies and longer-term coping ‘resources’ (Skinner & Zimmer-Gembeck, 2007). Results from this research resonate with other challenges faced by mothers with RA and other chronic health conditions in previous studies identified in the literature review. The results demonstrate that mothers face a number of challenges stemming from the impacts of RA, along with experiencing a lack of emotional, informational, and, to a lesser degree, physical support. The themes identified in this research reflect how mothers manage the impacts of RA, how they seek support, and from whom, and their subsequent coping strategies and ‘resources’ and/or ‘liabilities’.

The discussion is presented under three main sections: 1) emotions experienced by mothers, ‘support-seeking’ and subsequent coping strategies (Section 6.2); 2) the importance of emotional and informational support for mothers (Section 6.3); and 3) mothers’ use of interrelated ‘families of coping’ to develop coping strategies (Section 6.4). Implications for practice and future research are discussed at the end of each section. This chapter is concluded with the research strengths and limitations (Section 6.5).

6.2 Emotions experienced by mothers, ‘support-seeking’ and subsequent coping strategies

A key result for this research showed that the way mothers expressed emotion and coped with the emotional impacts of RA impacted on their ‘support-seeking’ behaviours and the subsequent development of coping strategies and longer-term coping ‘resources’. It was identified that mothers experienced a range of emotions in managing the impacts of RA. Some of these emotions included acceptance, denial, anger, frustration, happiness, gratefulness and guilt. For some mothers, the emotional distress associated with
an RA diagnosis had an eventual positive effect. An interesting result of the research was mothers stating that having to manage the impacts of RA had a positive effect on their lives by strengthening their own character and emotional bonds with their families.

For some mothers, ‘support-seeking’ alongside ‘self-reliance’ helped them to cope better with the emotional impacts of RA (Skinner & Zimmer-Gembeck, 2007). The findings resonate with previous studies, with mothers stating initially that they were scared and angry and found it hard to accept an RA diagnosis, but eventually found personal strength through the coping process. This demonstrated that, although the emotional impacts of RA were challenging, it was possible for mothers, through ‘support-seeking’ and strengthening their own character, to adapt, and eventually cope better (Mitton et al., 2007). Mothers in the present study who managed to regulate their emotions through utilising coping strategies, such as engaging in exercise, appeared to be better enabled to ‘seek support’ and develop longer-term coping ‘resources’ (Skinner & Zimmer-Gembeck, 2007). This aligns with the coping theory, which states that regulating emotions and developing adaptive coping strategies requires a person to express a range of flexible emotions to respond to stressful situations. The way people respond to or cope with stress can either cause emotional distress and long-term physical and mental health ‘liabilities’, or encourage the development of short and/or long-term coping ‘resources’ (Skinner & Zimmer-Gembeck, 2007). This was identified in the current research, with mothers ‘venting’ emotions, such as frustration at a lack of informational support, with other friends with RA to ‘seek support’.

Coping with the emotional impacts of RA, and in particular, the initial diagnosis, was challenging for mothers and their families in this research. Interestingly, developing adaptive coping strategies and longer-term coping ‘resources’ was linked to expressing, not suppressing, emotions, including those perceived as being negative, such as anger. According to the coping theory, adaptive coping benefits from “flexible access to a range of genuine emotions” (Holodynski & Friedlmeier, 2006 in Skinner and Zimmer-Gembeck, 2007, p 122). For most mothers, feeling supported was often due to having their emotional expressions acknowledged with either sympathy, empathy or understanding. Mothers stated that it was important to have their emotional expressions met with some form of positive or appropriate acknowledgement, not necessarily for the supporter to offer specific solutions to their problems. “My husband’s fantastic, he’ll help whichever way he can, but sometimes it’s hard for him if I’m a bawling mess, it’s hard for him to understand…but he tries very hard and he’s very compassionate…I’m very lucky to have him” (ID04). Having her husband acknowledge her emotional distress was enough for this participant to feel supported, even though she admitted he did not completely understand how she felt.
The expression of emotion is important in all stages of the coping process, including “vigilance, detection, and appraisals of threat to action readiness and coordinating responses during stressful encounters” (Skinner & Zimmer-Gembeck, 2007, p. 122). The theorists further emphasise the importance of expressing all types of emotions, even anger, in removing a threat or for clearly stating intentions. The importance of expressing emotions in relation to coping was also identified in the current research, with one participant stating, “Don’t hold the emotions in…it just ends up a big volcano and eventually it’s going to explode…I’ve done it myself and you harm yourself…physically, mentally, psychologically, it’s just hurting yourself…” (ID02). This is resonated in previous research, with a father of a daughter living with RA stating that even though he got angry sometimes at the situation, the family communicated better and had become closer as a result (Whitley et al, 1999). For mothers in this study, knowing that expressions of emotion have previously been met with support by someone in their network identified this person as a potential source of support in future coping episodes. This is a key component of the coping cycle ‘coping as an episodic process’. A link between factors, such as a mothers support network, current coping strategies utilised, emotions experienced, and the development of coping ‘resources’ was identified. Components of Skinner and Zimmer-Gembeck’s (2007) coping model, particularly ‘coping as an episodic process’, were utilised to explore how mothers engaged in ‘support-seeking’ and the influence of these methods on their coping strategies and ‘resources’. For example, the interrelationship of ‘previous episodes’ and how the participant coped with previous ‘demands’ and ‘appraisals’ is influenced by ‘individual factors’ (personality) and ‘social factors’ (availability of support), which then influence coping outcomes of ‘resources’ or ‘liabilities’ (Skinner & Zimmer-Gembeck, 2007, p. 138).

Having their emotional expressions met with some form of support was important in the coping process for mothers, even if the support did not entirely meet their needs. Results demonstrated a link between the impacts of RA, participant support needs and their subsequent coping strategies and longer-term coping ‘resources’. Knowledge of mothers’ day-to-day impacts and identifying how mothers can be better supported to cope assists in the development of appropriate and responsive supports. Mothers who felt emotionally supported expressed more positive feelings over those who felt unsupported. Mothers who felt that their support needs, and in particular, their emotional needs, were being met expressed being better enabled to express their emotions more freely and develop coping strategies and longer-term coping ‘resources’.

Previous research identified that emotional issues can negatively impact individuals and their ability to parent (Covic et al., 2006; Evans & de Souza, 2008; Sharpe et al., 2001). A need for future interventions to be in consultation with mothers to develop self-efficacy to reduce
negative psychological impacts, such as depression, anxiety and feelings of social isolation, was also identified. Depression was identified in previous research to be a major emotional issue for mothers with RA (Ackerman et al., 2015; Grant, 2001; Meade et al., 2013; Sinclair & Blackburn, 2008). In addition, the current research identified a need for family members, particularly husbands (as mothers’ most important supporters), to be educated and supported themselves to emotionally support their partners. This is also reflected in previous research that suggests that the whole family needs to be involved in supportive interventions for women with RA (Whitley et al., 1999). This could have positive flow-on impacts if people in mothers support networks are educated and skilled to respond appropriately to their emotional expressions and appeals for support. As depression and anxiety are more common amongst people with RA, compared to the general population, it is imperative to meet the emotional needs of mothers with RA to help prevent longer term psychological issues (Barlow et al., 1999; Mitton et al., 2007).

6.2.2 Mothers experiencing guilt at not fulfilling a perceived ‘normal’ parenting role

Another key result identified in the research is that emotions, such as guilt at not being able to fulfil a perceived ‘normal’ parenting role, served as a coping ‘liability’ for some mothers. A definition of guilt in this context is “a feeling of having committed wrong or failed in an obligation” ("Guilt," n.d.). Previous research found that some mothers felt ‘robbed of motherhood’ due to the impacts of RA (Mitton et al., 2007, p. 191). Further studies showed that mothers also expressed guilt at not being able to consistently fulfil all aspects of a parenting role (Barlow et al., 1999; Kristiansen et al., 2012). Not being able to fulfil all areas of parenting due to the impacts of RA was also a source of guilt for mothers in this research. The majority of guilt was associated with not being able to manage domestic chores or engage in physical activities with children and struggling to manage work outside the home. One participant stated, “My knees played up recently, that stops me from exercising…running around with the kids… I think it puts strain on the whole family. They don’t show it, but I feel guilty. I get the guilt’s” (ID04). Even mothers who had demonstrated adaptive coping strategies and utilised positive attributes, such as goal setting and ‘support-seeking’, struggled with guilt in response to RA-associated physical deficits. This is similar to previous research findings, which showed that mothers with RA felt guilty at not being there for their families in the ways they wanted to be (Abraido-Lanza, 2004; Evans & de Souza, 2008; Mitton et al., 2007). A mother in Grant’s (2001) study stated that she felt guilt at the lack of attention she was able to pay to her second child due to the severity of her arthritis.
Guilt, according to the coping theory, is associated with the ‘helplessness’ ‘higher-order family of coping’, which includes the ‘lower-order families’ of ‘confusion’, ‘cognitive interference’ and ‘cognitive exhaustion’ (Skinner & Zimmer-Gembeck, 2007, p. 126). This aligns with statements made by mothers in the research who felt a loss of control. This loss of control related predominately to not being able to manage the impacts of RA, such as fatigue and a loss of mobility, alongside parenting. Interestingly, in this research, mothers mostly expressed guilt about issues that were out of their control, such as the physical limitations RA placed on spending time with their children, including active play. However, a positive outcome of mothers’ physical limitations identified in previous research was that because of RA-associated physical limitations, their children became more independent. One mother detailed how her five year old learnt to tie her shoe laces for her when she had joint replacements on her fingers (Meade et al., 2013). In another study, a mother discussed how she had developed contingency plans, like having a snack box in the kitchen pantry so her son could help himself to food if she was physically unable to cook for him (Evans & de Souza, 2008). Some mothers in these studies expressed guilt over how much their children had to help out at home. Interestingly, in the current research, most participants did not express guilt at how much their children helped around the home, particularly with food preparation and general domestic chores. Instead, they mostly discussed with pride how helpful and emotionally mature their children were in assisting them to cope with the physical and emotional impacts of RA. One mother was positive that their family situation was teaching her children life lessons, “As much as I promote being able to do everything for yourself, I think it’s good to teach your children to help out too” (ID03).

6.2.3 Summary: The importance of emotional expression for mothers to develop coping strategies

In summary, the importance of emotional expression and for mothers to be heard and understood were surprising themes to emerge from this research. The majority of mothers reiterated the importance of simply having someone to talk to, and the mere presence of someone to listen to their challenges was a great source of support. Results show clear alignment between how mothers expressed their emotions and managed the impacts of RA, how they sought support, and their subsequent coping strategies and longer-term coping ‘resources’. These results align with the coping theory and previous research. Most mothers who were able to express their emotions, negative or positive, in relation to managing the impacts of RA alongside a parenting role were more effectively able to seek support and develop longer-term coping ‘resources’.
6.2.4 Implications for practice and future research

The results of this research identified to a degree the emotional impacts and support needs of mothers with RA. However, further in-depth qualitative research is needed to explore the impacts of emotions on mothers’ ability to cope and parent. More in-depth research focusing on the emotions experienced by mothers with RA, and their families, could be useful to ascertain more clearly the depth of the emotional impacts and how to develop appropriate and responsive interventions to support mothers with RA and their families. Methods such as utilising video diaries and online diaries, as utilised by Kanzaki et al. (2004), could prove useful to encourage mothers with RA to more deeply and freely express their emotions. Additionally, an area of further research could be developed to explore the impact of children having to adopt more mature behaviours in the home to assist mothers emotionally and physically to cope. Observations in naturalistic settings, such as the family home, would be useful to explore the communication and supportive structures of families managing with maternal RA.

6.3 The importance of emotional and informational support for mothers

It was identified that the majority of mothers had a strong preference for seeking emotional ‘comfort support’ and ‘informational support’ to meet their support needs. Feeling emotionally and responsively supported and appropriately informed helped mothers feel like they and their challenges managing RA alongside parenting mattered. This research showed not only the importance of mothers expressing their emotions, but also having some of their emotional needs met with appropriate and responsive support, particularly from family supporters, such as husbands. This was important in developing coping ‘resources’. The majority of mothers wanted to express their emotions in relation to an RA diagnosis and discuss the emotional impacts of RA. Interestingly, mothers were looking for emotional support and understanding and to have their struggles and challenges acknowledged, not necessarily to have their problems solved, and this was enough for the majority of mothers to feel supported. This was a surprising result, as few mothers discussed the need for physical support, despite the challenges of parenting children alongside of managing the physical disabilities associated with RA.

This need to have expressions of emotion met with some type of empathetic, sympathetic and understanding support was reflected in previous research, which identified the importance of support needs being matched by support provision and the importance of ongoing emotional support from families (Ryan et al., 2003). Seeking ‘comfort support’, particularly in the domestic domain from husbands and children, was an important part of the
‘support-seeking’ and coping processes for mothers. One participant stated, “There’s nothing like having a hug from one of the loved ones, whether it’s your children, your husband, a friend…to make you feel that little bit better and a little less guilty” (ID02). This participant also discussed the ‘comfort’ she got from simply being close to her children and relaxing with them, which she utilised to feel better emotionally and physically. The need for emotional support was identified in previous qualitative studies with mothers expressing a need for not only information on medications, pregnancy and early parenting, but also on emotional support services (Ackerman et al., 2015). Families were identified as the main source of support for mothers. This was also identified in other studies, with Whitley et al. (1999) stating that the impacts of RA are experienced by all family members on some level, with the research identifying a need for families to communicate and work together to support one another.

The need for ‘informational support’ was identified as highly important in this research. Mothers stated that they lacked information on medications, treatment and managing pregnancy and parenting. This resulted in mothers feeling anxious, scared, angry and frustrated. One participant stated, “…I do not think there is enough information or support …I feel like I might suffer PPD [post-partum depression] if I get to a point where I feel like a failure as a mum not being able to care for my own baby” (ID34). This is also resonated in other studies, with mothers stating that they found it difficult to access the information they needed, particularly on medications and treatments (Ackerman et al., 2015; Meade et al., 2013). The results in this research identified that friends with RA were often counted on as a source of ‘informational support’. These friends were also often relied upon for empathetic understanding, which was an important source of emotional ‘comfort’ support for mothers. Mothers wanted to be supported to be independent and ‘self-reliant’, and to be able to gather the information they needed to do this. Additionally, mothers identified the importance of ‘informational support’, particularly to have knowledge of other mothers’ self-identified coping strategies. Previous research also identified the importance of ‘peer-to-peer information’ exchange, with mothers connecting to share stories and support one another (Ackerman et al., 2015; Sinclair & Blackburn, 2008). This information could be useful to inform community-based public health strategies, with a particular focus on facilitating the sharing of coping strategies between mothers with RA.

### 6.3.1 The reliability and validity of information and support shared amongst mothers

An issue not explored in this research was the validity and reliability of information shared amongst mothers and their friends with RA. As identified by Skinner and Zimmer-Gembeck’s
(2007) coping theory, the process of coping is individualised. The majority of mothers in this research stated that it was important to establish individualised coping strategies. Previous studies identified that a strategy that may work for one mother may not work for another (Prodinger et al., 2014; Sinclair & Blackburn, 2008). Also, the issue of reliability of information shared, particularly on medications and treatments, needs to be further considered. Mothers with RA sharing practical strategies and information may be useful; however, the swapping of unqualified information from people without medical training regarding treatments could become problematic and dangerous. Previous studies have identified a need for arthritis organisations to act as ‘resource hubs’ for people to access reliable, up-to-date treatment information and available supportive services (Ackerman et al., 2015). This could serve as a more reliable and easily accessible form of information for mothers with RA, and could also be used as an information database to inform community-based public health strategies.

6.3.2 Summary: The impact of support on mothers coping strategies

Mothers in this research discussed a preference for emotional ‘comfort support’ and ‘informational support’. To meet these ‘support needs’, mothers sought support mostly from husbands, children and friends with RA. Most mothers in the research demonstrated a strong need to express their emotions and discuss the emotional impacts of RA. For these mothers, feeling emotionally supported and appropriately informed helped them to feel better enabled to develop coping strategies and longer-term coping ‘resources’ that supported their sense of independence and self-efficacy. Interestingly, most mothers preferred empathetic support and understanding, and to simply have their RA-associated challenges acknowledged, not necessarily solved. This was a surprising result, as few mothers discussed the need for additional physical and domestic support to manage the challenges of parenting alongside managing the impacts of RA. The majority of participants in current and previous research stated that there was a need for more information in regards to the impacts of RA, medications, pregnancy and managing parenting.

6.3.3 Implications for practice and future research

An area of further research could involve exploring in more depth the validly and reliability of peer support and the impact, for example, of this information dissemination particularly on newly diagnosed mothers. An area not previously researched is the consequent impact of this information on mothers, both positive and negative, especially if the information imparted is incorrect, misguiding or misinterpreted. The current research explored how mothers with RA shared information and support. However, further research involving online discussions and focus groups is still warranted to discuss the support needs of mothers with RA and
provide a forum for them to share coping strategies. Previous research suggested that this
type of information could then be collated into an online ‘resource hub’ to be shared amongst
mothers with RA and people in their support network, including key medical professionals
and family (Ackerman et al., 2015). Additionally, previous and current research identified a
need for further qualitative research to assess the emotional impacts and capabilities not just
of mothers with RA, but also their families. Future interventions and supportive programs
could assist ‘supporters’ to ‘seek support’ themselves to develop their own coping
‘resources’ to, consequently, be better equipped to support mothers with RA.

These results, particularly regarding the need for emotional support for mothers with RA, are
preliminary. Further in-depth qualitative research exploring mothers’ self-identified emotional
coping strategies is needed. In addition, exploring the supportive capabilities and confidence
levels of husbands, families and medical specialists to provide appropriate and responsive
support for mothers with RA would be useful. The results of this research identified that
physical ‘support needs’ were secondary to emotional and informational ‘support needs’ for
mothers to cope with the impacts of RA alongside a parenting role. This influenced mothers
‘support-seeking’ behaviours and subsequent coping strategies. Although most mothers
stated that they lacked informational support, some detailed other support they desired to
cope, for example, access to psychological support services to deal with a diagnosis. It could
be useful in future research to interview mothers with RA and their spouses together, and
then to individually explore mothers’ emotional impacts and support needs and how their
spouses can best fulfil these needs. Rheumatologists, occupational therapists and family
were identified as mothers’ most influential supporters; however, it was identified that these
supporters sometimes lacked the knowledge to appropriately support mothers. Future
research could also involve interviewing mothers and their rheumatologists, for example, to
explore mothers’ informational needs and rheumatologists’ capacity to meet these needs.
Previous studies concur, stating that it is vital for supportive services to help and inform
mothers with RA and their families to assist them to make medical decisions and maintain
their health alongside parenting. Future research could then be utilised to inform community-
based health strategies, educating not just mothers with RA, but also people in their support
network. This would better enable supporters to provide responsive and appropriate support.

6.4 Mothers’ use of interrelated ‘families of coping’ to develop
coping strategies

A key result to emerge from this research was that the utilisation of interrelated ‘families of
coping’ appeared to better enable mothers to develop longer-term coping ‘resources’. These
‘resources’ were then utilised by mothers in subsequent coping episodes, which aligns with
Skinner and Zimmer-Gembeck’s (2007) coping theories. The focus of this research was to primarily explore ‘support-seeking’, and then to analyse how this ‘family of coping’ was utilised alongside ‘self-reliance’, ‘problem solving’ and ‘information-seeking’. A clear alignment was identified between the use of these interrelated ‘families of coping’ and the development of participant coping strategies and longer-term coping ‘resources’. Key elements of Skinner and Zimmer-Gembeck’s (2007) coping theories were utilised to explore mothers’ ‘support-seeking’ behaviours and consequent coping outcomes, ‘liabilities’ and/or ‘resources’. Interestingly, the results identified that when ‘support-seeking’ was interrelated with various ‘families of coping’ at different times, in most cases, this led to the development of longer-term coping ‘resources’.

The results identified that ‘support-seeking’ was interrelated with ‘information-seeking’, as mothers turned to others to seek advice so that they could be better informed to make their own decisions. One participant stated, “I think the best support has come from my doctors. My rheumy is quite simply amazing. Every decision regarding my treatment was made by me, with him clearly explaining all the options” (ID02). Another participant stated, “The friends I have made who also have RA are my biggest support. They seem to be the only people who understand…I value their understanding and support” (ID11). Support of this nature was also identified in the literature, with one participant stating that after speaking with other mothers with RA, her specialists, and reading information online, she felt better prepared (Meade et al., 2013). The majority of mothers in this research stated that they felt that there was a general lack of information in regard to managing the impacts of RA alongside a parenting role, which impacted how they coped. Mothers were motivated to engage in ‘information-seeking’ to not only develop more adaptive coping strategies, but also to seek out appropriate and useful support. This is resonated in Ackerman et al.’s (2015) research exploring the informational needs of women with RA. The overall research results identified that there is a need to develop informational resources for women with RA, and in particular, a way to more broadly share stories of other mothers who have coped with RA.

Additionally, ‘support-seeking’ and ‘information-seeking’ were also identified to be interrelated with ‘problem solving’. A number of mothers in the current research discussed how they would ‘seek support’ and ‘information’ from other friends with RA to ‘problem solve’ RA and parenting issues. This ‘problem solving’ enabled some mothers to become more ‘self-reliant’, which assisted mothers to ‘regulate their emotions and behaviour’ (‘lower-order family’ of ‘self-reliance’). For example, one participant, after experiencing a difficult pregnancy and fearing she may suffer PPD, continually sought support from her friends with RA. Consequently, these friends provided ‘informational support’ and practical support to help her ‘problem solve’ in order to become more ‘self-reliant’. This process also helped her
to regulate her emotions and feel more in control. As a result, she felt more confident to continue to engage in ‘support-seeking’ and ‘information-seeking’, which assisted her to ‘problem solve’, and eventually develop coping ‘resources’. This coping process is closely aligned with the ‘coping as an episodic process’ detailed by Skinner and Zimmer-Gembeck (2007).

‘Information-seeking’ and ‘self-reliance’ were also closely interrelated. One participant in the research detailed the utilisation of these two ‘families of coping’ to manage her RA symptoms naturally and become more ‘self-reliant’. The participant stated, “So the take home message...is take control of your own life...do your own research... we need to just take information from everyone and mould it into what best fits for us. ...” (ID01). As an outcome, this participant was able to describe the coping strategies that she had developed over time, and how, as a result, she had developed longer term ‘coping resources’ and a sense of self-efficacy. This is resonated in Sinclair and Blackburn’s (2008) research, with results identifying that mothers who learnt to adapt, pace their activities and set more realistic goals were able to develop adaptive coping strategies and a sense of self-efficacy or control over managing the impacts of RA. However, due to the small sample size in this current research, further research, particularly involving observations in the home, could be utilised to more comprehensively understand how mothers with RA use the different ‘families of coping’ to develop coping strategies and ‘resources’.

‘Problem solving’ and ‘self-reliance’ were also interrelated; particularly the ‘lower-order family’ of ‘self-reliance’ (behaviour regulation). One mother detailed the use of ‘problem solving’ with different kitchen gadgets that allowed her to be more independent. However, at times, when she still couldn’t complete some tasks, she utilised ‘support-seeking’ to gain assistance with food preparation from her husband and daughter. The key result regarding successful ‘support-seeking’ for mothers with RA in this research was that support be appropriate and responsive to the support needs of mothers. Of importance to mothers, themselves, was that support assisted them to remain as independent as possible, but to also have access to support when needed. The importance of mothers with RA retaining a sense of independence and self-efficacy was resonated in previous research (Barlow et al., 1999; Grant, 2001; Mitton et al., 2007; Sinclair & Blackburn, 2008).

6.4.1 Balancing ‘self-reliance’ with ‘support-seeking’ to develop coping ‘resources’

An interesting result from this study was that ‘self-reliance’ led to coping ‘resources’ for some mothers, but coping ‘liabilities’ for others. When ‘self-reliance’ was utilised in isolation, this led to coping ‘liabilities’ for some mothers. For one mother, being overly ‘self-reliant’ left her
feeling overwhelmed, frustrated and angry. She admitted that in the past, she had repressed her emotions and was reluctant to 'seek support', which had negative outcomes, including the development of coping 'liabilities'. One of these coping 'liabilities' was to 'suck up' the pain, which she had witnessed the older residents at the retirement village where she worked doing. This sort of 'social referencing' contributed to her struggling to cope with managing the impacts of RA alongside parenting and managing a household. However, her older, retired clients had different life demands, and, therefore, their coping strategies may not have been appropriate for a busy working mother managing the impacts of RA. One of the areas this mother struggled with was domestic tasks, and she stated, “That's one of my biggest things, burdens I carry is a lot of guilt and that about it because I feel that I can't do a lot of things I used to do. But I battle though it and I fight it” (ID02). This mother regularly discussed fighting and pushing through the pain and fatigue, which could be identified as a form of denial and a lack of acceptance of her current capabilities in regards to managing the impacts of RA. Consequently, in being overly 'self-reliant' and resisting support, this mothers coping strategies developed into longer-term coping 'liabilities', which she admitted had impacted her, both physically and emotionally.

6.4.2 Summary: The need for mothers with RA to have a sense of self-efficacy

The results identified a need for mothers with RA to balance 'support-seeking' with other 'families of coping', such as 'self-reliance', in order to cope, but still retain a sense of independence and self-efficacy. Being overly 'self-reliant' led to issues for mothers, including feelings of being overwhelmed and a loss of control. Additionally, this impacted on their ability to 'seek support', and, consequently, to develop adaptive coping strategies. This situation has the potential for mothers to develop longer-term coping 'liabilities' instead of coping 'resources', with the latter being more beneficial for mothers coping abilities and long-term psychological well-being.

6.4.3 Implications for practice and future research

This research explored mothers' support needs and self-identified coping strategies by allowing mothers to detail their stories in relation to managing the impacts of RA alongside a parenting role. Future research, with a larger sample size of mothers with RA telling their individual stories, could elicit richer qualitative data. Allowing mothers to detail their self-identified coping strategies through methods of their choice, such as video diaries or paper-based diaries in the comfort of their own homes, could also elicit richer, more meaningful data. This research could then inform health strategies that could be added to an online ‘resource hub’, which was previously suggested by Ackerman et al. (2015). Additionally, this research could also inform community-based health strategies and help to educate health
professionals, for example general practitioners (GPs), community health nurses and rheumatologists, who are responsible for the day-to-day medical and informational needs of mothers with RA. Educating mothers and their supporters on the impacts of RA, previously identified mothers’ support needs, and an array of self-identified coping strategies could serve to improve support provision for mothers with RA and their families.

6.5 Strengths and limitations

6.5.1 Strengths

The strengths of the research are as follows:

1. The research responded to an identified gap in the knowledge regarding how mothers cope and are supported to manage the impacts of RA alongside a parenting role;
2. In-depth qualitative data was gathered, contributing to knowledge about the everyday lives of mothers with RA and their self-identified coping strategies and support needs; and
3. This research provides evidence to support the need for future in-depth research gathering stories from mothers with RA to inform others in a similar position, their families and health professionals on how best to support mothers with RA to cope.

6.5.2 Limitations

The limitations of the research include:

1. The results are limited to the self-reported responses of the participants involved; and
2. The research sample was limited to mothers with RA who were already actively involved in ‘support-seeking’ and the development of coping strategies and longer-term coping ‘resources’.
Chapter 7: Conclusion and Recommendations

This chapter presents the conclusions of the research and future recommendations.

7.1 Conclusion

The aim of the research was to explore the day-to-day support needs and coping strategies of mothers with rheumatoid arthritis (RA). A narrative literature review identified a lack of research on mothers' individual support needs and self-identified coping strategies to manage the impacts of RA alongside a parenting role. Previous research identified that parenting was often surrounded by fear and uncertainty, resulting in anxiety and depression for mothers. Researchers also identified a need for more supports and interventions to assist mothers to develop independent adaptive coping strategies. The need for informational, emotional and physical supports from different sources, such as medical professionals, and family and friends, was identified. This research sought to contribute to current knowledge, through utilising a qualitative exploratory case study methodology to elicit richer, more in-depth data.

The research question was answered by identifying the people in mothers' support networks, types of current support received, other desired support, initial coping strategies, longer-term coping ‘resources’ and the various impacts of RA. Additionally, mothers ‘support-seeking’ behaviours to manage the impacts of RA alongside a parenting role were explored, along with how participants engaged in ‘support-seeking’ in relation to Skinner and Zimmer-Gembeck’s (2007) coping theories. Through utilising a qualitative approach, as has been done in previous research (Ackerman et al., 2015; Grant, 2001; Mitton et al., 2007), this current research was able to elicit richer, more comprehensive data. In particular the use of semi-structured interviews (Method 2) which allowed mothers with RA to comprehensively detail their individual support needs and coping strategies. Following data collection through analysis of mothers’ support needs and coping strategies utilising this theoretical framework, it was possible to explore in more depth mothers’ support needs, and how support-seeking behaviours potentially led to coping strategies and longer-term coping ‘resources’.

Overall research results showed that most mothers wanted informational and emotional support from a variety of sources to more independently manage with self-care, care for their children, manage a household, and, for some participants, maintain outside employment. Physical support was also desired to assist mothers to retain independence, such as support to undertake food preparation. Husbands, children, other family, medical professionals and friends with RA were identified as valued supporters. The majority of mothers stated that they lacked informational support relating to key issues, such as medications, treatments
and access to support services. Mothers stated that they sought information from other friends with RA, from medical professionals, such as rheumatologists, reading books and searching online. An issue was identified in relation to the reliability of information, especially when some medical professionals were uncertain of which (if) medications were safe and best-suited for women with RA who were contemplating motherhood, were currently pregnant, or were caring for children. The results of this research also provided insight into the emotional impacts of RA. Most participants experienced emotional impacts that potentially influenced their ability to cope. Seeking support, particularly emotional and informational support, was identified as integral to assist mothers to cope. Desirable emotional support included empathy, sympathy, kindness, compassion, care, understanding and general concern. Mothers stated that this support made them feel “better”, “inspired” and “supported”, which potentially enabled them to develop adaptive coping strategies and longer-term ‘resources’. Additionally, informational support that assisted and educated participants to feel in control of making their own decisions, especially regarding treatment options, was valued. These ‘support-seeking’ strategies enabled participants to draw people into their support network to assist them in developing coping strategies and accumulate longer-term coping ‘resources’.

Overall, the results identified that for mothers, family plays an important supportive role. ‘Support-seeking’, when interrelated with other ‘families of coping’, such as ‘problem-solving’, ‘information-seeking’ and ‘self-reliance’, assisted the development of longer-term coping ‘resources’. Additionally, the results identified that different emotions, such as guilt, impacted on how participants engaged in ‘support-seeking’, and potentially impacted the coping cycle and how participants accumulated coping ‘resources’. Coping with the impacts of RA alongside a parenting role, as identified in the results, was an ongoing, challenging process. Mothers stated that they needed to continuously adapt and accept limitations, particularly physical, to cope with the impacts of RA. Mothers also stated the importance of expressing emotions, such as sadness, anger and frustration. Maintaining a sense of independence was important, as was also remembering that it was integral to ‘seek support’ at times in order to cope.

This research contributed to the literature through addressing research gaps regarding the support needs and self-identified coping strategies of mothers with RA. These research results provide further evidence to inform community-based health strategies, helping to educate not only mothers with RA, but also people in their support networks, including family, friends, colleagues and health professionals, who all provide ongoing physical, emotional and informational support for mothers with RA. As identified in the literature and the research, adaptive coping strategies are essential in managing a chronic health
condition, such as RA, which is currently incurable and has unpredictable impacts that fluctuate in severity, causing pain, fatigue and loss of mobility. An increased awareness for mothers and people in their support network, through community-based health education strategies, could provide not only awareness, but also more support to assist mothers to both cope with the impacts of RA and be better supported to parent. Although this research provided rich insight into the support needs and self-identified coping strategies of mothers with RA, further research is needed. The suggested future research directions revolve around gaining a more comprehensive understanding of the support needs of mothers with RA, so that they may be better supported to develop coping strategies and longer-term coping ‘resources’ to manage the impacts of RA alongside a parenting role.

7.2 Recommendations

7.2.1 Research

1. Further research exploring participants self-identified coping strategies through observations in a more naturalistic setting (mothers' homes).
2. Further research exploring supporters’ (family, friends, medical professionals) perceptions of mothers’ support needs.
3. Further research on self-reported coping strategies identifying what strategies mothers felt led to longer-term coping.

7.2.2 Practice

1. Advocate for further research exploring the emotional impacts and support needs of younger women and mothers with RA.
2. Advocate for the development of a social media network, in collaboration with arthritis organisations, that allows mothers with RA to connect, build supportive relationships and share stories and coping strategies.
3. Advocate to develop a mentor system for newly diagnosed mothers, similar to what is done by the Australian Breastfeeding Association (ABA), whereby mothers volunteer to operate a helpline and manage/host local support groups.
4. Advocate to develop interventions to “support the supporters” to be better equipped to appropriately and responsively support mothers with RA.

7.2.3 Policy

1. Advocate for the development of partnerships amongst arthritus organisations, key health professional associations (rheumatology, obstetrics, midwifery and community health) to share information and develop collaborative partnerships to better assist mothers with RA.
2. Advocate for collaboration to be developed amongst mothers with RA and key health professionals to inform community-based public health strategies to support not just mothers with RA, but also their supporters, including family, friends and health professionals.
Chapter 8: References


Chapter 9: Appendices

Appendix 1: Ethics approval

22 July 2016

Michelle Searle Director, Office of Research Tel: +61 7 5459 4574
Email: humanethics@usc.edu.au
F20750

Ms Shannyn Meloncelli Dr Jane Taylor
Dr Renee Barnes
University of the Sunshine Coast

Dear Researchers

Expedited ethics approval for amended research project: Exploring the day-to-day support needs and coping strategies of mothers with rheumatoid arthritis (RA).

This letter is to confirm that on 19 July 2016, the Chairperson of the Human Research Ethics Committee of the University of the Sunshine Coast granted expedited ethics approval for an amendment to the above project.

The amendment refers to:

1) a change of the project title to ‘Exploring the day-to-day support needs and coping strategies of mothers with rheumatoid arthritis (RA)’;
2) a change of supervisors from Professor Marion Gray and Dr Florin Oprescu to Dr Jane Taylor and Dr Renee Barnes;
3) a waiver of consent for the collection of Phase 1 pilot research data collected between May and November 2013;
4) the use of a revised version of the Low Risk Ethics Application Form including a revised project description, which no longer includes reference to the ‘filming of mothers with rheumatoid arthritis performing chores relating to looking after children and domestic duties, and the release of these films on You Tube and through other support organisations’ as per the amendment approved on 24 December 2014.

The conditions for ethics approval for this project as outlined in our original letter of approval continue to apply. If you have any queries in relation to this ethics approval or if you require further information please contact a Research Ethics Officer by email at humanethics@usc.edu.au or by telephone on +61 7 5459 4574 or 5430 2823.

Yours sincerely

Michelle Searle
Director, Office of Research

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*Figure 4. Links between higher order families of coping and adaptive processes. An asterisk indicates that that way of coping was considered to be a higher order category in Table 5.*
Appendix 3: Coping processes model (Skinner and Zimmer-Gembeck, 2007)

Figure 1
A model of coping as a multi-level adaptive system operating (a) as an adaptive process across developmental time, (b) as an episodic process across episodic time, and (c) as an interactional process across real time.
Appendix 4: Facebook online survey questions

Facebook online survey questions (2013)

Exploring the day-to-day support needs and coping strategies of mothers with rheumatoid arthritis (RA) (Ethics approval number S/13/501)

The questions included;

1. Who has best supported you on your RA journey? How have they better helped you to cope with having RA?

2. If you can cast your mind back to when you were first diagnosed what sort of intellectual/emotional/physical support do you think could have helped you transition better…as in accepting your diagnosis and moving on with life?

3. I am working on coping and resilience in my thesis today. Seeming as we have some new members I thought it may be cool to discuss ACCEPTANCE. If you have arrived at this tranquil town, how long your journey took and if it is a peaceful land with less pain?
Appendix 5: Participant information statements

Exploring the day-to-day support needs and coping strategies of mothers with rheumatoid arthritis (RA)  (Ethics approval number S/13/501)

Statement 1 2013 Phase 1 information

This message was ‘pinned’ (displayed) on the main pages of the two RA Facebook groups by the administrators of the groups for members to view.

It was communicated to members that if they wanted additional privacy they could personal message (PM) the lead researcher, Shannyn Meloncelli, on Facebook and be anonymous from the rest of the Facebook group.

Hi All. I have officially been given Ethics Approval by my uni (USC) (HREC: S/13/501) and I have cleared permission with admins to start asking questions. All responses will be anon. I can't and won't 'take' info from the site NOT relating to these questions. Please help out if you have a few moments as I think this research is really going to help us all...whether you are a mother or not. Thanks in advance for all your support. Gentle hugs.

Statement 2 2013 Facebook pilot research information

This message was also posted prior to the commencement of the research

Hello

As some of you may know I have undertaken a Master in Science with my research exploring the coping strategies and support needs of mothers with rheumatoid arthritis (RA). For those who don't know me I am a mother with RA. The purpose of this research is a positive one; to analyse and record how RA mothers cope, who supports them (us) and to inform allied health professionals. Additionally, a major focus will be to share coping and support mechanisms within a professional yet positive and informal forum. I hope you may have the time to answer questions I will be posting over the next two weeks.
Thanks in advance for your input and support. Please PM me if you have any other questions

Shannyn Meloncelli

Statement 3 2016 Phase 2 recruitment information

It is the primary researcher’s intention to ‘pin’ this message on the main pages of the two RA Facebook groups featured in Phase 1 of the research to recruit mothers for Phase 2.

I, as the lead researcher, have been researching the coping and support strategies of mothers with rheumatoid arthritis (RA) since 2013. Shortly ten mothers will be recruited from various RA Facebook groups to participate in phone interviews with the main topics of discussion being mothers coping strategies, support network and the use of Facebook for support. Conversational interviews will last between 30-40 minutes with the main purpose to give mothers a voice and to hear what their lives are like day-to-day coping with RA alongside a mothering role. You don’t have to be an active user of Facebook however you do have to have children and be willing to share your thoughts and feelings on how you cope and who supports you. Your identity will remain anonymous allowing you speak freely.

I am also a mother with RA and was diagnosed in 2010 three weeks before I had my first daughter, Amelie. I struggled to find information on how to cope and draw in support. After I had my second baby, Audrey, in 2012 I decided to undertake a research degree at the University of the Sunshine Coast (USC). The main aim of this research is to explore how different mothers cope and are supported to manage the impacts of having RA alongside a parenting role.

Please PM myself or admins (….. & …. ) if you are interested.

Thank you for your time

Shannyn Meloncelli

Master of Science candidate

University of the Sunshine Coast
### Appendix 6: Participant questionnaire

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<td><strong>Number of children and ages</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Length since diagnosis with RA</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Other auto-immune disorders</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Medicated/alternative treatment only, mixed treatment (alternative and traditional)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Availability (between Tues – Thurs)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>When given a chance to sit down and tell your story about being a mother with RA is there a particular idea or point you would like to express?</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Do you have a particular coping strategy or adaptation that you would like to demonstrate in your home that has made it easier to parent alongside managing the impacts of RA?</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Is there anything else you would like to tell us about being a mother with RA that is really important for other people to know?</strong></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 7: Research project information sheet (2015)

An exploration of how mothers with rheumatoid arthritis (RA) manage their parenting and domestic responsibilities. (S/13/501)

Research Team
Shannyn Meloncelli (Masters student), Gail Crimmins and Prof Marion Gray (Student supervisor)

Background
The aim of the research is to identify and record practical coping and support strategies employed by RA mothers and to give them a voice. The investigation, in particular, seeks to capture and re-present the resourcefulness of mothers with RA and demonstrate how they undertake specific parental responsibilities such as feeding and changing their babies. In addition, the project seeks to identify, acknowledge and share the practical strategies that mothers with RA devise and employ in order to carry out their domestic chores and responsibilities. The participants will volunteer to be involved in the project, in response to a local new item presented on Sunshine Coast FM (a local radio station). The participants of this study will be filmed whilst they carry out specific parenting and domestic tasks and will discuss to camera their practical management strategies and their rationale. The films will be available to the general public through YouTube and possibly other support organisations so that they can be used as a practical resource for other mothers with RA.

All participants will be provided with this Research Participant Information Sheet prior to the commencement of the interviews and will discuss the specific filming process with the project researchers. Participants will have access to film recordings before they are made public and will have the opportunity to withdraw any sections of film, or full films’ recordings, before they are made public. They will not need to offer a reason for withdrawing any footage from the public domain.

Research Significance and Purpose
Currently there is limited research that explores the coping and management strategies that mothers with RA create and employ. There is also a paucity of practical guidance as to how mothers with RA undertake parenting and domestic responsibilities.

Through discussions on closed Facebook sites with RA mothers and other members it appears their is also a lack of understanding of RA mothers’ lived experiences and performed practice. The intention of the research is to fill a gap in knowledge and to inform allied health professional practice and be of significant practical and emotional value to mothers with RA.

Newly diagnosed mothers have limited supportive literature outlining positive disease management and coping strategies. In particular, the research aims to inform and educate newly diagnosed mothers.
The research aims to document RA mothers’ experiences focusing on positive personal attributes such as resilience, coping, supportive relationships and life focus/sense of purpose, and how these attributes affect management of the issues associated with having RA. The project specifically aims to:

- Explore, demonstrate and describe resilience sources, coping strategies and support systems available for mothers with RA.
- Inform allied health professionals such as Rheumatologists, Occupational Therapists and GP’s of the lived experiences of RA mothers and the support strategies that they have devised to manage parenting and domestic responsibilities alongside managing the symptoms of RA.

**Participant Experience**

Participation in this study is voluntary and participants may withdraw at any stage, without explanation and there will be no consequences as a result. Participants may also withdraw the clips even after they have been made available through YouTube and support organisations.

Prior to the filming process participants will be sent a demographic survey to complete, which also contains questions that relate to health issues.

The filming will take place in the women’s homes at a time and date convenient to them. Participants can choose to have a supportive person to be present during the filming process.

Mothers will be recruited through radio interviews describing the project.

Practical parenting and housework demonstrations will be video-recorded with the option for participants to offer a discussion/interview to camera based on their practical coping and management practice.

**Duration**

Participants will be invited to volunteer approximately 2-4 hours once only. This time will be negotiable depending on the current wellness and availability of participants.

**Risks**

This research study has been identified as low risk. However, as a participant with health issues it is important to be aware of a need to cease filming or withdraw from the research at any time without penalty or the need of explanation.

Sensitive information about health issues will be requested in the initial survey. However, in the filming process participants will be asked to discuss and demonstrate only positive coping and management strategies that they have developed as a result of living with RA. It is likely that some participants will find this produces some discomfort.

Participants who experience negative emotional issues as a result of participating in this research are encouraged to discuss them with the researcher themselves. If participants do not feel comfortable with this option, BeyondBlue operates an anonymous phone counselling service 24 hours a day 7 days a week (1300 22 46 36) or by joining their online forums via www.beyondblue.org.au/get-involved
Results

Once the films have been viewed and accepted by the participants, the film clips will be uploaded into the public domain via YouTube. The findings will be used to acknowledge the lived experience and resilience of mothers with RA and to educate other mothers with RA how they may undertake certain parenting and domestic responsibilities. They will be used to establish how RA mothers cope and how they employ support mechanisms to manage a chronic illness while also caring for a family and home.

These findings will also be used to write a research thesis and are intended to be submitted to Qualitative Health Research online journals for the viewing of allied health professionals. Information may also be shared at conferences for medical professionals such as Rheumatologists.

Participants will have access to the film clips following their demonstrations and discussions allowing for changes to be made if participants feel their responses were inaccurately recorded. A one to two page summary outlining findings will be provided to participants following the completion of the research. Research information and transcriptions will be forwarded to participants via their designated email address or through written mail. Follow up phone calls, with the consent of the participants, will be conducted throughout the research.

Confidentiality

Data gathered during the study does identify you as a participant in order to acknowledge your resilience and coping strategies. You will be identified through the film clips on YouTube, and available to associations that support persons with RA. You can request to not have your name published. The information will also be used to inform future PhD studies of Shannyn Meloncelli.

Complaints

If you have any complaints about the way this research project is being conducted you can raise them with the Principal Researcher (Shannyn Meloncelli slm028@student.usc.edu.au) or Gail Crimmins (fgcirimmin@usc.edu.au), if you prefer an independent person, contact the Chairperson of the Human Research Ethics Committee at the University of the Sunshine Coast: (c/- the Research Ethics Officer, Office of Research, University of the Sunshine Coast, Maroochydore DC 4558; telephone (07) 5459 4574; email humanethics@usc.edu.au).

The Researchers and the University would like to thank you for your interest in this project and appreciate the effort involved.
Appendix 8: Recruitment press release

Media Release
x January 2015

For immediate release

Researchers seek mums with rheumatoid arthritis

Two University of the Sunshine Coast researchers have received funding to show how local mothers with rheumatoid arthritis are managing their illness, families and lives.

Master of Science student Shannyn Meloncelli, of Buderim, and Associate Lecturer in Communication Gail Crimmins will use the $x,000 USC Office of Engagement grant to produce three short films on the coping and support strategies of the women.

Ms Meloncelli was diagnosed with rheumatoid arthritis in 2009 when 36 weeks pregnant with her first daughter and is doing research at USC to turn her personal experience into professional practice.

She said the project aimed to help all mothers living with chronic health conditions.

“I hope we can help other mothers by showing what is possible,” she said. “Some days you’re exhausted and your joints are sore but I found little tips to conserve energy so I could better care for two babies under 18 months old.”

Ms Crimmins, who has a background in film and television casting, direction and production, said the films would be shot by a locally-based production company.

The researchers are seeking three local mothers with rheumatoid arthritis to discuss and demonstrate the adaptations they have made with everyday parenting and domestic responsibilities in the home.

Ms Meloncelli, who is also a USC graduate of Arts (Communication) and Education, said the project was designed to harness the knowledge and skills of the mothers and give them a voice.

For details email her on slm028@research.usc.edu.au

ENDS

For more information contact:
Media Relations, University of the Sunshine Coast
Ph: Julie Schomberg 5459 4553 or Terry Walsh 5430 1160
Email: jschomberg@usc.edu.au or terry.walsh@usc.edu.au

USC’s visitor safety information is available at:
Appendix 9: Participant consent form

CONSENT TO PARTICIPATE IN RESEARCH

Explore and document coping strategies and support mechanisms employed by mothers with rheumatoid arthritis (RA). (S/13/501)

I have read, understood and kept a copy of the Research Project Information Sheet for the above research project.

I realise that this research project will be carried out as described in the Research Project Information Sheet.

Any questions I have about this research project and my participation in it have been answered to my satisfaction.

I agree to participate in the research project researching the coping and support mechanisms of mothers with RA.

I give consent for data about my participation to be used for the purposes of this research project, and in future research projects.

Participant

Date