WHEN LIFE’S A PAIN: PERCEIVED STRESS AND PSYCHOSOCIAL FACTORS IN WOMEN WITH ARTHRITIS TRANSITIONING FROM MIDLIFE TO OLDER AGE

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A thesis submitted for the degree of Doctor of Philosophy (Gender and Health)

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August, 2013
Statement of Originality

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library**, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968.

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Melissa Harris

Date
Acknowledgements

You don't create your mission in life - you detect it ~ Viktor Frankl ~

I’d like to start by thanking everyone who played a role, whether big or small in facilitating the completion of this thesis, or has assisted in my professional growth over the period of my candidature. While this process has at times been difficult, I would not change it for the world. All of it has led me to this point. Thank you to the universe for conspiring in my favour. I would however like to make special mention of the following individuals or organisations that have made a significant contribution.

Anyways, you need people of intelligence on this sort of... mission... quest... thing
~ Pippin: The Lord of the Rings ~

Thank you to my supervision team, Associate Professor Deb Loxton and Professor Julie Byles from the Research Centre of Gender Health and Ageing at the University of Newcastle and Professor David Sibbritt from the Faculty of Health at The University of Technology, Sydney. I could not have done this without you. I look forward to our continued professional relationship beyond this PhD. Deb, I knew within the first five minutes of our initial meeting that I wanted you to be my Principal Supervisor and I haven’t looked back. Thanks for your guidance, kindness and understanding. Also, thanks for believing in my abilities long before I did. Julie, thank you for your continued support and providing advice at times when I have really needed it. Thank you for providing the leadership and environment that makes me proud to be associated with the Research Centre of Gender Health and Ageing. David, thanks for providing statistical advice and believing in my ability to conduct complex analyses. I have enjoyed watching your progression from Dr to Professor over the course of my candidature.

I’d also like to thank Professors Louise Newman and Lynne Parkinson who have assisted me during this process in honing my research skills. My experiences of working with you have been invaluable. Thank you to Dr Kerry Inder for providing advice and support and facilitating the award of a University of Newcastle scholarship in your role as Research Higher Degree Coordinator for the School of Medicine and Public Health. Thank you for employing me at a crucial point in my candidature that allowed me to complete this thesis and continue expanding my knowledge surrounding the role of psychosocial factors in chronic disease.

I’d also like to extend my gratitude to the late Professor Jill Cockburn whom I started the PhD journey with many years ago. Thank you for your dedication and friendship. I know you have had a serendipitous hand in a lot of things that have transpired during this period.
Acknowledgements

The bird a nest, the spider a web, man friendship. ~ William Blake ~

Thank you to everyone at the Research Centre of Gender Health and Ageing for your continued support. In particular, I’d like to thank my fellow students and kindred spirits Amy Anderson, Ashleigh Baker, Cath Chojenta, Ellie Gresham, and Jane Rich. Thank you for your unwavering support and providing moments of immense joy and laughter. This process would not have been the same without you. Thanks to my friends for understanding the importance of this process to me and being comfortable with hearing ‘no’ on a regular basis.

Turn your wounds into wisdom ~ Oprah Winfrey ~

Thank you to the women who have given their time over the past two decades to advancing knowledge in the area of women’s health by participating in the Australian Longitudinal Study on Women’s Health, funded by the Commonwealth Department of Health and Ageing. I would like to make special mention to the 19 women who gave up their time to tell their stories. As one participant indicated “everyone has a story, every woman has a story”. I hope I have done your stories justice.

Where there is great love, there are always miracles ~ Willa Cather ~

Lastly, I would like to thank my family who have lived this experience from the very beginning. Thank you for taking every step with me and not letting me give up. I’d like to acknowledge my late Nan Thelma, who once cleaned the university that I will graduate from. The significance of this achievement is not lost on me. To my favourite little boy Angel, thank you for sitting with me for hours as I wrote the majority of this thesis. You are the best! To my Mum and sister Belinda, you are my world. I love you with every fibre of my being. Thank you for your support; administrative assistance and listening to me talk through ideas. This thesis is for you.
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<tr>
<td>ACR</td>
<td>American College of Rheumatology</td>
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<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<tr>
<td>ALSWH</td>
<td>Australian Longitudinal Study on Women's Health</td>
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<tr>
<td>BMI</td>
<td>Body mass index</td>
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<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
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<tr>
<td>CI</td>
<td>Confidence interval</td>
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<td>GEE</td>
<td>Generalised Estimating Equation</td>
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<td>g/dl</td>
<td>Grams/decilitre</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<td>HPA</td>
<td>Hypothalamic-pituitary-adrenal</td>
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<td>HRQoL</td>
<td>Health-related quality of life</td>
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<td>HRT</td>
<td>Hormone replacement therapy</td>
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<td>Kg</td>
<td>Kilogram</td>
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<td>LOT-R</td>
<td>Life Orientation Test-revised</td>
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<td>m</td>
<td>Metre</td>
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<td>MET</td>
<td>Metabolic rate</td>
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<td>MRI</td>
<td>Magnetic resonance imaging</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<td>OA</td>
<td>Osteoarthritis</td>
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<td>OR</td>
<td>Odds ratio</td>
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<td>RA</td>
<td>Rheumatoid arthritis</td>
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<td>SAM</td>
<td>Sympathetic-adrenal-medullary</td>
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Abstract

Arthritis represents an ongoing public health challenge. This disease contributes substantially to global healthcare expenditure and is a major cause of disability, limited mobility and chronic pain. The overarching aim of this thesis was to examine the contribution of perceived stress and associated psychosocial factors to the burden of arthritis and disease onset in a cohort of women transitioning from midlife to older age. In order to achieve these aims, a multi-method approach was applied.

Women from the 1946-1951 cohort of the Australian Longitudinal Study on Women’s Health (ALSWH) provided the sampling frame for all analyses contained within this thesis. Specifically, the first study aimed to determine the relative importance of psychosocial factors in arthritis diagnosis. This study focused on 10,509 women who responded to questions on arthritis in the fifth survey of the ALSWH conducted in 2007. Findings from this analysis indicated that arthritis was characterised by widespread psychosocial concerns, particularly relating to chronic stress and poor mental health. Following the adjustment for behavioural, demographic and health-related characteristics, anxiety was the only psychosocial factor associated with arthritis (OR=1.4, 95% CI=1.2, 1.7; p<0.001).

The second quantitative analysis aimed to examine the role of perceived stress as a risk factor for arthritis development. This analysis focused on 12,202 women from the 1946-1951 cohort who completed at least one ALSWH survey in either 2001, 2004 or 2007. Longitudinal analyses were modelled using Generalised Estimating Equations, with and without a time lag. Findings from these analyses indicate that perceived stress is a strong risk factor for arthritis, with both minimal (OR=1.7, 95%CI=1.5, 2.0; p<0.001) and moderate/high (OR=2.4, 95%CI=2.0, 2.9; p<0.001) levels of perceived stress contributing to the onset of arthritis three years later.

In order to provide a holistic view, the psychosocial experience of women with arthritis was qualitatively explored. This method provided a complementary approach to the quantitative analyses and allowed for the expansion and clarification of pertinent issues...
and provided the scope to examine factors that were not able to be examined at an epidemiological level. In-depth semi-structured telephone interviews using a realist-oriented framework were conducted with a sub-sample of the 1946-1951 cohort (n=19).

The aim of the first qualitative analysis was to explore the lived psychosocial experience of women with arthritis paying particular attention to identifying and clarifying psychosocial challenges to, and resources that facilitate, the adjustment to arthritis, including coping perceptions. The findings indicated that the emotional burden of arthritis is considerable, and the process of psychological adjustment complex. Importantly, women transitioning from midlife to older age have psychological difficulties associated with pain and functional impairment. Coping with pain and limitation involved the implementation of a myriad of strategies including a strong focus on self-management. Psychological adjustment over time was attributed primarily to cognitive and attitudinal factors. This was a dynamic ‘day to day’ process involving a constant struggle between grieving physical losses and increasing dependence amidst symptom management.

The second qualitative analysis aimed to extend the quantitative findings regarding perceived stress by exploring the stress appraisal process. The findings indicate that while women transitioning from midlife to older age experienced stressful life events varying in intensity and chronicity over the life course, they attributed particular meanings to the experience of stress and its role in chronic disease. For participants, coping with stress appeared to involve both static attitudinal coping processes developed early in life, coupled with stressor-dependent cognitive and support-based responses. Coping with stress over the life course, however, was complex, with women describing a dualistic process involving both a reduction in the ability to cope with ongoing stress over time, coupled with a degree of personal growth.

The findings from this multi-method thesis add to the current understanding of the burden associated with arthritis and highlight the important role of psychosocial factors in this process, particularly for women as they transition from midlife to older age. Findings from this thesis also provide the most convincing evidence to date regarding the role of perceived stress in the onset of arthritis. These findings highlight the insufficiencies associated with viewing arthritis within a biomedical model, both in terms of pathophysiology and disease management and have implications for clinical interventions, public health education and policy.
Chapter 1

General Introduction

From psychology to biology: perceived stress and psychosocial factors in women with arthritis

1.1 Chronic disease: a public health concern

Chronic illness represents an ongoing public health challenge. Characterised by long-term development and persistent symptomatology, chronic conditions such as cardiovascular disease, cancer and diabetes contribute significantly to global healthcare expenditure and burden of disease in terms of health service use, hospitalisations as well as costs associated with treatment regimens [1-3]. Current estimates suggest that over half of adults report at least one chronic health condition [4,5]. When focused on individuals aged 65 and over this figure is approximately 80% [6]. For older adults, chronic conditions remain the leading cause of disability and contribute significantly to decreased quality of life [4,7-9]. Specifically within Australia, chronic illnesses are responsible for around 80% of the total burden due to illness and injury (measured in terms of disability-adjusted life years) [3]. In light of an ageing population trend this figure is likely to increase [10]. As such, the prevention and treatment of chronic disease has become a key priority for health policy makers [11-13].

Women in particular appear to be over-represented, with the prevalence of chronic health problems beginning to increase around the time of menopause [14]. This period of life has been described as a time of increasing psychosocial stress with women often experiencing increased responsibility associated with caring for ageing parents and grandchildren, coupled with maintaining their own parental roles, spousal responsibilities and work commitments [15-17]. This period has been highlighted as a critical life stage in which the intersection of biological, psychological and social spheres culminates in deleterious health-related effects [2].

---

1 The concept of disability-adjusted life years was developed as a measure of assessing the total burden of disease and injury in order to provide information to support health policy and determine priority setting at a global level. Disability-adjusted life years describe the amount of time lost due to both fatal and non-fatal events (i.e. years of life lost to premature death coupled with years of ‘healthy’ life lost due to disability [9].
1.2 Chronic disease and the paradigm shift

Chronic illness has traditionally been viewed within a biomedical framework based upon the 17th century notion of “Cartesian dualism” [18] which emphasises the disparate nature of mind and body. While this model of health and illness has been influential in facilitating attempts to understand disease pathology and current treatment regimes, Jung proposed that this separation of psychology and biology is “purely artificial” as the “human psyche lives in dissoluble union with the body” [19]. The current paradigm shift within the disciplines of medicine and public health involves a movement away from the mechanistic, reductionist perspective driven by the biomedical model to a ‘holistic’ model of health and illness. This notion was driven by the redefinition of health by the World Health Organization (WHO) which suggested that “health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” [20]. This approach applies a systems philosophy, with health and disease influenced by biological, psychological and social systems, thus acknowledging the active interaction between the individual and environment in the process [21]. In line with this thinking, Engel [22] proposed a biopsychosocial model which does not replace the biomedical model but expands upon it (see Figure 1.1).
While it is hypothesised that increased vulnerability and susceptibility to disease results from a decreased ability to respond physically [23], this process is complex and remains poorly understood in terms of its involvement in the development and progression of chronic disease over the life course. In the absence of a single genetic vulnerability, recent evidence suggests that this process is multifactorial and is under both genetic and environmental influence [24-26]. Thus, significant interest is being generated around understanding the complex interactions associated with gender, ageing and chronic disease [27].

1.3 The psychosocial influence

Considerable interest has been generated around understanding the role psychosocial factors may play in influencing disease trajectories including susceptibility, progression and adjustment. In addition to influencing health-related quality of life (HRQoL) [28-30], as well as disease progression and relapse [31-34], psychosocial factors have been related to mortality in some chronic conditions [35-37]. For instance, depression has been associated with reduced survival rates in individuals with cancer [38,39] and cardiovascular disease [40-43]. Psychosocial factors are also now beginning to be
considered in concert with traditional risk factors (e.g. overweight and obesity, poor nutrition and smoking) for the development of some chronic diseases including cardiovascular disease and type 2 diabetes [44-48]. Accordingly, research conducted at whole system and cellular levels have increasingly highlighted the role of psychological stress in the aetiology and progression of chronic disease [49-51].

1.4 The stress connection: an overview

The effects of psychological stress, conceptualised in terms of either a stimulus (noxious stimuli such as an interpersonal event) or a response (appraising the event as stressful) are becoming well-established [52]. Stress has been suggested as a contributor to illnesses such as coronary heart disease [53], diabetes [51], some cancers [54,55], disease risk and progression in human immunodeficiency virus (HIV) [50,56] as well as symptom expression in inflammatory diseases [57] and functional gastrointestinal disorders [58]. The role of psychological stress in the onset and course of disease has been highlighted as particularly pertinent to women, with research suggesting that women are exposed to a greater number of life stressors and have a tendency to perceive stressors as more stressful than men [59].

Conceptions of stress and its impact on health, particularly in terms of the aetiology and progression of disease have evolved considerably over time. The process of reintegrating psychology and biology was facilitated by the work of Cannon [60] who discovered consistent physiological activation of the sympathetic-adrenal-medullary (SAM) axis in response to acute stress in mammals. This primitive reflex, commonly referred to as ‘fight or flight’ was found to promote mobilisation of the organism’s energy resources including increased adrenaline, increased heart rate and redirection of blood to vital organs necessary for threat confrontation or escape. Coping with the threat in this instance was defined by physiological readjustment to homeostasis (i.e. equilibrium). Selye [61] expanded upon this single process model by implicating the pituitary gland in the adaptive phase of the adrenaline-driven response to a stressor. While this General Adaptive Syndrome model acknowledged the long-term cost associated with physiological adaptation, it posited that the readjustment to a given stressor was non-specific. Although these models of stress identified the underlying physiological processes elicited during the stress response, they failed to consider psychological processes involved in coping with a stressful situation (i.e. a stressor).
Current thinking surrounding the stress-chronic disease paradigm suggests that the role of psychological stress is complex and involves more than the simple physiological response to a negative stressor. Findings from previous research suggest that perceived stress is an important determinant of physical health problems and has been shown to be a better predictor of health-related outcomes than objective stressors [62,63].

Holmes and colleagues [64,65] proposed a socially-based stimulus model in which stress is defined as the adjustment or adaptation required by selected major life change events. Early iterations of this model viewed the individual as a passive recipient, with life change events deemed to be stressful regardless of the desirability of the event and as a result, required similar levels of readjustment. Later, the individual’s interpretation of the life event as positive or negative was incorporated in the level of adjustment required [66]. According to this model, cumulative life change events within a short period of time were believed to increase the individual’s vulnerability to illness. Other variants of this model include the role of minor stressors or daily hassles in compounding the effects of a major stressor. In the stressor-vulnerability model it is posited that major life events may sensitise the individual to the occurrence of, and negative amplification of minor stressors. While this model of stress acknowledges variation in the level of adjustment required in order to cope with various stressors, it fails to account for individual differences.

The Transactional Model of Stress and Coping by Lazarus and Folkman [67] on the other hand takes a more holistic view of stress and suggests that stress is a dynamic process involving a transaction between the person and the environment. This theoretical framework posits that the appraisal process is the primary mediator of this interaction. In particular, primary and secondary appraisals have been highlighted as key processes in this model. During primary appraisal the individual assesses the level of threat associated with the stressor. Once the event is perceived as stressful, secondary appraisal is invoked in which the individual determines what coping approaches are available to mitigate the threat. Lazarus and Folkman [67] proposed two distinct coping processes that are elicited in an attempt to ameliorate the impact of a stressor. These include emotion-focused and problem-focused approaches. Emotion-focused coping includes invoking strategies that are directed at regulating affect, while problem-focused coping involves attempts to minimise or resolve the impact of the stressor. Despite this, secondary appraisal is also contingent upon the individual’s belief system, vulnerabilities and resources. Throughout this process the individual is
continually evaluating, changing or relabelling primary and secondary appraisals in an
effort to reduce the effect of the stressor. As such, the chronic perception of stress in
the absence of perceived personal resources (i.e. demand exceeds the capacity to cope) has been highlighted as critical to the relationship between stress and illness. At
a cellular level, Epel and colleagues [49] noted that chronic perceived stress in women
was associated with key physical markers of cellular ageing, including higher oxidative
stress, lower telomerase activity and shortened telomere length. At an epidemiological
level, Strodl et al. [53] found perceived stress to be a significant and independent
predictor of new cases of coronary heart disease in older women. It must be noted that
Lazarus [68] suggested that this process is cyclical, with cognitions playing a key role
in causally determining outcomes and somatic outcomes influencing cognitions and
coping capacities.

The allostatic load model proposed by McEwen [69] has generated increased attention
as representing a true biopsychosocial model of illness. This model takes into account
the physiological consequences (i.e. cumulative wear and tear) associated with chronic
perceived stress. Chronic stress has been suggested to affect homeostatic structures,
set-points and processes that are designed to support physiological resilience via
dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis [70]. Chronic
glucocorticoid release or blunting is hypothesised to instigate a negative feedback loop
to the immune system, thereby increasing susceptibility to chronic disease [71]. Thus,
the allostatic load hypothesis incorporates aspects of the previously discussed models
and takes into account the physiological sequelae of prior stressor behaviour on
physical and mental health [see 72 for review].

1.5 The pain of arthritis

Arthritis is one of the most prevalent chronic conditions within Australia, affecting over
three million adults. The condition disproportionately affects women and when present
post-menopause is more debilitating in this population [73,74]. Arthritis and
musculoskeletal conditions were identified as the fourth largest contributor of direct
healthcare expenditure ($4 billion) in Australia during the period 2004-2005 [75]. Of
this, osteoarthritis (OA) and rheumatoid arthritis (RA), the most prevalent forms of the
disease, accounted for one-third of the cost. Arthritis has also been found to contribute
substantially to increased healthcare utilisation, with the disease the eighth most
frequently managed problem by Australian General Practitioners (GPs) [75]. Given the
global burden of these diseases, the period 2000-2010 was declared ‘the Bone and
Joint Decade’ in order to address the worldwide burden associated with arthritis. In particular, prevention and health promotion were highlighted by the United Nations, WHO, and more than 60 countries around the world [76].

With significant variability associated with arthritis disability, factors extraneous to the disease may contribute to the burden of arthritis, particularly for women. Despite the increasing body of research regarding the role of psychosocial factors, and in particular chronic stress in the aetiology and adjustment to chronic disease (as discussed above), limited epidemiological-based research exists regarding their role in arthritis, a major cause of chronic pain [77,78]. Researchers have speculated that psychological stress may be involved in the genesis of RA, however less is known about its role in the onset of OA (see Section 5.4 for further discussion).

1.6 Thesis overview

Taking a public health approach, the overarching aim of this thesis is to examine the role of perceived stress and psychosocial factors in women with arthritis. Following this chapter, the current literature surrounding arthritis will be discussed (Chapter 2). This chapter provides an overview of arthritis including diagnostic criteria associated with the most prevalent forms (OA and RA). The over-representation of arthritis among women will be discussed in detail and the literature concerning the contribution of psychological stress and psychosocial factors to disease aetiology and burden (including disease progression) will be explored within a biopsychosocial framework.

Chapter 3 will outline the methodological processes employed in the development and administration of the Australian Longitudinal Study on Women’s Health (ALSWH), a nationally representative project designed to assess various aspects of women’s health. This cohort study provided the data for the quantitative analyses located in Chapter 4 and Chapter 5 and the sampling frame for the qualitative research reported in Chapter 7 and Chapter 8.

Chapter 4 includes the major findings relating to the relative importance of psychosocial factors in arthritis for women from the 1946-1951 cohort of the ALSWH, while the role of perceived stress as a predictor in the onset of arthritis for these women is explored in Chapter 5. In each of the results chapters, an introduction to literature pertinent to the analysis will be provided, along with the methods employed, a presentation of the results, and a discussion of the findings within the broader context
of arthritis research. Components of these chapters have undergone the peer review process and have been published.

Chapter 6 will provide an overview of the qualitative research paradigm undertaken to build upon the quantitative results. The study aims, in conjunction with the protocol utilised in data collection and analysis, are also included. Chapter 7 will expand upon the findings from Chapter 4 by examining the lived psychosocial experience of women with arthritis. Additionally, Chapter 8 will extend the findings from Chapter 5 by focusing on the stress appraisal process, particularly in terms of the meanings attributed to stress, the processes involved in coping with stress and how the relationship between stress and health is perceived by women with arthritis. The final chapter (Chapter 9) provides a contextualised and integrated synthesis of the main thesis findings and discusses implications for clinical interventions and policy as well as directions for future research.
Chapter 2

Literature Review

The contribution of psychosocial factors to the onset and disease burden of arthritis in women

The introduction to this thesis (Chapter 1) has provided an overview of the influence of psychosocial factors, particularly psychological stress, on disease processes. Particularly, the deleterious effects of psychological stress on disease adaptation were highlighted. The growing body of evidence surrounding the role of psychological stress in disease aetiology was also discussed. Relevant to this discussion was the current public health challenge surrounding arthritis, a major contributor to chronic pain and disability. In light of the increasing personal, economic and societal burdens associated with this chronic disease, understanding the contribution of psychological stress and associated psychosocial factors to arthritis risk and disease burden is of major public health significance. The following chapter provides a review and critique of the current literature surrounding arthritis. Specifically, a description of the disorder, including diagnostic criteria for specific arthritis forms will be discussed. In addition, the over-representation of arthritis among women will be highlighted. Finally, the contribution of psychological stress and psychosocial factors to disease onset and the burden of arthritis will be explored within a biopsychosocial framework.

2.1 Arthritis: a heterogeneous disorder

‘Arthritis’ is a collective term used to describe a subset of diseases or conditions characterised by inflammation of tissues in or around a joint. Although the disorder denotes over 100 diverse diseases, OA and RA are the most prevalent forms [79]. Despite distinct and disparate diagnostic criteria in disease classification, these progressive and potentially debilitating disorders are commonly marked by pain, stiffness and swelling. The following review will primarily focus on research relating to these two conditions.

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2 The literature discussed in this chapter is based upon searches conducted in databases relevant to health and psychology, including MEDLINE, Psycinfo, CINAHL, Embase and the Cochrane library. Literature obtained from the databases was limited to peer reviewed human studies that were published in English between 2000 and 2012. The reference lists of all identified articles were hand searched for other relevant studies. Literature on arthritis from peak bodies including the Australian Institute of Health and Welfare, Arthritis Australia, The Centers for Disease Control and Prevention, and the World Health Organization were also searched. Returned citations, from all searches, were downloaded and combined into a single database using Endnote X4.
2.1.1 Disease classification and description

**Osteoarthritis**

OA is considered the most common of the arthritis forms [80-82], representing 60-70% of joint disease diagnoses [83]. The condition arises as a result of degradation of articular cartilage (i.e. fibrous connective tissue within the synovial joint) which is associated with hypertrophy (enlargement) of the bone through the development of marginal osteophytes and subchondral bone sclerosis, in conjunction with thickening of the joint capsule [82,84,85]. In some instances, these structural alterations are accompanied by subchondral cysts [83,86]. In addition to evidence of structural pathology, OA may be marked by the presence of clinical symptomatology, including joint pain, tenderness, crepitus (grating of the bone), joint effusion, localised non-systemic inflammation and joint deformity. Limitation in joint mobility and function, particularly upon waking or following periods of inactivity often ensues [84,87,88].

Although any joint may be affected by OA, it primarily affects weight-bearing joints such as the knee, hip and spine, with the neck, feet and hand regions also implicated [79,89]. Localised OA (confined to a single joint) most commonly affects the distal and proximal interphalangeal joints of the hand and is largely asymptomatic [90,91]. Conversely, generalised OA typically involves structural alterations to the hand in conjunction with degradation in at least one other major joint, most notably the joints of the knee or hip [92,93]. The presence of articular cartilage degradation in the weight-bearing joints is predominantly symptomatic, thus contributing to pain and functional limitation [90,91]. OA is regarded as a progressive disease and the expression of OA symptoms may vary over time and between individuals.

To date, diagnostic evaluation of OA has primarily relied upon radiographic (typically x-ray) changes to the joint structure for verification of disease presence and progression [94,95]. The Empire Rheumatism System described by Kellgren and Lawrence [96] in which the sequential appearance of joint space narrowing, osteophytes, subchondral sclerosis and subchondral cysts is used to denote the severity of OA [97]. This staged method of determination has been widely utilised in defining OA for the purposes of epidemiological research, however considerable discordance between radiographic evidence of OA and symptomatology have been noted [95,98-106]. Research has indicated that not all OA sufferers with radiographic evidence experience symptoms, and conversely not all individuals with symptomatic OA (consistent presence of pain in
and around the joint) have the presence of joint degradation \[95,107,108\]. This notion is supported by Hannan et al. \[95\] who found, in their cross-sectional analysis of nationally representative U.S. data (n=6,880 persons aged 25-74 years) that only half of patients with radiographic knee OA reported pain. Consequently, it has been asserted that the application of strict radiological criteria in arthritis case definition will lead to classification errors regarding individuals with early or mild disease \[87\].

In light of these findings, some researchers have included both radiographic evidence of OA and the presence of joint pain in order to define the disorder \[109-111\]. The use of clinical and radiographic evidence in classifying hand, knee and hip OA is currently endorsed by the American College of Rheumatology (ACR). Specific morphological changes and symptoms for clinical diagnosis are located in Appendix A (see Table A.1). Others [e.g. 112] are beginning to use techniques offering greater resolution and sensitivity to early structural pathology, such as magnetic resonance imaging (MRI) in order to define OA. While promising, this is still preliminary and as such a lack of validated consensus in identifying OA disease presence and progression currently exists \[113\].

**Rheumatoid arthritis**

RA is the second most commonly diagnosed form of arthritis. This chronic autoimmune disease is characterised by the progressive destruction of healthy synovium (joint lining) via thickening of the synovial membrane and over-production of synovial fluid \[79\]. This process plays a central role in the development of synovial inflammation and irreversible structural alterations to surrounding bone and articular cartilage. The course of RA may further be complicated by the development of subcutaneous nodules at pressure points, most notably within the proximal interphalangeal and metacarpophalangeal joints of the hands \[79,114\].

As RA is a systemic disorder, disease expression is often polyarticular (affecting three or more joints simultaneously) and the pattern of joint involvement has a propensity to be symmetrical \[79\]. Despite possessing the ability to cause inflammation or manifestations prominent in other autoimmune disorders including lung disease, pleurisy and vasculitis \[115\], RA typically affects the peripheral joints such as the hands, wrist and feet \[84\]. RA may also be accompanied by persistent or intermittent joint pain, joint stiffness, as well as warmth and redness of the affected area \[79,114\]. Importantly however, the clinical expression of RA is highly variable between
individuals and the course of RA may be marked by periods of exacerbations and remissions [79].

RA has the potential to result in severe disfigurement of the affected joint and damage to the surrounding tissue. Specifically, joint instability significantly contributes to deformities including subluxation (dislocation), deviation of the ulna (misalignment of the wrist), as well as swan necking and Z deformities (misalignment of the finger joints) [116,117]. Varus and valgus deformities (rubbing together) of the knees, eversion of the heel, as well as hallux valgus (overlapping) and misalignment (‘cock-up’) of the toes have also been noted as a consequence of RA [117,118].

While onset may be acute, radiological evidence of joint destruction in RA suggests that the onset and progression of the disease appears to be linear [119]. Goldbach-Mansky and Lipsky [120] found that radiographic evidence of joint destruction was apparent in 70% of cases within the first two years of presentation. Despite this, the identification and diagnosis of RA has proven difficult due to the lack of symptom and feature specificity early in disease onset compared to that of other self-limiting arthritis forms (e.g. OA, systemic lupus erythematosus) [121-123]. As such, significant disease progression and impairment may occur prior to diagnosis. Current diagnostic procedures for the classification of persistent RA rely upon clinical, immunological and radiological observations. The established ACR criteria [124] located in Appendix A (see Table A.2) remains the gold standard despite concerns regarding its specificity and sensitivity to the detection of early RA[^3] [122,126,127], particularly those relating to positive inflammatory markers (most notably, rheumatoid factor). More recently, MRI and ultrasound have been investigated as alternatives to x-ray in order to improve the detection of structural changes, particularly early in the disease process. These methods however, require further validation and refinement [120,122].

[^3]: The 1987 ACR classification criteria for RA was updated in September, 2010 [125] in order to address criticisms associated with the lack of sensitivity in detecting early disease. The new criteria focuses on identifying patients newly presenting with undifferentiated inflammatory synovitis, and factors that best discriminate between those at risk for persistent and/or erosive disease. Definite RA is classified as confirmed presence of synovitis in at least 1 joint, absence of an alternative diagnosis that better explains the synovitis, and achievement of a total score of 36 out of 10 in 4 domains: number and site of involved joints (score range 0-5); serologic abnormality (score range 0-3); elevated acute-phase response (score range 0-1); and symptom duration (2 levels; 0-1).
2.2 Women, arthritis and the transition from midlife to older age

With non-descript symptoms early in the disease course reflective of a number of arthritis forms, coupled with considerable conjecture regarding disease diagnosis, there is often a delay between symptom onset, diagnosis, and treatment [128-130]. Arthritis is therefore considered one of the most insidious, as well as pervasive, chronic conditions affecting middle-aged and older adults [131-133]. The following section describes the public health significance of the disease in terms of prevalence and incidence, with a particular focus on women.

2.2.1 Prevalence

Depending upon the case definition utilised (e.g. radiographic presentations, symptomatic, self-report or self-report doctor-diagnosed), estimates from epidemiological research suggest that the prevalence of some form of arthritis is in the vicinity of 20%. Findings from three waves of data of a nationally representative sample of non-institutionalised U.S. citizens (n=~30,000) estimate that 21.6% of individuals self-report doctor-diagnosed arthritis [134]. This figure was found to be relatively stable during the period 1989-2005 [134-136]. Data from the years 2007-2009 however, suggest that the prevalence of arthritis is increasing with 22.2% of individuals over the age of 18 affected [137]. Using a similar definition of arthritis (i.e. self-report doctor-diagnosed), the Centers for Disease Control and Prevention (CDC) suggest that the prevalence of arthritis could be even higher [138]. Using data from a representative state-level telephone survey, the authors found that the U.S. state median for self-reported arthritis was approximately 27.0%. However, in a cross-comparative population-based study between Canada and the U.S., Badley and Ansari [139] found self-reported professionally-diagnosed arthritis to be slightly lower when fibromyalgia is excluded from the analysis, with 18.7% of Americans and 16.9% of Canadians reporting arthritis.

Figures obtained from outside North America paint a similar picture with the prevalence of self-reported doctor-diagnosed arthritis in other population-based studies estimated at between 14.8% and 27.4% [77,140-143]. Specifically within Australia, the prevalence

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4 For the purposes of this thesis, the term “transition from midlife to older age” is used to describe a cohort of women that are no longer “middle-aged” (i.e. 45-50 years) but are not yet classified as “older aged” (>65 years). This is the period when the onset of arthritis increases.
of arthritis is estimated between 16.7% and 23.0% [77,141,142]. Knox and colleagues, [5] in their national study of GP activity found crude prevalence for arthritis to be 22.8%, with OA accounting for the majority of cases. Similarly, Hill et al. [142] found the prevalence of medically validated arthritis to be 22.1% in their representative population-based survey. A similar prevalence trend to North America [134,136,138,144] has been found in Australia with an increase in arthritis reported [77,141]. These findings indicate that almost four million Australians are currently affected by some form of arthritis.

When studies have focused on middle-aged and older adults, prevalence estimates for the presence of arthritis often approach or exceed 50% [144-146]. van Saase and colleagues [147] found radiological evidence of arthritis in three-quarters of Dutch individuals aged 60-70 years. Likewise, between 42% and 54% of Australians age 75 years and over have been found to have self-reported physician-diagnosed arthritis [77,141,146], with a peak prevalence rate of approximately 60% between the ages of 65 and 74 [77]. Disease specific prevalence estimates suggest that radiological signs of knee OA are present in 27% of individuals under the age of 70, with this figure increasing to 44% for individuals aged 80 and over [99]. Mannoni and colleagues [148] also reported that approximately one-third of Italian community-dwelling adults aged 65 and over were affected by symptomatic OA in one or more peripheral joints. In Australia, prevalence of OA has been reported at 4.2% for individuals aged 35-44, increasing to 11.1% for those aged 45-54, with a peak prevalence rate of 31.9% when aged 65-74 [77]. Haq and colleagues [149] present more conservative figures, suggesting that between 10% and 15% of individuals over the age of 60 have some degree of OA.

Additionally, between 0.3% and 1.6% of the worldwide adult population is affected by RA [150-159]. The prevalence of RA has also been shown to increase with age. In particular, 2% of individuals aged 60 and over have been found to have the disease [160]. Karsh et al. [161] have found the prevalence of RA in Canadian older persons to be even higher with an increase from 2.82% and 4.01% for men and women aged 35-49 to 7.88% and 9.67% respectively, for those aged 50 and over. This trend is paralleled within Australia with prevalence of RA increasing from 2.2% for those aged 35-44 to 3.3% for individuals aged 45-54 and peaking in prevalence at 8.2% for those aged 65-74 [77]. Although these figures are considerably higher than those reported elsewhere, they reflect the current consensus that arthritis prevalence is on the rise,
particularly among ageing populations. It is important to note that improved and changing diagnostic criteria may play a role in differing prevalence rates over time.

2.2.2 Incidence

As a result of the aforementioned issues regarding disease diagnosis and definition, estimating the incidence of arthritis has proven difficult. The number of new cases identified are dependent upon the definition utilised and thus will vary accordingly between studies [162]. Findings from studies involving OA and RA however, suggest that the incidence of arthritis intensifies with age, specifically after the age of 40 [163,164]. Findings from the U.S. suggest that age- and sex-standardised incidence rates for symptomatic hand, hip and knee OA are 100, 88 and 240 new cases per 100,000, respectively [164]. Examining symptomatic hip OA only, Wilson et al. [165] found disease incidence to be slightly lower, with 47.3/100,000 new cases per year. In this study, the authors also identified an incidence rate of 163.8 persons per 100,000 for the development of knee OA each year. With respect to RA, incidence as with prevalence appears to rise until the age of 70, after which it begins to decline [166]. RA has been found to develop during the child-bearing years [159], with peak onset identified between the ages of 55 and 64 in earlier studies and more recently between 65 and 74 [167,168]. Annual incidence rates of definite RA in the U.S. have been estimated between 21.6 and 48.0 cases per 100,000 [166]. More recent research suggests that in populations of northern European origin the incidence is between 20 and 300 cases per 100,000 persons [169]. To date, no Australian prospective population-based data exists. As a result, accurate worldwide incidence rates are difficult to establish.

2.2.3 Prevalence and incidence of arthritis among women

Relevant to the discussion on arthritis is the disproportionate prevalence of the disorder among women, particularly after the age of 50 [74,77,147]. Data from the 2004-2005 National Health Survey in Australia suggests that approximately 20% of women are affected by some form of arthritis compared to 17% of men. Within this report it was identified that 61.3% of individuals with OA and 57.1% with RA are women [77]. Similar findings have been reported in North America [139,144,145]. A Canadian study found that between the ages of 35 and 44, arthritis affected men and women relatively equally (4.3% for women vs. 3.3% for men). However, by age 45-54 the gender divide
in arthritis prevalence increased, with 22.0% of women and 12.3% of men affected by the disease. This gap increased substantially to 55.6% and 38.4%, respectively by age 75 [144]. Likewise, using nationally representative data of non-institutionalised U.S. adults aged 18 and over, the CDC [137] found age-adjusted arthritis prevalence to be higher among women (24.3% vs. 18.2%). Other factors such as lower education, obesity and smoking status (either current or former) were also implicated during this prevalence analysis.

Concerning specific arthritis forms, it has been found that women tend to report experiencing symptomatic OA at almost twice the rate of men when considering populations aged over 60 years [170]. Zhang and colleagues [171], using data from a U.S. state-based study, reported similar differences in prevalence rates of symptomatic and radiographic hand OA (26.2% for women and 13.4% for males) for individuals aged over 70 years. Thus, while men appear to have higher prevalence rates of OA in most joints prior to middle age, women are most affected after this point [172]. Based on the Australian Bureau of Statistics (ABS) National Health Survey data in Australia, it is estimated that around 27,000 new cases of radiological OA are diagnosed in women per year in comparison to 15,500 among men. Onset for the disease peaked at 14 cases per 1,000 head of population for women during the ages of 65-74, while for men, peak incidence did not occur until aged over 75 [79].

Sex-specific differences have also been identified with respect to RA. RA has been found to affect women at two to three times the rate of men [153,159]. When focused specifically on women, an Australian study noted that the prevalence of RA doubled between the ages of 35-44 and 45-54, reaching 4.3% and peaking at 9.2% when aged 65-74 [77]. Additionally, it has been found that when present in women they have more arthritis-associated disability than men, notably after the age of 45 [73,173,174]. These findings highlight the mounting public health burden associated with arthritis, particularly for women. With increased prevalence of the disorder beginning to emerge at middle age [145], an examination of arthritis during the transition from midlife to older age may be critical to understanding factors that contribute to disease risk and burden. However, there is currently a paucity of research focused on women at this significant life stage.
2.3 Arthritis development

While significant progress has been made regarding the understanding of particular aspects of arthritis, notably relating to disease progression (e.g. development of new treatment options, assessment of treatment efficacy), the pathogenesis of arthritis remains unclear. In the absence of a single genetic vulnerability, arthritis is viewed as a disease of multifactorial origin, with both genetic and environmental factors contributing to its occurrence and expression [151,169,175-186]. Consequently, prevention strategies have focused on identifying factors which place an individual at heightened risk for disease development [176,187]. This section highlights the current understanding surrounding non-modifiable and modifiable risk factors for OA and RA and posits a role for perceived stress in the aetiology of arthritis.

2.3.1 Non-modifiable risk factors

The onset of OA and RA has been attributed to a number of non-modifiable factors. The following outlines the key factors.

**Age**

Increasing age has been identified as the most consistent risk factor in arthritis development. Prevalence and incidence of OA has been found to increase with age for all joints, particularly after the age of 45 [80,164,188] (see Sections 2.2.1 and 2.2.2 for review). Radiological and autopsy studies suggest that joint changes consistent with OA can be found after the age of 30, however peak prevalence for the disease does not occur until 65-74 [77,80]. Prevalence and incidence for RA follows a similar ageing trend, although some studies suggest that peak prevalence for the disease appears one decade earlier than for OA [167].

**Gender**

Female gender has been identified as a risk factor for arthritis development. Women have an increased risk of developing (bilateral) knee, hand, and hip OA compared to men, particularly after menopause [94,97,172,189]. Likewise, women are two to three times more likely to develop RA, with increased incidence coinciding with the time of menopause [153,159](see Section 2.2.3).
Family history

Both RA and OA appear to have a strong genetic component [151,177,180,181,190]. Genetic factors have been found to account for at least 50% of cases of OA in the hands and hips, and a smaller percentage in the knees of women [181]. Children of parents with early onset OA or OA involving more than one joint have been found to have increased risk of developing the disease [191]. Findings from twin studies suggest that the genetic risk for RA is in the vicinity of 60%, with the leukocyte antigen region suggested as a contributing factor [186,192].

Female sex hormones

Female sex hormones, particularly oestrogen, have been implicated in the genesis of both OA and RA. In a prospective cohort study involving over 30,000 Iowa women (aged 55-69 at baseline), the risk of self-reported RA development (n=158; validated by medical record) at 11 year follow-up was reduced for women who had achieved menopause after the age of 51. This was compared to those who entered menopause prior to the age of 45. [193]. Likewise, an increased association between the risk of OA and hysterectomy or oophorectomy has been found [194,195]. However, others have failed to support this notion [196,197].

Inconsistent evidence exists to suggest that oestrogen therapies may confer a protective effect against RA and OA [167,198-204]. Longitudinal cohort studies, including the U.S. Women’s Health Initiative (the largest randomised, double-blind trial of hormone therapy in post-menopausal women aged 50-79 at the study’s inception) have provided support for a role of oestrogen in arthritis (n=26,321) [205]. Zhang and colleagues [206], using data (n=551) from a U.S. state-based study, identified a protective effect of hormone replacement therapy (HRT) use (following adjustment for age and other potential confounding factors) among women aged 63-91 (based on radiographic changes according to Kellgren/Lawrence scores). The greatest protection was noted for current users. In a cross-sectional analysis of 4,366 older women (aged 65 years and over) from an osteoporotic fracture cohort, Nevitt et al. [207], using radiographic and interview data, found a lower relative risk of hip OA for women who had taken HRT compared to those who had not. The protective effect was greatest for women who had long-term use (>10 years). Some studies, have reported contradictory findings, with oestrogen therapies suggested as a risk factor for disease onset [e.g. 208].
Congenital abnormalities

Congenital abnormalities, including congenital subluxation, Legg-Calve-Perthes disease and slipped capital femoral epiphysis have been associated with the onset of hip OA [82,209-211]. When the relationship between more common developmental abnormalities such as acetabular dysplasia, and hip OA are examined, the findings are less conclusive [212-216]. However, in a prospective analysis of 176 U.S. women aged 65 and over, radiographic evidence of abnormal centre-edge angle and acetabular dysplasia was associated with an increased risk of hip OA at eight year follow-up, following the adjustment for potential confounders [212].

Bone density

Increasing evidence from cross-sectional and longitudinal studies also suggests that knee, hip and hand OA may be associated with high bone mineral density [82,217-222]. Nevitt and colleagues [219], using data from a multi-centre U.S. prospective cohort study, found that women (n=4,855) aged 65 and over with moderate/severe hip OA (according to the Kellgren/Lawrence grading system) had higher bone mineral density at the femoral neck and wards triangle, trochanter, lumbar spine, distal radius and calcaneus compared to women with mild disease. Likewise, in a longitudinal study involving 473 U.S. women aged 63-91 (mean age=71 years), the risk of incident radiographic OA increased from 5.6% among women in the lowest age-specific quartile of bone mineral density, to between 10.3% and 14.2% for women in higher quartiles [217].

Ethnicity

While any person may develop arthritis, the prevalence of OA and the pattern of its involvement have been found to vary among ethnic groups. Asian populations have been found to have a reduced risk of developing hip and hand OA and an increased risk of radiographic and symptomatic knee OA compared to Caucasian populations [223-226]. Similarly, RA has been found to disproportionately affect Native American populations, with reduced risk associated with Asian and African heritage [227-229].

2.3.2 Modifiable risk factors
In addition to age, gender, ethnicity and family history (i.e. genetic predisposition), potentially modifiable risk factors for arthritis have been identified. The following highlights traditional and non-traditional risk factors that are potentially modifiable through intervention.

**Obesity**

Overweight and obesity have been identified as the most consistent modifiable risk factors for the development of OA, particularly in women [230-233]. Findings from cross-sectional and prospective studies suggest that obesity is associated with the onset and progression of OA in weight-bearing joints [94,176,187,188,233-235]. Although obesity may contribute to the onset of hip and hand OA [234,235], the strongest relationship has been found for knee OA. A U.S. study showed that obesity predicted the onset of symptomatic and asymptomatic knee OA in men and women up to 30 years prior to disease onset [236]. This relationship was found to be stronger for women than men. Further, an increase in body mass of 5kg has been found to increase the risk of knee OA by 36% [237], while a reduction in weight of the same amount in the preceding ten years has been found to reduce the incidence of knee OA by over 50% [230,238]. Meanwhile, around a 20-fold increase in the onset of knee OA has been found for individuals with a body mass index (BMI) in the upper quartile (i.e. morbid obesity) [230]. Similarly, population-based control studies have identified obesity as a risk factor for the onset and progression of RA [167,182]. In a retrospective population-based study (n=813) of Minnesota residents fulfilling 1987 ACR criteria for RA, Crowson and colleagues [239] found that during the period 1985-2007, the incidence of RA rose by 9.2 per 100,000 women, with obesity accounting for 52% of this increase.

**Joint trauma**

Individuals with a history of joint trauma, either as a result of direct damage to the articular cartilage (primary) or from excess stress on load-attenuating tissues (secondary), have been found to develop knee and hip OA [89,240-243]. Specific injuries associated with OA development include dislocation, contusion, fracture (particularly trans-articular), meniscal tears requiring meniscectomy and anterior cruciate ligament damage [82,243-246]. The relationship between joint injury and development of knee and hip OA has best been demonstrated through cross-sectional and case-control studies [230,231,247]. Using cross-sectional Framingham census-
tract data from 991 ambulatory adults aged 50-90 years (57% of which were women). Englund et al. [248] found the prevalence of meniscal damage (via MRI) to be higher in individuals with radiographic OA compared to those without the disease. However, this increased association was primarily found in relation to increasing severity of OA. Although the association between joint injury and OA onset has been more difficult to demonstrate in prospective studies, an increase in cumulative self-reported incidence of knee and hip OA by age 65 (median follow-up period=36 years) has been found in former U.S. medical students (n=1,321) reporting site specific injury during adolescence or early in adulthood [240]. However, the majority of this sample comprised males (91%).

**Physical activity/inactivity**

Physical inactivity has been indirectly implicated in the development of OA through obesity pathways [249]. Evidence also exists to suggest that excessive physical activity, particularly exercise which demands high intensity, contact with playing surfaces, equipment and other individuals (e.g. soccer, netball, and running); may contribute to joint trauma and increase risk of OA development in load-bearing joints [164,250-253]. McAlindon and colleagues [254], using data (n=473) from the population-based Framingham study found that highly physically active men and women (mean age=70.1 years) had a three-fold increase in the development of radiographic knee OA at eight year follow-up, compared to those with a sedentary lifestyle. Similar results have been found for the onset of hip OA, with physical activity levels for women prior to menopause implicated [255]. Athletes without a history of joint trauma or biomechanical joint abnormalities have been found to have similar OA risk to the general population [256]. Therefore, moderate recreational physical activity may provide a protective effect [94,257,258].

**Joint overload**

There is evidence to suggest that certain occupations that require repetitive joint movement place an individual at an increased risk of developing OA [259-263]. Specifically, occupations involving kneeling, squatting and stair climbing have been found to be associated with higher knee OA prevalence, while the onset of hip OA has been related to farming practices [82,241,260,262].
Socioeconomic status

The development of arthritis has also been inconsistently associated with lower socioeconomic status (SES) [142,264]. While it is suggested that SES may have a greater impact on disease progression [265,266], it may increase the risk of knee OA through physical inactivity and obesity pathways [113,267]. Hill and colleagues [142] found an inverse relationship between income and education and the prevalence of arthritis in their representative population-based survey of 3,001 South Australian men and women aged 15 and over. In this study SES (based on lifetime occupation using the Australian Standard Classification of Occupations) was correlated with traditional risk factors including obesity, age and gender. An inverse relationship between educational attainment (a proxy measure of SES) and incidence of RA has also been suggested [268,269]. A case-control study of 2,056 individuals aged 18-70 from a geographically defined area in Sweden, found that individuals without university qualifications were at an increased risk of RA development (based on 1987 ACR criteria) compared to those with a degree [268]. This finding was more pronounced for those testing positive for rheumatoid factor, particularly for women. Similar findings are supported by other case-control studies [269].

Tobacco smoking

Tobacco smoking has been found to be the most consistent modifiable risk factor associated with RA disease onset [178,179,270-274]. Smoking has been associated with the onset of RA in a number of cross-sectional and cohort studies. The association appears to be dose-dependent, with the duration of smoking more important than smoking intensity [151,178,182,271-273]. A U.S. population-based study of 103,818 female nurses aged 35-50 in 1976, demonstrated a linear relationship between smoking (measured in pack-years)\(^5\) and RA incidence at follow-up in 2002 (confirmed by survey and medical record) [272]. Heavy smokers (i.e. >40 pack-years) were found to be at twice the risk of disease development in comparison to individuals that had never smoked. Some studies, however, have found that smoking is a risk factor for RA development in certain subgroups only, namely those testing positive for rheumatoid factor and males [179,182,270,274,275]. Krishnan et al. [275] did not find an association between smoking (current or past) and RA onset in Finnish women classified as either rheumatoid factor positive or negative in their case-control study.

\(^5\) Pack-years is defined as the product of years of smoking and packs of cigarettes per day.
Sugiyama et al. [276], on the other hand, found a higher risk of RA incidence in men, as opposed to women, in their meta-analysis of observational studies. However, when heavy smokers were examined in isolation, no gender-specific association was noted.

Contrary to these findings, some studies have indicated that smoking may provide a protective effect against the development of OA [261,277,278]. Early studies on arthritis supporting this notion, including those involving the Framingham cohort, however were plagued by methodological concerns, particularly relating to the control population [231,277,279-281]. Others have found a reduction in Heberden’s nodes (for hand OA), but not radiological disease [278] or no association at all [282,283]. When risk factors such as BMI have been controlled for in prospective analyses, the protective effect of smoking on OA onset is nullified [279,284].

**Alcohol consumption**

Inconsistent evidence also exists regarding the protective effect of moderate alcohol consumption and the risk of RA development [285-287]. The protective effect of alcohol has been found to extend only to women in some studies [179,288]. However a Scandinavian matched case-control study of 3,052 men and women aged 18-70, found a dose-dependent inverse relationship between regular alcohol consumption and RA risk (according to ACR criteria) compared to non-drinkers. This finding was independent of gender and cyclic citrullinated peptide antibodies status [287]. Although these results support those focused on the inverse relationship between alcohol consumption and RA severity [289], much of the work surrounding alcohol and RA incidence has been examined cross-sectionally.

**Additional factors: muscle weakness, infection and nutritional factors**

Although less established as risk factors for arthritis, previous research has provided some support for the following factors. Muscle weakness has been implicated as a risk factor as well as a consequence of knee OA [290-292], while factors such as infection (e.g. Epstein-Barr virus, human parvovirus B19, cytomegalovirus, retrovirus and mycobacterium) have been suggested as a contributor to the onset of RA. Currently there is a lack of epidemiological or serological evidence to support this viewpoint [121,293]. Additionally, factors such as nutritional deficiencies (most notably vitamin D deficiencies) may be associated with the onset of arthritis however the evidence is
currently inconclusive [82,294,295]. Reduced serum and dietary levels of vitamin D have been associated with the onset and progression of hip OA [294,296,297]. A prospective cohort study of 29,368 Iowa women (aged 55-69 at baseline) has provided additional support for an inverse relationship between vitamin D intake and RA incidence (validated by medical records) at 11 year follow-up [298]. However, a U.S. prospective observational cohort study (n=556) of men and women (mean age=70.3 years) reported contrasting findings [294]. While a three-fold increase in risk of progressive knee OA was noted for participants in the lowest and middle tertiles for serum 25-hydroxyvitamin D compared to those in the highest tertile, vitamin D deficiency was not associated with disease incidence. Meanwhile, findings from a prospective osteoporosis cohort suggest that the association between vitamin D deficiency and arthritis onset may be dependent upon arthritis measurement [296]. In this study, a three-fold increase in the development of hip OA, defined by joint space narrowing, was found for older women (n=237) categorised as having middle or low serum 25-hydroxyvitamin D levels compared to those with high levels. When serum vitamin D levels were analysed in relation to the onset of hip OA, characterised by osteophytes or the Kellgren and Lawrence grading system, the association disappeared.

While arthritis remains incurable and considerable conjecture exists regarding its onset, identifying additional modifiable factors that contribute to increased risk is of public health significance. As a number of the previous factors have demonstrated importance in arthritis aetiology (and are endorsed by the National Arthritis and Musculoskeletal Advisory Group [299]), they will be considered as covariates in the analyses contained in this thesis (see Chapter 4 and Chapter 5).

Psychological stress

Research conducted at whole system and cellular levels have increasingly highlighted the role of psychological stress in the aetiology of chronic disease (see Chapter 1). Psychological stress has been suggested as a contributor to the onset of a number of illnesses including cardiovascular disease [300], cancer [54], and HIV [56]. Likewise, Epel and colleagues [49] have shown that chronic perceived stress in women is associated with key physical markers of cellular ageing, including oxidative stress, lower telomerase activity and shortened telomere length. Despite this increasing body of research, relatively little attention has been paid to understanding the role of psychological stress as a risk factor for arthritis onset.
When the relationship between psychological stress and arthritis risk has been addressed in epidemiological studies, it has primarily been examined in response to a specific life stressor (e.g. traumatic childhood histories) [301-303]. A retrospective analysis of data from ten countries participating in the World Mental Health Survey (n=18,309), noted that men and women’s (mean age=45.5 years) reporting of two or more childhood adversities, was associated with increased self-reporting of adult onset arthritis [303]. Likewise, in a sub-analysis of data from a Canadian representative community sample (n=11,108), it was found that after controlling for factors such as age, race, sex and SES, the experience of physical abuse was associated with a two-fold increase in being diagnosed with OA in adulthood [302]. The examination of perceived stress and psychosocial processes (that influence the stress process), with control for traditional risk factors has not previously been undertaken.

Qualitative research suggests that this relationship may be more complex. In a convenience sample of 20 Dutch women aged 55-75 years with generalised OA, it was found that of the women interviewed, all had described some sort of negative life event, particularly around gynaecological issues and difficulties with conception [304]. Others however, reported experiencing either a depressive episode or unhappiness at the time their arthritis symptoms first emerged. Further, while earlier retrospective studies have produced mixed results regarding the relationship between major life events and the onset of disease [305-312], there has been some support for an association between emotional trauma prior to disease onset in RA [313-315]. Marcenaro and colleagues [306] using clinical interviews, found that the contribution of major and minor life events to RA disease development (using ACR criteria) were comparable. Consequently, the authors proposed that the response to stress is individual, resulting from a perceived discrepancy between the person and their capacities to cope, independent of the objective experience. This finding, although from a small study (n=15), suggests that perceived stress may be a critical factor in the stress-chronic disease process.

In a prospective population-based study focused on the relationship between childhood trauma and the onset of self-reported medically diagnosed arthritis in Canadian men and women (n=9,159), perceived stress was found to have a significant confounding effect on this relationship. Particularly, chronic perceived stress conferred a similar risk to experiencing multiple childhood adversities [301]. While perceived stress may be a key risk factor in arthritis onset, these findings may reflect symptom expression as opposed to disease onset. It is important to gain an understanding of the role perceived stress may play in the onset of arthritis, particularly for women. The current study (see
Chapter 5) aims to address the gap in knowledge regarding the specific role of perceived stress in arthritis onset for women by addressing these methodological limitations in a representative sample of Australian women.

Coping with stress

According to transactional models of stress and coping (see Chapter 1), for stress to have a significant impact on physical health, the individual must first appraise the stressor as threatening or exceeding his or her adaptive resources [67]. While current perspectives on stress and illness acknowledge appraisal as responsible for initiating the stress response system either directly (i.e. physiologically) or indirectly (i.e. engagement in adverse health behaviours) to induce negative effects on physical health, limited research has focused on understanding the concept of stress and coping in relation to physical health in arthritis populations.

Previous research within stress and coping has indicated that the response to stress is highly individualised, with some individuals demonstrating resilience in the face of stress while others are highly vulnerable [316]. This individual variation has prompted the search for personal and social resources that may moderate the relationship between stressor exposure and stress perception [317]. Studies primarily focused on RA sub-populations have demonstrated that coping strategies employed by the individual may have a significant impact on psychological and physical disease-related outcomes [318-320]. Particularly, maladaptive coping efforts (generally referred to as passive, or emotion-focused coping) have been found to be associated with increased pain, disability and depression in comparison to those who employ active, problem-based coping strategies [318,321-324] (see Section 2.5 for further discussion). Garnefeski et al. [325] argued that cognitions are particularly important to coping with stress via their ability to manage or regulate emotions following the exposure to potentially stressful stimuli. Strategies that involve self-blame, rumination and catastrophising have been found to have differential effects than those involving acceptance and positive reappraisal of stressful circumstances [326], and may result in maladaptive adjustment. In addition, social support has been found to be particularly important to long-term physical health and psychological outcomes [327,328]. It has been posited that social support may have direct and moderating effects on the stress response in arthritis populations [329-333] and as such, influence health trajectories. Additionally, Sarason and Sarason [328] noted that the effectiveness of social support is dependent on the perceived adequacy between the type of support and its source.
Not all research however has found relationships between psychological mechanisms, social support and physical health outcomes [334].

With significant variability in the adjustment to stress being noted in arthritis studies, further research surrounding stress and appraisal processes are warranted in order to qualify these relationships. However, limited empirical evidence exists regarding the adjustment to non-disease specific stress in arthritis populations. In one study involving focus groups of Canadian men and women aged 45-78, stress was found to play a major role, with participants suggesting that it was “the biggest factor” in their lives. Non-arthritis specific coping efforts concerned either “just getting through the day”, or the participation in leisure-time activities in order to achieve “enjoyment” or “balance” [335]. An examination of daily stress, coping strategies, and social support resources amongst a convenience sample of 13 older adults (mean age=72.8 years), revealed that coping efforts to reduce the effects of stress were identified as either cognitive-based (e.g. prayer or faith-based coping), behavioural and social diversion-based activities (e.g. doing jigsaw puzzles) or assertive actions (e.g. directly addressing the problem by seeking a solution to talking to someone) [336]. Despite this, these studies were primarily focused on understanding arthritis-related stress and coping and do not provide insight into the meanings women attribute to stress, how they perceive events over the life course, the processes involved in the adjustment to stress, and how the relationship between stress and health is perceived. These factors may have particular implications for the role of perceived stress in the onset of arthritis however they are difficult to examine using current quantitative approaches. This thesis aims to address the gap in knowledge surrounding perceptions of non-arthritis related stress and coping practices in women with arthritis transitioning from midlife to older age.

2.4 Burden of arthritis

With substantial discordance between objective disease indicators (including radiographic evidence and joint inspection) and the severity of symptomatology [100-104], the burden of arthritis has been largely focused on reduced HRQoL indicators. The WHO defines HRQoL as physical, emotional and social aspects of life influenced by an individual’s disease and/or its treatment [337]. To date, a number of cross-sectional and longitudinal studies have highlighted the negative impact of arthritis on

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8 Non-arthritis related stress refers to aspects of the individual’s life that produces stress (e.g. life events) excluding stress associated with arthritis symptoms (e.g. pain) and physical limitation.
An Australian population-based survey found that individuals aged 15 and over with medically confirmed arthritis displayed broad dysfunction, with lower HRQoL scores reported across all eight of the Medical Outcomes Study Short Form-36 (SF-36) domains compared with individuals without the disease [142]. A cross-sectional analysis of data from a representative telephone survey (n=54,154) of non-institutionalised U.S. adults (aged 18 and over) identified significantly worse HRQoL outcomes for those with arthritis in terms of reporting fair or poor health. This was reported at three times the rate of those without the condition (23.8% vs. 7.3%) [342]. In addition, those with arthritis reported on average four more physically unhealthy days, as well as almost two and a half more mentally unhealthy days. In a study specifically focused on women, Hootman et al. [349] using data from a national probability sample of non-institutionalised U.S. citizens reported that women with arthritis averaged five more unhealthy days per month than women without arthritis. Thus, HRQoL outcomes may be critical to the disablement process in women with arthritis. The following sub-section will therefore provide an overview of the physical and psychosocial burden associated with arthritis, particularly in relation to women.

2.4.1 Physical burden

**Pain, functional impairment and disability**

Despite its slow development, arthritis is progressive in nature and eventually leads to joint destruction and significant loss of function [137,142,350-355]. The presence of pain and activity limitation (including those essential to the maintenance of daily activities such as walking, ascending and descending stairs, sitting and standing) have been identified as long-term indicators of functional disability in individuals with arthritis [356,357]. Findings from the CDC in the U.S. have indicated that one in three individuals with arthritis report activity limitations as a result of their condition [135]. In a 2007-2009 follow-up study of the in-person interview survey data (n= 72,905 for all three survey waves), it was found that of the estimated 49.9 million adults in the U.S. aged 18 and over who self-reported doctor-diagnosed arthritis, almost half (42.4%) also reported arthritis-associated activity limitations [137]. In a national probability sample of older adults (n=5,715) in the U.S., 19.7% of those with arthritis reported functional limitations, with 12.9% indicating at least one limitation in the performance of daily activities [351]. In addition, older women (aged 65 and over) were found to experience

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7 The eight domains of the SF-36 concern physical, mental and social functioning, general health, vitality, bodily pain and physical and emotional role limitations.
greater functional limitations than their age-equivalent male counterparts (22.0% vs. 15.5%). Importantly, more than one in seven women reported difficulties associated with the performance of at least one basic task, while 3.3% reported severe limitations.

Among 4,922 individuals (from a U.S. national probability sample) with incident functional limitations, functional ability declined by 13.6% within a two year follow-up period [351]. Functional deterioration was found to increase according to age, gender, and race/ethnicity. Women in particular were found to have an increase in odds of experiencing functional decline in comparison to men (OR=1.4, 95%CI=1.2, 1.7). This finding was consistent across all three age groups (65-74, 75-85, 85 and over).

Findings confined to OA populations have revealed that 80% of people experience limitations in movement, with 25% unable to perform major daily activities [113]. Further, approximately 10% of people aged over 60 are disabled as a result of the disease [163,358], with increased levels associated with concomitant disease [359,360]. Similar findings have been reported with respect to RA. Allaire et al. [361] indicated that while RA disability is usually considered moderate, 6.5-12% of individuals report being severely disabled. Evidence has been provided to suggest that functional decline develops early in the RA disease process and increases with disease duration [362,363]. Severe functional decline has been noted in 10% of individuals within two years, and up to half of persons with RA are work disabled within ten years of diagnosis [329,364-369]. Evers and colleagues [329,365] however, found in a small Dutch hospital outpatient sample (n<100), that RA may have an impact even earlier. The authors found that RA contributed to impaired functioning and increased pain symptomatology within the first year following diagnosis, with these findings comparable to those with long-standing illness. On the other hand, a Swedish prospective study of recent onset of RA (n=320), reported that although disease activity remained stable during the first two years, function slowly deteriorated, particularly in women [370]. Differences in findings may be related to the samples studied, follow-up periods or to the influence of factors extraneous to disease activity. Importantly, research conducted in OA and RA populations supports the notion of early development, worsening symptoms, and activity limitations over time. As such, arthritis-associated disability appears to be a significant issue for women, particularly as they age.
Physical comorbidity

The burden of arthritis is further complicated by disease comorbidity. In a retrospective assessment of 1,000 medical records relating to hip OA, Marks and Allegrante [359] found that over half of individuals (55%) had at least one cardiovascular or respiratory-related comorbidity and almost one-quarter had at least two. Only 10% of the sample studied reported no co-existing disease or disease history. This finding is supported within the RA literature. In a Canadian study of consecutive patients (>55 years) recruited from Rheumatology and GP clinics, Maetzel et al. [371] suggested that of the 23 specific comorbidities surveyed, patients with OA (n=191) reported an average of 3.5 (SD=2.1) additional chronic conditions, while those with RA (n=253) reported 3.1 (SD=2.0). In a systematic review of chronic disease in Australia, Caughey and colleagues [372] identified four studies that examined multimorbidity in arthritis [i.e. 339,373-375]. The overall findings suggested that over 70% of individuals with arthritis have concomitant cardiovascular disease (including hypertension). Cardiovascular diseases have been found to be the leading contributor to excess mortality in persons with RA, accounting for up to half of all RA-related deaths [376-383]. RA has also been associated with incident congestive heart failure [384] and myocardial infarction [385]. More specifically, women with RA appear to be at a heightened risk of myocardial infarction compared to women without RA [376,386]. In a prospective study containing over 100,000 women (aged 30-55 at baseline in 1976) it was found that women with RA (self-reported and confirmed by medical record) had an increased risk of myocardial infarction twice that of women without the disease over the 20 year study period. [376]. This figure increased for women with established disease greater than ten years. Despite, this, not all studies have demonstrated a gender bias in RA-associated cardiovascular mortality [383,387,388].

Individuals with arthritis have also been found to be at heightened risk for gastrointestinal morbidity and mortality [383,389-391]. In particular, current pharmacological approaches (including non-steroidal anti-inflammatory drugs and corticosteroids) have been found to place individuals with arthritis (notably RA), at heightened risk for gastrointestinal adverse events including bowel ischaemia, bleeding, ulceration, peptic ulcer and infection [392-400]. In a longitudinal analysis of consecutive U.S. rheumatology outpatients (n=1,221), it was found that the risk of hospitalisation as a result of gastrointestinal complications equated to 1.54 per 100 patient-years for both RA and OA [390]. Additionally, arthritis has been associated with diabetes [372,401] and osteoporosis [402,403]. However, in a nationally representative
non-institutionalised sample of U.S. adults aged 18 and over (n=9,282), Stang et al. [401] found that the most consistently significant comorbidities associated with arthritis were other chronic pain conditions (including back/neck pain, migraine, and other chronic headaches; ORs 2.1-3.9). Support has also been found for the comorbid association between OA and RA and other forms of arthritis and musculoskeletal conditions [404-409]. Specifically, Isik et al. [405] found in their small clinical sample (n=82) that secondary fibromyalgia was present in approximately 15% of RA patients, while Wolfe and Michaud [409] found the prevalence to be slightly higher (17.1%) in their large epidemiological study (n=11,866). Likewise, in a Canadian three year prospective study of individuals aged 55 and over (n=834), fibromyalgia was identified in 10.8% of individuals with moderate/severe hip or knee OA [404].

Individuals with RA have also been found to report other non-specific symptoms including disruptions in appetite and low grade fever. Additionally, RA and OA have been found to be accompanied by disturbances in sleep [79,114,410]. The experience of fatigue is also common to both conditions. Although the prevalence has varied according to the measurement used and level of active disease present, it has been suggested that between 13% and 93% of individuals with OA or RA experience fatigue [411-417]. When clinically significant levels of fatigue have been investigated, this figure approaches 50% [412]. Moreover, haematological manifestations have been found to be prominent in arthritis, particularly in RA sub-populations. The prevalence of mild anaemia in RA has ranged from 33-60% [418]. Wolfe and Michaud [419] found that mild anaemia (as defined by the WHO), was present in 31.5% of participants with RA, with lifetime prevalence being in the vicinity of 50% (58.3% for women). Importantly, in 11.1%, haemoglobin levels were below 11 g/dl and 3.4% of individuals were identified as having severe anaemia (defined as haemoglobin levels <10 g/dl).

The considerable comorbidity associated with arthritis may have substantial consequences on disease progression, functional disability and psychological adjustment. It is important to account for the impact of comorbid chronic conditions, particularly key diseases mentioned above, when considering the burden of arthritis.

2.4.2 Psychosocial burden

The pervasive nature of pain and limitation has a significant impact on not only physical but also psychosocial functioning. Verbrugge and Juarez [420] indicated that
individuals with arthritis are more likely to perceive themselves as 'disabled' compared to other chronic conditions. The following describes this impact.

**Psychological distress**

Psychological status, in particular, has been found to be a significant contributor to the burden associated with arthritis [421]. Analyses from a state-based telephone survey of non-institutionalised U.S. adults found that 13.4% of individuals aged 45 and over with self-reported arthritis experienced more than 14 unhealthy days per month. Likewise, a study of 238 Norwegian patients (mean age=52 years) with clinically diagnosed early RA (≤4 years duration) found that 20% had scores on the Arthritis Impact Measurement Scale indicating possible psychiatric disturbance [422]. Other studies have demonstrated that individuals with arthritis have around a two-to-three-fold increase in the odds of reporting depressive and anxiety symptoms compared to the general population [329,338,345,422-429]. However, the prevalence of mental distress in arthritis is dependent upon the populations studied and the measures utilised, with this figure exceeding 50% in some studies [430]. A ten year study of 6,153 consecutive RA outpatients (mean age=56 years at baseline) found that 20% fulfilled criteria for ‘probable’ depression, while 16.8% of individuals with OA of the knee or hip, and 14.3% with OA of the hand, were found to experience ‘probable’ mental distress [431]. On the other hand, slightly higher depression figures for men and women (mean age=61 years) with OA (according to ACR criteria) were reported in a German primary care sample (n=1,250; 19.4%) [432]. Dunlop et al. [433] using data from a population-based cohort of men and women aged 54-65 (n=7,825), have suggested that as much as 18% of experienced major depression may be attributed to having arthritis.

While anxiety has been less frequently studied in isolation from depression, current research suggests that between 21% and 70% of individuals with arthritis experience heightened levels of anxiety [426,427,429,430,434]. Where women are concerned, El-Miedany and El Rasheed [430] noted in their Egyptian outpatient study (n=80), that 63.4% of women with arthritis (mean age=41.45) experienced depression, while an even greater proportion reported anxiety (66.2%). Taken together, these findings suggest that affective disturbance may have important implications over the disease course. Depression, when present in its clinical form has been attributed to mortality in RA patients [435,436]. However, findings from a prospective study suggest that the prevalence or severity of depression in individuals with RA is not dissimilar to individuals with other chronic diseases [431] and as such may be related to reduced
HRQoL and not a function of the disease per se [431,437]. Further research is required to understand the psychosocial burden of arthritis within the context of disease severity, comorbidity, disability and other psychosocial factors. This thesis will aim to address this gap in knowledge by examining the psychosocial burden of arthritis within a comprehensive model, taking into account current health perceptions. This work will be extended by qualitatively exploring the psychosocial experiences of women with arthritis.

**Psychological status over time**

Despite the increased reporting of mental health problems in individuals with arthritis, longitudinal studies have found that the process of psychological adjustment is complex with considerable variability in findings. Some studies have found a reduction in emotional distress over time [438-440], while others have found that mental health remains relatively stable over the disease course [441,442]. A longitudinal analysis of data from 158 Swedish primary care patients (64% female) found that a latent effect may be associated with psychological adaptation in those newly diagnosed with RA. Improvements were not identified until the three year follow-up [440]. Meanwhile, in a three year prospective study of Hungarian and Austrian RA outpatients aged 40-75 years (n=118) it was found that compared to population norms, mild depressive symptoms were noted early in the RA disease process [443]. It has also been suggested that anxiety may present early in the disease course, with the onset of depression occurring later [444].

However, findings from qualitative research suggest that arthritis involves a spectrum of emotions ranging from frustration and annoyance to fear, anger, resentment, misery and helplessness [445-449]. In one U.S. study of older women (n=18) with OA (aged 65-92 years), arthritis was described as an ever-present and unwelcomed entity which dominated their attention. This feeling was likened to “wearing a heavy garment” [445]. An increase in depressive symptoms over time is supported by findings from a longitudinal analysis of consecutive RA patients (n=53) involved in a randomised controlled trial [450]. However, despite indicating an overall trend in the reduction of emotional distress over time, Persson et al. [440] has noted that a minority of participants consistently reported high levels of distress. In their longitudinal analysis of Swedish primary care patients (n=158), higher risk of distress was associated with younger age, female gender and a number of psychosocial factors including lower social support and higher distress at baseline. Similarly, Evers et al. [439] in a
longitudinal study of Dutch RA outpatients (n=78; predominantly female) noted that anxiety and depression at three and five years was associated with both disease-related stressors and psychosocial vulnerability, including neuroticism. While previous research has been largely RA-focused, the findings suggest that psychosocial factors may be pivotal in the adjustment process. Understanding additional psychosocial factors that may facilitate, or provide a barrier to adaptation in arthritis may provide avenues for intervention. Capturing the depth and breadth of emotion is difficult to achieve using quantitative approaches. Therefore, this thesis aims to address this issue by employing a qualitative approach to understanding the complex relationship between arthritis and mental health over time.

**Psychological stress**

Psychological stress may also play an important role in adjustment to arthritis, particularly for women. The following section provides an overview of the current understanding regarding the relationship between psychological stress and arthritis. For the purposes of this review a stimulus and process (or transactional) perspective will be taken regarding stress (see Section 1.4).

**Psychosocial stressors: the influence of major and minor events**

Arthritis is considered an unpredictable and chronic stressor that impacts substantially upon the individual. van Lankveld et al. [451] in a qualitative study of 14 Dutch rheumatology outpatients (mean age=55 years), found that perceived illness-related stressors such as physical limitations, pain and dependence on others were responsible for distress in middle-aged adults with RA. A content analysis of qualitative interview data from 77 older individuals (mean age=60 years) with long-term RA, found an increase in psychological distress associated with arthritis-related stressors such as physical limitations, pain and lack of control [452]. In addition, a content analysis of qualitative data from a U.S. convenience sample (n=13), revealed that stressors experienced by older adults with arthritis (mean age=72) concerned their health and loss of functional ability, in conjunction with family and social relationship issues [336].

The majority of research involving stress and arthritis has focused on the occurrence of major or minor negative life events in relation to symptom expression or psychological adaptation in RA [330,333,453-456]. In a predictive analysis of depressive symptoms in 1,227 Canadian men and women with hip and knee OA (mean age=75 years), almost
three-fifths of those surveyed reported experiencing at least one negative life event (excluding those related to sleeping or eating) within the previous 12 months [457]. Of the life events examined, major personal illness or injury was the most commonly reported stressful life event (25.9%), followed by serious illness or death of a close friend (18.3%), family member (16.6%), and spouse (11.3%). Additional findings from this study suggested that poor adjustment to OA (in terms of depressive symptomatology) was significantly and independently associated with female gender, experiencing greater disease-related symptoms (pain and fatigue), employing more coping behaviours, as well as receiving treatment for depression or another mental health disorder and low coping efficacy (the role of coping with arthritis will be discussed later in this section). A U.K. case-control study (n=38) found that RA patients (mean age= 41.9 years), meeting ACR criteria who experienced more chronic major and minor daily stressors over a six month period, experienced poorer mood [454]. On the other hand, in a U.K. longitudinal observational study (n=134) involving self-report and clinical data, it was noted that greater life stress impacted on the psychological well-being of RA outpatients over the course of the disease, with increases in anxiety levels noted six months later [453]. Additionally, in a sub-sample of recently diagnosed RA patients (n=54; mean age=56 years) from a Dutch population-based study, a significant correlation between the number of stressful life events experienced and anxiety was found. A trend towards significance was also noted for depression [330].

The findings surrounding the role of chronic minor and major interpersonal stressors in the functional adaptation to arthritis are less clear, with the majority of findings coming from cross-sectional analyses. As such, the findings have been inconsistent [333,455,456,458-461]. Findings from a clinical sample in the U.S. (n=59) found that following adjustment for disease severity and major life stress, minor stressful life events were positively correlated with (r=0.333, p<0.01), and accounted for a significant amount of the variance associated with RA inflammation levels [456]. Similarly, in a U.S. study involving clinical and self-report data (n=50), higher daily stress was found to be predictive of poorer outcome (including positive rheumatoid factor, increased swollen joints, and malaise), and significantly more radiographic erosions at five year follow-up [459]. However, a between-subjects assessment of 50 RA patients (meeting ACR criteria) from a U.S. prospective daily cohort study, failed to establish a link between daily life events (using a diary method) and disease activity (i.e. joint pain and inflammation after controlling for the effects of neuroticism). An expanded multivariate analysis (controlling for mood), provided support for the association between minor stressors experienced during the week preceding the
Literature Review: Contribution of psychosocial factors to the onset and disease burden of arthritis

Clinical exam and increased joint pain, as well as changes in soluble interleukin-2 receptors and joint inflammation [462].

Perceived stress in arthritis: an under-researched phenomenon

As highlighted in Chapter 1, the role of psychological stress on disease outcome is complex and may involve more than the simple physiological response to a negative stressor. Current approaches to understanding the role of stress in chronic disease such as the transactional theory of stress and coping and the allostatic load model [67,69] have acknowledged that the appraisal process may be more critical to the adjustment process. Thus, perceived stress may have a greater influence on chronic disease than the exposure to chronic stressors. Epel and colleagues [49] noted the influential role of perceived stress on cellular ageing (see Chapter 1). Specific findings related to the role of perceived stress in the course of arthritis are limited to a few small studies that are primarily cross-sectional and have mostly examined the relationship between stress and depression. However, in study of Irish women (n=59) with established RA (mean age=60 years) attending an outpatient clinic, it was found that perceived stress was associated with affective disturbance at one year follow-up [463]. Correlational and hierarchical regression analyses revealed that psychological stress was the best predictor of depression and was a better predictor than disease severity on measures of positive and negative emotionality. Treharne et al. [453] provide additional support for the significant impact of perceived stress on mental health outcomes in arthritis. In their longitudinal study involving 134 U.K. outpatients with RA, the authors found that perceived stress had the strongest relationship with psychological well-being at baseline and perceived stress had an impact on anxiety levels at six month follow-up. Moreover, coping resources had an impact on psychological adjustment in RA. Perceived stress in this instance was not related to inflammation, pain or functional disability levels.

Zautra and Smith [464] present contrasting results regarding the role of perceived stress in the physical adjustment to the disease. In their study involving 188 post-menopausal women (mean age=63.8) with RA and OA, the authors found that perceived stress relating to interpersonal domains was associated with increased pain sensitivity. Weekly pain reports in RA patients were predicted by perceived stress, depressive symptoms and an interaction between perceived stress and depression. For those with OA, weekly pain was predicted by independent associations of perceived stress and depression (i.e. no interaction). As such, perceived stress may be
a critical factor in the daily physical adjustment to arthritis in women as they age. Further, in a U.S. clinically-based prospective study, Zautra et al. [465] found elevated biological and clinical markers of disease activity in response to interpersonal stress (measured weekly) among 20 female patients with RA (mean age=53 years). Importantly, marital relationships were shown to reduce the vulnerability to those stressors. Moreover, Rios and Zautra [466] in a U.S. community sample (n=250; mean age=57.3 years) found that in conjunction with experiencing economic hardship, perceiving financial situations as more stressful was predictive of increased daily pain in women with OA and fibromyalgia.

Coupled with the fact that women have been found to perceive life as more stressful than their male counterparts [59] (see Chapter 1), and are more likely to report arthritis-related symptoms including joint pain, weakness and fatigue as more severe [467], perceived stress may play a key role in the burden of arthritis for women. Studies to date have generally focused on small RA sub-samples and have failed to consider various aspects of the stress process (including additional psychosocial factors that may facilitate the stress response; see Section 2.5) within the one model, thereby limiting the scope of their findings [468,469]. In addition, a lack of evidence regarding the role of stress in arthritis exists from representative samples and research outside North America. This thesis will aim to fill this gap in knowledge by assessing the contribution of perceived stress to arthritis within a comprehensive model, using data from a representative sample of Australian women. Additionally, the intricacies associated with stress and coping (which is difficult to assess using current coping inventories) in the context of arthritis burden will be examined using qualitative interview data.

2.5 Coping with the burden of arthritis

Studies primarily focused on RA sub-populations have consistently demonstrated that the coping processes employed by an individual in response to a stressful event have a significant impact on psychological and physical outcomes [318-320]. The following provides an overview of research that describes coping in arthritis.

2.5.1 Coping efforts
Coping with pain and limitations associated with arthritis is a complex process. Bombardier and colleagues [470] have suggested that the adjustment to chronic illness is dependent upon the individual’s coping responses more so than disease-related aspects. Within this type of research, coping efforts (or strategies) aimed at disease-related minimisation have been the most widely examined concept in arthritis populations [471-479]. Studies focused on RA sub-populations have consistently demonstrated that coping strategies employed by an individual in response to a stressor (e.g. pain) have a significant impact on psychological and physical health outcomes [318-320,322,323,480]. The majority of this research has generally concentrated on assessing the way individuals manage chronic pain according to the dichotomous problem-focused and emotion-focused approaches (or variants thereof, e.g. active vs. passive coping) proposed by Lazarus and Folkman [67] (see Chapter 1). Particularly, although Curtis et al. [469] found that perceived stress was associated with affective disturbance and was the best predictor of depression in 59 Irish RA outpatients, the use of avoidant coping efforts (i.e. efforts to distract from, or avoid the stressor) contributed to the prediction of negative affect. In this study, psychological stress did not explain the variability in either physical or social adjustment. Disease indicators and social support were found to contribute most to these respective indices. These findings were supported in a 12 month follow-up study of this cohort of women [463]. With regard to pain-specific coping, qualitative findings from a convenience sample of U.K. hospital patients (n=8), revealed that older adults (mean age=71 years) with RA used physical activity and distraction tactics (e.g. reading) [472].

Emotion or passive-based approaches to coping have generally been regarded as maladaptive. Snow-Turek and colleagues [481] indicated that passive, maladaptive coping approaches have qualities that outweigh the benefits of active coping. These approaches have been previously associated with increased arthritis pain, disability and depression in comparison to individuals who employ problem-based (or active) coping strategies [321-324,331,468,482,483]. This is particularly important for women. Affleck et al. [484], in a prospective 30-day diary study (n=147 from a larger community cohort), reported that women with RA and OA (mean age=~63 years) used more emotion-focused coping strategies each day than men, regardless of disease and pain level. Therefore, the way in which women approach coping with pain may have implications for adjustment to the disease.

While coping efforts have been suggested as key factors in developing a sense of control and mastery over chronic illness [485-488], coping research has often been
limited, particularly in arthritis populations, with its focus on problem vs. emotion-focused coping and implications regarding coping as an endpoint [489]. For instance, a U.S. qualitative study of 16 men and women with recent onset RA (mean age=50 years), found that although the coping strategies employed included both cognitive and behavioural methods, they were distinctly defined as either problem-focused approaches or not problem-focused approaches [471]. A Canadian longitudinal qualitative study involving three time points [448] found that older men and women with RA (n=39; mean age=75 years) used a variety of strategies (i.e. confrontive, palliative, supportant, fatalistic, self-reliant, evasive, optimistic and emotive) in order to cope. Meanwhile, Gignac and colleagues [478] using content analysis noted that Canadian community-dwelling older adults with OA (n=286) employed thirteen distinct behavioural efforts in order to adapt to their condition. These coping efforts concerning ‘selection’ (i.e. performing activities less often), ‘optimisation’ (i.e. augmenting or enriching reserves to enable continued functioning), ‘compensation’ (i.e. substituting activities) and ‘receiving help’ were integral to perceptions of dependence and facilitated psychological adjustment.

Further, in a narrative review of major and minor stress in rheumatic conditions, Herrmann et al. [490] noted that optimistic and confronting coping strategies were the most frequently identified and were perceived to be most effective in the face of stressors. On the other hand, a content analysis of 105 structured interviews, found that Hispanic women aged 19-86 years (mean age=50.6 years) with chronic musculoskeletal conditions used an average of 2.16 different types of coping strategies [491]. While the most common was the engagement in activities, other strategies including religion or prayer, cognitive strategies (e.g. distraction), seeking social support and positive reappraisal were noted. Another study utilising a narrative biographic approach, found that Austrian RA outpatients (n=10, 8 of which were women) described their experience as positive, with the disease seen as a challenge and facilitator of personal growth [492]. Others [e.g. 493] have suggested that adjusting to a chronic illness is a dynamic process, influenced not only by the disease but by the individual’s life circumstances and personal resources. Limited research exists regarding the coping practices of women as they transition from midlife to older age. As coping is a difficult concept to measure using a quantitative approach, a focus of this thesis is to explore in-depth the specific coping strategies these women employ in an effort to reduce the burden of arthritis, using a qualitative approach.

2.5.2 Social support
Social support has been found to have direct and moderating effects on the stress response in arthritis populations [329-333]. Social support can be defined as the existence or perceived availability of people who care about an individual and whom they can rely on when needed [494]. In a Dutch study of 229 randomly selected RA outpatients, the support of a spouse was found to be a significant predictor of depression and anxiety of individuals with RA (mean age=61.3 for men and 56.6 for women) [495]. Evers et al. [329] found that recently diagnosed Dutch RA outpatients (n=91; mean age=57 years) who had smaller networks (i.e. quantity of social support) experienced greater psychological maladjustment in their first year after diagnosis compared to those with a larger network. An analysis of data from an international longitudinal cohort study [496] found that RA patients (n=542) who received more social support (i.e. perceived satisfaction with support given) or had a larger social network had better functional and psychological adjustment over time. However, it has been argued that the perceived availability and quality of the support received is a more important factor in the appraisal of stress than the size of an individual’s network [497]. Perceived social support in particular has been found to be beneficial for both physical and psychological outcomes in arthritis [494,496,498-501]. Sherman and colleagues [498,500] found that perceived social support was associated with reduced depressive symptoms in older adults with OA. This finding is supported by Curtis and colleagues [469]. Although perceived stress was associated with affective disturbance in their study of Irish outpatients, the use of avoidant coping efforts also contributed to the prediction of negative affect. In this study, psychological stress did not explain variability in social adjustment, with social support found to contribute most to this index.

2.5.3 Personality and attitudinal-based coping

Personality-based characteristics have been found to influence the way in which individuals appraise a given situation and the selection of coping strategies (either adaptive or maladaptive) [502]. A longitudinal study of Dutch outpatients with early RA (n=78) found that neuroticism (i.e. the tendency to be relatively more tense and emotionally unstable) at diagnosis was the most consistent and effective predictor of increased psychological distress (depression and anxiety) at both three year and five year follow-up [439]. Further, Scheier and Carver [503,504] have posited that an optimistic life approach may play a protective role in chronic disease, facilitating the choice of disease-related coping strategies and engagement in health behaviours. Optimism has been positively associated with psychological well-being (both cross-
sectionally and prospectively) [505-507] and HRQoL [508-510] and inversely with symptom expression [498,511-513]. Additionally, it is suggested that individuals with an optimistic outlook employ problem-based coping in response to situations appraised as controllable, and emotion-based strategies aimed at harm minimisation in response to situations appraised as uncontrollable [503]. Similarly, a U.K. longitudinal study of 134 RA outpatients (predominantly women) identified pessimism as a predictor of increased anxiety at baseline and increased depression, anxiety, and decreased life satisfaction at six month follow-up [453]. Individuals who reported greater levels of optimism reported better adjustment in terms of anxiety at baseline and depression at one year follow-up. The authors argued that this finding suggests that pessimism and optimism may differ in their ability to attenuate stress over time, with optimism playing a greater role long-term. The current research aims to add to the arthritis literature by examining the role of personality and attitudes as coping resources in the adjustment to arthritis.

Coping with arthritis over time

Current knowledge regarding coping with arthritis has primarily relied upon information obtained from RA-focused studies concerned with specific pain-coping strategies. As discussed previously, Stamm and colleagues [492] using a narrative biographic approach found that individuals with RA (n=10) described their experience over time as positive, with the disease seen as a challenge and facilitator of personal growth. Others [e.g. 493] have suggested that adjusting to a chronic illness is a dynamic process, influenced not only by the disease but by the individual's life circumstances and personal resources. In this qualitative study of Norwegian RA outpatients (n=26) enrolled in an educational self-management trial, participants reported embarking on a process of redefining their reference for what constituted normal life after long periods of imbalance. This involved oscillating between “going on as usual” and “listening to their body”. It is currently unknown what processes underlie long-term coping with arthritis for those with OA, particularly for women transitioning from midlife to older age. While coping practices have been examined within arthritis, they have largely focused on cognitive coping in the form of coping checklists [457]. It is vital to understand what personal and psychological resources women perceive as important to coping with arthritis. With factors such as living a normal life and maintaining a sense of independence viewed as important treatment goals by individuals with arthritis [514], greater attention is required regarding the role of coping (such as attitudes, coping strategies and personal resources) in adjustment. This thesis will aim to fill this gap by assessing coping resources using a qualitative approach.
2.6 Summary and thesis aims

The primary aim of this chapter was to provide an overview of the evidence surrounding the role of psychosocial factors in the burden of arthritis and posit a potential role for perceived stress in arthritis onset for women. This literature which is heavily focused on RA studies conducted in North America and Europe has indicated that psychosocial factors may contribute to the burden associated with arthritis, particularly for women. However, Hawley and Wolfe [431] assert that this burden is not significantly different from other chronic diseases and as such may be a factor of reduced HRQoL and not a function of the disease [431,437]. It is essential to gain an understanding of how perceived stress and psychosocial processes may be associated with arthritis at an epidemiological level for women as they age, taking into account factors that influence psychosocial health, including traditional risk/protective factors and HRQoL indicators. This type of research has not been previously undertaken. The overarching aim of this thesis is to provide a holistic view of the arthritis experience for women transitioning from midlife to older age. Thus, the **first aim** of this thesis is to **determine the relative importance of psychosocial factors in arthritis diagnosis in a representative cohort of Australian women transitioning from midlife to older age** (see Chapter 4).

Additionally, this chapter provided an overview of currently accepted non-modifiable and modifiable risk factors for RA and OA. With psychological stress being considered in the onset of other chronic diseases and theoretical models of stress with biopsychosocial underpinnings hypothesising that perceived stress is a critical factor in the stress-chronic disease paradigm [67,69], it is important to gain an understanding of the role perceived stress may play in the onset of arthritis within a comprehensive model. The **second aim** of this thesis is to **examine longitudinally the relationship between perceived stress and arthritis in Australian women transitioning from midlife to older age, taking into account traditional risk/protective factors for arthritis and additional psychosocial processes that may influence the stress-chronic disease relationship** (see Chapter 5).

Moreover, psychosocial factors have been highlighted as significant to the adjustment to arthritis. Current knowledge regarding coping with arthritis has primarily relied upon information obtained from RA-focused studies concerned with specific pain-coping strategies. However, this process is complex. With factors such as living a normal life and maintaining a sense of independence viewed as important treatment goals by
individuals with arthritis [514], greater attention is required regarding the role of psychosocial processes including attitudes, coping efforts and personal resources in the long-term adjustment to arthritis. These factors are often difficult to measure using quantitative approaches. **Aim three** of this thesis will clarify and expand upon the findings from **aim 1**. Specifically, it will **examine the lived psychosocial experience of women with arthritis transitioning from midlife to older age, paying particular attention to identifying and clarifying the psychosocial challenges to, and resources that facilitate the adjustment process** (see Chapter 7).

Finally, it is important to understand how women with arthritis perceive stress, particularly in terms of the meanings attributed to stress, the context surrounding perceptions of life events, the processes involved in coping with stress and perceptions regarding the relationship between stress and health. With a lack of current research within the arthritis field focused on understanding (non-disease related) stress appraisal processes, the **fourth aim** of this thesis is to **qualitatively explore the stress appraisal process in a subset of Australian women with arthritis** (see Chapter 8). This will clarify and expand upon the findings resulting from **aim 2**.

With arthritis projected to affect upwards of 40% of women by the year 2050 [77,515], the identification of psychosocial factors that may influence the burden of disease and facilitate risk in an ‘at risk’ population, the findings from this thesis may have important implications for clinical interventions and policy. The following chapter outlines the methods associated with the ALSWH, a nationally representative cohort study of women that provided the sample for these analyses.
Chapter 3

Quantitative Methods

The Australian Longitudinal Study on Women’s Health

The following chapter describes the methodological processes employed in the development and administration of the ALSWH, a large-scale multidisciplinary project designed to assess various aspects of women’s health. This cohort study provided the data for the quantitative analyses presented in Chapter 4 and Chapter 5.

Specifically highlighted within this chapter is a synopsis of the research project and design, as well as the protocol utilised in data collection. Additionally, a description of the cohort is provided, with the specific survey measures and data analyses used in this thesis outlined. Likewise, concerns relating to ethical practices are addressed.

3.1 Overview of research project and design

The ALSWH project, is a longitudinal cohort study assessing physical, psychological, environmental, social and economic factors in Australian women aged 18–23 years, 45–50 years and 70–75 years (i.e. born 1973-1978, 1946-1951 and 1921-1926 respectively) at the time of the project’s inception in 1996.

Moving beyond a narrow medical focus of women’s health, the foundation for this study is to present women’s health within a social context, a notion which was born out of the 1989 Australian National Women’s Health Policy [516]. The project is funded by the Australian Government Department of Health and Ageing and data from the study are used to inform Australian Government policy on women’s health [517].

In excess of 42,000 women were recruited through the Health Insurance Commission’s (now known as Medicare Australia) Medicare database. Medicare is part of a nationally funded universal system of healthcare providing medical and public hospital care at minimal cost to the Australian community. This database was considered to contain the most accurate age, sex and contact details of Australian dwelling people. To ensure an adequate representation of Australian women, a stratified random sampling frame was
utilised with intentional oversampling of women from rural and remote areas (i.e. women from rural and remote areas were purposely sampled at twice the rate of women in metropolitan and regional areas) [518]. Variants of the self-report surveys are designed to be administered to each cohort at two-three year intervals (see Table 3.1 for data collection schedule), with issues pertinent to understanding the ageing process across the lifespan examined (e.g. pregnancy, menopause, retirement, and assistance with daily living). Methodological practices associated with the design and implementation of this longitudinal study have been extensively published in peer reviewed journals [e.g. 517,518,519,520,521], and are briefly described in Sections 3.3 and 3.4.

Table 3.1. Data collection schedule for the Australian Longitudinal Study on Women’s Health [522]

<table>
<thead>
<tr>
<th>Cohort</th>
<th>Survey 1</th>
<th>Survey 2</th>
<th>Survey 3</th>
<th>Survey 4</th>
<th>Survey 5</th>
<th>Survey 6</th>
<th>Survey 7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(18-23 yrs)</td>
<td>(22-27 yrs)</td>
<td>(25-30 yrs)</td>
<td>(28-33 yrs)</td>
<td>(31-36 yrs)</td>
<td>(34-39 yrs)</td>
<td>(37-42 yrs)</td>
</tr>
<tr>
<td></td>
<td>(45-50 yrs)</td>
<td>(47-52 yrs)</td>
<td>(50-55 yrs)</td>
<td>(53-58 yrs)</td>
<td>(56-61 yrs)</td>
<td>(59-64 yrs)</td>
<td>(62-67 yrs)</td>
</tr>
<tr>
<td></td>
<td>(70-75 yrs)</td>
<td>(73-78 yrs)</td>
<td>(76-81 yrs)</td>
<td>(79-84 yrs)</td>
<td>(82-87 yrs)</td>
<td>(85-90 yrs)</td>
<td>(88-93 yrs)</td>
</tr>
</tbody>
</table>

For the purposes of this thesis, the focus of this chapter will be limited to the 1946-1951 cohort who completed surveys in 1996 (baseline survey), 1998 (survey 2), 2001 (survey 3), 2004 (survey 4) and 2007 (survey 5).

3.2 Participants: the 1946-1951 cohort

3.2.1 Survey 1 (1996)

Based upon pilot study response rates, 28,000 women aged 45-50 years were randomly selected from the Australian Medicare database by Medicare Australia [518]. A total of 14,099 women with a mean age of 47.16 (SD=1.47) responded to the initial invitation to participate in this longitudinal study. Due to confidentiality restrictions, it was difficult to ascertain the exact response rate of this sample. After excluding women who were either uncontactable or deemed ineligible, the response rate was estimated at 53.5% [518] which was comparable to other large-scale longitudinal studies using similar protocols [e.g. 523]. This response rate was achieved despite statutory
restrictions which prevented researchers from employing methods in order to increase participation. For example, researchers did not have access to the names and addresses of potential participants. Follow-up procedures were limited to those conducted by Medicare Australia. Further, the chosen sampling frame also contributed to limited information being made available regarding women who declined to participate. Known reasons for declining participation are detailed in Table 3.2.
Table 3.2. Reasons given by women from the 1946-1951 cohort for declining initial invitation to participate [518]

<table>
<thead>
<tr>
<th>Reason given</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t want to do it</td>
<td>232</td>
</tr>
<tr>
<td>Not interested</td>
<td>282</td>
</tr>
<tr>
<td>Too busy/no time</td>
<td>137</td>
</tr>
<tr>
<td>Couldn’t be bothered</td>
<td>404</td>
</tr>
<tr>
<td>Husband rang to say she doesn’t want to do it</td>
<td>74</td>
</tr>
<tr>
<td>I can’t help you</td>
<td>24</td>
</tr>
<tr>
<td>No reason</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1,161</strong></td>
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</table>

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Invasion of privacy/health deemed own business</td>
<td>151</td>
</tr>
<tr>
<td>Questions too personal</td>
<td>165</td>
</tr>
<tr>
<td>Concerned about confidentiality</td>
<td>47</td>
</tr>
<tr>
<td>Not comfortable with idea/study</td>
<td>7</td>
</tr>
<tr>
<td>Medicare concerns</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>378</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Questionnaire issues</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Too many surveys/dislikes longitudinal nature</td>
<td>62</td>
</tr>
<tr>
<td>Doesn’t like surveys</td>
<td>87</td>
</tr>
<tr>
<td>Too long/too many questions</td>
<td>38</td>
</tr>
<tr>
<td>Too difficult/confusing/complicated</td>
<td>26</td>
</tr>
<tr>
<td>Questions are boring/pointless/irrelevant</td>
<td>58</td>
</tr>
<tr>
<td>Disapproves of sampling/reminder process</td>
<td>10</td>
</tr>
<tr>
<td>Waste of time/money/stupid idea/tore it up</td>
<td>30</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>311</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Personal issues</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal reasons</td>
<td>47</td>
</tr>
<tr>
<td>Too distressing/too many problems</td>
<td>26</td>
</tr>
<tr>
<td>Family reasons</td>
<td>30</td>
</tr>
<tr>
<td>Too healthy</td>
<td>25</td>
</tr>
<tr>
<td>Caring for husband/another person</td>
<td>11</td>
</tr>
<tr>
<td>Constantly moving/moving now</td>
<td>31</td>
</tr>
<tr>
<td>Spouse died recently</td>
<td>1</td>
</tr>
<tr>
<td>Wants to be paid</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>172</strong></td>
</tr>
</tbody>
</table>

**TOTAL**                                                                  **2,022**

Proportion of invited sample 7.2%

The sample of women was, however, shown to be largely representative of Australian women within this age group when compared with 1996 Australian National Census
data, despite a slight over-representation of Australian born, employed and tertiary educated women [524] (see Table 3.3). Details regarding the sociodemographic characteristics of respondents have been previously documented by Brown and colleagues [518,524].
Table 3.3. Sociodemographic characteristics for respondents from the 1946-1951 cohort in 1996 and women of the same age in the general population\textsuperscript{a}

<table>
<thead>
<tr>
<th></th>
<th>ALSWH Cohort</th>
<th>ABS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td><strong>Number</strong></td>
<td>14,072</td>
<td>734,155</td>
</tr>
<tr>
<td><strong>Main current employment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed full-time</td>
<td>36.1</td>
<td>36.0</td>
</tr>
<tr>
<td>Employed part-time</td>
<td>30.1</td>
<td>28.5</td>
</tr>
<tr>
<td>Worked (without pay)/employed (other)</td>
<td>7.0</td>
<td>2.0</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1.9</td>
<td>4.0</td>
</tr>
<tr>
<td>Total not in labor force</td>
<td>21.6</td>
<td>27.0</td>
</tr>
<tr>
<td>Not stated</td>
<td>3.3</td>
<td>2.5</td>
</tr>
<tr>
<td><strong>Highest qualification completed</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No post-school qualification</td>
<td>63.1</td>
<td>61.8</td>
</tr>
<tr>
<td>Trade/apprenticeship</td>
<td>3.5</td>
<td>7.0</td>
</tr>
<tr>
<td>Certificate/diploma</td>
<td>15.9</td>
<td>8.7</td>
</tr>
<tr>
<td>University degree</td>
<td>16.3</td>
<td>11.6</td>
</tr>
<tr>
<td>Other (not stated, inadequately described)</td>
<td>1.2</td>
<td>10.8</td>
</tr>
<tr>
<td><strong>Aboriginal/Torres Strait Islander</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-indigenous</td>
<td>98.1</td>
<td>96.7</td>
</tr>
<tr>
<td>Aboriginal or Torres Strait Islander</td>
<td>0.8</td>
<td>1.1</td>
</tr>
<tr>
<td>Not stated</td>
<td>1.1</td>
<td>2.1</td>
</tr>
<tr>
<td><strong>Country of birth</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>69.0</td>
<td>62.6</td>
</tr>
<tr>
<td>Other English speaking</td>
<td>13.9</td>
<td>11.6</td>
</tr>
<tr>
<td>Other European</td>
<td>8.7</td>
<td>11.0</td>
</tr>
<tr>
<td>Asia</td>
<td>4.3</td>
<td>8.2</td>
</tr>
<tr>
<td>Other/not stated</td>
<td>4.2</td>
<td>6.5</td>
</tr>
<tr>
<td><strong>Present marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>75.1</td>
<td>73.0</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>13.2</td>
<td>18.7</td>
</tr>
<tr>
<td>Widowed</td>
<td>2.1</td>
<td>2.7</td>
</tr>
<tr>
<td>Never married</td>
<td>3.9</td>
<td>5.6</td>
</tr>
<tr>
<td>De facto (not collected by ABS)</td>
<td>5.7</td>
<td>------</td>
</tr>
<tr>
<td><strong>Present housing situation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>House</td>
<td>84.7</td>
<td>89.2</td>
</tr>
<tr>
<td>Flat/apartment</td>
<td>7.1</td>
<td>6.5</td>
</tr>
<tr>
<td>Other</td>
<td>8.2</td>
<td>4.3</td>
</tr>
</tbody>
</table>

\textsuperscript{a} as measured by the Australian Bureau of Statistics (ABS)

\textsuperscript{b} at the time of publication a total of 14,072 women had returned completed surveys
3.2.2 Survey 2 (1998)

Of the women who completed the baseline survey (n=14,099) in 1996 it was found that 384 had failed to provide contact information necessary for continuance in the ALSWH and were thus lost to follow-up. As a consequence, a total of 13,715 women were considered eligible for inclusion in the longitudinal study.

During the two year period between surveys 1 and 2, 57 women were deemed ineligible as a result of death (n=50) or incapacity (n=7) and a further 53 women had withdrawn from the study prior to 1998. Additionally, 155 women withdrew from the study following receipt of the second survey, while other non-respondents were either non-contactable (n=858), or were followed-up but failed to return the survey (n=254). These results are highlighted in Table 3.4.

Of the potential longitudinal study participants (n=13,606), 12,338 (90.7%) women aged between 47 and 52 returned completed surveys in 1998. The women in this sample had a mean age of 49.10 (SD=1.46) years and were sociodemographically similar to respondents in the original survey. However, non-respondents to survey 2 were more likely to have previously reported being born outside of Australia, possessing less education, being separated or divorced and a current smoker [520,525].

3.2.3 Survey 3 (2001)

A total of 11,200 women completed and returned the subsequent 2001 survey. The sample, now aged between 50 and 55, had a mean age of 52.08 (SD=1.45) and responded at a rate of 84.3% of the eligible sample from the prior survey (n=13,310). During the three year follow-up period it was noted that a further 295 participants had become ineligible to continue with the longitudinal study through death, incapacitation or withdrawal from the study. Furthermore, 2,084 women failed to respond to the survey due to a variety of reasons (see Table 3.4 for details).

Data obtained from the women at this time point was again compared with the Australian National Census of the same year [526] in order to assess the representativeness of the women remaining in the ALSWH. This comparison revealed that women who remained a part of the longitudinal project were sociodemographically
consistent with those of the initial census comparison conducted with the 1996 baseline questionnaire.

### 3.2.4 Survey 4 (2004)

At the time of the completion of the fourth survey in 2004, 10,905 women with a mean age of 55.04 (SD=1.45) returned completed questionnaires. At this survey the rate of attrition remained relatively stable with 84% of eligible women being retained.

A greater proportion of women were lost to follow-up through prior withdrawal from the study (n=229) and death (n=88) than with the previous survey, while the number of women withdrawing due to frailty (e.g. from a stroke) remained constant (n=14). Conversely, as indicated in Table 3.4, the rate of non-response from women decreased slightly from the previous survey with the majority of these being women whom the research team had lost contact with (n=1,052). Moreover, the subset of women who remained in the ALSWH and completed survey 4 showed similar sociodemographic profiles as the women from the three previous surveys and remained largely representative of the Australian female population within this age range [527].

### 3.2.5 Survey 5 (2007)

A total of 10,638 women with a mean age of 58.49 (SD=1.49) returned completed surveys in 2007. In line with the previous two surveys administered in 2001 and 2004, the response rate was relatively consistent with 83.8% of eligible women returning the fifth survey. During the three year follow-up period, however, it was noted that a greater number of women became ineligible through either death (n=99) or incapacitation (n=19) than in any of the previous four study periods (see Table 3.4).

Additionally, although the number of participants who failed to respond to the survey was slightly lower than in the previous 2004 survey (2,056 vs. 2,074 respectively), a greater number of women either withdrew from the study following receipt of the survey (n=226) or were contacted but failed to complete the questionnaire (n=995) than in all previous surveys. However, the women who remained in the longitudinal study were sociodemographically similar to the original cohort recruited in 1996. Likewise, in comparison to 2006 Australian Census data these women were shown to be largely representative of Australian women within this age bracket, despite a slight over-representation of Australian born, tertiary educated and married women. [527].
Table 3.4. Longitudinal retention rates and participation among women from the 1946-1951 cohort

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>M(SD) age in years</td>
<td>49.10 (1.46)</td>
<td>52.08 (1.45)</td>
<td>55.04 (1.45)</td>
<td>58.49 (1.46)</td>
</tr>
<tr>
<td>Failed to provide contact details for longitudinal follow-up</td>
<td>384</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Eligible at previous survey</td>
<td>13,715</td>
<td>13,605</td>
<td>13,310</td>
<td>12,979</td>
</tr>
<tr>
<td>Ineligible</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deceased between surveys</td>
<td>50</td>
<td>65</td>
<td>88</td>
<td>99</td>
</tr>
<tr>
<td>Frailty or incapacitation (e.g. stroke, dementia)</td>
<td>7</td>
<td>14</td>
<td>14</td>
<td>19</td>
</tr>
<tr>
<td>Withdrew from project prior to survey date</td>
<td>53</td>
<td>216</td>
<td>229</td>
<td>167</td>
</tr>
<tr>
<td>Total ineligible</td>
<td>110</td>
<td>295</td>
<td>331</td>
<td>285</td>
</tr>
<tr>
<td>Eligible at current survey</td>
<td>13,605</td>
<td>13,110</td>
<td>12,978</td>
<td>12,694</td>
</tr>
<tr>
<td>Non-respondents</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Withdrew from project after receipt of survey</td>
<td>155</td>
<td>155</td>
<td>136</td>
<td>226</td>
</tr>
<tr>
<td>Contacted but failed to complete survey</td>
<td>254</td>
<td>998</td>
<td>886</td>
<td>995</td>
</tr>
<tr>
<td>Uncontactable</td>
<td>858</td>
<td>931</td>
<td>1,052</td>
<td>835</td>
</tr>
<tr>
<td>Total non-respondents</td>
<td>1,268</td>
<td>2,084</td>
<td>2,074</td>
<td>2,056</td>
</tr>
<tr>
<td>Respondents of survey</td>
<td>12,338</td>
<td>11,200</td>
<td>10,905</td>
<td>10,638</td>
</tr>
<tr>
<td>Retention rate of eligible respondents (%)</td>
<td>90.7%</td>
<td>84.3%</td>
<td>84.0%</td>
<td>83.8%</td>
</tr>
</tbody>
</table>

*Means and standard deviations are reported.

3.3 Procedures

3.3.1 Survey 1

Medicare Australia, on behalf of the ALSWH research team, distributed a postal survey package to Australian women randomly selected from its database. Phase one of the mailing protocol was based upon the methods employed by Dillman [528] which have been found to maximise response rates for mailed surveys [519]. Due to confidentiality...
restrictions recruitment was based solely on mailed materials and the process was modified accordingly.

The women representative of the 1946-1951 cohort were issued an invitation to participate in a longitudinal study regarding women’s health in April, 1996. As an adjunct to the introductory letter, the package also contained an information brochure, a consent form, 24 page questionnaire and a reply paid envelope. The women were asked to complete and return the primarily quantitative questionnaire and signed consent form within the supplied envelope. At this time, a free call number was established. This service provided women with additional project-related information and allowed them to complete the questionnaire by phone in a variety of languages or decline participation.

All women were forwarded a thank you card one week following the initial administration period. The card also served as a reminder for women who had not as yet responded to the invitation. In the ensuing two weeks, women who had completed the questionnaire by mail or telephone, as well as those who had declined participation or were “uncontactable” were removed from the mailing list [518].

Phase two of the protocol initiated one week following the collation of participation information involved the dissemination of replacement packages to women remaining on the mailing list, with a final reminder card posted four weeks later (phase three) to women still unresponsive. Data collection of the baseline survey remained active until September, 1996.

As a result of the statutory restrictions associated with the sampling frame, during the time period prior to the collection of data, the project was widely publicised through cohort appropriate mass media (e.g. radio, television, magazines and newspapers) thereby raising community awareness regarding the significance of the project to potential respondents.

3.3.2 Survey 2

The protocol established for the circulation of the first of the follow-up surveys was comparable to that of the original questionnaire, with the exception of the involvement from Medicare Australia. The package on this occasion contained the 24 page booklet in conjunction with a letter of invitation and a consent form in order for data linkage
between the current and 1996 surveys to occur. This time however, the consent form contained a space on the reverse side in order to provide information regarding a secondary contact so that participants could be tracked if they changed residence within the study period.

Preservation of contact with the cohort during this period also involved the issuing of yearly newsletters detailing the progress and nature of study findings as well as continual media coverage regarding the significance of the project. The protocol established in order to maintain and trace participants enrolled in the longitudinal study have been described in detail [520,529,530].

Follow-up questionnaire packages were dispatched during the beginning of March 1998 with thank you and reminder cards distributed one week later to women remaining in the participant pool. Additional reminder cards were distributed towards the end of April to women who had still failed to return completed surveys. However, contrary to the methods employed during phase three of the data collection process in 1996, the research team attempted to pursue non-respondents via telephone. This process was undertaken almost two months after the initial survey mail out, with data collection finalised by the end of June, 1998.

3.3.3 Survey 3

The distribution of survey 3 paralleled that of survey 2. Initial questionnaire packages including the 28 page booklet, letter of invitation, change of details card and reply paid envelope were distributed in mid-March, 2001. Thank you and reminder cards were mailed one week later to the entire cohort with the exclusion of women who had previously withdrawn from the study. In a similar vein to the protocol implemented in surveys 1 and 2, reminder leaflets were disseminated at the beginning of May to non-respondents, with replacement packages circulated to participants who had either not received the initial survey or had been originally “lost” to follow-up by the eighth week of the data collection period. Final attempts to obtain completed surveys were conducted via telephone in June, 2001.

3.3.4 Survey 4

The collection of data at time point four of the scheduled follow-up commenced in March, 2004, with the process being congruent to that of the survey 3 protocol. Phase
one data collection including the distribution of thank you as well as primary and secondary reminder cards, was completed by the end of April. Phase two processes involving the redistribution of survey packages to women who had been tracked or had not previously received a package took place during the period from August to October. Final attempts to obtain completed questionnaires for this time point were conducted via telephone three months following the initial mail outs and were finalised prior to additional surveys being dispatched in August.

3.3.5 Survey 5

Processes employed in the collection of data at the previous three time points were implemented again at survey 5. Initial mailed packages including the survey, reply paid envelope, letter of invitation and change of details card were distributed to participants in March, 2007. Thank you and reminder cards (excluding those who had withdrawn from the survey), were posted approximately one month later, with final reminders to non-respondents issued in May. Additional packages were disseminated over a six month period beginning in June to women who had previously not received one. Final reminders to non-respondents were made by telephone from June, with data collection ceasing at the end of August, 2007.

3.4 Measures

The following section details the nature of the surveys utilised at each wave of data collection for the 1946-1951 cohort. It is important to note that while a number of items and measures were examined at every time point in an effort to maximise consistency necessary for longitudinal analysis, some of the factors examined over the years became less relevant to the cohort as they aged and as a result were phased out (e.g. items related to parity). Likewise, certain factors became more relevant to the midlife transition (e.g. issues related to retirement) and were added to the survey when appropriate. Furthermore, other items were reflective of health policy themes at the time of each survey (e.g. obesity) and were included accordingly [520,521]. Although much of the content from the surveys has remained unchanged from the original survey administered in 1996, some items have been removed or altered, while others have been added. For a discussion on the development and design of the longitudinal surveys used in this study see Loxton and Young [521]. Copies of each of the surveys
used in this thesis can be obtained from http://www.alswh.org.au/for-researchers/surveys.

3.4.1 Survey 1

The baseline survey comprised a total of 298 items designed to assess a range of physical, psychosocial and lifestyle factors including contraception and menopause, emotional life events, perceptions of stress, coping styles, abuse, social support, smoking and physical activity. Additionally, the questionnaire also investigated issues concerning HRQoL and medical histories, including diagnosed chronic health conditions, symptomatic complaints, medication use and hospital admissions, as well as access to, and satisfaction with health services. Fundamental sociodemographic information including marital status, area of residence, household composition, educational attainment, employment and income management were also examined.

Questions presented in the 24 page booklet were extensively pilot tested [518] within this age group and wherever possible scientifically validated questionnaires and items were incorporated and further validated within the ALSWH [520]. These included the SF-36 [531], the Duke Social Support Index [532]; and the Hwalek-Sengstock Elder Abuse Scale [533,534]. Where measures were unavailable or deemed unsuitable for the cohort, researchers modified existing instruments (e.g. modes of coping with stress) [535] or developed new measures.

3.4.2 Survey 2

The first of the follow-up surveys consisting of 400 items followed a similar format to, and contained many of the items present in the baseline questionnaire, with the inclusion of the short form of the Centre for Epidemiological Studies-Depression scale [536] in order to evaluate depressive symptomatology. This survey also contained additional items assessing mental health, including psychiatric diagnoses, symptoms and associated pharmacotherapies. Social support in this questionnaire was measured via the Medical Outcomes Study Social Support Survey [537] with the Duke Social Support Index being discontinued.
3.4.3 Survey 3

Survey 3 conducted in 2001 contained an additional 169 items than the previous questionnaire. This survey included new items directed towards the assessment of life approach (i.e. dispositional optimism) [538], perceived life control [539], suicidality, neighbourhood satisfaction and nutrition, as well as the modification of standardised risk measures (e.g. alcohol consumption) in order to reflect current scientific consensus. The assessment of chronic health conditions was increased to include conditions emerging in this population such as arthritis as well as their associated pharmacological and alternative treatments.

Specific items from this and following surveys (i.e. 2004 and 2007) pertaining to the analyses contained within this document are addressed in detail in Section 3.5.

3.4.4 Survey 4

The fourth survey containing 575 items was revised and questions no longer important to the longitudinal project were removed (e.g. the majority of items with an emphasis on nutrition). With the exception of the inclusion of a measure to assess anxiety symptoms (Goldberg Anxiety and Depression Scale) [540], and items related to incontinence and retirement, the survey remained relatively unchanged.

3.4.5 Survey 5

The fifth survey administered in 2007 followed a similar format to that of the previous survey. This 627 item document reflected the changing circumstances of the cohort now aged between 56 and 61 and included a number of new items focused on health practice (e.g. oral health, waist measurement and weight control strategies, and alternative therapies) or expanded upon relevant themes including alcohol consumption, physical activity and retirement. In particular, the question relating to arthritis diagnosis or treatment was expanded to include specific forms of arthritis (i.e. OA, RA and other arthritis forms). Some items however, were no longer cohort appropriate (e.g. items related to parity) and as a result were removed from the survey.
3.5 Survey measures and statistical analyses used in this thesis

Quantitative analyses contained within this thesis utilised data from the three surveys which contained questions relating to arthritis diagnosis and treatment (i.e. surveys 3 to 5). The following section highlights the specific measures used in Chapter 4 and Chapter 5, and provides an overview of the statistical approach.

3.5.1 Survey measures

Arthritis

Arthritis status was determined from questions regarding doctor-diagnosed cohort specific chronic health conditions. At surveys 3 and 4 women were asked to indicate whether they had been diagnosed or treated for ‘arthritis/rheumatism’ in the past three years. At survey 5, this item was amended to reflect the major arthritis forms with separate questions relating to diagnosis or treatment of OA, RA or another form of arthritis (other arthritis). As there are inherent difficulties associated with the self-reporting of specific arthritis forms [541], and to maintain consistency across surveys, responses were dichotomised to indicate the presence or absence of at least one form of arthritis. This method of case definition is considered a valid approach for epidemiological research [542-544].

Psychosocial factors

Psychological stress

The ALSWH developed Perceived Stress Scale [545] was used to assess levels of psychological stress across ten life domains, including own health, health of a family member, money and personal relationships. Women were asked to rate how stressed they had felt in these areas within a 12 month period on a five point likert-type scale from ‘not stressed at all’ to ‘extremely stressed’. To reflect stress chronicity, mean scores were aggregated into ‘no stress’ (mean score of 0), ‘minimal stress’ (scores >0 and ≤1) and ‘moderate/high stress’ (scores >1). This method of classification has been previously adopted [53,546]. This measure has shown acceptable internal consistency (Cronbach’s $\alpha=0.70$) for the 1946-1951 cohort [547] and has demonstrated convergent
and discriminant validity [548,549]. Convergent construct validity was demonstrated most strongly with measures of mental health, life events and symptoms, and more weakly with the health behaviours.

**Stressful (negative) life events**

Cohort specific life events were extracted from a modified version of the Life Event Questionnaire [550]. Women were asked to indicate whether they had experienced any of these events in the previous 12 months via a checklist. The original list comprised 33 life stage events covering several life domains including health, relationships, family and friends, retirement and the menopause transition. A further item was added to indicate the absence of all listed life events. For the purposes of this thesis only negative life events of varying severity and chronicity were included. Specifically, items relating to death of a spouse or partner, death of a child, death of another close family member and death of close friend were combined into ‘death of a family member/close friend’. Similarly, items concerning major decline in the health of spouse or partner and major decline in health of another close family member or close friend were combined into ‘major illness of family member/close friend’. Other life spheres extracted included items relating to interpersonal/relationship difficulties, and financial strain. ‘Interpersonal/relationship difficulties’ included items relating to infidelity of a spouse, break-up of a close personal relationship, divorce, major conflict with teenage or older children, and having a family member/close friend being arrested or in gaol. Meanwhile, ‘financial strain’ referred to items surrounding being made redundant, your spouse/partner being made redundant and decreased income. Responses were dichotomised to represent the absence or presence of one of these life events (i.e. yes/no). Negative life events relating to interpersonal violence were excluded due to the low event prevalence, while others such as personal illness (i.e. the experience of major personal illness and major surgery) and those relating to the menopause transition were excluded due to confounding with arthritis status and covariates used in the analyses such as ‘menopause status’. This measure has been previously used to examine health disparities in longitudinal cohort studies [551]. The modified version of the Life Events Questionnaire appears to be a valid measure for reporting events occurring within 12 months of survey completion [552].

*Psychiatric comorbidity*
Psychiatric mood disorders were determined from age-appropriate items modelled on the ABS National Health Survey items for self-reporting doctor-diagnosed conditions [553]. Women were considered to have doctor-diagnosed depression and anxiety if they reported being diagnosed with, or treated for depression and anxiety/nervous disorder in the past three years (i.e. answered ‘yes’).

*Perceived social support*

The abbreviated version of the Medical Outcomes Study Social Support Survey [537] was used to measure perceived social support. The full multidimensional 19 item index is designed to measure functional social support across five spheres including emotional support (expression of affect, empathic understanding and the encouragement of emotional expression), informational support (offering of advice, provision of information, guidance or feedback necessary for problem-solving), tangible or instrumental support (behavioural assistance or offer of material aid), positive social interaction (companionship or the interaction through leisure and recreational activities), appraisal support (provision of information required for self-evaluation) and affectionate support (expression of love and affection) in chronic health conditions [537]. The abbreviated version includes two items from each of the emotional/informational (e.g. “someone to share your most private worries and fears with”), tangible (e.g. “someone to take you to the doctor if you need it”) and affectionate/positive social interaction scales (e.g. “someone to turn to for suggestions about how to deal with a personal problem”). Respondents were asked to rate how often these types of support were made available to them when needed, on a five point likert-type scale from ‘none of the time’ to ‘all of the time’. Mean scores for the scale were aggregated into ‘all of the time’ (scores >4 and ≤5), ‘most of the time’ (scores >3 and ≤4), ‘some of the time’ (>2 and ≤3) and ‘none/little of the time’ (scores ≤2). The abbreviated index has shown strong agreement with the original 19 item scale [545]. The Medical Outcomes Study Social Support Index has previously been used in arthritis populations [554].

*Dispositional optimism*

The revised Life Orientation Test (LOT-R) [538] was used as a measure of dispositional optimistic life approach. This modified version of the LOT contains six active and four filler items and correlates well with the original version [511]. Only the six active items related to positive and negative expectations were utilised to conserve
space. This is common practice in epidemiological research when using the LOT-R [545]. Respondents were asked to indicate their agreement with statements including “In uncertain times, I usually expect the best” and “I hardly ever expect things to go my way” on a five point likert-type scale ranging from ‘strongly disagree’ to ‘strongly agree’. Summed scores ranged from 0-30, with higher scores reflecting more optimism. Through confirmatory analysis, the LOT-R for the 1946-1951 cohort was found to represent a unifactorial construct with high internal reliability (Cronbach’s $\alpha=0.84$) [545]. This measure has been previously used in order to assess changes in health status [507,554,555].

**Health behaviours**

**Body mass index**

BMI was calculated for each participant from self-reported height and weight using the formula: weight(kg) $\div \sqrt{\text{height(m)}}^2$. According to WHO guidelines BMI was aggregated into four categories where women with a BMI of less than 18.5 were classified as ‘underweight’, those with a BMI of 18.5-24.99 as ‘healthy’, and women with a BMI of 25-29.99 as ‘overweight’. Women with a BMI of 30 or more were classified as ‘obese’ [556]. Women with BMI scores over 55 were excluded. While there is potential for adults to over-report height and under-report weight [557,558], McAdams and colleagues indicated that the correlations between self-reported and measured BMI values were very high for Caucasian, Hispanic and African ethnicities [559]. Self-reported and measured BMI values were also equally correlated in terms of obesity-related biomarkers (e.g. fasting glucose).

**Physical activity**

Items from Active Australia’s National Activity Survey [560] based upon the frequency and duration of walking briskly, moderate leisure-time activity and vigorous-intensity leisure-time activity in the last week (lasting 10 minutes or more) was used as a measure of physical activity. Weekly minutes in each of the three categories were assigned a resting metabolic rate (MET) equivalent using the formula: $(3.0 \times \text{minutes of walking}) + (4.0 \times \text{minutes of moderate activities}) + (7.5 \times \text{minutes of vigorous activities})$ [561]. As such, physical activity was categorised as ‘nil/sedentary’ (<40 MET

---

8 MET is a unit of resting metabolic rate which varies with sex, age, height and weight and is usually taken to be 3.5ml oxygen/kg/min.
mins/week), ‘low’ (>40 and <600 MET mins/week), ‘moderate’ (600-<1200 mins/week), and ‘high’ (≥ 1200 MET mins/week).

**Alcohol consumption**

Alcohol consumption was determined from survey items relating to frequency and quantity. Potential responses included ‘non-drinker’, ‘1 or 2 drinks per day’, ‘3 or 4 drinks per day’, ‘5 to 8 drinks per day’ and ‘9 or more drinks per day’. Risk was categorised according to the Australian National Health and Medical Research Council (NHMRC) guidelines [562] into ‘low risk’ (1 to 14 drinks per week), ‘moderate risk’ (15-28 drinks per week) and ‘high risk’ (28 or more drinks per week). A fourth category was added to reflect those who did not consume any alcohol (‘non-drinker’).

**Smoking**

Tobacco consumption was measured using a modified version of the Australian Institute of Health and Welfare (AIHW) data dictionary [563] in which women were classified according to cigarettes smoked each day. Women were asked to indicate how often they smoked tobacco products. Response categories included ‘daily’, ‘at least weekly (but not daily)’, ‘less often than weekly’ and ‘not at all’. Women who reported smoking either weekly or daily were asked to estimate the number of cigarettes they smoked on a weekly basis. Meanwhile, participants who reported smoking less often than weekly or not at all were asked to indicate the age they had stopped smoking daily or that they had never smoked. Responses were subsequently categorised as ‘never smoked’, ‘ex-smoker’, ‘current smoker – smokes <10 cigarettes per day’, ‘current smoker – smokes 10-19 cigarettes per day’ and ‘current smoker – smokes 20 or more cigarettes per day’. For the analyses in this thesis, categories relating to current smoking were collapsed. Women were categorised as a ‘non-smoker’, ‘ex-smoker’ and ‘current smoker’.

**Demographics**

**Age**

Age was determined from date of birth and reported as a continuous variable in years.

**Marital status**
Marital status was also modified from the ABS 1996 Census of Population and Housing survey [564]. Responses reflecting married, de facto, separated, divorced, widowed or single relationship status were aggregated into ‘married/de facto’, ‘separated/divorced/widowed’ and ‘never married’.

**Area of residence**

Area of residence was determined via postcode and was categorised according to the Rural Remote and Metropolitan Areas classification system [565]. To reflect urban and non-urban status, the categories of ‘rural’ and ‘remote’ were collapsed into ‘rural/remote’ while the category ‘urban’ remained intact.

**Educational attainment**

Highest educational qualifications question from the baseline questionnaire administered in 1996 was used as a proxy measure for SES. This item was modelled on the ABS 1996 Census of Population and Housing survey [564]. Response options included ‘no formal qualifications’, ‘school or intermediate certificate (or equivalent)’, ‘higher school or leaving certificate’, ‘trade/apprenticeship’, ‘certificate/diploma’, ‘university degree’ and ‘higher university degree’. Educational attainment was aggregated into four categories to reflect the major educational achievements in Australia. These comprised no formal education, secondary schooling (including both school and higher school certificate or equivalent), technical and further education (including a trade or diploma), as well as some form of university education (undergraduate degree or postgraduate degree). Educational attainment has been found to be the most appropriate measure of SES in disease-related research [566,567] and has been used in studies concerning arthritis [268].

**Occupation**

Occupational status was modelled on the Australian Standard Classification of Occupations [568]. Women were asked to indicate their main type of employment according to a number of skill-related categories including manager or administrator (e.g. magistrate, school principal), professional (e.g. teacher, allied health professional), associate professional (e.g. youth worker, police officer), tradesperson or related worker (e.g. hairdresser, cook), advanced clerical or service worker (e.g. flight attendant, personal assistant), intermediate clerical, sales or service worker (e.g. child
care worker, accounts clerk), intermediate production or transport worker (e.g. machine operator, bus driver), elementary clerical, sales or service worker (e.g. sales assistant, housekeeper) or labourer or related worker (e.g. cleaner, factory worker). A separate category was allocated to having no paid employment. For this thesis, occupational categories were created based upon hierarchical occupational status [569], with ‘highly skilled’ occupations (manager or administrator, professional, associate professional) grouped together. Other categories included ‘skilled’ (tradesperson or related, advanced clerical or service worker, intermediate clerical, sales or service worker, intermediate production or transport worker, elementary clerical, sales or service worker), ‘less skilled’ (labourer or related worker), and no paid employment.

**Health-related factors**

**Menopause status**

Menopause status was determined on the basis of self-report menstrual bleeding using a similar approach to that of Brambilla and colleagues [570]. Women who reported amenorrhea in the previous twelve months were classified as ‘post-menopause’. Women who reported menstruation in the past twelve months but displayed irregular menstrual patterns (i.e. no menstruation in the past three months and infrequency of periods) were classified as ‘peri-menopause’. Similarly, women who reported consistent menstruation in the past three months were defined as ‘pre-menopause’ while women who reported having had a hysterectomy were classified as having undergone ‘surgical menopause’. Due to the low frequency of women classified as ‘pre-menopause’, women representing late-onset menopause were combined into ‘pre/peri-menopause’.

**Hormone replacement therapy**

Current HRT usage was assessed in a separate question which contained dichotomous response categories (yes/no).

**Health perceptions**

**Health-related quality of life**
HRQoL was assessed using the standard Australian version of the SF-36 [571]. This measure is designed to provide a profile of HRQoL across eight domains including physical, mental health and social functioning, general health, vitality, bodily pain and role limitations (physical or emotional). Specifically with regard to physical function, women were asked to rate how limited they were in performing a range of physically demanding activities in the previous four weeks. These included strenuous (running or lifting heavy objects, participating in strenuous sport) or moderately strenuous activities (moving a table, pushing a vacuum cleaner, bowling or playing golf), as well as those focused on everyday activities such as lifting or carrying groceries, climbing flights of stairs, bending, kneeling or stooping, walking various distances (half a kilometre, one kilometre and more than one kilometre) and self-care activities (bathing or dressing). Response options ranged from ‘yes, limited a lot’, ‘yes, limited a little’ to ‘no, not limited at all’. Bodily pain on the other hand, focused on the experience of pain in terms of frequency of discomfort and extent of interference with normal activities in the previous four weeks. Pain discomfort was assessed on a scale ranging from ‘none’ to ‘very severe’, while pain interference was rated on a five point likert scale ranging from ‘not at all’ to ‘extremely’.

Meanwhile, the mental health subscale included items related to feelings of anxiety, depression, loss of behavioural or emotional control and psychological well-being over the previous month (e.g. “have you been a happy person?” and “have you felt so down in the dumps that nothing could cheer you up?”). Similarly, vitality concentrated on items reflecting perceived energy levels (e.g. “did you feel full of life?” and “did you feel tired?”). Response options for both subscales ranged from ‘all of the time’ to ‘none of the time’. Social functioning was concerned with the impact of physical or emotional problems on the quality and quantity of social activities with others. The extent to which physical and emotional health problems interfered with social activities over the previous month were assessed on a likert-type scale ranging from ‘not at all’ to ‘extremely’, while the amount of interference was rated on a scale from ‘all of the time’ to ‘none of the time’.

The general health index reflected current global health ratings, with response options ranging from ‘poor’ to ‘excellent’ in reference to overall health. Comparisons with others (e.g. “I am as healthy as anybody I know” and “I seem to get sick a little easier than other people”) and health projections (e.g. “I expect my health to get worse”) were also assessed on a continuum from ‘definitely true’ to ‘definitely false’. Additionally, physical and emotional role limitations were assessed using dichotomous yes/no responses to a
series of questions surrounding restrictions in relation to work or other daily activities as a result of their physical or emotional health in the previous four weeks. Example items included “cut down the amount of time you spend on work or other activities” and “accomplished less than you would like”.

Raw scores were linearly transformed to produce dimension scores ranging from 0 to 100 where lower scores reflect poorer health/functioning in each area (see Table 3.5). The SF-36 has been extensively validated particularly for the use with older populations and possesses high internal consistency, test-retest reliability, and responsiveness [572]. The appropriateness of the SF-36 as a measure of HRQoL within arthritis populations has been validated [573-575].

Table 3.5. Information relating to the eight SF-36 subscales and the interpretation of low and high scores [531]

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Number of Items</th>
<th>Meaning of Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>10</td>
<td><strong>Low</strong> Limited a lot in performing all physical activities including bathing or dressing</td>
</tr>
<tr>
<td>Role limitations due to physical problems</td>
<td>4</td>
<td>Problems with work or other daily activities as a result of physical health</td>
</tr>
<tr>
<td>Social functioning</td>
<td>2</td>
<td>Extreme and frequent interference with normal social activities due to physical and emotional problems</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>2</td>
<td>Very severe and extremely limiting</td>
</tr>
<tr>
<td>General mental health</td>
<td>5</td>
<td>Feelings of nervousness and depression all of the time</td>
</tr>
<tr>
<td>Role limitations due to emotional problems</td>
<td>3</td>
<td>Problems with work or other daily activities as a result of emotional problems</td>
</tr>
<tr>
<td>Vitality</td>
<td>4</td>
<td>Feels tired and worn out all of the time</td>
</tr>
<tr>
<td>General health perceptions</td>
<td>5</td>
<td>Believes personal health is poor and likely to get worse</td>
</tr>
</tbody>
</table>
**Disease-related factors**

**Comorbid conditions**

Comorbid physical conditions were determined from age-appropriate items modelled on the ABS National Health Survey [553]. Items selected for inclusion in this thesis were based upon the consistency of evidence available regarding the impact of comorbid chronic disease on arthritis (see Section 2.4.1). Women were considered to have chronic medical comorbidity if they reported being diagnosed with, or treated for diabetes, cardiovascular disease, low iron/anaemia, or osteoporosis in the past three years (i.e. answered ‘yes’). At survey 3, responses relating to being diagnosed with either insulin-dependent or non-insulin dependent diabetes were collapsed to reflect a diagnosis of some form of ‘diabetes’. At the follow-up surveys in 2004 and 2007, this item was amended in line with this generic terminology. ‘Cardiovascular disease’ on the other hand reflected the combination of items regarding the diagnosis of heart disease (heart attack, angina), stroke and hypertension (high blood pressure) at each of the three surveys. Responses were subsequently dichotomised to represent the presence or absence of some form of cardiovascular disease. Meanwhile, low iron/anaemia and osteoporosis were examined in separate single item questions consistent across all three surveys.

**Somatic symptomatology**

Comorbid somatic symptomatology was assessed from a list of predetermined cohort specific common symptoms. Women were asked to indicate how often they experienced these symptoms in the previous 12 months according to a four point ordinal scale (never, rarely, sometimes and often). Items examined as a result of theoretical considerations were dichotomised into never/rarely and sometimes/often to reflect chronicity of symptoms concerning headaches/migraine, fatigue, and gastrointestinal problems. Specifically in relation to experiencing gastrointestinal problems, items relating to indigestion/heartburn, haemorrhoids and other bowel associated problems were collapsed to indicate the presence or absence of experiencing at least one of these symptoms sometimes or often.

**Health service use**

**Health service consultations**
Health care utilisation was assessed by asking women to indicate the number of visits they made to their family doctor and another GP in the previous 12 months. These items were modified from the ABS National Health Survey [553]. For the purposes of this thesis, response categories for GP consultations were aggregated into ‘none’, ‘one or two’, ‘three or four’, ‘five or six’ and ‘seven or more’ consultations.

3.5.2 Data and statistical analyses

Quantitative analyses contained within this thesis utilised data from the three surveys which contained questions relating to arthritis diagnosis and treatment (i.e. surveys 3 to 5). Cross-sectional binary logistic analyses examining the relative importance of psychosocial factors in arthritis (using data from survey 5) are presented in Chapter 4. Meanwhile, the role of perceived stress as a predictor in arthritis onset was examined using binary logistic Generalised Estimating Equation (GEE) models with and without a time lag. These analyses are presented in Chapter 5 of this thesis.

Data for the analyses were provided by the ALSWH research team in a workable SPSS for Windows format (SPSS v.19). Access to supplementary resources including a data dictionary featuring information regarding survey items and derived variables were provided in order to assist data analysis. These documents are available from http://www.alswh.org.au/for-researchers/data.

3.6 Ethical considerations

Rigorous protocols were implemented and sustained during the various phases of the ALSWH. The recruitment process, in addition to the collection, collation, storage and analysis of data was conducted in accordance with the legal and ethical requirements for performing human research at the time of the project’s inception (e.g. NHMRC Guidelines for Privacy in the Conduct of Medical Research [576]; Information Privacy Principles [577]).

Anonymity of women listed on the Medicare database was protected under Section 130 of the Medicare Australia Act [578] with no third party contact between the ALSWH and the potential study participant being permitted until written informed consent was ascertained. As a result, women who declined to participate remained anonymous to the research team.
Confidentiality of the consenting women was maintained via the de-identification and storage of data in coded numerical form, as well as data being reported in anonymous aggregated form only. All personal information pertaining to the participants, including names and addresses was stored separately from the main data files with senior data management staff solely possessing access to linked records [519].

Ethics approval for the pilot study was granted by the University of Newcastle’s Human Research Ethics Committee (approval number: H-076-0795) in 1995. The ALSWH baseline and follow-up surveys acquired subsequent approval in 1996 for survey 1, 1998 for survey 2, 2001 for survey 3, 2004 for survey 4 and 2007 for survey 5. In addition, access to data for this research was approved by the ALSWH Publications, Analyses and Substudies Committee (EOI A179) and ethical approval was obtained for the project from the University of Queensland’s Human Research Ethics Committee (approval number: 2004000224) for the years 2001, 2004 and 2007.

### 3.7 Conclusion

The ALSWH is one of the largest known projects undertaken to date examining the health of Australian women within a holistic biopsychosocial framework. The longitudinal nature of the study design will allow researchers to clarify causal relationships between women’s health and concomitant physical, psychological, social and lifestyle determinants [517]. The outcomes of this thesis will provide an opportunity to alter the fabric of governmental policies concerning women and their health. In particular, the findings from the quantitative analyses contained within this thesis will inform policy and practice regarding the influence of psychosocial factors and in particular psychological stress in the onset of, and poor outcomes associated with arthritis in women transitioning from midlife to older age. The relative importance of psychosocial factors in arthritis will be explored in the following chapter.
Chapter 4

Results from the ALSWH

The relative importance of psychosocial factors in arthritis for women

An extensive review of the literature concerning the association between psychosocial factors and arthritis in women was outlined in Chapter 2 of this thesis. Similarly, a detailed overview of the ALSWH project and methods was provided in Chapter 3. This chapter will highlight the major findings relating to the relative importance of psychosocial factors in arthritis for women in the ALSWH 1946-1951 cohort. An introduction to the literature relevant to this analysis and the methods employed will be discussed. This will be followed by the presentation of the cross-sectional study results and a discussion of the findings within the broader context of arthritis research.

Components of this chapter have undergone a peer review process and have been published in the *Journal of Psychosomatic Research*. Citation: **Harris ML, Loxton D, Sibbritt DW, Byles JE.** The relative importance of psychosocial factors in arthritis in women: findings from 10,509 Australian women. J Psychosom Res. 2012;73(4):251-256.

4.1 Introduction

The influence of psychosocial factors on disease processes in arthritis has primarily focused on psychological adaptation (most notably depression). However, evidence of an increased association between poor mental health and arthritis has been inconsistent [329,338,423,424,430]. In a ten year study of consecutive RA outpatients Hawley and Wolfe [431] found that 20% fulfilled criteria for ‘probable’ depression, while cross-sectionally, Ho and colleagues [434] found that 15% and 26% of RA patients reported depression and anxiety, respectively. Similar findings have been reported for OA populations [432] (see Chapter 2). When specifically focused on women, El-Miedany and El Rasheed noted that around 60% of women with RA experienced depression, with anxiety found to approach 70% [430]. Meanwhile, prospective findings indicate that the prevalence or severity of depression in RA is not dissimilar to
individuals with other chronic diseases, and as such may be a factor of reduced HRQoL and not a function of the disease, per se [431,437]. It would appear important to understand the role of psychosocial factors within a comprehensive model, taking into account current health perceptions.

Psychological stress may also play an important role in poor adjustment to arthritis, particularly for women. The majority of stress-related research within the arthritis field has focused on the occurrence of major or minor negative life events in relation to symptom expression or psychological adaptation in RA [330,333,453-456]. Turner et al. [454] found that patients who experienced more chronic major and minor daily stressors over a six month period experienced poorer mood, while Treharne and colleagues [453] noted that greater life stress impacted on psychological well-being over the course of the disease, particularly in relation to anxiety. Additionally, Thomason et al. [456] found that following the adjustment for disease severity and major life stress, minor stressful life events were positively correlated with \( r=0.333, p<0.01 \), and accounted for a significant amount of the variance associated with inflammation levels (11%). Other studies, depending upon the stress measurement employed and covariates examined, have produced inconsistent findings [458,461] (see Chapter 2).

Moreover, it is increasingly acknowledged that stress appraisal in the absence of perceived personal coping resources (such as social support and personality characteristics) may be more critical to the adjustment process and as such may have a greater impact on the disease than exposure to chronic stressors [67]. In particular, Epel and colleagues [49] have demonstrated that chronic perceived stress is associated with key physical markers of cellular ageing, with high levels of perceived stress found to increase cellular ageing by one decade in comparison to women with lower perceived stress levels. Research related to the impact of perceived stress on women with arthritis however is limited. Curtis and colleagues [469] found perceived stress to be associated with affective disturbance in Irish women with established RA (mean age=60 years), while Zautra and Smith [464] in their study of post-menopausal women with RA and OA found perceived stress to be associated with both pain sensitivity and poor mood. Interpersonal stress has also been found to be associated with elevated biological and clinical markers of disease activity in American women with RA [465]. Studies to date however have generally focused on small RA sub-samples and have failed to consider various aspects of the stress process (including
additional psychosocial factors that may facilitate the response) within the one model, thereby limiting the scope of their findings [468,469].

It is important to gain an understanding of how perceived stress and psychosocial processes may be associated with arthritis at an epidemiological level for women, taking into account factors that influence psychosocial health including traditional risk/protective factors and current health perceptions (as detailed in Chapter 2). Therefore, the aim of this study is to determine the relative importance of psychosocial factors in arthritis diagnosis using a broadly representative cohort of Australian women transitioning from midlife to older age.

4.2 Methods

4.2.1 Sample

For the purposes of this study, data from women in the ALSWH 1946-1951 cohort who completed the fifth survey in 2007 were analysed. Of the 14,099 women who responded to the initial invitation in 1996, 10,638 (75.5%; unweighted data) women aged between 56 and 61 years completed the follow-up survey in 2007. This sample was found to be largely representative of the original cohort, with a slight over-representation of married, Australian born and tertiary educated women [520] (see Section 3.2). The final sample for this analysis however, related only to those women who responded to the questions about arthritis diagnosis. The final sample comprised 10,509 (74.5%) women (unweighted data).

4.2.2 Measures

The variables used in this analysis are listed below. These measures selected as a result of their potential impact on the arthritis experience (see Chapter 2) are described in detail in Section 3.5.1 of the quantitative methods chapter.

Arthritis case definition (outcome)

‘Arthritis’ was defined as those women who reported being diagnosed with, or treated for OA, RA, or another form of arthritis (other), in the past three years at survey 5. As there are inherent difficulties associated with the self-reporting of specific arthritis forms
[541], responses were dichotomised to indicate the presence or absence of at least one form of arthritis.

**Psychosocial factors**

**Psychological stress**

The Perceived Stress Scale [545] was used to assess levels of psychological stress. Mean scores were aggregated into ‘no stress’ (mean score of 0), ‘minimal stress’ (scores >0 and ≤1) and ‘moderate/high stress’ (scores >1).

**Negative life events experienced within the past 12 months**

Cohort specific life events were extracted from a modified version of the Life Event Questionnaire [550]. Women were asked to indicate whether they had experienced life events of varying severity and chronicity including a significant trauma (e.g. death of a spouse) or constant sources of stress (e.g. financial difficulties) in the previous 12 months.

**Psychiatric comorbidity**

Women were considered to have doctor-diagnosed depression and anxiety if they reported being diagnosed with, or treated for these conditions in the past three years.

**Perceived social support**

The abbreviated version of the Medical Outcome Study Social Support Survey [537] was used to measure perceived social support. Mean scores for the scale were aggregated into ‘all of the time’ (scores >4 and ≤5), ‘most of the time’ (scores >3 and ≤4), ‘some of the time’ (>2 and ≤3) and ‘none/little of the time’ (scores ≤2).

**Dispositional optimism**

The LOT-R [538] was used as a measure of dispositional optimistic life approach. Summed scores ranged from 0-30, with higher scores reflecting more optimism.
Covariates

The following arthritis risk/protective factors and current health perceptions were included in the multivariate model.

Body mass index

BMI was calculated for each participant from self-reported height and weight and was aggregated into four categories according to WHO guidelines [556]: ‘underweight’ (<18.5), ‘healthy’ (18.5-24.99), ‘overweight’ (25-29.99) and ‘obese’ (≥30).

Alcohol consumption

Alcohol consumption was determined from survey items relating to frequency and quantity. According to the Australian NHMRC guidelines [562], risk was categorised into ‘low risk’ (1 to 14 drinks per week), ‘moderate risk’ (15-28 drinks per week), ‘high risk’ (28 or more drinks per week) and ‘non-drinker’.

Smoking

Women were also classified according to cigarettes smoked each day as ‘non-smoker’, ‘ex-smoker’, and ‘current smoker’ using a modified version of the AIHW data dictionary [563].

Age

Age was determined from date of birth and reported as a continuous variable in years.

Marital status

Marital status was modified from the ABS 1996 Census of Population and Housing survey [564] and was aggregated into ‘married/de facto’, ‘separated/divorced/widowed’ and ‘never married’.

Area of residence
Area of residence was determined via postcode and was categorised according to the Rural Remote and Metropolitan Areas system [565] as ‘urban’ and ‘rural/remote’.

**Educational attainment**

Highest educational qualifications survey question from the baseline questionnaire administered in 1996 was used as a proxy measure of SES. This item was modelled on the ABS 1996 Census of Population and Housing survey [564]. Educational attainment was aggregated into four categories to reflect the major educational achievements in Australia: ‘no formal education’, ‘secondary education’, ‘trade/diploma’ and ‘tertiary/post graduate’.

**Menopause status**

Menopause status was determined on the basis of self-report menstrual bleeding in a similar fashion to that of Brambilla and colleagues [570]. As such, menopause status was classified as ‘pre/peri-menopause’, ‘post-menopause’, and ‘surgical menopause’.

**Hormone replacement therapy**

Current HRT usage was assessed in a separate question which contained dichotomous response categories (yes/no).

**Health-related quality of life**

HRQoL was assessed using the standard Australian version of the SF-36 [571]. This measure is designed to provide information on health perceptions across eight domains including physical, mental health and social functioning, general health, vitality, bodily pain and role limitations (physical or emotional). Raw scores were linearly transformed to produce dimension scores ranging from 0 to 100 where lower scores reflect poorer health/functioning in each area.

### 4.2.3 Statistical analyses

Univariate analyses were initially conducted in order to examine the association between psychosocial factors and arthritis status. Chi-square analyses (for categorical variables) and independent t-tests (for continuous variables) were employed to report
associations/differences between women who had arthritis from those who did not. Unadjusted logistic regression analyses were carried out to examine the odds ratios (95% CI) associated with arthritis status and individual variables. Due to the ALSWH sampling frame, univariate analyses were weighted for area to correct for the oversampling of women from rural and remote areas (see Section 3.1). Exploratory univariate analyses for the predetermined covariates were also conducted and are located in Appendix B. In addition, tests for multicollinearity using correlation and linear regression were conducted between the independent variables. The results of these analyses indicated that multicollinearity was not a concern. A final multivariate model adjusting for behavioural, demographic (including ‘area of residence’ in order to correct for the oversampling of rural/remote women) and health-related characteristics was then constructed using a backward stepwise procedure. All psychosocial and confounding variables were entered equally in the initial model regardless of univariate results and variables found not to contribute significantly to the model were manually eliminated via a backward stepwise procedure, employing the maximum likelihood ratio test. Due to the large sample size, statistical significance was set at p<0.005. All analyses were conducted using the software package SPSS v.19 (SPSS Inc., Chicago, IL, USA).

4.3 Results

4.3.1 Sample characteristics

A total of 3,025 (29.1%; weighted for area of residence) women in the 1946-1951 cohort reported being diagnosed with, or treated for arthritis in the previous three years. Of these women, 410 reported more than one arthritis condition. While women with arthritis were slightly older than women without arthritis (mean age=58.6±1.5 and 58.5±1.5 respectively), the majority of women from both groups were involved in partnered (i.e. married or de facto) relationships (75.8% vs. 77.7%) and situated in urban areas (68.6% vs. 67.2%). No statistically significant differences between age, marital status or area of residence and arthritis status were identified (p>0.005) (see Table 4.1). Women with arthritis however, reported lower levels of educational attainment than other women. While almost half of women in both groups had achieved lower levels of formal education (i.e. 12 years or less), significantly more women with arthritis reported no formal education (19.6% vs. 13.3%; p<0.001). Note that when entered into the final multivariate model, the association between all demographic
variables (with the exception of age; OR=1.1, 95% CI=1.0, 1.1; p=0.001) and arthritis status became non-significant (see Table 4.3).
Table 4.1. Sociodemographic characteristics of women from the 1946-1951 cohort according to arthritis diagnosis

<table>
<thead>
<tr>
<th>Age&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Missing n (%)</th>
<th>No arthritis n (%)</th>
<th>Arthritis n (%)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>58.5 (1.5)</td>
<td>58.6 (1.5)</td>
<td>0.009</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/de facto</td>
<td>5689 (77.7%)</td>
<td>2276 (75.8%)</td>
<td>0.031</td>
<td></td>
</tr>
<tr>
<td>Separated/divorced/widowed</td>
<td>1416 (19.3%)</td>
<td>611 (20.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>220 (3.0%)</td>
<td>116 (3.9%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Area of residence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>4992 (68.6%)</td>
<td>2012 (67.2%)</td>
<td>0.186</td>
<td></td>
</tr>
<tr>
<td>Rural/remote</td>
<td>2289 (31.4%)</td>
<td>981 (32.8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational attainment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tertiary/post graduate</td>
<td>1382 (18.9%)</td>
<td>448 (14.9%)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Trade/diploma</td>
<td>1553 (21.2%)</td>
<td>580 (19.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School/higher school certificate</td>
<td>3416 (46.6%)</td>
<td>1383 (46.1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal education</td>
<td>976 (13.3%)</td>
<td>587 (19.6%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup> weighted for area.
<sup>b</sup> for continuous variables, means and standard deviations are reported.

4.3.2 The univariate relationship between psychosocial factors and arthritis status

At a univariate level, the strongest psychosocial factor associated with arthritis was the presence of perceived stress (see Table 4.2). Relative to experiencing no stress, women experiencing minimal levels of stress were 1.6 times more likely to report having been diagnosed with arthritis (95% CI=1.4, 1.9; p<0.001), and women reporting moderate to high levels of stress were 2.6 times more likely to report arthritis compared to women experiencing no stress (95% CI=2.1, 3.1; p<0.001). Of the negative life events examined, significant associations were found between having a family member or close friend with a major illness (unadjusted OR=1.4, 95% CI=1.3, 1.5; p<0.001), experiencing interpersonal/relationship difficulties (unadjusted OR=1.4, 95% CI=1.2, 1.6; p<0.001) and financial strain (unadjusted OR=1.2, 95% CI=1.1, 1.3; p=0.004) and arthritis status. Further, being diagnosed with either depression (unadjusted OR=2.1,
Results from the ALSWH: The relative importance of psychosocial factors in arthritis for women

95% CI=1.8, 2.3; p<0.001) or anxiety (unadjusted OR=1.9, 95% CI=1.9, 2.4; p<0.001) was associated with a two-fold increase in arthritis. There was also a trend towards statistical significance for death of a family member or close friend (unadjusted OR=1.1, 95% CI=1.0, 1.3; p=0.009).

Meanwhile, an inverse association between positive life approach (as measured by the LOT-R) and arthritis was identified (unadjusted OR=0.93, 95% CI=0.92, 0.93; p<0.001). At a univariate level, women who were less likely to perceive adequate availability of social support were more likely to report arthritis. In particular, compared to women who had functional forms of social support available all the time, women who were more likely to have functional forms of social support available occasionally or not at all were 1.5 times more likely to report a diagnosis of arthritis (95% CI=1.3, 1.8; p<0.001).
Table 4.2. Unadjusted odds ratios with 95% confidence intervals (CI) for psychosocial factors associated with arthritis diagnosis for women born between 1946 and 1951

<table>
<thead>
<tr>
<th>Perceived stress</th>
<th>Missing n (%)</th>
<th>No arthritis n (%)</th>
<th>Arthritis n (%)</th>
<th>Unadjusted odds ratio (95% CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>None [ref]</td>
<td>721 (9.8%)</td>
<td>177 (5.9%)</td>
<td>37 (2.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minimal</td>
<td>5823 (79.2%)</td>
<td>2329 (77.2%)</td>
<td>1.6 (1.4, 1.9)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Moderate/high</td>
<td>812 (11.0%)</td>
<td>512 (17.0%)</td>
<td>2.6 (2.1, 3.1)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>37 (0.4%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Negative life events experienced within the past 12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death of a family member/close friend</td>
</tr>
<tr>
<td>No [ref]</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Missing</td>
</tr>
<tr>
<td>Major illness of family member/close friend</td>
</tr>
<tr>
<td>No [ref]</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Missing</td>
</tr>
<tr>
<td>Interpersonal/relationship difficulties</td>
</tr>
<tr>
<td>No [ref]</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Missing</td>
</tr>
<tr>
<td>Financial strain</td>
</tr>
<tr>
<td>No [ref]</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Missing</strong></td>
</tr>
<tr>
<td><strong>Psychiatric diagnoses</strong></td>
</tr>
<tr>
<td>Depression</td>
</tr>
<tr>
<td>No [ref]</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td><strong>Missing</strong></td>
</tr>
<tr>
<td>Anxiety/nervous disorder</td>
</tr>
<tr>
<td>No [ref]</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td><strong>Missing</strong></td>
</tr>
<tr>
<td><strong>Perceived social support</strong></td>
</tr>
<tr>
<td>All of the time [ref]</td>
</tr>
<tr>
<td>Most of the time</td>
</tr>
<tr>
<td>Some of the time</td>
</tr>
<tr>
<td>None/little of the time</td>
</tr>
<tr>
<td><strong>Missing</strong></td>
</tr>
<tr>
<td><strong>Life approach</strong>&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Mean (SD)</td>
</tr>
<tr>
<td><strong>Missing</strong></td>
</tr>
</tbody>
</table>

<sup>a</sup> weighted for area.

<sup>b</sup> for continuous variables, means and standard deviations are reported.
4.3.3 The multivariate relationship between psychosocial factors and arthritis status

At a multivariate level, although perceived social support, positive life approach, and having a family member/close friend with a major illness remained in the final model, having an anxiety disorder was the only statistically significant psychosocial factor related to arthritis at the p<0.005 level (see Table 4.3). As such, being diagnosed, or treated by a physician in the past three years for an anxiety disorder was associated with a 1.5-fold increase in self-reported diagnosis of arthritis (95% CI=1.2, 1.7; p<0.001).

Table 4.3. Adjusted odds ratios with 95% confidence intervals (CI) for psychosocial, demographic and health-related factors associated with arthritis diagnosis for women born between 1946 and 1951

<table>
<thead>
<tr>
<th>Factor</th>
<th>Adjusted odds ratio (95% CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Negative life events experienced within the past 12 months</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Major illness of family member/close friend</td>
<td>No [ref]</td>
<td>--------</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1.1 (1.0, 1.2)</td>
</tr>
<tr>
<td><strong>Psychiatric diagnoses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety/nervous disorder</td>
<td>No [ref]</td>
<td>--------</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1.5 (1.2, 1.7)</td>
</tr>
<tr>
<td><strong>Perceived social support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All of the time [ref]</td>
<td></td>
<td>--------</td>
</tr>
<tr>
<td>Most of the time</td>
<td>1.2 (1.0, 1.3)</td>
<td>0.011</td>
</tr>
<tr>
<td>Some of the time</td>
<td>1.2 (1.0, 1.5)</td>
<td>0.013</td>
</tr>
<tr>
<td>None/little of the time</td>
<td>1.0 (0.8, 1.3)</td>
<td>0.846</td>
</tr>
<tr>
<td><strong>Life approach</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.99 (0.98, 1.00)</td>
</tr>
<tr>
<td><strong>BMI</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under weight</td>
<td>0.9 (0.5, 1.5)</td>
<td>0.583</td>
</tr>
<tr>
<td>Healthy weight [ref]</td>
<td></td>
<td>--------</td>
</tr>
<tr>
<td>Overweight</td>
<td>1.2 (1.1, 1.4)</td>
<td>0.005</td>
</tr>
<tr>
<td>Obese</td>
<td>1.4 (1.2, 1.6)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Alcohol consumption</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-drinker [ref]</td>
<td></td>
<td>--------</td>
</tr>
<tr>
<td>Low risk</td>
<td>1.3 (1.1, 1.6)</td>
<td>0.007</td>
</tr>
<tr>
<td>Moderate risk</td>
<td>1.4 (1.0, 1.8)</td>
<td>0.035</td>
</tr>
</tbody>
</table>
Results from the ALSWH: The relative importance of psychosocial factors in arthritis for women

<table>
<thead>
<tr>
<th>Smoking status</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-smoker [ref]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ex-smoker</td>
<td>1.1 (1.0, 1.3)</td>
<td>0.039</td>
</tr>
<tr>
<td>Current smoker</td>
<td>0.8 (0.7, 1.0)</td>
<td>0.035</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1.1 (1.0, 1.1)</td>
<td>0.001</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital status</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Married/de facto [ref]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separated/divorced/widowed</td>
<td>0.9 (0.8, 1.0)</td>
<td>0.123</td>
</tr>
<tr>
<td>Never married</td>
<td>1.2 (0.9, 1.6)</td>
<td>0.307</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Area of residence</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban [ref]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural/remote</td>
<td>1.0 (0.9, 1.1)</td>
<td>0.970</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Educational attainment</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Tertiary/post graduate [ref]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trade/diploma</td>
<td>0.9 (0.8, 1.1)</td>
<td>0.306</td>
</tr>
<tr>
<td>School/higher school certificate</td>
<td>0.8 (0.7, 1.0)</td>
<td>0.024</td>
</tr>
<tr>
<td>No formal education</td>
<td>0.9 (0.8, 1.1)</td>
<td>0.544</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Menopause status</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre/peri menopause</td>
<td>0.7 (0.5, 1.1)</td>
<td>0.114</td>
</tr>
<tr>
<td>Post-menopause [ref]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgical menopause</td>
<td>1.1 (1.0, 1.2)</td>
<td>0.146</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HRT use</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No [ref]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.3 (1.1, 1.4)</td>
<td>0.001</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HRQoL (SF-36)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>0.92 (0.90, 0.94)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>0.85 (0.84, 0.87)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Mental health</td>
<td>1.03 (1.00, 1.05)</td>
<td>0.040</td>
</tr>
<tr>
<td>Social functioning</td>
<td>1.06 (1.04, 1.08)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>General health</td>
<td>0.95 (0.94, 0.97)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Emotional role functioning</td>
<td>1.00 (0.99, 1.01)</td>
<td>0.193</td>
</tr>
<tr>
<td>Physical role functioning</td>
<td>1.00 (0.98, 1.01)</td>
<td>0.887</td>
</tr>
</tbody>
</table>

*5 point change in index for the HRQoL subscales (physical functioning, bodily pain, general health, social functioning, mental health, emotional and physical role functioning.*
4.4 Discussion

This study examined the relative importance of psychosocial factors in arthritis in a nationally representative sample of women transitioning from midlife to older age. The findings suggest that women with arthritis have widespread psychosocial concerns, particularly relating to chronic stress perception and poor mental health. Most importantly, being diagnosed with an anxiety disorder was associated with significantly greater odds of reporting arthritis, a factor that remained as the only statistically significant psychosocial factor associated with arthritis at a multivariate level. Perceived stress had the strongest association with arthritis in univariate analyses but was not retained in the multivariate model. The findings of this study add important information to the wider body of knowledge surrounding the role of psychosocial factors in arthritis and also provide a unique perspective regarding the psychosocial experience of women as they age. Particularly, these women transitioning from midlife to older age appear to have psychosocial needs that may benefit from targeted clinical interventions aimed at reducing chronic stress and anxiety.

The findings of this study are strengthened by a number of factors. Firstly, the results are based on a nationally representative cohort sample involving over 10,000 women. This large sample size provided the ability to control for a comprehensive range of risk/protective factors and health perceptions that may influence the arthritis experience. Additionally, various aspects of the stress process within the one model were able to be examined. The failure to include (or control) for aspects of the stress process (such as life events or stress perception) within the same model is a criticism of previous research.

Most notably, the multivariate analysis showed that women with anxiety/nervous disorder were more likely to report being diagnosed with arthritis. Understanding of the anxiety-arthritis connection remains poorly understood, with the majority of research focused on psychiatric illness primarily concentrating on the role of depression, or psychological distress [338,579]. In this study, although women with arthritis were at an equally heightened risk for being treated for depression or anxiety at a univariate level, depression did not contribute to the final model. These findings support the work of Smith and Zautra [580] who found that when examined separately, depression and anxiety had similar effects on the reporting of weekly pain. However, when examined in concert, depression was reduced to non-significance. The findings from this study extends that of Smith and Zautra [580] by examining mental health within a
Results from the ALSWH: The relative importance of psychosocial factors in arthritis for women

comprehensive model, controlling for health-related factors that may influence the arthritis experience for women. In addition, by using a national sample, as opposed to a convenience sample, the findings may be generalisable to similar ageing populations. With others [581,582] providing support for significant increases in levels of anxiety in rheumatic as well as other chronic pain conditions, this suggests that anxiety may be a primary and somewhat overlooked concern in arthritis populations. This study is the first to highlight the specific association between anxiety and arthritis extending beyond a relationship with pain perception in a national sample of women transitioning from midlife to older age.

Interestingly, previous studies have linked the experience of both depression and anxiety in arthritis to the expression of pain and functional impairment, particularly in RA sub-populations [580,583]. Here, it was possible to control for a number of possible confounding factors within the one model, including perceptions of bodily pain and physical functioning (as measured by the SF-36). These findings add to the arthritis literature by highlighting the unique association between anxiety and arthritis in women. This may have particular implications for disease onset in arthritis. Von Korff and colleagues [303] noted in their longitudinal study that the experience of mental health problems (depression and anxiety) prior to age 21 was associated with an increased risk of developing adult onset arthritis. van't Land and colleagues [584] on the other hand found that while arthritis predicted the onset of psychiatric disturbance, a temporal relationship between the presence of a mood disorder and arthritis onset did not exist. Although the findings provide support for increased attention on the anxiety-arthritis relationship, the role of anxiety as a predictor of arthritis onset would have to be examined via longitudinal analyses. The role of anxiety as a precursor to arthritis onset is examined within the analyses located in Chapter 5.

Perceived stress was found to have the strongest relationship with arthritis status at a univariate level, with the odds of reporting arthritis incrementally increasing for women experiencing either minimal or moderate/high levels of stress. While these women also reported experiencing more negative life events within the previous three years, it appears that the chronic perception of these events as stressful in the face of a perceived lack of personal coping resources may be important to the stress-arthritis paradigm. Studies have shown that chronically appraising a situation as harmful may initiate a cascade of physiological reactions which weakens the response of key allostatic systems (notably immune and neuroendocrine) [585,586]. Particularly within this highly integrated process, it is posited that dysregulation of the HPA axis through
chronic glucocorticoid release or blunting is key in instigating a negative feedback loop to the immune system, thereby increasing susceptibility to chronic disease [71]. Likewise, long-term activation of the HPA axis has been hypothesised to hamper defence mechanisms in the hippocampus [587]. This may affect the ability to employ effective coping mechanisms in order to reduce the negative impact of stress. In this study, women diagnosed/treated for a psychiatric disorder were also twice as likely as women without mental health problems to report arthritis. Taken together, the univariate and multivariate analyses suggest that chronic stress perception may be a precursor to anxiety and affect arthritis via mood pathways. Chronic stress appraisal and anxiety may also play a contributory role in arthritis risk, however this intricate interactional process would have to be confirmed via longitudinal analyses. The role of perceived stress as a risk factor for arthritis onset is the primary focus of Chapter 5.

The current study must be considered in light of a few limitations. Firstly, this study relied upon a self-report measure of arthritis. The prevalence of arthritis within this sample of women was found to be similar to point prevalence rates reported previously [134,145,588], particularly those using a similar definition of arthritis. For instance, although researchers using the U.S. 2003-2005 National Health Interview survey data [134] did not report age-stratified prevalence rates for each gender, they found arthritis prevalence for women to be approximately 25%, and 29% for individuals aged 45-64. Additionally, this figure is only slightly lower than that reported by Szoekoe et al. [588] who examined self-reported arthritis in Australian women aged 45-55 (34%). The results are conservative compared to other Australian studies relying on self-report. Age-stratified prevalence rates for women 55-64 years using data from the 2007-2008 National Health Survey have been reported in excess of 40% [77]. In their study, a broader definition of arthritis diagnosis was considered and prevalence rates included all arthropathies. Despite this, March and colleagues [589], have found that self-reported physician-diagnosed general arthritis has good congruency with clinically derived diagnoses (sensitivity 81% and specificity 99%). Moreover, there was no information regarding time since arthritis diagnosis. This may have impacted upon the study findings as women may report different psychosocial responses at certain stages of the disease process. Studies focused on RA however, have reported no statistical difference in psychological well-being between patients with early, as opposed to established disease [590,591].
4.5 Conclusion

The findings of this large national cohort study add to the current understanding of the burden associated with arthritis and highlight the important role of psychosocial factors in this process, particularly for women as they transition from midlife to older age. Prospective research is required in order to understand the role of perceived stress and psychosocial factors on the long-term impact of arthritis (in terms of HRQoL outcomes) for women. The findings from this analysis however, provide greater insight into the relationship between chronic stress perception and anxiety. In particular, being able to control for factors that confound the arthritis experience (e.g. bodily pain, physical functioning and obesity), the analyses demonstrated that the experience of anxiety extends beyond a direct connection with pain expression. As the experience of anxiety has the potential to adversely influence treatment outcome, research focused on understanding the complexities surrounding the relationship between anxiety and arthritis has the potential to inform the development of targeted interventions aimed at addressing the psychosocial needs of women, thereby reducing the deleterious health effects associated with arthritis. Importantly, the identification of key psychosocial factors that contribute to the onset of arthritis may facilitate public health strategies associated with reducing the incidence of arthritis in women. The role of perceived stress and associated psychosocial factors in the onset of arthritis is examined in Chapter 5. Meanwhile, the lived psychosocial experience of women with arthritis is qualitatively explored in Chapter 7 and Chapter 8, with particular attention paid to understanding the impact of perceived stress and anxiety on health for these women.
Chapter 5

Results from the ALSWH

The influence of perceived stress on the onset of arthritis in women

Findings from Chapter 4 of this thesis indicate that psychosocial factors play an important role in the adjustment of arthritis for women, particularly in terms of chronic stress perception and mental health. In order to achieve the overarching aim of the thesis, this chapter will aim to explore the role of perceived stress as a risk factor for arthritis onset (taking into account additional psychosocial processes that may influence this relationship) in women from the 1946-1951 cohort. An introduction to the literature relevant to this analysis and the methods employed will be discussed. This will be followed by the presentation of the study results and a discussion of the findings within the broader context of risk factors for arthritis.

Components of this chapter have undergone a peer review process and have been published in the Annals of Behavioral Medicine. Citation: Harris ML, Loxton D, Sibbritt DW, Byles JE. The influence of perceived stress on the onset of arthritis in women: findings from the Australian Longitudinal Study on Women’s Health. Ann Behav Med. 2013;46(1):9-18.

5.1 Introduction

While significant progress has been made regarding disease progression (e.g. development of new treatment options and assessment of treatment efficacy), the pathogenesis of arthritis remains unclear [592,593]. Arthritis is viewed as a disease of multifactorial origin, with both genetic and environmental factors contributing to its occurrence and expression [151,180]. Prevention strategies have focused on identifying risk factors for disease development [187]. Notably, age [82,145,167], gender [74,153,189], and genetic predisposition [151,177,180,190] have been highlighted as risk factors for arthritis onset. In addition to these non-modifiable factors, potentially modifiable factors have been found to place individuals at an increased risk of developing both OA and RA. Specifically, in relation to OA, factors such as overweight and obesity [231], physical activity [231,252], joint trauma [242], and
occupational-based repetitive joint loading [259,262] have been identified. With respect to RA, tobacco smoking [178,271,272] has been found to be the best established modifiable risk factor (see Section 2.3.2 for further details). While arthritis remains incurable, identifying additional factors that contribute to increased risk is of public health significance.

Psychosocial factors and in particular psychological stress (defined in terms of an interpersonal event such as trauma or response to an event such as stress perception) are beginning to be considered in concert with traditional risk factors (e.g. overweight and obesity, and poor nutrition) for chronic diseases other than arthritis [45,54,594] (see Chapter 1). Despite this increasing body of research, relatively little attention has been paid to understanding the role of psychological stress as a risk factor for arthritis onset.

When the relationship between psychological stress and arthritis risk has been addressed in epidemiological studies, it has primarily been examined in response to a specific life stressor [301-303]. A comprehensive review of the research surrounding psychological stress and arthritis onset is detailed in Section 2.3.2. The perception of stress and psychosocial processes, with control for traditional risk factors has not been undertaken. As highlighted in Chapter 1, chronically perceiving life as stressful has been hypothesised to be a more important factor in the stress-chronic disease process than the experience of specific life events [67]. Although primarily focused on RA subpopulations, previous research has indicated that perceived stress may play a pertinent role with regard to symptom expression [464-466,468] and psychological adjustment to the disease [453,469]. However, prospective evidence for the role of perceived stress in arthritis onset is limited. In a prospective population-based study focused on the relationship between childhood trauma and the onset of medically diagnosed arthritis in Canadian men and women, perceived stress was found to have a significant confounding effect on this relationship. Particularly, chronic perceived stress conferred a similar risk to that of experiencing multiple childhood adversities [301]. While perceived stress may be a key risk factor in arthritis onset, these findings may reflect symptom expression as opposed to disease onset.

It is important to gain an understanding of the role perceived stress may play in the onset of arthritis, controlling for additional psychosocial processes (e.g. social support and mental health) that may influence the stress-chronic disease relationship in conjunction with traditional risk/protective factors for arthritis (including socioeconomic
status, age, obesity, physical activity, occupation, and gynaecological status). Social support, in particular has been found to have both direct and moderating effects on the stress response in arthritis populations [329-333]. Modelling these distinct relationships may assist in qualifying this relationship. The main aim of this study is to examine longitudinally the relationship between perceived stress and arthritis in a broadly representative cohort of women transitioning from midlife to older age. It is hypothesised that perceived stress will precede the onset of arthritis in these women. Additionally, it is hypothesised that personal psychosocial coping resources (i.e. social support) will act as a moderator of this relationship.

5.2 Methods

5.2.1 Sample

The focus of this study is on women from the ALSWH 1946-1951 cohort who completed surveys in 2001 (survey 3), 2004 (survey 4) and 2007 (survey 5) when the diagnosis of arthritis was examined. Of the 14,099 women (aged 45-50 years) who responded to the initial invitation in 1996, 11,220 (79.6%), 10,905 (77.3%) and 10,638 (75.5%) completed the follow-up surveys in 2001, 2004 and 2007, respectively (unweighted data). These women were found to be largely representative of the original cohort with a slight over-representation of married, Australian born and tertiary educated women [520] (see Chapter 3). According to ALSWH recommendations, all cross-sectional analyses were weighted for area of residence in order to correct for the oversampling of women from rural and remote areas. The weighted sample sizes at each survey comprised 11,042 (survey 3), 10,715 (survey 4) and 10,532 (survey 5). The longitudinal analysis related to those women who provided at least one data point at either survey 3, 4 or 5. Thus, the final sample for the longitudinal analysis comprised 12,202 (86.5%; unweighted data) women.

5.2.2 Measures

The following variables were included in analyses examining the role of perceived stress as a predictor of arthritis. These measures are described in detail in Section 3.5.1 of the quantitative methods chapter.
Arthritis case definition (outcome)

‘Arthritis’ was defined as those women who reported being diagnosed with, or treated for any form of arthritis in the past three years at either survey 3, 4 or 5. At surveys 3 and 4 women were asked to indicate whether they had been diagnosed or treated for ‘arthritis/rheumatism’. At survey 5 however, this item was amended to reflect the major arthritis forms with separate questions relating to diagnosis or treatment of OA, RA or another form of arthritis (other arthritis). Responses were dichotomised to indicate the presence or absence of at least one form of arthritis. This method of arthritis case definition is considered a valid approach for epidemiological research [542-544]. As arthritis is considered a chronic unremitting condition, once a respondent indicated having arthritis, they were considered to have the disease thereafter.

Predictor variable

Psychological stress

The ALSWH developed Perceived Stress Scale [545] was used to assess levels of psychological stress. Mean scores were aggregated into ‘no stress’ (mean score of 0), ‘minimal stress’ (scores >0 and ≤1) and ‘moderate/high stress’ (scores >1).

Covariates

The following psychosocial processes (that influence the stress process) and traditional arthritis risk/protective factors (see Section 2.3 for a review of traditional risk factors) were included in the multivariate model examining perceived stress as a predictor of arthritis onset.

Negative life events experienced within the past 12 months

Cohort specific life events were extracted from a modified version of the Life Event Questionnaire [550]. Women were asked to indicate whether they had experienced life events of varying severity and chronicity including a significant trauma (e.g. death of a spouse) or constant sources of stress (e.g. financial difficulties) in the previous 12 months.

Psychiatric comorbidity
Women were considered to have doctor-diagnosed depression and anxiety if they reported being diagnosed with, or treated for these conditions in the past three years.

**Perceived social support**

The abbreviated version of the Medical Outcomes Study Social Support Survey [537] was used to measure perceived social support. Mean scores for the scale were aggregated into ‘all of the time’ (scores >4 and ≤5), ‘most of the time’ (scores >3 and ≤4), ‘some of the time’ (>2 and ≤3) and ‘none/little of the time’ (scores ≤2).

**Body mass index**

BMI was calculated for each participant from self-reported height and weight and was aggregated into four categories according to WHO guidelines [556]: ‘underweight’ (<18.5), ‘healthy’ (18.5-24.99), ‘overweight’ (25-29.99) and ‘obese’ (≥30).

**Physical activity**

Items from Active Australia’s National Activity Survey [560] based upon the frequency and duration of leisure-time activity in the last week was used as a measure of physical activity. Weekly minutes were assigned a resting MET equivalent and were defined as ‘nil/sedentary’ (<40 MET mins/week), ‘low’ (>40 and <600 MET mins/week), ‘moderate’ (600-<1200 mins/week), and ‘high’ (≥ 1200 MET mins/week).

**Smoking**

Women were also classified according to cigarettes smoked each day as ‘non-smoker’, ‘ex-smoker’, and ‘current smoker’ using a modified version of the AIHW data dictionary [563].

**Age**

Age was determined from date of birth and reported as a continuous variable in years.

**Marital status**
Marital status was modified from the ABS 1996 Census of Population and Housing survey [564] and was aggregated into ‘married/de facto’, ‘separated/divorced/widowed’ and ‘never married’.

**Area of residence**

Area of residence was determined via postcode and was categorised according to the Rural Remote and Metropolitan Areas classification system [565] as ‘urban’ and ‘rural/remote’.

**Educational attainment**

Highest educational qualifications survey question from the baseline questionnaire administered in 1996 was used as a proxy measure of SES. This item was modelled on the ABS 1996 Census of Population and Housing survey [564]. Educational attainment was aggregated into four categories to reflect the major educational achievements in Australia: ‘no formal education’, ‘secondary education’, ‘trade/diploma’ and ‘tertiary/post graduate’.

**Occupation**

Occupational status was modelled on the Australian Standard Classification of Occupations [568]. For this analysis occupational categories were created based upon hierarchical occupational status [569], with ‘highly skilled’ occupations (manager or administrator, professional, associate professional) grouped together. Other categories included ‘skilled’ (tradesperson or related, advanced clerical or service worker, intermediate clerical, sales or service worker, intermediate production or transport worker, elementary clerical, sales or service worker), ‘less skilled’ (labourer or related worker), and no paid employment.

**Menopause status**

Menopause status was determined on the basis of self-report menstrual bleeding using a similar approach to that of Brambilla and colleagues [570]. As such, menopause status was classified as ‘pre/peri-menopause’, ‘post-menopause’, and ‘surgical menopause’.
**Hormone replacement therapy**

Current HRT usage was assessed in a separate question which contained dichotomous response categories (yes/no).

In conjunction with the above mentioned variables, the following disease-related covariates were also included as part of sensitivity analyses examining arthritis as a predictor of perceived stress. Detailed variable descriptions are located in Section 3.5.1 of this thesis.

**Comorbid conditions**

Women who reported being diagnosed with, or treated for anaemia, osteoporosis, diabetes, or cardiovascular disease in the past three years were considered to have chronic medical comorbidity.

**Somatic symptomatology**

Women were considered to have comorbid somatic symptomatology if they reported experiencing fatigue, gastrointestinal problems, or headaches/migraine sometimes/often in the previous 12 months.

**Health service consultations**

Health service use was assessed by the number of visits made to a GP in the previous 12 months. For the purposes of this thesis, response categories for GP consultations were aggregated into ‘none’, ‘one or two’, ‘three or four’, ‘five or six’ and ‘seven or more’ consultations.

**5.2.3 Statistical analyses**

Chi-square analyses were employed to report differences between women who had arthritis from those that did not at each of the three surveys. Unadjusted logistic regression analyses were performed to examine the association with the arthritis-perceived stress relationship. All univariate analyses were weighted for area (i.e. where area of residence was not included in the model) in order to correct for the oversampling of women from rural and remote areas.
Graphical representations of the relationship between perceived stress and arthritis were derived from classifying women as having prevalent, incident or no arthritis at each of the three surveys. Women who reported arthritis at survey 3 in 2001 were classified as having ‘prevalent’ arthritis, while women who did not report arthritis at any of the three surveys were classified as having ‘no’ arthritis. Women who did not report arthritis in 2001 but indicated arthritis in either of the subsequent surveys (i.e. survey 4 or 5) were classified as having ‘incident’ arthritis. Separate cross-sectional multinomial logistic regressions were fitted to the data, with perceived stress as the dependent variable and arthritis status, along with the psychosocial, behavioural, demographic and health-related covariates as independent variables.

The longitudinal association between perceived stress and arthritis status was examined using binary logistic GEE models (based upon the identity link function) with an independent correlation matrix. Models were constructed with and without a time lag (i.e. one survey period or three years) at both a univariate (weighted for area of residence) and multivariate level. This method allowed for the examination of a temporal sequence (i.e. cause and effect) between perceived stress and arthritis onset (with psychological stress preceding arthritis diagnosis). With a slight variation to the standard GEE model, the GEE time lag model was used to examine whether psychological stress (the predictor variable) repeatedly studied over time was related to arthritis diagnosis (the outcome variable) one survey later, taking into account the temporal sequence of cause and effect [595].

Limited research has suggested that a delay between the onset of symptoms and the diagnosis of arthritis, particularly for OA may exist [128-130]. In order to mitigate the potential impact of possible undiagnosed arthritis on the analysis, the time lag model was also conducted on a sub-sample of women (n=10,986) excluding women without arthritis at any survey who reported experiencing joint pain ‘often’ at either survey 4 or 5; women with incident arthritis at survey 4 who reported experiencing joint pain ‘often’ at survey 3; and women with incident arthritis at survey 5 who reported joint pain ‘often’ at either survey 3 or 4 (n=1,216).

Moreover, interaction GEE models (with and without time lags) for social support were also fitted to the data in order to test the hypothesis regarding the moderating effect of psychosocial processes on the relationship between perceived stress and arthritis. Finally, sensitivity analyses were conducted in order to provide further support for the role of perceived stress as a predictor in the onset of arthritis. Adjusted multinomial
GEE models (with and without a time lag), controlling for arthritis onset predictors and factors that impact on the arthritis experience (e.g. disease comorbidity and health service use) were conducted in order to examine the role of arthritis as a predictor of perceived stress over time.

Odds ratios were reported based upon the Wald statistic using the maximum likelihood method. Due to a large sample size, statistical significance was set at $p<0.005$. All analyses were conducted using the software package SPSS v.19 (SPSS Inc., Chicago, IL, USA) and graphs were constructed in Microsoft Excel 2010.

### 5.3 Results

#### 5.3.1 Sample characteristics

In 2001, a total of 2,441 (22.2%) women reported being diagnosed with, or treated for arthritis in the previous three years. Demographically, the majority of these women with a mean age of 52.5 (SD=1.5) years were living in partnered relationships (79.8%), resided in urban areas (69.8%), and had achieved secondary education (46.4%) or higher (20.1% and 17.3% for trade and tertiary education, respectively). The women reported diverse occupations with 33.4% employed in highly skilled occupations, 30.0% in skilled occupations and 6.0% in less skilled occupations. Meanwhile, a total of 2,510 women (22.7%) reported no paid employment.

At the following survey, 3,452 (32.4%) women reported being diagnosed or treated for arthritis within the following three years, while in 2007, 41.2% of women reported arthritis ($n=4,301$). A total of 9,116 women completed the question relating to arthritis diagnosis at all three surveys, with 2,013 (22.1%) reporting arthritis at all three time points. An additional 965 (10.6%) women reported arthritis twice and 782 (8.6%) women reported arthritis on one occasion.

A sensitivity analysis was conducted using chi-square for arthritis diagnosis between women who remained in the cohort at either of the follow-up 2004 and 2007 surveys from women who did not in order to assess for sample bias arising from attrition between each of the surveys. These comparisons revealed no significant differences in arthritis status between women who provided data at each of the time points from
women who did not. Chi-square comparisons for arthritis status are located in Appendix C.1.

5.3.2 Cross-sectional associations between perceived stress and arthritis

As indicated in Table 5.1, women with arthritis consistently reported significantly higher prevalence estimates of moderate/high perceived stress in comparison to women without arthritis. Peak prevalence was reported in 2001 with 22.1% of women (n=536) with arthritis experiencing higher levels of perceived stress compared to only 14.2% (n=1,214) of women without the disease.
Table 5.1. Cross-sectional analyses for perceived stress according to arthritis status for the 1946-1951 cohort during the survey periods 2001-2007

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</thead>
<tbody>
<tr>
<td></td>
<td>Missing n (%)</td>
<td>No arthritis n (%)</td>
<td>Arthritis n (%)</td>
</tr>
<tr>
<td>None [ref]</td>
<td>696 (8.2%)</td>
<td>100 (4.1%)</td>
<td>689 (9.6%)</td>
</tr>
<tr>
<td>Minimal</td>
<td>6626 (77.6%)</td>
<td>1790 (73.8%)</td>
<td>5520 (77.2%)</td>
</tr>
<tr>
<td>Moderate/high</td>
<td>1214 (14.2%)</td>
<td>536 (22.1%)</td>
<td>942 (13.2%)</td>
</tr>
<tr>
<td>Missing</td>
<td>80 (0.7%)</td>
<td>131 (1.2%)</td>
<td>123 (1.2%)</td>
</tr>
</tbody>
</table>

* all analyses were weighted for area of residence.

* all associations significant (p<0.001).
Additionally, Figure 5.1 shows that women with prevalent arthritis consistently reported the highest levels of moderate/high perceived stress across the three time points. The proportion of women with moderate/high levels of perceived stress were the highest across the six year study period for women with prevalent arthritis, however by 2007 these levels approached those of women with incident arthritis. In 2001, women categorised as having no arthritis reported higher levels of minimal stress, while those with prevalent arthritis reported the least. In 2004, the proportion of women reporting minimal stress by women with no arthritis and incident arthritis were the same, and by 2007 all three groups were reporting similar proportions. Fewer women with prevalent arthritis reported experiencing no stress in comparison to the other two groups. However, in the follow-up surveys, the proportions of women contributing to the prevalent and incident arthritis groups were similar. Further, while women who did not report arthritis at any survey reported higher levels of moderate/high stress in comparison to no stress in 2001, the proportion of women contributing to either group were similar in 2004 and 2007.
Figure 5.1. The relationship between arthritis and perceived stress for the 1946-1951 cohort across three time points according to arthritis status (prevalent, incident and no arthritis)
5.3.3 The longitudinal relationship between perceived stress and arthritis

The longitudinal relationship between perceived stress and arthritis was examined using binary logistic GEE models. As shown in Table 5.2, the unadjusted odds associated with arthritis significantly increased over time. Specifically, women who reported experiencing minimal stress were 1.7 (95% CI=1.5, 2.0; p<0.001) times more likely to report having arthritis than women who had experienced no stress during the study period. Likewise, women who reported moderate/high levels of perceived stress were found to have a 2.6 (95%CI=2.2, 3.0; p<0.001) increase in odds of reporting arthritis. Univariate associations for the covariates are located in Appendix C.2.
Table 5.2. Unadjusted longitudinal GEE models reporting odds ratios and 95% confidence intervals (CI) for the relationship between perceived stress and arthritis during the period 2001-2007<sup>a</sup>

<table>
<thead>
<tr>
<th>Perceived stress</th>
<th>GEE Model without time lag</th>
<th>GEE Model with time lag</th>
<th>GEE Model with time lag (excluding persistent joint pain)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Odds ratio (95% CI)</td>
<td>P Value</td>
<td>Odds ratio (95% CI)</td>
</tr>
<tr>
<td>None [ref]</td>
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</tr>
<tr>
<td>Minimal</td>
<td>1.7 (1.5, 2.0)</td>
<td>&lt;0.001</td>
<td>1.8 (1.5, 2.1)</td>
</tr>
<tr>
<td>Moderate/high</td>
<td>2.6 (2.2, 3.0)</td>
<td>&lt;0.001</td>
<td>3.0 (2.5, 3.6)</td>
</tr>
</tbody>
</table>

<sup>a</sup> weighted for area.
When psychosocial, behavioural, demographic and health-related confounders were included in the model, the odds of experiencing arthritis dropped slightly with minimal stress found to be predictive of a 1.5-fold (95% CI=1.4, 1.8; p<0.001) increase in the odds of reporting arthritis and a 1.9-fold increase for those moderately to highly stressed (95% CI=1.6, 2.2; p<0.001). Of the psychosocial variables included in the multivariate model, major illness of a family member/close friend (OR=1.1, 95% CI=1.1, 1.2; p<0.001), having diagnosed depression (OR=1.4, 95% CI=1.2, 1.5; p<0.001) or anxiety (OR=1.2, 95% CI=1.1, 1.4; p<0.001) and perceiving the availability of functional social support most of the time (OR=1.2, 95% CI=1.1, 1.3; p<0.001) were also independently associated with arthritis (see Table 5.3).
Table 5.3. Adjusted longitudinal GEE models reporting odds ratios and 95% confidence intervals (CI) for the relationship between perceived stress and arthritis during the period 2001-2007

<table>
<thead>
<tr>
<th>Perceived stress</th>
<th>GEE Model without time lag</th>
<th>GEE Model with time lag</th>
<th>GEE Model with time lag (excluding persistent joint pain)</th>
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<tbody>
<tr>
<td></td>
<td>Odds ratio (95% CI)</td>
<td>P Value</td>
<td>Odds ratio (95% CI)</td>
</tr>
<tr>
<td>None [ref]</td>
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<tr>
<td>Minimal</td>
<td>1.5 (1.4, 1.8)</td>
<td>&lt;0.001</td>
<td>1.6 (1.4, 1.9)</td>
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<td>Moderate/high</td>
<td>1.9 (1.5, 2.1)</td>
<td>&lt;0.001</td>
<td>2.0 (1.7, 2.4)</td>
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<td>Negative life events experienced within the past 12 months</td>
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<tr>
<td>Death of a family member/close friend</td>
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<tr>
<td>No [ref]</td>
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<tr>
<td>Yes</td>
<td>1.1 (1.0, 1.1)</td>
<td>0.148</td>
<td>1.0 (0.9, 1.1)</td>
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<tr>
<td>Major illness of family member/close friend</td>
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<tr>
<td>No [ref]</td>
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<tr>
<td>Yes</td>
<td>1.1 (1.1, 1.2)</td>
<td>&lt;0.001</td>
<td>1.2 (1.1, 1.2)</td>
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<tr>
<td>Interpersonal/relationship difficulties</td>
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<tr>
<td>No [ref]</td>
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<tr>
<td>Yes</td>
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<td>1.1 (1.0, 1.2)</td>
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<tr>
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<td>0.033</td>
<td>1.1 (1.0, 1.2)</td>
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<td>Psychiatric diagnoses</td>
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<td>Depression</td>
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<td>No [ref]</td>
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<tr>
<td>Yes</td>
<td>1.4 (1.2, 1.5)</td>
<td>&lt;0.001</td>
<td>1.4 (1.3, 1.6)</td>
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### Results from the ALSWH: The influence of perceived stress on the onset of arthritis in women

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<td></td>
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<tr>
<td>Most of the time</td>
<td>1.2 (1.1, 1.3)</td>
<td>&lt;0.001</td>
<td>1.2 (1.1, 1.3)</td>
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<td>None/little of the time</td>
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<td>BMI</td>
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<td>0.9 (0.7, 1.3)</td>
<td>0.764</td>
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<td>0.9 (0.6, 1.4)</td>
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<td>Healthy weight [ref]</td>
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<td>Marital status</td>
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<td>1.3 (1.2, 1.5)</td>
<td>&lt;0.001</td>
<td>1.4 (1.3, 1.5)</td>
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<tr>
<td>Obese</td>
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<td>&lt;0.001</td>
<td>2.0 (1.8, 2.2)</td>
<td>&lt;0.001</td>
<td>2.1 (1.9, 2.3)</td>
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<tr>
<td>Physical activity</td>
<td>Nil/sedentary</td>
<td>1.2 (1.1, 1.4)</td>
<td>&lt;0.001</td>
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<td>0.001</td>
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Note: time was entered as a within subjects variable and as a predictor.
5.3.4 The longitudinal relationship between perceived stress and arthritis using a time lag approach

Findings related to the time lag analyses provided similar results to those using the GEE approach without a time lag (see Table 5.2 and Table 5.3). Notably, the odds associated with reporting arthritis increased when using this technique. Univariate analyses revealed that compared to women who experienced no stress, women who experienced minimal levels of perceived stress in the previous 12 months were found to be 1.8 times more likely to report arthritis (95% CI=1.5, 2.1; p<0.001) at the following survey (i.e. three years later), while moderate/high stress resulted in a three-fold increase (95% CI=2.5, 3.6; p<0.001) in the odds of reporting of arthritis three years later (see Table 5.2).

Moreover, the multivariate time lag GEE model (see Table 5.3) indicated a 1.6 (95% CI=1.4, 1.9; p<0.001) increase in odds of reporting arthritis when experiencing minimal levels of stress compared to women with no stress, three years later. This number increased slightly when considering moderate/high levels of perceived stress, with a two-fold (95% CI=1.7, 2.4; p<0.001) increase in odds noted.

Findings relating to perceived stress as a predictor of arthritis onset increased further, particularly in relation to moderate/high stress when the time lag model was employed following the exclusion of women with persistent joint pain.9 Particularly, at a univariate level, compared to women who experienced no stress, women with minimal levels of stress were found to be 1.8 times more likely to report arthritis (95% CI=1.6, 2.2; p<0.001) at the following survey, while those with moderate/high stress levels resulted in a 3.7 increase (95% CI=3.1, 4.5; p<0.001) in the odds of reporting arthritis three years later (see Table 5.2).

At a multivariate level, women with minimal levels of stress reported a 1.7-fold increase (95% CI=1.5, 2.0; p<0.001) in arthritis diagnosis at the following survey compared to women without stress. On the other hand, women with moderate/high perceived stress levels were 2.4 times more likely to report being diagnosed with arthritis three years later than women without stress (95% CI=2.0, 2.9; p<0.001) (see Table 5.3).

9 This method was employed in order to mitigate the potential impact of undiagnosed arthritis on the analysis.
In both time lag models, psychosocial factors such as major illness of a family member/close friend, having diagnosed depression and perceiving functional forms of social support either most of the time and none/little of the time were also significantly associated with arthritis diagnosis three years later (see Table 5.3).

5.3.5 Social support as a moderator of the perceived stress-arthritis relationship

Higher order multivariate interactional analyses testing social support as a moderator of the perceived stress-arthritis relationship revealed no significant associations (all ps>0.005) for all examined models (see Table 5.4).
Table 5.4. Adjusted longitudinal GEE interaction models (social support) for the relationship between perceived stress and arthritis during the period 2001-2007

<table>
<thead>
<tr>
<th></th>
<th>GEE Model without time lag</th>
<th>GEE Model with time lag</th>
<th>GEE Model with time lag (excluding persistent joint pain)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Odds ratio (95% CI)</td>
<td>P Value</td>
<td>Odds ratio (95% CI)</td>
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<td>Perceived stress</td>
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<tr>
<td>Minimal</td>
<td>1.6 (1.3, 1.8)</td>
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<td>Moderate/high</td>
<td>1.8 (1.4, 2.2)</td>
<td>&lt;0.001</td>
<td>2.3 (1.7, 3.1)</td>
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<td>Perceived social support</td>
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<tr>
<td>All of the time [ref]</td>
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<tr>
<td>Most of the time</td>
<td>1.3 (1.0, 1.7)</td>
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<td>1.2 (0.8, 1.8)</td>
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<td>Some of the time</td>
<td>1.3 (0.7, 2.1)</td>
<td>0.393</td>
<td>2.2 (1.1, 4.7)</td>
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<td>None/little of the time</td>
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<td>Perceived stress x social support</td>
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<tr>
<td>None x some of the time</td>
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<tr>
<td>None x none/little of the time</td>
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<tr>
<td>Minimal x all of the time</td>
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<tr>
<td>Minimal x most of the time</td>
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<td>Minimal x none/little of the time</td>
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<td>Moderate/high x all of the time</td>
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<tr>
<td>Moderate/high x most of the time</td>
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## Negative Life Events Experienced within the Past 12 Months

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<td><strong>Death of a family member/close friend</strong></td>
<td>1.1 (1.0, 1.1)</td>
<td>0.147</td>
<td>1.0 (0.9, 1.2)</td>
<td>0.440</td>
<td>1.1 (1.0, 1.2)</td>
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<td><strong>Major illness of family member/close friend</strong></td>
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<td>&lt;0.001</td>
<td>1.2 (1.1, 1.3)</td>
<td>&lt;0.001</td>
<td>1.2 (1.1, 1.4)</td>
<td>&lt;0.001</td>
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<tr>
<td><strong>Interpersonal/relationship difficulties</strong></td>
<td>1.1 (1.0, 1.2)</td>
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<td>1.1 (0.9, 1.2)</td>
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<td>1.0 (0.9, 1.2)</td>
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<td><strong>Financial strain</strong></td>
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<td>1.1 (1.0, 1.2)</td>
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## Psychiatric Diagnoses

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<th>p-value</th>
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<td><strong>Depression</strong></td>
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<td>&lt;0.001</td>
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<td><strong>Anxiety/nervous disorder</strong></td>
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## BMI

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<td><strong>Under weight</strong></td>
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<td>0.744</td>
<td>0.9 (0.6, 1.4)</td>
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<td><strong>Healthy weight</strong></td>
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<td><strong>Overweight</strong></td>
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<td><strong>Obese</strong></td>
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## Physical Activity

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<tbody>
<tr>
<td><strong>Nil/sedentary</strong></td>
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<td>&lt;0.001</td>
<td>1.3 (1.1, 1.5)</td>
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<td><strong>Low</strong></td>
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<td>0.732</td>
<td>1.0 (0.9, 1.1)</td>
<td>0.773</td>
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Results from the ALSWH: The influence of perceived stress on the onset of arthritis in women

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</table>

Note: time was entered as a within subjects variable and as a predictor.
5.3.6 Sensitivity analyses

Findings from the adjusted multinomial GEE models (with and without a time lag) examining arthritis as a predictor of perceived stress also produced non-significant findings (all ps>0.005) (see Table 5.5).
Table 5.5. Adjusted multinomial GEE models (with no stress as the reference category) for the impact of arthritis on perceived stress during the period 2001-2007, controlling for onset predictors, chronic conditions and health service use

<table>
<thead>
<tr>
<th></th>
<th>GEE Model without a time lag</th>
<th>GEE Model with a time lag</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Minimal stress</td>
<td>Moderate/high stress</td>
</tr>
<tr>
<td></td>
<td>Odd Ratio (95%CI)</td>
<td>P Value</td>
</tr>
<tr>
<td>Arthritis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Yes</td>
<td>1.2 (1.1, 1.4)</td>
<td>0.005</td>
</tr>
<tr>
<td>Negative life events experienced</td>
<td></td>
<td></td>
</tr>
<tr>
<td>among the past 12 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death of a family member/close friend</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Yes</td>
<td>1.0 (0.9, 1.1)</td>
<td>0.753</td>
</tr>
<tr>
<td>Major illness of family member/close friend</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Yes</td>
<td>2.5 (2.1, 2.8)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Interpersonal/relationship difficulties</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Yes</td>
<td>3.3 (2.5, 4.4)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Financial strain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Yes</td>
<td>1.9 (1.6, 2.3)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Psychiatric diagnoses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Yes</td>
<td>2.2 (1.5, 3.0)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>
### Anxiety/nervous disorder

<table>
<thead>
<tr>
<th></th>
<th>No [ref]</th>
<th>Yes</th>
<th>2.6 (1.7, 3.9)</th>
<th>&lt;0.001</th>
<th>6.4 (3.8, 10.8)</th>
<th>&lt;0.001</th>
<th>1.5 (1.0, 2.3)</th>
<th>0.050</th>
<th>2.8 (1.7, 4.8)</th>
<th>0.001</th>
</tr>
</thead>
</table>

### Perceived social support

<table>
<thead>
<tr>
<th></th>
<th>All of the time [ref]</th>
<th>Most of the time</th>
<th>1.7 (1.5, 2.0)</th>
<th>&lt;0.001</th>
<th>3.6 (2.9, 4.5)</th>
<th>&lt;0.001</th>
<th>1.5 (1.3, 1.8)</th>
<th>&lt;0.001</th>
<th>2.5 (2.0, 3.2)</th>
<th>&lt;0.001</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Some of the time</td>
<td>2.4 (2.0, 3.0)</td>
<td>&lt;0.001</td>
<td>8.7 (6.4, 11.9)</td>
<td>&lt;0.001</td>
<td>2.0 (1.6, 2.5)</td>
<td>&lt;0.001</td>
<td>3.9 (2.8, 5.3)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>None/little of the time</td>
<td>1.4 (1.1, 1.8)</td>
<td>0.008</td>
<td>7.0 (5.0, 9.9)</td>
<td>&lt;0.001</td>
<td>1.4 (1.0, 1.9)</td>
<td>0.023</td>
<td>4.1 (2.7, 6.3)</td>
<td>&lt;0.001</td>
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</tbody>
</table>

### BMI

<table>
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<tr>
<th></th>
<th>Under weight</th>
<th>Healthy weight [ref]</th>
<th>Overweight</th>
<th>Obese</th>
<th>0.8 (0.5, 1.4)</th>
<th>0.507</th>
<th>1.1 (0.5, 2.2)</th>
<th>0.848</th>
<th>0.8 (0.4, 1.6)</th>
<th>0.599</th>
<th>1.0 (0.5, 2.1)</th>
<th>0.975</th>
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</thead>
</table>

### Physical activity

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<tr>
<th></th>
<th>Nil/sedentary</th>
<th>Low</th>
<th>1.0 (0.9, 1.1)</th>
<th>0.919</th>
<th>1.1 (0.9, 1.4)</th>
<th>0.321</th>
<th>0.9 (0.8, 1.1)</th>
<th>0.330</th>
<th>1.0 (0.8, 1.2)</th>
<th>0.879</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Moderate [ref]</td>
<td>High</td>
<td>0.8 (0.7, 0.9)</td>
<td>&lt;0.001</td>
<td>0.7 (0.5, 0.9)</td>
<td>0.006</td>
<td>0.9 (0.7, 1.0)</td>
<td>0.054</td>
<td>0.9 (0.7, 1.1)</td>
<td>0.249</td>
</tr>
</tbody>
</table>

### Smoking status

<table>
<thead>
<tr>
<th></th>
<th>Non-smoker [ref]</th>
<th>Ex-smoker</th>
<th>1.2 (1.1, 1.4)</th>
<th>0.006</th>
<th>1.5 (1.2, 1.9)</th>
<th>&lt;0.001</th>
<th>1.3 (1.1, 1.5)</th>
<th>0.002</th>
<th>1.5 (1.2, 1.9)</th>
<th>&lt;0.001</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Current smoker</td>
<td>1.3 (1.1, 1.6)</td>
<td>0.006</td>
<td>2.0 (1.5, 2.8)</td>
<td>&lt;0.001</td>
<td>1.2 (1.0, 1.5)</td>
<td>0.084</td>
<td>2.0 (1.4, 2.7)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
</tbody>
</table>

### Age

|                          | 0.94 (0.90, 0.98) | 0.002 | 0.86 (0.80, 0.92) | <0.001 | 0.93 (0.89, 0.98) | 0.003 | 0.81 (0.75, 0.87) | <0.001 |

### Marital status

<table>
<thead>
<tr>
<th></th>
<th>Married/de facto [ref]</th>
<th>Separated/divorced/widowed</th>
<th>1.0 (0.8, 1.2)</th>
<th>0.842</th>
<th>1.0 (0.8, 1.4)</th>
<th>0.878</th>
<th>1.0 (0.8, 1.2)</th>
<th>0.975</th>
<th>1.1 (0.8, 1.5)</th>
<th>0.650</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never married</td>
<td>0.7 (0.5, 1.0)</td>
<td>0.066</td>
<td>0.5 (0.2, 0.9)</td>
<td>0.026</td>
<td>0.8 (0.5, 1.2)</td>
<td>0.257</td>
<td>0.7 (0.4, 1.3)</td>
<td>0.259</td>
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### Area of residence

<table>
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<tr>
<th></th>
<th>Urban [ref]</th>
<th>Rural/remote</th>
<th>0.9 (0.8, 1.0)</th>
<th>0.099</th>
<th>0.8 (0.6, 0.9)</th>
<th>0.008</th>
<th>0.9 (0.8, 1.1)</th>
<th>0.277</th>
<th>0.7 (0.6, 0.9)</th>
<th>0.002</th>
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</thead>
</table>
## Educational attainment

<table>
<thead>
<tr>
<th></th>
<th>Tertiary/post graduate [ref]</th>
<th>Trade/diploma</th>
<th>School/higher school certificate</th>
<th>No formal education</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>0.6 (0.5, 0.8)</td>
<td>&lt;0.001 0.5 (0.3, 0.7) &lt;0.001 0.7 (0.5, 0.9) 0.001 0.5 (0.3, 0.7)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.5 (0.4, 0.7)</td>
<td>&lt;0.001 0.4 (0.3, 0.6) &lt;0.001 0.6 (0.5, 0.8) &lt;0.001 0.5 (0.3, 0.7)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.4 (0.3, 0.5)</td>
<td>&lt;0.001 0.3 (0.2, 0.5) &lt;0.001 0.5 (0.4, 0.7) &lt;0.001 0.4 (0.3, 0.6)</td>
<td>&lt;0.001</td>
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<tr>
<td>occupation</td>
<td>Highly skilled [ref]</td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Skilled</td>
<td>0.9 (0.8, 1.0)</td>
<td>0.138 0.8 (0.6, 1.1) 0.198 0.9 (0.8, 1.1) 0.356 1.0 (0.8, 1.3)</td>
<td>0.993</td>
</tr>
<tr>
<td></td>
<td>Less skilled</td>
<td>0.6 (0.5, 0.8)</td>
<td>&lt;0.001 0.4 (0.3, 0.7) &lt;0.001 0.7 (0.5, 0.9) 0.008 0.7 (0.5, 1.1)</td>
<td>0.108</td>
</tr>
<tr>
<td></td>
<td>No paid employment</td>
<td>0.7 (0.6, 0.8)</td>
<td>&lt;0.001 0.4 (0.3, 0.6) &lt;0.001 0.7 (0.6, 0.8) &lt;0.001 0.6 (0.4, 0.7)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Menopause status</td>
<td>Pre/peri-menopause</td>
<td>1.0 (0.8, 1.2)</td>
<td>0.841 0.9 (0.7, 1.2) 0.693 0.9 (0.8, 1.1) 0.411 1.0 (0.7, 1.3)</td>
<td>0.785</td>
</tr>
<tr>
<td></td>
<td>Post-menopause [ref]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Surgical menopause</td>
<td>0.9 (0.8, 1.1)</td>
<td>0.271 0.9 (0.7, 1.2) 0.609 0.9 (0.7, 1.0) 0.106 1.0 (0.7, 1.2)</td>
<td>0.745</td>
</tr>
<tr>
<td>HRT use</td>
<td>No [ref]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1.1 (0.9, 1.2)</td>
<td>0.342 1.2 (1.0, 1.6) 0.098 1.2 (1.0, 1.4) 0.053 1.2 (1.0, 1.6)</td>
<td>0.092</td>
</tr>
<tr>
<td>Comorbid conditions</td>
<td>Anaemia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No [ref]</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1.3 (1.0, 1.6)</td>
<td>0.059 0.9 (0.6, 1.4) 0.790 1.2 (0.9, 1.6) 0.169 1.3 (0.9, 2.0)</td>
<td>0.108</td>
</tr>
<tr>
<td></td>
<td>Osteoporosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No [ref]</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1.0 (0.7, 1.3)</td>
<td>0.903 0.9 (0.6, 1.6) 0.836 1.1 (0.8, 1.6) 0.598 1.5 (1.0, 2.4)</td>
<td>0.075</td>
</tr>
<tr>
<td></td>
<td>Diabetes</td>
<td></td>
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<tr>
<td></td>
<td>No [ref]</td>
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<td></td>
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<tr>
<td></td>
<td>Yes</td>
<td>0.7 (0.6, 1.0)</td>
<td>0.050 1.0 (0.7, 1.6) 0.864 0.6 (0.5, 0.9) 0.012 0.6 (0.4, 1.1)</td>
<td>0.123</td>
</tr>
<tr>
<td></td>
<td>Cardiovascular disease</td>
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<tr>
<td></td>
<td>No [ref]</td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1.1 (1.0, 1.3)</td>
<td>0.138 1.0 (0.8, 1.3) 0.766 1.0 (0.8, 1.1) 0.640 0.9 (0.7, 1.2)</td>
<td>0.501</td>
</tr>
<tr>
<td>Somatic symptomatology</td>
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<td></td>
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</table>


### Fatigue

<table>
<thead>
<tr>
<th></th>
<th>Never/rarely [ref]</th>
<th>Sometimes/often</th>
<th>Sometimes/often</th>
<th>Sometimes/often</th>
<th>Sometimes/often</th>
<th>Sometimes/often</th>
<th>Sometimes/often</th>
<th>Sometimes/often</th>
</tr>
</thead>
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<tr>
<td>Gastrointestinal problems</td>
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<tr>
<td>Headache/migraine</td>
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</tbody>
</table>

**Note:** time was entered as a within subjects variable and as a predictor.
5.4 Discussion

This is the first study to examine the role of perceived stress in the onset of arthritis in a cohort of Australian women transitioning from midlife to older age. Findings from the longitudinal analyses indicate that perceived stress is a strong risk factor for arthritis, with both minimal and moderate/high levels of perceived stress contributing to the onset of arthritis three years later. Although the use of a longitudinal study design does not allow the implication of causality, the comparison of GEE models with and without a time lag component, along with the adjustment for traditional risk factors provides evidence towards perceived stress playing a causal role in arthritis onset.

Perceived stress may contribute to disease onset through multiple pathways. As highlighted in Chapter 1, chronically appraising situations as harmful may initiate a cascade of physiological reactions which weakens the response to key allostatic systems [585,586]. In particular, researchers have speculated that psychological stress may influence the onset of arthritis, notably RA via neuroendocrine and immune pathways [71,596,597]. Dysregulation of the HPA axis has been identified as crucial to this process [598]. Chronic activation of the HPA axis and associated mechanisms, in conjunction with resultant amplification of pro-inflammatory cytokines through the experience of chronic stress perception (or alternatively depression) may have long-term health effects, including the onset of inflammatory disorders [599]. Importantly, McEwen and colleagues have argued that in the process of restoring allostatic (equilibrium) following psychological insult, chronic stress activation may result in cumulative changes that lead to allostatic overload (i.e. an inability to restore itself to the previous state of equilibrium), and thus a reorganisation in order to set a new equilibrium [600,601]. Chronically stressed individuals have been found to have rigid patterns of cortisol secretion and reduced variation [69]. Perry [602] has also suggested that repeated exposure to psychological insult may also result in activation and subsequent sensitisation of the nervous system. A response to decreasingly intense stimuli such as minor stressors may occur through this anticipatory action [603]. The findings of this study support this hypothesis, with women who develop arthritis found to have greater stressor reactivity (in terms of diagnosed depression). This may have important clinical implications.

Less evidence exists for the role of psychological stress in the onset of OA, however it has been posited that psychological stress remains a substantial contributor to cellular ageing [49,604,605] and thus may be a significant contributor to accrued joint
Results from the ALSWH: The influence of perceived stress on the onset of arthritis in women

degeneration through similar pathways to RA. This notion is supported by the work of Epel and colleagues [49] who found in their study of 58 pre-menopausal women that chronic perceived stress was associated with key physical markers of cellular ageing, including higher oxidative stress, lower telomerase activity and shortened telomere length. The authors concluded that high levels of perceived stress resulted in increased cellular ageing equivalent to one decade compared to women with low levels of stress. Others have suggested that the effects of perceived stress may be elicited via behavioural or metabolic pathways, altering health through increased engagement in adverse behaviours (e.g. poor nutrition leading to increased BMI), or through psychosocial processes (e.g. depression and poor coping), thus increasing allostatic load [606,607]. Similar pathways have been posited for conditions with chronic stress at its core [608].

The consistency in odds ratios between the multivariate models in this study suggests that women who develop arthritis chronically perceive their lives as stressful. These women may have coping mechanisms that, while adaptive in the first instance, are maladaptive in the long-term. Although an under-researched phenomenon within the arthritis literature, findings from other chronic disease studies, including those with pain as a key feature support the results of this study [609,610]. Grimby-Ekman and colleagues [610] noted that perceived stress was both a short-term, and long-term predictor of pain development in their study involving both men and women. Additionally, Smith et al. [611] demonstrated that perceived stress partially mediated the relationship between traumatic events and mental as well as physical health in women with fibromyalgia. The authors concluded that the findings suggested that although women with, and without the condition had relatively little difference in stress exposure, an exposure to trauma may have contributed to ongoing cognitive appraisals. Traumatic events may lead to long-term dysregulation of stress response systems and increased sensitivity to ongoing life demands [69,612]. Although the cumulative impact of traumatic events related to abuse was unable to be examined, arthritis was associated with the stress of having a family member/close friend with a major illness in all models (i.e. GEE models with, and without a time lag), although to a far lesser extent than perceived stress. While the role of allostasis would have to be examined in further prospective analyses, women in this study did show a hypersensitivity to this ongoing stressor.

This is supported by work involving escapable and inescapable shock in animal models. Notably, Gleitman and Holmes [613] argued that when fear is conditioned it
does not dissipate quickly as per the response to a predictable stressor such as escapable shock, but is readily retained in the organism’s memory for months or years before forgetting occurs. Similarly, Amat and colleagues [614] found in their study of the ventral medial prefrontal cortex (an area of the brain responsible for cognitive and affective processing) and the dorsal raphe nucleus (a nucleus that provides serotonin input to cortical and limbic structures that regulate autonomic and neuroendocrine functioning) in Sprague-Dawley rats, that the uncontrollability of a stressor such as inescapable shock plays a role in defining the default stress circuitry of the brain whereby exposure to a stressor activates the dorsal raphe nucleus neurons and instigates the release of serotonin. This process contributes to autonomic activation and results in the failure to learn escape abilities in novel situations. In comparison, stressor controllability inhibits activation of the dorsal raphe nucleus via the ventral medial prefrontal cortex, thereby preventing autonomic activation and preserving mechanisms around escape learning. This finding has implications for humans, particularly with regard to the experience of ongoing stress.

Further, while having functional types of social support available most of the time was found to be a modest predictor of arthritis onset in all GEE models (ORs=1.2), specific relationship sources were identified as more pertinent to arthritis onset. Notably, never being in a partnered relationship compared to those in married or de facto relationships (ORs=1.5-1.6) produced similar increases in arthritis risk as experiencing low levels of chronic stress (ORs=1.5-1.7). Although, further quantitative research is required in order to elucidate the complex interplay between stressors (including the impact of trauma histories), coping resources and stress appraisal, the results of this study suggest that having functional forms of social support available is ineffective in mitigating the deleterious effects of perceived stress. These psychosocial factors appear to act independently in increasing arthritis risk, with perceived stress far more pertinent. Concepts surrounding the meaning of stress, the perceived impact of stress on health and patterns of coping over the life course are qualitatively explored in-depth in Chapter 8.

Moreover, the findings from analyses with and without time lags indicate that arthritis risk increased for women who experienced chronic depression during the study period. This finding parallels that of Magin et al. [615] who found that perceived stress and depression predicted the onset of skin disease. While the strength of the relationship between perceived stress and arthritis onset was stronger for those women with either minimal (ORs=1.5-1.7) or moderate/high levels of stress (ORs=1.9-2.4), the experience
of chronic depression also predicted the onset of arthritis in the time lag analyses (ORs=1.4-1.5). Evidence for the depression-chronic disease link is provided in other chronic disease populations [e.g. 594,616-619]. This finding suggests that perceived stress and depression may act through similar pathways in order to induce arthritis. Interestingly, being diagnosed with an anxiety disorder was not predictive of arthritis onset in either of the time lag models (ps>0.005). This finding is supported by the work of van’t Land and colleagues [584] who failed to find a temporal relationship between anxiety and arthritis onset in their analysis of Netherlands Mental Health Survey and Incidence Study data. Similar to the findings from Chapter 4, arthritis status predicted the onset of anxiety only. Anxiety therefore appears to be a consequence of the arthritis experience rather than a risk factor for disease onset.

Taken together, the findings from this study add pertinent information to the wider body of knowledge surrounding the role of psychological stress in the onset of arthritis and have important clinical implications. The results suggest that focusing on public health strategies aimed at reducing perceived stress and poor mental health, as well as increasing personal coping resources (such as increasing social networks), coupled with current modifiable preventive strategies (focused on overweight and obesity, occupational joint overload, physical activity) may prove beneficial in the reduction of arthritis. Notably, in the time lag models, moderate/high levels of perceived stress (ORs=1.9-2.4) had a similar risk of arthritis onset to being in the highest BMI category (ORs=2.0-2.1).

In addition to being the first study to examine the role of perceived stress in the onset of arthritis in women, the study has a number of strengths. Firstly, the results are based on a nationally representative cohort sample involving over 10,000 women. This large sample size provided sufficient power to control for a number of accepted arthritis risk factors including BMI, physical activity, smoking, age, occupation and gynaecological status. Further, various aspects of the stress process were explored within the one model. Using a measure of perceived stress allowed for the examination of individual stress-associated vulnerabilities [620], while life events and psychosocial processes that may influence the perception of stress were controlled for. To date, no epidemiological studies examining stress have been able to examine stress within such a comprehensive model. A third strength of the study revolves around the statistical technique employed which allowed the examination of causality between perceived stress and arthritis onset at the following survey (i.e. three years later).
The current study must however, be considered in light of a few limitations. Firstly, this study relied upon a self-report measure of arthritis. March and colleagues [589] however, have found that self-reported physician-diagnosed general arthritis has good congruency with clinically derived diagnoses. Likewise, due to the nature of the survey, arthritis forms were unable to be distinguished. While it has been more commonly accepted that stress may play a role in the onset and exacerbation of RA due to its relationship with systemic inflammation, this study examined arthritis onset in a cohort of women transitioning from midlife to older age. It is likely that the numbers of arthritis were driven by OA. Therefore, the findings from these analyses provide the most convincing evidence that perceived stress also plays a substantial role in the onset of OA. Additionally, ‘arthritis’ is a collective term used to describe a subset of conditions characterised by inflammation of tissues in or around a joint. Symptom intensity at onset may vary according to arthritis form with differing lag times between symptom onset and diagnosis [128-130]. There is the potential for reverse causality in which individuals with undiagnosed arthritis report increasing psychological stress. Unlike the Kopec and Sayre study [301] women without arthritis with persistent joint symptoms were excluded in order to minimise this effect. While there is discordance between clinical symptomatology and radiographic evidence of OA [101,102], pain has been found to be present in approximately 75-85% of individuals with abnormalities of the knee, hips, and hands [621]. Moreover, sensitivity analyses examining arthritis as a predictor of perceived stress, controlling for factors that impact on the arthritis experience (e.g. disease comorbidity and health service use) produced non-significant findings (see Table 5.5). Given this result, it is unlikely that reverse causality contributed to the study findings, suggesting that factors other than arthritis are responsible for increased levels of stress over the course of the disease. The role of perceived stress as a risk factor to arthritis is of greater potential significance. This causal pathway however would require investigation in future studies. A further limitation of this study is that the role of perceived stress was examined in a cohort of women. Studies have shown gender differences in stress reactivity [622-624]. As such, these findings may not be generalisable to the development of arthritis in males. However, with women in this age group twice as likely as men to develop arthritis, this is an appropriate cohort to study [144].
5.5 Conclusion

The findings of this large national cohort study add to the current understanding of arthritis risk factors and highlight the importance of perceived stress in disease onset, particularly for women. Importantly, the findings indicate that chronic perceived stress has significant health consequences, with the effects of such cognitive appraisals evident years later. While further prospective evidence, is required in order to elucidate the complex pathways between stressors (including the impact of trauma histories), coping resources and stress appraisal, the findings of this study provide support for perceived stress to be considered alongside other modifiable risk factors such as obesity and physical activity.

In addition to the implementation of cognitive-behaviour interventions in order to minimise the disability associated with arthritis by reducing psychological stress and increasing psychosocial coping resources (detailed in Chapter 4), these findings provide support for the inclusion of stress and psychosocial coping as a part of the public health prevention approach. An emphasis on psychosocial factors may be pertinent to preventing or delaying the onset of arthritis in women.

The findings from this chapter in conjunction with those from Chapter 4 provide substantial information regarding the role of psychosocial factors in arthritis, particularly in terms of emotional consequences and disease onset. These findings however, are limited in their ability to fully capture the lived experience of arthritis. The following chapters will examine the lived experience of arthritis in women transitioning from midlife to older age in order to expand upon the quantitative findings and gain an understanding of aspects of the coping process unavailable from the survey data.
Chapter 6

Qualitative Methods

The Australian Longitudinal Study on Women’s Health

The findings from the quantitative cross-sectional and longitudinal analyses provide unique insight into the role that psychosocial factors play in the health of women with arthritis during the transition from midlife to older age. Specifically, these analyses identified that women with arthritis have widespread psychosocial concerns, particularly relating to stress perception and anxiety (Chapter 4). Likewise, the findings discussed in Chapter 5, provide new insight into the role that psychosocial factors may play in the onset of arthritis. Particularly highlighted was the role of perceived stress, where moderate/high levels of perceived stress were found to confer a similar risk in the onset of arthritis as being in the highest BMI category (obese).

While these findings provide an understanding of the phenomenon being studied at an epidemiological level, allowing for generalisation and prediction of outcomes [625,626], this method of enquiry does not provide an in-depth understanding of the ‘lived’ arthritis experience. In order to provide a holistic view [627], the psychosocial experiences of women with arthritis transitioning from midlife to older age were qualitatively explored. This method provided a complementary role to the quantitative analyses [628-631], allowing for the expansion and clarification of pertinent issues highlighted (i.e. the ability to unearth the meaning attributed to their experience) as well as providing the scope to uncover factors associated with the psychosocial experience that were not able to be examined at the epidemiological level.

This chapter will outline the methods employed in the development and administration of the ALSWH qualitative sub-study that forms the basis of the findings in the following two chapters. This chapter includes an overview of the research paradigm and the protocol utilised in data collection and analysis. Additionally, a description of the sampling frame and participant sample will be provided in conjunction with concerns relating to ethical practices and methodological rigour addressed.
6.1 Overview of the research paradigm and study aims

The primary purpose of qualitative or naturalistic enquiry is to extrapolate and attempt to understand the human experience [632,633]. While this process is viewed as inductive and allows the complexity and depth of phenomena to be captured [627], it may be conducted with a certain degree of objectivity. Phillips [634] has argued that objectivity provides the regulatory ideal that underpins all scientific enquiry and while this process does not necessarily guarantee ‘truth’, it provides the scope for conducting the best possible research. The present sub-study will be conducted within a ‘realist-oriented’ paradigm [635].

Moving beyond a fundamental positivistic perspective, the realist approach to qualitative research maintains that while knowledge is socially and historically constructed and therefore imperfectly apprehensible, there is an ‘external reality’ that exists independently of the researcher’s mind [636,637]. As such, there are patterns of behaviour and perceptions that display this ‘common truth’ (i.e. meaning) that may be captured [635,638]. These processes are viewed as real phenomena and are not simply abstractions from behaviour or constructions of the observer [639]. This ‘truth’, which is concept-dependent [640] (i.e. time and place specific), is negotiated through dialogue and the goal is to interpret and explain the phenomena with a certain degree of confidence [635].

This specific approach is consistent with current opinion surrounding the conducting of multi-method or mixed method research, insofar as the method and philosophical underpinnings of the realist framework allow the insights provided by the qualitative enquiry to fit synergistically with those provided by the quantitative component [641]. It is acknowledged that due to the subjective nature of the human experience, a certain degree of pragmatism must be considered in order to achieve the objectives of the research.

With this in mind, the purpose of this study is to extend the findings from the quantitative analyses (see Chapter 4 and Chapter 5) by qualitatively exploring the ‘lived’ psychosocial experience of women with arthritis transitioning from midlife to older age using a realist-oriented framework. Specifically, this study will:

1) expand upon and clarify the findings from Chapter 4 by exploring the ongoing psychosocial impact of being diagnosed with arthritis. Particular attention will be
given to identifying and clarifying the psychosocial challenges to, and resources that facilitate the adjustment process, including coping perceptions and attitudes towards arthritis;

2) expand upon and clarify findings from Chapter 5 regarding the role of perceived stress in arthritis. Particularly, the meanings attributed to stress, how life events are perceived over the life course and the processes involved in coping with stress will be examined. Additionally, as perceived stress was found to be a predictor of arthritis onset, it is important to determine the level of understanding participants have regarding the relationship between stress and health and in particular its role in arthritis.

6.2 Participants: the 1946-1951 cohort

6.2.1 Sampling frame

Participants in this sub-study were purposefully sampled from the 1946-1951 cohort of the ALSWH10. From the 10,638 women who completed the fifth survey (conducted in 2007), women who indicated that they had been diagnosed or treated for arthritis in the previous three years were included in the sampling frame. Of the 3,088 women meeting these criteria, 286 were deemed ineligible. Women who did not speak fluent English, had a proxy such as a carer complete their surveys, or had withdrawn from either the longitudinal study or further sub-studies were removed from the participant pool. A total of 2,802 women were retained in the final sampling frame for this study. These women were considered to provide the most ‘information rich’ [635] informants. The ALSWH data manager randomly selected potential participants based upon these criteria. As it was anticipated that up to 30 women would be required to meet the objectives of the study, a random sample of 60 women meeting the inclusion criteria was initially drawn, assuming a 50% response rate. Women however were sampled until ‘theoretical saturation’ [627,642] (i.e. no new or relevant information emerging from the interviews that would further develop a conceptual theme) had been reached using a systematic process similar to Francis et al. [643] (see Section 6.5.2 for the process employed in determining data saturation). A total of 19 women contributed to this study.

10 Purposive sampling involves the purposeful and conscious selection of certain participants that permit the enquiry into and understanding of phenomena in-depth [635].
6.3 Procedure

The following section details the nature of participant recruitment and aspects surrounding the interview process.

6.3.1 Recruitment

Potential participants randomly selected from the study participant pool were mailed a letter of invitation/participant information statement by the ALSWH at the University of Newcastle during August and December, 2011. The letter of invitation informed potential participants about the purpose of the study, the researchers involved, study requirements, as well as potential risks associated with participating and issues relating to confidentiality. Contact details of the ALSWH in conjunction with the candidate and principal supervisor were provided for any participant queries. Additionally, a ‘do not wish to participate’ tear off slip and reply paid envelope were also included for participant convenience. A copy of the letter of invitation/participant information statement is located in Appendix D.1.

As the final sample size was determined by reaching the point of data saturation, invitations were sent out in small batches of ten. Potential participants were contacted by the candidate approximately two to four weeks following the mailout. This process provided the opportunity to ensure that the potential participant had received and understood the content of the letter of invitation. Particularly pertinent to the conversation were issues relating to what was being asked of participants, voluntary participation and confidentiality. This telephone conversation also served as a further opportunity for the women to ask any questions before providing informed consent. For women wishing to participate in the study, a time convenient for the participant was scheduled in order for the telephone interview to take place. At this time, women were reminded of the avenues available to them (i.e. contacting the candidate or alternatively the ALSWH office by phone or email) should they have any further questions or issues prior to the scheduled date.

6.3.2 Interview schedule

The semi-structured telephone interview schedule located in Appendix D.2 aimed to illuminate the ‘lived’ psychosocial experiences of women with arthritis during the midlife
transition. The schedule, which covered three key areas relevant to this discussion was
developed in consultation with the literature (see Chapter 2) and was informed by the
findings of the quantitative analyses using the ALSWH survey data (see Chapter 4 and
Chapter 5). The interview guide was designed to guide women with arthritis towards
reflection upon their life experiences and coping mechanisms prior to, and at the time
of diagnosis, as well as their conceptions surrounding the stress-illness relationship.

Consistent with the realist approach, the main interview questions which were
anchored to the research questions (e.g. "How has your life been affected by being
diagnosed with arthritis?") were open-ended in order to elicit the participant’s story, free
from bias. The first question was designed to ease the participant into the interview
process and provided a basis for understanding the particulars surrounding their
diagnosis (including the symptoms that led to seeking medical attention). The second
question was designed to uncover the psychosocial issues pertinent at the time of
diagnosis, while the third and fourth questions revolved around understanding the
psychosocial burden associated with the disease. The fifth question aimed to explore
the psychosocial experiences of the women prior to diagnosis, particularly regarding
how their experiences may have impacted on their health. The sixth question, on the
other hand, was designed to illuminate an in-depth understanding of the stress process
and its impact on the participant’s health. The final interview questions centred on how
the participant’s life had changed since diagnosis and the provision of information
important to their story not previously discussed. These questions were designed to
end the interview on a positive note and allowed the participant to reflect on their
personal growth.

In addition to the base questions, a series of prompts related to the research aims such
as “How has having arthritis affected you physically? Emotionally? With your
relationships with friends and family?” were incorporated in order to aid discussion (see
Appendix D.2 for the detailed interview schedule and relevance to each research aim).
While the main questions and associated prompts provided a certain amount of
structure in order to conduct the interview, they were not prescriptive. In order to
provide the contextual material necessary to understand the phenomenon, the content
of the interview was ultimately co-determined by both the researcher and participant.
Therefore, if a participant deemed a particular aspect of their lives as important, this
experience was explored in detail regardless of its perceived relevance to the research
aims.
The interview schedule was pilot tested by the candidate with the first two participants and was reviewed by the candidate and principal supervisor. The schedule was deemed appropriate and was used for the remaining 17 interviews.

### 6.3.3 Interview process

The 19 semi-structured telephone interviews were conducted by the candidate at the offices of the Research Centre for Gender, Health and Ageing located at the University of Newcastle. All interviews were digitally recorded using a microphone pick up device that allows both sides of the telephone conversation to be recorded. Prior to the commencement of the interview, with the digital recorder turned off, the researcher again confirmed that the participant had received the letter of invitation regarding the project. At this time, the participant was also afforded the opportunity to ask any questions relating to the study and was reminded that their participation was voluntary and that they were free to pause or discontinue the interview at any time. When the participant was satisfied, the tape recorder was turned on and formal verbal consent to the interview and its recording was sought. A series of statements were read to the participant (see Appendix D.3 for the telephone interview script) and they were asked to indicate their agreement with each statement before commencing the interview.

The interviews were primarily guided by the interview schedule, with all eight anchor questions being asked. Participants however were able to direct the conversation within these areas of interest and concentrate in-depth on issues they felt were most important. During the interview period, field notes were collected which focused on points of interest to follow-up at an appropriate time, the emotional condition of the participant as well as notes regarding noise and interruptions. At the conclusion of the interview, the women were debriefed regarding the emotional content of their discussion and avenues for psychological support such as Lifeline or their GP were reiterated. Following cessation of the interview, the researcher added to the field notes generated during the interview process and recorded further reflections and impressions regarding such issues as the rapport generated between the researcher and participant, the quality of the data produced and a summary of significant findings. During this time, feedback was also obtained from the principal supervisor regarding interviewing techniques, interview progress and initial impressions emerging from the data.
All interviews were carried out in accordance with the University of Newcastle’s Human Research Ethics Committee policies regarding telephone interviewing (000317) and ranged in duration from 15 mins to 2 hours 50 mins, with an average time of 1 hour 10 mins. For interviews approaching the allocated time limit (i.e. one hour), participants were informed by the interviewer at the 55 minute mark that the interview time had almost elapsed. All participants at this time expressed a wish to continue the interview. Interviews were continued until the participant was satisfied with the level of information they had imparted. Interviewing of participants ceased when ‘theoretical saturation’, had been achieved [627,642]. The process employed to determine data saturation is discussed in Section 6.5.2.

6.4 Participant characteristics

A total of 44 women (based upon the processes involved in achieving saturation) were invited to take part in the qualitative sub-study. In all, 25 women declined to take part. Reasons for declining the invitation included undergoing treatments for other chronic illnesses (e.g. cancer), caring for an ill family member, being too busy and lack of confidence in being able to contribute to the area of study. The final participant sample included 19 women who were on average 62.5 years old (range = 60-65) at the time of the interviews (see Table 6.1). All of the women had OA, with three women having both OA and inflammatory forms of arthritis. Over half of the sample first reported being diagnosed with arthritis at survey 3 in 2001, while approximately 38% reported arthritis in 2007 (survey 5).

Data from the most recent survey completed in 2010 (survey 6) revealed that the majority of participants were living in married or de facto relationships (n=14), were situated in rural areas (inner and outer regional areas) (n=13), were either unemployed or retired (n=9) and had achieved high school education or above (n=15). In terms of health-related factors, approximately half of the women were either overweight or obese. Participation in physical activity (including walking briskly, moderate leisure-time activity and vigorous-intensity leisure-time activity) varied with equal numbers of women participating in high or low (i.e. sedentary) levels of activity. SF-36 scores for

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Adherence to this policy included providing advanced written advice in the form of an information statement indicating that telephone contact would be made with the potential participant. This information included how the participant’s name, address and telephone number was obtained, why they were being asked to participate, the nature of the questions they may be asked to answer, when the interview would take place and its expected length as well as avenues for the potential participant to decline contact with the researcher. Additionally, the candidate provided evidence to the University of Newcastle’s Human Research Ethics Committee of the training undertaken in order to conduct qualitative telephone interview and the ethics approved telephone interview script clearly identified the researcher, the University, the project and made reference to the written advice previously sent to potential participants. A copy of the policy can be located at http://www.newcastle.edu.au/policy/000317.html
the women were widely variant. Scores relating to physical functioning ranged from 25-95, with a mean of 70.8 (SD=23.0). Likewise, mental health subscale scores ranged from 48-100 with participants averaging a score of 80.7 (SD=16.4). Pain subscale scores ranged from severe pain to no pain at all (range=32-100) with a mean score of 60.8 (SD=18.4) (see Table 6.1). Mean scores reflecting physical functioning and bodily pain were similar to those reported for Australian norms for women with arthritis [644]. Women in this sample reported slightly better mental health than the suggested norms for women with arthritis. Moreover, the psychosocial profile of participants reflected a range of levels in terms of perceived social support and optimism, while women most often reported experiencing minimal levels of stress. As a result, this sample appeared to be relatively diverse.
<table>
<thead>
<tr>
<th>Table 6.1. Participant characteristics</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Arthritis-related factors</th>
<th>Missing n (%)</th>
<th>Frequency n (%)</th>
<th>Range M(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of arthritis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OA only</td>
<td>16 (84.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OA &amp; inflammatory arthritis</td>
<td>3 (15.8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>First reported arthritis diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Survey 3 (2001)</td>
<td>11 (57.9%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Survey 4 (2004)</td>
<td>1 (5.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Survey 5 (2007)</td>
<td>7 (36.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Psychosocial factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Perceived stress</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>3 (15.8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minimal</td>
<td>14 (73.7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate/high</td>
<td>2 (10.5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Perceived social support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All of the time</td>
<td>8 (42.1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most of the time</td>
<td>7 (36.8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some of the time</td>
<td>3 (15.8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None/little of the time</td>
<td>1 (5.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Life approach</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LOT-R</td>
<td>6.0 – 24.0</td>
<td>16.4 (4.6)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0.0%)</td>
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<td></td>
</tr>
<tr>
<td><strong>Demographics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>60.3 – 64.7</td>
<td>62.5 (1.3)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0.0%)</td>
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<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/de facto</td>
<td>14 (73.7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separated/divorced/widowed</td>
<td>4 (21.1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>1 (5.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0.0%)</td>
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<td></td>
</tr>
<tr>
<td><strong>Area of residence</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>6 (31.6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural/remote</td>
<td>13 (68.4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0%)</td>
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<td></td>
</tr>
<tr>
<td><strong>Educational attainment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tertiary/post graduate</td>
<td>2 (10.5%)</td>
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<td></td>
</tr>
<tr>
<td>Education</td>
<td>Frequency</td>
<td>Percentage</td>
<td></td>
</tr>
<tr>
<td>--------------------</td>
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<td></td>
</tr>
<tr>
<td>Trade/diploma</td>
<td>6</td>
<td>31.6%</td>
<td></td>
</tr>
<tr>
<td>School/higher school certificate</td>
<td>7</td>
<td>36.8%</td>
<td></td>
</tr>
<tr>
<td>No formal education</td>
<td>2</td>
<td>10.5%</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
<td>10.5%</td>
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<table>
<thead>
<tr>
<th>Occupation</th>
<th>Frequency</th>
<th>Percentage</th>
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<tr>
<td>Highly skilled</td>
<td>4</td>
<td>21.1%</td>
</tr>
<tr>
<td>Skilled</td>
<td>2</td>
<td>10.5%</td>
</tr>
<tr>
<td>Less skilled</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>No employment</td>
<td>9</td>
<td>47.4%</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>15.8%</td>
</tr>
</tbody>
</table>

**Health behaviours**

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<thead>
<tr>
<th>BMI</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under weight</td>
<td>6</td>
<td>31.6%</td>
</tr>
<tr>
<td>Healthy weight</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>Overweight</td>
<td>4</td>
<td>21.1%</td>
</tr>
<tr>
<td>Obese</td>
<td>6</td>
<td>31.6%</td>
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<tr>
<td>Missing</td>
<td>2</td>
<td>10.5%</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Physical activity</th>
<th>Frequency</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Nil/sedentary</td>
<td>6</td>
<td>31.6%</td>
</tr>
<tr>
<td>Low</td>
<td>4</td>
<td>21.1%</td>
</tr>
<tr>
<td>Moderate</td>
<td>2</td>
<td>10.5%</td>
</tr>
<tr>
<td>High</td>
<td>6</td>
<td>31.6%</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>5.3%</td>
</tr>
</tbody>
</table>

**HRQoL (SF-36)**

<table>
<thead>
<tr>
<th>Physical functioning</th>
<th>Frequency</th>
<th>Minimum – Maximum</th>
<th>Mean (Standard Error)</th>
</tr>
</thead>
<tbody>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>Bodily pain</th>
<th>Frequency</th>
<th>Minimum – Maximum</th>
<th>Mean (Standard Error)</th>
</tr>
</thead>
<tbody>
<tr>
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<table>
<thead>
<tr>
<th>Mental health index</th>
<th>Frequency</th>
<th>Minimum – Maximum</th>
<th>Mean (Standard Error)</th>
</tr>
</thead>
<tbody>
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<table>
<thead>
<tr>
<th>Social functioning</th>
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<th>Minimum – Maximum</th>
<th>Mean (Standard Error)</th>
</tr>
</thead>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>General health</th>
<th>Frequency</th>
<th>Minimum – Maximum</th>
<th>Mean (Standard Error)</th>
</tr>
</thead>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>Vitality</th>
<th>Frequency</th>
<th>Minimum – Maximum</th>
<th>Mean (Standard Error)</th>
</tr>
</thead>
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</table>

<table>
<thead>
<tr>
<th>Emotional role functioning</th>
<th>Frequency</th>
<th>Minimum – Maximum</th>
<th>Mean (Standard Error)</th>
</tr>
</thead>
<tbody>
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</table>

<table>
<thead>
<tr>
<th>Physical role functioning</th>
<th>Frequency</th>
<th>Minimum – Maximum</th>
<th>Mean (Standard Error)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Missing</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\[a^{*}\] means and standard deviations are reported.
\[b^{*}\] age at the time of the interview.
6.5 Data analysis

Data were coded using thematic content analysis following the principles outlined by Braun and Clarke [645]. According to Braun and Clarke, thematic analysis is the “foundational method for qualitative analysis” (p. 78). Unlike other qualitative analysis methods (e.g. grounded theory, thematic discourse analysis, and interpretative phenomenological analysis) thematic analysis is not tied to a specific epistemology (e.g. it can be applied to data with a realist or social constructionist philosophy). Interpretative phenomenological analysis and grounded theory on the other hand are theory driven [645-647]. As the aim of the research was to uncover the meaning associated with the participants’ experiences and the information derived from the qualitative interviews was deductive in the first instance (i.e. designed with the purpose of expanding upon and clarifying findings from the quantitative analyses), thematic analysis was deemed the most appropriate approach. An overview of the process used to analyse the data is highlighted in Table 6.2 and is covered in more detail in the remainder of this section.

**Table 6.2. Phases of thematic analysis developed by Braun and Clarke [645]**

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description of the process</th>
</tr>
</thead>
<tbody>
<tr>
<td>Familiarisation with the data</td>
<td>Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.</td>
</tr>
<tr>
<td>Generating initial codes</td>
<td>Coding interesting features of the data in a systematic fashion across the entire dataset, collating data relevant to each code.</td>
</tr>
<tr>
<td>Searching for themes</td>
<td>Collating codes into potential themes, gathering all data relevant to each potential theme.</td>
</tr>
<tr>
<td>Reviewing themes</td>
<td>Checking if the themes work in relation to the coded extracts (level 1) and the entire dataset (level 2), generating a thematic ‘map’ of the analysis.</td>
</tr>
<tr>
<td>Defining and naming themes</td>
<td>Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.</td>
</tr>
<tr>
<td>Producing the report</td>
<td>The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating of the analysis to the research question and literature, producing a scholarly report of the analysis.</td>
</tr>
</tbody>
</table>

The specific processes involved in the analysis are detailed below.
6.5.1 Transcription

Digitally recorded interviews were transcribed verbatim prior to analysis. As the level of transcription detail is designed to complement the level of analysis according to the research questions [648], contextual details such as mispronunciations, slang, grammatical errors, pauses in speech and nonverbal cues (e.g. laughter, sighing and emotional distress) were noted [649,650]. In order to protect the anonymity of the participant and any named third parties such as family members, transcripts were also de-identified. Participants were assigned a participant identification number, while named third parties, identifiable places, events or personal characteristics (e.g. potentially identifiable high profile professions) were omitted from the transcript and replaced with a generic description (e.g. [husband’s name]).

The two pilot interviews were transcribed by the candidate. This process allowed the researcher to not only become immersed in the data but also gain a sense of the quality of the interview questions. The remainder of the semi-structured interviews were transcribed by a transcription service external to the project in accordance with the University of Newcastle’s Human Research Ethics Committee policy regarding the recording and transcription of telephone interviews (000417). All interviews were checked for accuracy by the candidate and the data were entered into the qualitative management program Nvivo v.9 (QSR International Pty Ltd, 2010) for analysis.

6.5.2 Coding

Familiarisation with the data

Finalised transcripts (from over 22 hours of audio interviews) were systematically read and re-read by the candidate prior to thematic coding in order to obtain an overall sense of the data and its relation to the research questions [651]. During this process, preliminary notes were made regarding the content of the text, particularly in terms of identified patterns and meanings within the data. Listening to the audio recording was accompanied on at least one read through of the transcript in order to verify that the meaning being attributed to the text was accurate.
Generation of initial codes

Phase two of the coding process involved generating initial codes from the raw data. Transcripts were read in a line by line fashion, giving equal attention to each data item within the dataset, with sections of text relevant to the research, and thesis aims entered into NVivo as free standing ‘nodes’ (i.e. categories). Where possible, these initial nodes reflected the participants own words and all nodes were defined using descriptive labels. In order to maintain the context and meaning of the coded extracts, relevant surrounding data was retained [645,652]. At this stage of data identification and categorical organisation, substantive codes were generated, with text able to be coded in multiple nodes. This process ensured that repeated patterns within the dataset were adequately captured.

The search for, and refinement of themes

Throughout the coding process, all transcripts were repeatedly reviewed and analysed. Similarities and differences were constantly compared to each other in an iterative fashion, with similar phenomena (or similar aspects of a phenomena) grouped together. As Glaser and Strauss [653] have suggested that qualitative data should be summarised in as few categories as possible whilst explaining as much of phenomena under study as possible, this ‘broader level’ analysis of the codes facilitated the progression from description to interpretation. At this point, any themes that did not have enough data to support them or were too diverse were discarded. Importantly, comparisons were made within and across transcripts [654]. While initial codes were devised based on the research question (i.e. a deductive process) (see Section 6.1) all initial codes relevant to the research question were incorporated into a theme in an inductive manner [645,655]. The refinement of higher order concepts (i.e. themes) involved ensuring that the generated codes formed coherent patterns within and across the datasets with disconfirming, as well as confirming evidence (i.e. deviant case analysis) sought [636,656,657]. This process ensured that the themes accurately reflected the lived psychosocial experience of women with arthritis as a whole [645]. At this point, all 19 transcripts were checked in order to verify that no codes had previously been missed. The content of the identified themes and example extracts were then reviewed by, and discussed, with the principal supervisor until a consensus was reached.
Data saturation

Data saturation was systematically determined by employing practices similar to that suggested by Francis et al. [643]. Francis and colleagues [643] recommend an initial (a priori) analysis sample size of ten be set, and a stopping criterion of three for structured interviews. Due to the diverse nature of the interview schedule and semi-structured approach, an initial sample size of 15, with a stopping criterion of three was established. The stopping criterion was employed in order to determine the point when no more themes (or sub-themes) were identified in the data. The stopping criterion was tested after each successive interview (e.g. at interview 16, 17, 18 etc.). For the purposes of this study, at the point when three successive interviews had been analysed without further thematic identification, data saturation was said to be achieved. As the final two interviews were carried out in succession, this criterion was exceeded by one. A sample size of 19 was therefore deemed sufficient. The process for obtaining data saturation for this sample is located in Appendix D (see Table D.1).

Defining and naming themes

Themes were further refined by identifying the story or ‘essence’ contained within each theme in relation to both the research questions and overall data. Each theme was then provided with a definition for inclusion. To demonstrate meaning within the hierarchy of themes, sub-themes were developed. This also provided structure for the discussion of complex concepts. Based upon the aims of the qualitative research (see Section 2.6) the following clusters of themes were identified. The first theme concerned the psychosocial consequences of having arthritis. This theme involved understanding the psychosocial impact of arthritis in terms of the language used to describe the emotional impact of the disease and specifically the emotional impact on physical aspects of the disease (e.g. pain and physical function). A second major theme was identified surrounding coping with arthritis. This theme involved the identification of coping efforts used to deal with arthritis symptoms and limitations. Sub-themes included pharmacological and alternative therapy approaches to coping, coping approaches with a behavioural (e.g. physical activity) or cognitive (e.g. distraction) focus in conjunction with personal beliefs and attitudes (e.g. reasons for having arthritis) or help-seeking (e.g. social support) efforts. A third sub-theme included factors that contributed to psychological adjustment over time.
Another major theme focused on stress and its perception. Components of this theme included the language participants used to describe stress, the context in which stress was perceived and perceptions regarding the impact of stress on health. A final theme focused on coping with stress. Sub-themes involved approaches to coping with stress (e.g. cognitive, behavioural and support-based coping efforts), the origins of the participants’ coping responses, and changes in coping approaches over time, as well as factors identified as contributors of reduced coping abilities over time. A final sub-theme concerned factors associated with long-term adjustment to stress over the life course.

Following this, the final phase of analysis involved grouping these major themes and sub-themes into two overarching themes. These themes, discussed separately, revolved around ‘coming to terms with a deteriorating body’ (see Chapter 7) and ‘making sense of stress’ (see Chapter 8). The final thematic maps for each of these overarching concepts are located in their respective chapters.

**Report production**

The final stage of the analysis process involved the selection of quotes from the transcripts that best illustrated each theme and sub-theme. Data extracts contained within Chapter 7 and Chapter 8 provided clear and vivid illustrations of the issues relevant to the discussion of each theme in relation to the research questions and provided evidence for the theme’s prevalence [645]. The final thesis chapters were then peer reviewed in relation to the individual transcripts to ensure that the content reflected the ‘essence’ of the women’s stories.

**6.6 Methodological rigour**

Within a realist framework, the primary goal of the qualitative investigator is to produce research that is credible, confirmable, dependable and transferable [656] through the striving for ‘truth’. In essence, to conduct research that is trustworthy through the implementation of rigorous methodological procedures. The criteria employed to critically evaluate qualitative research is diverse [658] and the choices made are dependent upon the nature of the research conducted [659]. Trustworthiness of the research conducted in this sub-study was evaluated according to the criteria suggested by Kitto et al. [660]. The research was evaluated in terms of its theoretical, procedural,
interpretative and evaluative rigour. Likewise, sample representativeness and factors facilitating transferability of the findings are also discussed$^{13}$.

6.6.1 Theoretical rigour

Rigour in theory was demonstrated by providing a comprehensive account of the current state of knowledge surrounding the phenomenon [626] (see Chapter 2). This included the provision of a clear rationale for employing a qualitative approach and justification for the paradigm in which to explore the issue. Further, the detailed processes involved in the formulation of the study objectives and research questions were made explicit [633], thereby displaying an overall 'soundness' in the fit of the research [660,665].

6.6.2 Procedural rigour

Procedural rigour was shown by creating transparency at each stage of the research process [666]. This included a comprehensive description of the decisions and procedures involved in the collection, recording and analysis of the data, as well as creating an 'audit trail' that may be subject to external scrutiny [656]. Particularly relevant to the process was the provision of details regarding the recruitment of the participant sample and the nature of the interview process. In addition, a description of the interview schedule and the purpose of each item, in conjunction with information regarding interview transcription and auditing were provided. Dependability and confirmability of the research findings [656,667] were also enhanced by the provision of a step-by-step data analysis plan, including details relating to the iterative process [668] and justification of the methods employed (e.g. constant comparative method). Likewise, the method used to achieve data saturation was overt and carried out in a systematic fashion.

6.6.3 Representativeness

Representativeness of the study findings was enhanced by rigour in terms of the sampling frame. This was demonstrated by clearly outlining the processes involved in

$^{13}$ Please note that although member checking was considered as a method of increasing trustworthiness of the data by validating the themes, interpretation and conclusions, there are inherent difficulties associated with the use of this approach [661-664]. Particularly, Lillibridge and colleagues [662] suggest that experiences described during an interview represent particular moments in time and revisiting these experiences can be distressing and unwanted. This is relevant to this analysis as women with arthritis disclosed information that had not previously been expressed. Likewise, Sandelowski [661] suggests that participants may forget or regret what they said or feel compelled to agree with researchers. Member checking in these instances would create confusion rather than confirmation of the data.
the purposeful selection of participants in relation to the research question and methods [669]. Credibility and transferability of the study findings were further increased by employing a random sampling procedure [635]. This technique provided data diversification and allowed various representations of the phenomena to be captured [670]. Moreover, data pertinent to the study sample, including the sociodemographic characteristics of informants and information pertaining to non-respondents were made explicit. Likewise, validity and generalisability of the research findings were enhanced by the systematic sampling of participants until the point of data saturation. It must be noted that the purpose of purposive sampling is not to provide a sample that is statistically representative. However, by employing specific methods to achieve saturation, such as those suggested by Francis et al. [643], it created transparency of process and provided overt validation for the final sample size.

### 6.6.4 Interpretative rigour

Reliability and validity of the study findings were demonstrated by the comprehensive and systematic analysis of the data [651]. This process involved a line by line analysis of the transcripts and use of techniques such as the constant comparison method [654] and deviant case analysis [636,656,657]. This ensured that the identified emergent themes were dependable and credible. The fidelity of the research was further enhanced by employing additional practices such as researcher triangulation and peer review. These processes provided the opportunity for discussion regarding the emergent themes, with each researcher providing interpretations of the data within the context of their professional backgrounds and schools of thought. The inclusion of a number of verbatim interview quotes supporting the emergent themes (see Chapter 7 and Chapter 8) further contributed to the credibility of the study and aided in the transferability of the findings to other clinical populations.

### 6.6.5 Reflexivity and evaluative rigour

The integrity of the research was maintained by the provision of ethical approval from the University of Newcastle’s Human Research Ethics Committee. Ethical rigour was also demonstrated by the identification of the potential adverse effects of the research and implementing protocols to minimise ‘risk of harm’ to participants. These included avenues for obtaining psychological support, the ability to withdraw consent at any time, as well as detailing the nature of the study and associated potential risks in the
letter of invitation and supplementary telephone call. Rigour was further demonstrated by the maintenance of participant confidentiality and anonymity at all times throughout the research process. This process included the de-identification of data, deletion of identifiable information in the text, as well as the provision of unique participant identification numbers (see Section 6.7 for additional details regarding ethical considerations). Likewise, the processes involved in obtaining informed consent, as well as issues surrounding the preservation of voluntary consent were made explicit. Additionally, rigour was demonstrated via knowledge and implementation of the policies and procedures relevant to the conducting of telephone interviews. Meanwhile, reflexivity was demonstrated via the maintenance of meticulous field notes which included the researcher’s thoughts and feelings regarding the interview and interview process. Included in the documentation were reflections regarding the impact of researcher-participant rapport and disclosure of the personal perspective of the researcher. The implementation of these processes provided a vehicle for reflection about the research [671] and identification of any potential influences on data collection and interpretation [672]. Thus, this added to the confirmability and dependability of the research [656].

6.7 Ethical considerations

Protocols were implemented and sustained throughout the study period to ensure the ethical and legal conduct of the research. As stated previously, confidentiality and anonymity of the consenting women was maintained via the de-identification of the data (including the provision of participant identification numbers for participants in the transcribed text and deletion of identifiable third parties or places) and participant files. Participant anonymity was facilitated by storing interview transcripts with a unique identification number that was dissimilar to their ALSWH details. This was particularly important as this sub-study included the linkage of previously collected survey responses with the qualitative information. These procedures ensured that only the ALSWH data manager was able to link the identity of study participants to the master index.

Issues surrounding informed voluntary participation were addressed by ensuring that participants clearly understood the nature of the study and study requirements prior to providing verbal consent. This process was facilitated by a letter of invitation and supplementary telephone call from the candidate. Participants were afforded the opportunity to clarify any issues surrounding the interviews during these times as well
as prior to conducting the interview. The participant was continually reminded throughout the research process that their participation in the study was voluntary and that they could withdraw their consent at any time, for any reason, and that this would not jeopardise their continued involvement in the ALSWH project.

Further, while it was not anticipated that partaking in this study would cause undue anxiety or distress to participants, it was acknowledged that these women would be asked to discuss their life experiences in relation to their diagnosis of arthritis. As such, there was the potential that participants may become emotionally distressed during the interview. In order to minimise the potential ‘risk of harm’ a number of protocols were implemented. These included the provision of information regarding the interview content on the letter of invitation prior to providing informed consent, as well as offering to pause or discontinue the interview, and referring the participant to appropriate services for psychological support (e.g. Lifeline) during the interview process. Women were also debriefed following cessation of the interview and avenues for support were reiterated should the participant show signs of distress at a later date. Further, consistent with the University of Newcastle’s Human Research Ethics Committee policy regarding the conduct of telephone interviews (000351), participants were asked at regular intervals to reaffirm their willingness to continue the interview.

With respect to the storage, access and disposal of data, all information derived from the personal interviews were transcribed, coded and numerically de-identified, with the audio recordings being deleted following analysis and interpretation. During the research process, password protected de-identified copies of the transcripts and interviews were stored securely with unique identification numbers on the Research Centre for Gender, Health and Ageing server. This information was accessible to the principal supervisor and candidate only. Further, in accordance with the University of Newcastle’s data and management policy (000869), the data will be securely backed up and retained for a minimum period of five years following the publication of results.

Approval for this sub-study was obtained by the ALSWH Publications, Analyses and Substudies Committee (EOI W074) and ethical approval was granted by the University of Newcastle’s Human Research Ethics Committee prior to the commencement of data collection (approval number: H-2011-0191). A copy of the approval notice is located in Appendix D.4.

14 University of Newcastle research is guided by the provisions of the State Records Act 1998. Projects which are not of major significance – where the research does not have potential long-term effects are to be retained for a minimum of five years after the project is completed, then destroyed. A copy of the policy is located at http://www.newcastle.edu.au/policy/000869.html.
6.8 Conclusion

This chapter discussed the methodological practices and methods employed in conducting a qualitative exploration of psychosocial factors in women with arthritis transitioning from midlife to older age using a sub-sample of women from the 1946-1951 cohort. The aims of this research involve increasing understanding of the psychosocial impact of arthritis on women in conjunction with barriers and facilitators of psychological adjustment. Participants’ meanings of stress, as well as the appraisal process and perceptions surrounding the contribution of stress to physical health will also be addressed. These ideas will be discussed under the overarching themes of ‘coming to terms with a deteriorating body’ (Chapter 7) and ‘making sense of stress’ (Chapter 8), respectively. An in-depth understanding of these concepts will assist in informing policy and practice regarding the role of psychosocial factors, and in particular, psychological stress in arthritis for women as they age.
Chapter 7

Coming to terms with a deteriorating body

Qualitative results from the ALSWH

The previous chapter (Chapter 6) provided an outline of the qualitative methodology and methods used for the analyses in the following two chapters. This chapter will focus on the major findings related to the psychosocial experience of a sub-sample of women with arthritis from the ALSWH 1946-1951 cohort. A detailed profile of the women participating in the sub-study is located in Chapter 6. While an extensive review of the literature concerning the role of psychosocial factors in arthritis was outlined in Chapter 2 of this thesis, the following chapter will contain an introduction to the literature relevant to this analysis. This will be followed by the presentation of the study results and a discussion of the findings within the broader context of arthritis research.

7.1 Introduction

Arthritis is one of the most pervasive chronic conditions affecting middle-aged and older adults [131,673]. It is progressive and destructive in nature, leading to significant pain and loss of joint function [77,137,142,350-355]. Management of arthritis has heavily focused on symptom relief including the reduction of pain and inflammation [674]. However, disease-related factors have been found to only modestly predict future arthritis disability [675,676]. Psychological status has been found to be a significant contributor to the burden associated with arthritis [421] (see Chapter 2). Moreover, in Chapter 4 of this thesis it was found that women with arthritis transitioning from midlife to older age are at heightened risk of developing anxiety as a result of their condition. Despite this finding, some studies have found a reduction in emotional distress over time [438-440], while others have found that mental health remains relatively stable [441,442] (see Chapter 2 for review). Findings from qualitative research suggest that arthritis involves a spectrum of emotions ranging from frustration and annoyance to fear, anger, resentment, misery and helplessness [445-449]. However, in one U.S. study of older women with OA (aged 65-92 years), arthritis was described as an ever-present and unwelcomed entity which dominated their attention. This feeling was likened to “wearing a heavy garment” [445]. With significant variability
associated with the psychological burden of arthritis over the course of the disease, it is important to understand factors that may facilitate, or provide a barrier to psychological adaptation, particularly for women as they age. Such factors may provide additional avenues for intervention.

Psychosocial factors have been highlighted as important to the adjustment process [451,452]. It is also suggested that the adjustment to chronic illness is dependent upon the individual's coping responses and attitudes more so than disease-related aspects [470]. Coping efforts aimed at disease-related stress minimisation have been the most widely examined concept in arthritis populations [471-479]. While coping efforts have been suggested as key factors in developing a sense of control and mastery over chronic disease [485-488], coping research has often been limited, particularly in arthritis populations, with its focus on problem vs. emotion-focused coping and implications regarding coping as an endpoint [489]. In a content analysis of community-dwelling older Canadian adults with OA (n=286), it was noted that men and women employed thirteen distinct behavioural efforts in order to adapt to their condition [478]. These coping efforts revolved around 'selection' (i.e. performing activities less often), 'optimisation' (i.e. augmenting or enriching reserves to enable continued functioning), 'compensation' (i.e. substituting activities) and 'receiving help' which were integral to perceptions of dependence and facilitated psychological adjustment. Further, in a narrative review of major and minor stress in rheumatic conditions, it was found that optimistic and confronting coping strategies were the most frequently identified and were perceived to be most effective in the face of stressors [490]. Meanwhile, in a content analysis of structured interviews from 109 Hispanic women (aged 19-86 years) with chronic musculoskeletal conditions, an average of 2.16 different types of coping strategies were identified in the mitigation of arthritis-related stressors [491]. While the most common was the engagement in activities, other strategies including religion or prayer, cognitive strategies (e.g. distraction), seeking social support and positive reappraisal were noted. Additionally, in a longitudinal descriptive study of 48 U.S. men and women aged 60 and over with diagnosed RA (based on ACR criteria), a variety of strategies (e.g. confrontive, palliative, supportant, fatalistic, self-reliant, evasive, optimistic and emotive) were identified in relation to illness-related stressors [448]. In another longitudinal qualitative study of Austrian rheumatology outpatients, it was found that men and women who had retired as a result of RA described their experience as positive with the disease seen as a challenge and facilitator of personal growth [492]. Others [e.g. 493] have suggested that adjusting to a chronic illness is a dynamic
process, influenced not only by the disease but by the individual’s life circumstances and personal resources.

With factors such as living a normal life and maintaining a sense of independence viewed as important treatment goals by individuals with arthritis [514], greater attention is required regarding the role of psychosocial processes (such as attitudes and coping resources) in adjustment. These factors are often difficult to measure using quantitative approaches. However, the identification of such factors may be pertinent for the adjustment to arthritis for women, particularly for those transitioning from midlife to older age. Previous qualitative research surrounding arthritis has generally concentrated on the management of arthritis and patient-perceived treatment outcomes [514,677-680]. When psychosocial factors have been examined, they have primarily involved both men and women from RA sub-populations and focused heavily on coping efforts. The purpose of this study is to qualitatively explore the lived psychosocial experience of women with arthritis transitioning from midlife to older age using semi-structured telephone interviews. A realist-oriented framework (i.e. aiming to explain the phenomenon with a degree of objectivity) was employed in the development and coding of the interviews (see Section 6.1). Particular attention will be given to identifying and clarifying the psychosocial challenges to, and resources that facilitate the adjustment process, including coping perceptions and attitudes.

7.2 Thematic structure

Based upon the study aims, one overarching theme ‘coming to terms with a deteriorating body’ emerged from the data during analysis. This theme encompassed aspects related to the psychosocial impact of arthritis and adjustment process. Within this overarching theme, two major themes were identified. These revolved around the psychosocial consequences of arthritis and dealing with arthritis symptoms and limitations. The thematic structure highlighting both the major and sub-themes is located in Figure 7.1. The results will be presented using the following format: the major theme will be described in relation to its sub-themes. Sub-themes will be provided with an example quote that illustrates an aspect of the content. This will be followed by a description with supportive evidence from the transcripts that best illustrated each theme/sub-theme.
Coming to terms with a deteriorating body: Qualitative results from the ALSWH

The psychosocial consequences of arthritis

- The emotional language of arthritis: “I don’t know how to explain that one…”
- The psychosocial impact of chronic pain: “I mean if it’s really bad, I do get a bit depressed”
- The psychosocial impact of arthritis-associated limitations and disability: “it affects everything you do, it affects everything you want to do”

Pharmacological and alternative approaches in the quest for pain relief: “popping pills … is not the solution”

Behavioural approaches to coping with pain and limitation
- Physical activity: “use it or lose it”
- Constant adaptation: if “you can’t do it one way, you’ll do it some other way”

Cognitive approaches to coping with pain and limitation
- Distraction: “forget about it”
- Accepting arthritis-related pain and limitation: “you can’t do what you used to do”
- Pain minimisation: “it’s just a niggle really”
- Comparative coping: “I’m not crippled with it or anything like that”
- Positive self-talk: “a bit mind over matter”
- Cognitive reappraisal: “I don’t take things for granted anymore”

Personal beliefs and attitudes associated with coping with pain and limitation
- Faith-based practices: “I hand it over … when I get to the point where I can’t do it anymore”
- Stoicism: “just get on with it”
- Reasons for having arthritis: “they seem to think it’s old age, don’t they?”

Help-seeking and support-based approaches to coping with pain and limitation: “a good network around you helps”
- The process of adjusting to arthritis over time: “you learn to live with it and … that’s basically it”

Dealing with arthritis-related symptoms and limitations

• Coming to terms with a deteriorating body

Figure 7.1. Thematic map for the overarching theme ‘coming to terms with a deteriorating body’
7.3 The psychosocial consequences of arthritis

This theme describes the psychosocial impact of arthritis on the women interviewed. Included in this section is a description of the language and points of reference the women used to label initial (global) perceptions of the emotional impact of arthritis (“the emotional language of arthritis”). Additionally, specific feelings associated with key physical aspects of the disease, namely chronic joint pain (“the psychosocial impact of chronic pain”) and increasing restrictions and disability (“the psychosocial impact of arthritis-associated limitations and disability”) are examined in-depth.

7.3.1 The emotional language of arthritis: “I don’t know how to explain that one ….”

Participants reported a spectrum of emotions in response to arthritis. A few women were clear about the emotional toll arthritis had taken, describing it in terms of depression. For instance, “I definitely think it makes you depressed” [Participant 11]. However, the majority of women, described the psychological impact by using language such as ‘frustration’, ‘annoyance’ or finding it ‘hard’. Some women openly expressed difficulties with labelling the global emotional impact of arthritis and were often reluctant to describe it in terms of ‘depression’, preferring to use other semantics. For instance:

\begin{quote}
I don’t know how to explain that one …. it’s just that you know, you just wish it would, I don’t know how I will explain this, um … I, you can’t just say I wish it would go away because you do but … you just don’t see any joy in life. It’s not a depression um but it is in one way, but you’re not depressed [Participant 16].
\end{quote}

Thus, terms such as ‘depression’ and ‘frustration’ were often used interchangeably:

\begin{quote}
… you tend to get a little bit depressed with it and um … frustrated I s’pose, a little bit. When I say depressed I s’pose just a bit yeah I s’pose depressed [would] be as good a word as any [Participant 1].
\end{quote}

In addition, the potential psychological impact was minimised by some participants who measured their arthritis-related feelings against their perceptions of what constituted depression:

\begin{quote}
It’s not a depression like you vision, like you think depression is. Um you know when you don’t do things, you don’t want to go out and you don’t want to talk to
\end{quote}
people it’s not that, it’s, it’s um maybe you could call it melancholy more than depression … [Participant 16].

This impact was also explained by the relative psychological impact of other life events. This was a particular response from women who had difficult life histories involving clinical depression:

… I’ve had times in recent years where I’ve really been, I have been clinically depressed over things but it wasn’t to do with [arthritis], so I don’t think this has affected my mental situation no [Participant 10].

Therefore, arthritis was often viewed as a secondary threat to their emotional well-being. A few women maintained that they were relatively unaffected by the disease “[it’s] never got[ten] me down” [Participant 18], suggesting that while it was “another obstacle” [Participant 3] to overcome, it was “not a big deal” [Participant 3]. Participants often described the condition as, “just a niggle really” [Participant 13].

Despite these assertions of relative acceptance, the psychosocial impact of arthritis for these women was complex. The true extent of the emotional impact of arthritis was often illustrated in the participants’ accounts of their physical deterioration.

7.3.2 The psychosocial impact of chronic pain: “I mean if it’s really bad, I do get a bit depressed”

Joint pain was identified as the primary symptom of arthritis for the majority of participants. Some participants reported pain in just one or two regions, while others described widespread arthritis. For some, pain was an ever-present entity “mine’s a constant ache at times um it’s, it’s not sharp peaks of pain, it’s just that constant ache …” [Participant 13]. For others, there appeared to be an ebb and flow, with the level of pain constantly changing and increasing in intensity. One participant noted that when her arthritis flared “you just don’t know where to put your hand, you don’t know where to put the joint that’s hurting, it’s, you can’t describe it” [Participant 19]. In this respect, arthritis pain acted as a chronic stressor for the women. Factors related to pain persistence and symptom severity invoked negative emotions reflecting degrees of depression such as sadness and feeling a ‘bit down’. Feeling ‘sick of the constant pain’ or being depressed were also reported by some interviewees. For example, “Oh yes, I mean if [the pain’s] really bad, I do get a bit depressed” [Participant 4] and:
I’ve had a lot of pain in the last few months, arthritic pain and the fibromyalgia pain. I don’t like that. That gets me down and I find that, that hard to get on top of at times yeah, yeah I do find that hard because it’s pain you know mmm [Participant 16].

Poor mood was often a result of pain and discomfort that precluded the women from obtaining sufficient sleep “… waking up several times during the night with little aches and pain … that kind of means you tend to get a little bit down” [Participant 1]. One participant in particular who experienced knee and back pain suggested that “[it] affects your sleep so you’re a bit tired and grumpy the next day” [Participant 12]. She described the ability of chronic pain to erode a person’s sense of well-being using the analogy of “a dog hanging on and not letting go”. When questioned about the severity of this pain, she indicated that it would be comparable to the pain experienced by a burns victim “the pain I’m talking about … look maybe a burns victim um and things like that, they would suffer extreme pain” [Participant 12]. Sleep disturbance was also associated with women becoming withdrawn or “inwardly focused”, a “bit stroppy” [Participant 19] or impatient with people “to the point that you can’t really be bothered” [Participant 19]. Irritability and the expression of non-provoked fatigarelated anger was often directed at a spouse “you know my husband took a real battering” [Participant 12].

For two women, the chronicity and intensity of the pain culminated in feelings of suicide or escape. The daily struggle with never-ending pain is illustrated by Participant 12. Dealing with this stressor became the focal point of her daily activities, precluding her from participating in the life she once had (particularly in terms of family and social activities) and experiencing the joys associated with her current life stage (such as the quality of her interactions with her grandchildren). This was compounded by feelings of fear and isolation associated with the ‘invisibility’ of arthritis that was met with a lack of understanding about chronic pain from those without the disease:

… it’s just going back to this fact of feeling alone … the thing is you don’t look sick [laughs] and you haven’t lost your leg or had your knee done where people can say oh yes she might be in some pain, or that and it, really affected my life in the fact that um for quite a few months I had problems sitting so I had to stand or lay down and then laying down was painful after a while so um I couldn’t go to the movies with friends, um I couldn’t go to other things where I had to sit down for too long, um my father was still alive at that time … and for a certain amount of time I couldn’t even go in the car to see him [Participant 12].
Lack of understanding and isolation were also attributed to interactions with the medical profession for women with severe chronic pain. These women described fear-based emotions such as ‘desperation’ and ‘fright’ over the lack of treatment options, with the pain not adequately addressed. The inability to achieve effective pain reduction was associated with reductions in quality of life and culminated in feelings of suicide as a source of release:

*Um, well I think it goes back to the fact that you, you haven’t got a proper focus ‘cause it’s just pain, um and you do get to the point where you wonder, you can’t keep going on like that, you just cannot put up with that pain for the rest of your life, um and have I thought of suicide? Yes I have …* [Participant 12].

This was coupled with feelings of isolation, as mentioning suicidal thoughts may affect pain management practices.

Chronic pain was also a source of anxiety for women with arthritis. One participant indicated that “it is very hard when you’re in pain not to worry” [Participant 12]. In particular, the uncontrollability associated with increasing pain was referenced as a source of rumination and increased ‘worry’. Increased anxiety was not congruent with either the presence or absence of pain but related more to feelings of maintaining a sense of control over the disease and symptoms “if the pain’s under control um I’m not saying no pain, but the pain is under control then um I probably don’t tend to worry so much”.

7.3.3 The psychosocial impact of arthritis-associated limitations and disability: “it affects everything you do, it affects everything you want to do”

Arthritis was found to have a major impact, both physically and psychologically on the women interviewed. The following sub-theme describes the psychosocial impact of increasing physical deterioration. The magnitude of this impact is highlighted against a backdrop of arthritis-imposed limitation and previous levels of physical and social functioning.

Over 90% of women described arthritis-associated difficulties or disability. Women spoke about “being physically awkward” [Participant 8], having difficulties closing their hands and writing, no longer being able to wear jewellery, lack of strength in the affected area, and restrictions associated with walking, bending, squatting and sitting.
for extended periods of time. The degree of interference with activities of daily living experienced among the respondents varied widely. Some women described what appeared to be relatively minor limitations. For instance “Um it’s like taking lids off jars and bottles. Um, I just don’t have the strength in me wrists and me hands anymore like I used to have” [Participant 2]. Other women reported moderate to severe limitations, requiring assistance with tasks (e.g. meal preparation) “… well it’s certainly becoming more restricting in so far as you know lifting a jug I need to support it with my left hand as well as use my right hand …” [Participant 5],

Um, I find now, yes umm, you know, to hold the spoon and actually stir. The Christmas puddings and the five dozen what have yous mixers, heavy mixers are more difficult … it’s just that increasing degree of difficulty that you see with doing things … [Participant 11],

or the use of assistance aids “I’ve made some adaptations at home with taps … instead of trying to turn it on, I have a lever” [Participant 7].

The specific site of the arthritis was often critical to its psychological impact. Having arthritis in key functioning areas (e.g. the hands) caused considerable frustration for the women as it served as a constant reminder of the disease and provided an overt signal regarding increasing physical deterioration. For instance:

It’s more frustrating when it’s in your hands, because you do so much with your hands … Everything you do you are reminded that you can’t pick things up because you have no strength. You can’t open the lid of a jar because it hurts like mad, so having arthritis in your hand is the worst place you can have it … [Participant 19].

Increasing arthritis-associated pain and deformity coincided with significant modifications surrounding leisure activities such as travelling, hobbies and sports. Arthritis-imposed limitations resulted in the ‘giving up’ of vigorous sporting pursuits such as running, tennis and golf “I can’t play sport like I did … you know you can’t run. I can’t run anymore, so I can’t play tennis or anything like that” [Participant 8], while others reported no longer being able to participate in social activities such as dancing.

Loss was not only attributed to the activity itself but was also related to a loss in social connection:

… I miss the tennis because I just, really enjoyed playing and I, I know that I can’t ever do it again, so I’m sad about that … giving up the tennis was also giving up the social group as well [Participant 10].
While the participants often described the psychological impact of arthritis increasingly impinging on their way of life in terms of ‘frustration’, the underlying theme ultimately revolved around sadness as a result of a ‘loss of independence’ and the ‘struggle to maintain a sense of self’ amidst the changing landscape of a “cruel disease” where “you can see the changes happening” [Participant 17]. As one participant noted “a loss of depend, independence is something that is just, [it] eats away at you inside psychologically” [Participant 19]. This was particularly as a result of conflicting self-concepts of who they were, and what they had achieved prior to arthritis “you become less of a person in your own eyes and ah, and that sort of um, I suppose gets me more frustrated …” [Participant 19].

While a couple of women expressed having long-term physical conditions that began in childhood “I was born with a needle in my arm” [Participant 17], the majority of women had lead physically healthy and active lives. Women described being constantly active, feeling strong and being able to achieve whatever they liked physically without fatiguing. For example, “I was fit as a fiddle. I could do anything I liked, yeah it was great” [Participant 6]. Others spoke about having the ability to take more risks physically as well as being freer to travel or participate in activities without risking injury. A life with arthritis, on the other hand, was one of caution:

… before I think I sort of took more risks in doing things, … I probably did a lot more travelling ‘cause I’m more aware now of um, um how you say putting myself in a risky situation you know like carrying bags or um walking far is, is probably gonna you know end up with me in a problem [Participant 4].

For most women, this inner conflict arose from perceived inadequacies associated with fulfilling their gender-specific caring roles particularly as wives, mothers and grandmothers. As one participant suggested:

Well I think you have a degree of depression when you’ve lost your … ability to do what you used to do. Very, very frustrating and I’ve always done all the handling, fixing, doing whatevering. Packing, shifting, lifting boxes … [Participant 11].

This inability to undertake caring roles conjured up feelings of inadequacy for some women.

Women also felt as though they were being prevented from fully engaging in life:
it just gets you to the point where you think, dear if I didn’t have this, you know how much more I could engage in things and um yeah I guess that frustration is, is constantly, constantly there for me [Participant 19].

At times “it almost ma[de] life not worth living” [Participant 19].

The struggle to maintain a ‘sense of self’ was often described by women as a “constant fight” [Participant 19] against feelings of “being useless, … or being rendered … not able to do what you know you can do or should be able to do if that wasn’t there” [Participant 19]. It was particularly difficult for the women to watch the progressive and permanent physical deterioration reflective of an “old” person:

You don’t like watching your, you know your body, I mean you can get big, you can get fat, you can get skinny and you can get wrinkly, but watching the bones deform as they go along … and you know that, that will continue, that won’t stop once it starts [Participant 17].

A grief process often ensued following a series of ‘losses’ and recognition of increasing dependence on others:

Different things so yeah and you sort of realise you can’t do it. I think there is probably a period of, has been a period of grief at each stage where I have finally admitted that things are getting beyond me because I always had this concept of myself as I got older as being a slim active person who cares, I’ve always been a carer and to have to be cared for I find very difficult … [Participant 14].

This particular participant indicated that she had “always been the one who you know showered other people, looked after elderly invalid rellies and people” [Participant 14] and “missed being capable” and running “the household”. A wave of emotions surrounding “huge resentment” and “sadness” followed. For her, she was “happy to be older”, but didn’t like being a “dependent older person” [Participant 14]. The concept of ‘not wanting to be a burden’ expressed by the women was primarily born out of concern for their children. This perception culminated in the selling of property that could no longer be managed without the assistance from others:

Well I just knew I had to do it, because I just couldn’t do the things ‘cause like I had cattle and um it’s pretty hard you know working with cattle on your own … [Participant 9],

suggesting that “I wasn’t going to expect my children to come and help me. I said once the time comes that they have to come and help me, that is the time to get out”
[Participant 9]. This sentiment was echoed by other women who indicated that they did not want their children “crippled with guilt” [Participant 11] over having to provide care.

Some women spoke about their anxiety concerning loss of physical capacity as they aged. One participant with severe arthritis noted that the stillness of the night was particularly difficult as this was a time when you were no longer able to “just push it out of your consciousness”. She often woke up with her stomach “kind of seizing up” and being “petrified of what might be down the track” [Participant 12]. Meanwhile, other participants reported feeling regretful about a lack of physical fulfilment:

Oh, regret I think, regret that I’ll never have that time again where I was able to do that … I used to always think how great it would be to go and do a parachute jump, well that’s not going to happen now and I think there’s a lot of regret there for that … [Participant 3].

Thus, for women with arthritis, the emotional burden was high with women reporting a spectrum of emotions in relation to pain and increasing disability. The primary focus of this burden concerned the grief associated with the struggle to maintain a sense of identity in light of permanent physical deterioration.

7.4 Dealing with arthritis-related symptoms and limitations

For the interviewees, having arthritis was met with a quest to find appropriate symptom relief. This theme describes the approaches used by participants in order to cope with, or minimise the pain and functional limitations imposed by arthritis. Coping efforts employed included active attempts to reduce the pain through the use of conventional pharmacological and alternative medicine or therapies. In addition, self-management strategies with a cognitive or behavioural focus, help-seeking/support-based practices as well as personal beliefs and attitudes were also identified as mechanisms essential to the coping process. Lastly, coping practices important to the long-term psychological adjustment to arthritis are discussed.

7.4.1 Pharmacological and alternative approaches in the quest for pain relief: “popping pills … is not the solution”

Women with arthritis often chose to self-manage their symptoms by using a combination of pharmacological and complementary, alternative and allied health treatment regimens (e.g. vitamin and mineral supplementation, massage, Bowen and
chiropractic therapies). This process involved trial and error, with no one method of pain control effective for all individuals.

When pharmacological treatments were used by the women, either milder forms of arthritis pain relief such as aspirin, paracetamol or codeine and paracetamol combinations were considered and managed according to symptoms, as opposed to prescribed guidelines. For instance:

*I’m supposed to be on six a day but I’ve cut myself down now I might take two every three days … they think because they can take six a day that they’ve got to take six a day to keep on top of it, no you don’t you only take them when you feel pain* [Participant 3].

However, the majority of the women disliked the idea of “pain killers” suggesting that “popping pills … is not the solution” [Participant 9]. It was suggested that medication only masked symptoms and failed to get to the “root of the problem” [Participant 19], while other women reported additional health concerns preventing their ingestion preferring to use topical creams (e.g. voltaren gel, tiger balm, or a little bit of relief), hot water bottles, complementary medicines such as glucosamine and fish oil or dietary changes. The reluctance to take medications, for some, was born out of a lack of effectiveness, concerns relating to side effects, and “feeling like a medicine cabinet” [Participant 8].

Participants acknowledged that although arthritis management was a “day by day” process and “the less drugs you take the better” [Participant 11], there were times when pain relievers were necessary. A nuanced approach was taken by most women, depending upon activities undertaken (e.g. sport) and the anticipated level of pain to be experienced. Others described pain management processes or proven routines that aided pain-coping. For example:

*I take calcium tablets and I take fish oil capsules and I have a little of the um glucosamine with chondroitin with my breakfast and that’s about it. … I have been … given a script for anti-inflammatory tablets I’ve had ah had those for a long time. Usually [I] get up, make a cup of tea have, I’ve got panadol osteo which um I find extremely effective um I use that and a hot pack um [I] get up, read for an hour or so and then go back to bed. By then the panadol osteo usually has worked. There are not a lot of times when it doesn’t work most of the time it’s effective …* [Participant 13].

For the most part, pain-coping practices involved strategies other than medications. These factors are described in Sections 7.4.2-7.4.5.
7.4.2 Behavioural approaches to coping with pain and limitation

Behavioural coping strategies involved both active (i.e. trying to control pain or to function despite pain) and passive attempts (i.e. withdrawing and surrendering control over pain) to reduce arthritis pain levels or modifying activities as a result of arthritis-imposed limitations. These involved increasing or ceasing physical activities in times of increased pain as well as adapting tasks and using assistance aids congruent with the participant’s level of functional disability.

Physical activity: “use it or lose it”

For women with arthritis, physical activity emerged as a key factor in coping with pain. The participants held a “use it or lose it” [Participant 7] philosophy maintaining that “getting the joints … moving always helps” [Participant 19] as it “eases everything out [and] just gets everything moving” [Participant 6]. Physical activities ranged from simply getting up and moving around following periods of being sedentary, to engaging in sporting activities or structured exercise (e.g. yoga and tai chi). Physical activity was seen as being important regardless of physical abilities or arthritis-associated difficulties:

I think the main thing to do with it, ahh is walk but I will admit you probably can’t walk as far. Um, but you never stop walking umm you must have exercise, like I’ve never been to the stage where I can’t walk … [Participant 9].

Two women highlighted the importance of having a consistent routine involving physical exercise and working through the pain and stiffness as important to symptom management. For instance:

... just my stretches every day. I spend about half an hour every day doing, stretching my body out so that keeps me um flexible and I think that helps too because if you’re um, if your body’s more flexible then I don’t think it seize up so much, don’t get so much pain so, so um yeah that’s my routine as I do about half an hour of stretches and then I walk for about half an hour and then um that sort of gets me, and then I have no pain left [Participant 6].

Having a routine around maintaining fitness, while only part of the pain-coping process, was a significant factor in reducing arthritis disability:

... I’m better if I do something every day. Yeah if I have some sort of work out every day or nearly every day, then I, then I manage my arthritis really well and
I do have regular massages and that really helps with my, um just added flexibility and so on um, the other thing that I’ve done right through um with all that is um yoga and I think that has been a real saviour because I honestly don’t find [that] my arthritis restricts me very much at all but I know that it actually, I know from x-rays that have been done over the years that it is quite progressed especially in my spine and neck, my feet and hands um so if, I think if I didn’t do the exercise I might be quite impaired [Participant 15].

In contrast, for some women, although they recognised that physical activity was important to maintaining functionality, this often proved difficult and was a source of frustration. One participant described it as a “catch 22” situation where “you walk and you get sore and if you don’t walk you probably get sore [laughs]” [Participant 1]. Pain and the anticipation of pain resulted in coping strategies concerning activity limitation, “If there’s something that’s causing it I try not to do that” [Participant 10]. Consequently, some women reported limiting their time in leisure activities (including sport) and avoiding heavy lifting “When I think about it I have limited the amount of gardening that I do during that period of time so that I don’t have to kneel down” [Participant 13].

**Constant adaptation: if “you can’t do it one way, you’ll do it some other way”**

The process of coping with arthritis limitations was one of constant adaptation15. A number of participants often reported that if “you can’t do it one way, you’ll do it some other way” [Participant 9]. One participant indicated that with arthritis it was important to “keep trying to do the things you’ve always done but find different ways around them” [Participant 14]. Women adapted activities ranging from sport and recreation to those revolving around basic self-care and activities of daily living. For women who intended to remain physically active, adapting their exercise regimens according to symptoms experienced or severity of arthritis was paramount. One participant noted that the process was facilitated by age-related changes in focus:

> Well I used to play sport and I realised I couldn’t do that so I keep to my walking thing you know, but as you get older you change focus, you do different things you see, so arthritis doesn’t stop me from doing anything [Participant 7].

Others found alternate ways of “getting yourself undressed” [Participant 5] as well as “turning keys in locks and opening jars and what have ya” [Participant 14]. When kneeling down having something to haul up on such as a cupboard was also found to

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15 For the purposes of this thesis, “constant adaptation” is defined as adopting new behaviours that allow the individual to cope with the physical changes associated with arthritis.
be useful. The process of adaptation appeared to be natural for a number of women with only one participant noting that she had formally learned skills during a stay in a rehabilitation centre:

“It's amazing how many different ways you can do things that you always, you always thought there was one way to do something but then when you can't do it that way anymore you find other ways of doing things … [Participant 14].

For some of the more affected women who had difficulties with bending and using their wrists, adaptation in terms of the use of assistance aids such as wrist supports or home modifications in order to reduce the burden on the affected limb was required. For example,

I've got what I call a pick up stick so that I can pick things up off the floor so I don't have to bend … [Participant 12].

7.4.3 Cognitive approaches to coping with pain and limitation

While the women accessed various coping mechanisms in order to cope with arthritis-related pain, cognitive strategies were perhaps the most often cited. These involved active and passive attempts to modify thoughts and feelings associated with arthritis-related stressors. Cognitive approaches to coping included distraction, accepting arthritis-related pain and limitations, cognitive restructuring techniques, in conjunction with pain minimisation and comparative coping strategies.

**Distraction: “forget about it”**

A number of women attempted to use distraction in order to remove the focus from the pain. Women spoke about trying “not to dwell on it” [Participant 1] or trying to “forget about it” [Participant 18] through participating in activities they could absorb themselves in such as watching television, going for a drive, doing puzzles, reading, knitting, sewing, painting, getting out in the fresh air and sunshine, and listening to music. The participants found their “own little niche” [Participant 16] with activities chosen dependent upon the level of disability and pursuits. Passive forms of distraction such as sleeping were viewed as the optimal escape from pain-related exhaustion. Others chose to focus on relationships. For instance, one participant acknowledged that despite her limitations, her role as a grandmother was an important distraction and
beneficial to coping with severe pain. This form of distraction also appeared to have benefits to her mental well-being:

*I try and distract myself if I can. Um you know maybe you know the grandkids come here quite a lot so like tomorrow I have my granddaughter here and although my husband will have to do a fair bit of it, she can sit with me and read books and do a lot of other things and that. I know that tomorrow I will be distracted by her, and I love that …* [Participant 12].

Engaging with family and friends or the community was also viewed as a positive form of distraction. For instance:

*I take it in my stride. I have to go, I volunteer at Vinnies, I will go there this afternoon and I don’t even notice [the pain] when I am doing something like that because you are busy doing things …* [Participant 18].

Having idle time was viewed as a danger to mental health and opened up avenues for “feeling sorry for yourself” [Participant 18] and worrying about the arthritis.

While some women used specific activities to distract themselves from arthritis, two women suggested focusing on “anything” as long as it achieved the required outcome:

*… well it could be anything, could be a plane going over head, I love looking at planes, I just go out and watch a plane or helicopter … TV, I’ve got a DVD, cup of tea, reading, playing some cards …* [Participant 17].

*Just take your mind off it and um you know read a book, watch a movie whatever you know do anything [laughs] go and talk to somebody [laughs], talk about anything …* [Participant 16].

**Accepting arthritis-related pain and limitation: “you can’t do what you used to do”**

Acknowledging that they could no longer physically do what they used to facilitated coping for a number of women. Women indicated that arthritis involved having both good and bad days and that understanding that “you can’t do everything” [Participant 4] was particularly important. One participant expressed that this involved a gradual process of learning to listen to her body and identifying physical limits:

*Yeah probably learnt to listen to my body now and don’t overdo things if I can’t do it then I just have to stop for awhile and you wait until everything comes good again or improves a bit. So yeah so I guess it’s I guess I’m learning um not to push myself as much as I used to* [Participant 6].
Another participant articulated that the key factor in accepting the limitations of the disease concerned modifying expectations of physical ability. It was important to “lower your own expectations of what you can do” otherwise “you can set yourself up for disappointment all the time” [Participant 19]. Having accurate and positive perceptions about physical abilities over time was particularly important. Maintaining high expectations of what can still be accomplished physically was suggested as a threat to psychological adjustment “in my circumstances I have to be realistic otherwise I just wouldn’t be here I don’t think” [Participant 19].

**Pain minimisation: “it’s just a niggle really”**

The participants highlighted the detrimental impact that complaining and catastrophising had on mental health. Cognitive processes involving pain minimisation techniques were used to facilitate psychological adjustment, despite sometimes significant arthritis-associated disability. Pain and its impact was often described using minimising language such as ‘niggle’, ‘ache’, ‘nuisance’, ‘annoyance’, and a ‘little bit of pain’. Few women used strong terms such as ‘nagging’, ‘gnawing’, and ‘excruciating’ or analogies such as “sticking a knife in” [Participant 19]. Pain-focused coping strategies also revolved around perceptions of having, or developing a “high pain tolerance”. The permanence of pain also assisted coping with it likened to living near a train station.

**Comparative coping: “I’m not crippled with it or anything like that”**

The perceptions women held about arthritis assisted with coping with arthritis. Participants used comparative coping strategies in order to minimise the severity of their illnesses, for example “you’ve just gotta put up with your lot in life … [it] could be worse” [Participant 18]. Women compared themselves against other people with arthritis, including friends, relatives and individuals within the community. “Being crippled” was often used as a point of reference “it’s not as if I’m crippled with it you know, it slows me down but you know [it’s] nothing compared to what heaps have got” [Participant 5]. Having someone to measure their arthritis against appeared to be critical for minimising the impact of the disease.

Women also compared themselves to individuals with conditions perceived to be more debilitating such as heart disease or cancer “well as I say it’s a condition, it’s not life threatening, I haven’t got cancer... I can talk, I can move, I can walk…” [Participant 7]. Cancer in particular was viewed as having a “death sentence” and given the choice
between having arthritis or cancer “they[’d] rather have arthritis” [Participant 18]. Additionally, participants who had other chronic conditions in conjunction with arthritis often perceived them as more debilitating, painful or isolating. As a result, arthritis often took a back seat. For instance, “um don’t even consider [arthritis] would be one of my biggest issues, for me the genetic cardiac crap is probably more of an issue” [Participant 11].

Comparisons were not restricted to those around chronic disease. For example, one participant compared the difficulties associated with arthritis to global events, such as earthquakes, suggesting that there were many people less fortunate and that it was important not to “grizzle about a few aches and pains” and to be “thankful for what you’ve got” [Participant 5]. Some women chose to “count their blessings” [Participant 6] and focused on positive aspects of their lives including family and friends “… like I say that’s nothing, I’ve still got family and friends and I’m upright and breathing …” [Participant 5]. Thus, the women’s perceptions of arthritis were also shaped by their outlook on life.

**Positive self-talk: “a bit mind over matter”**

Four women spoke about using informal cognitive strategies that provided encouragement or motivation through internal conversations such as ‘positive self-talk’ or through simply trying to ignore the pain, suggesting that dealing with pain is “a bit mind over matter” [Participant 18]:

Um, well sometimes you know you can be feeling down and, and you’ve and you have to say to yourself well come on it’s in the mind, your, it’s not as bad as you think it is. It’s just the way you’re feeling … it really is in your mind rather you know kind of conjure things up that they’re worse than they actually are. Yeah that’s when you’ve got to, talk positively and think positive … [Participant 5].

One participant indicated that if she “sensed bad thinking” it was a cue to “get out of the house” [Participant 11], while another used a mantra such as “I don’t want pain, no I do not have pain” [Participant 1] with some success.

**Cognitive reappraisal: “I don’t take things for granted anymore”**

While the majority of women interviewed failed to see any benefit associated with having been diagnosed with arthritis, some women described reappraising their
situation (i.e. used cognitive processes to reframe a negative situation or feeling into a positive) and reported personal growth in terms of developing a greater awareness and appreciation for the struggle others face:

I suppose um [it] makes me more tolerant of people who’ve you know [are] in a bad way ‘cause I think yeah this is what you feel like, [a]lot worse than this then. Yeah I guess that’s, it’s taught me a bit more tolerance for other people who’ve got problems ‘cause when you don’t have any problems you don’t sort of think about that [Participant 6].

Another participant focused on being thankful for what she still can achieve in the face of chronic illness:

I’m more thankful for the things that I can do. I think before you ah have a health problem you take so much for granted and then when you do have a health issue and I guess we’re talking about arthritis now um I’m just thankful for the things that I can do when I can do them [Participant 4].

Participants also spoke about gaining an awareness of their bodies and having greater attunement to physical limitations associated with arthritis “… I think I’m more aware of my body and what it can and cannot do and therefore the limitations so therefore I am kinder to myself” [Participant 7]. Moreover, one participant articulated that enduring chronic pain is beneficial to personal growth, likening it to a muscle that requires exercise. This ability appeared to be enhanced by the maturity gained with older age:

… endurance is a quality that doesn’t get um better unless it’s exercised. Like a muscle, the more you exercise the muscle the stronger it gets, that’s what I think. The quality of endurance, if you have nothing to endure you never get to build up that quality in yourself and so yeah I’d say perhaps if anything, ah enduring um hardship and, and battles in your life, and including the pain of arthritis teaches you at least that you can endure … [Participant 19].

Others expressed that having arthritis and especially limitations around previous practices or activities, opened up new opportunities around sporting and recreational pursuits.

7.4.4 Personal beliefs and attitudes associated with coping with pain and limitation

While cognitive coping strategies were often the most employed, accessing ingrained attitudes or personal beliefs were critical to coping with arthritis. Practicing faith-based principles and possessing a ‘stoic’ attitude, (i.e. displaying self-control in the face of
arthritis-related stressors and remaining unemotional in order to overcome potentially destructive emotions) were noted as key factors in pain acceptance.

**Faith-based practices: “I hand it over ... when I get to the point where I can't do it anymore”**

A few women used prayer as a method of coping with arthritis pain, handing the burden over to a higher power when it became overwhelming. For one participant this form of coping, in conjunction with other cognitive processes was viewed as a reliable source when conventional treatments failed. It was often instigated after a period of emotional repression. For instance:

> Things have to have been going on for a very long time for me to be affected emotionally. I carry it well for quite some time, then when I feel like it’s getting too heavy and I can't carry it anymore that's when I hand it over, that’s when I get to the point where I can't do it anymore [Participant 19].

**Stoicism: “just get on with it”**

Women with arthritis tended to employ a stoic attitude towards arthritis and in particular arthritis-related pain, with common phrases “just get on with it” and “I just don’t let it get to me” uttered by the majority of women when questioned about their coping practices. This specific coping style seemed to be born out of generational and gender role attitudes and transferred to other areas of their lives (see Chapter 8 for a discussion), “that’s how you were brought up in my time [laughs]. Suck it in and get on with it” [Participant 3]. Stoicism often coincided with the participants behaving physically as they had done prior to having arthritis or ignoring key arthritis-related symptoms which was often to their physical and emotional detriment.

Having a stoic attitude facilitated the acceptance of pain. Women reported the acceptance of pain by using terms such as being “stuck with it” [Participant 1] and suggested that by definition having the disease meant that “you have to learn to live with a certain amount of pain” [Participant 12]. Three women described accepting the pain associated with physically demanding activities. For instance, “I'm a gardener, I still do it. I'm incapacitated by the time I come inside but um er I just see that as part of it yeah ...” [Participant 8].
For one participant, while over-exerting herself physically was a consequence of having a lack of physical assistance, suggesting that:

\[ I \text{ just get to the point where I think no damn it this has to be done and there's no one else to do it but me and I'll get in and I'll do a bit of gardening, I'll clean the garden bed out or whatever you know and then I'll pay for it [laughs] and it's, but that's, there's nobody else but me so I'm, it's all on my shoulders [Participant 19]. \]

she voiced a certain amount of satisfaction associated with having a reason for the pain and not allowing things to crumble:

\[ \text{Well nobody's looking forward to the pain when it comes at least you have the satisfaction in the back of your mind that there's a reason for it and you've accomplished what you, what you set out to do [Participant 19].} \]

Additionally, participants disliked others who complained about pain and saw voicing any pain-related discomfort as ‘whinging’. For example “I try not to be a complainer. There’s nothing worse [than] being around somebody that’s constantly complaining and whinging about their pain [laughs]” [Participant 19].

**Reasons for having arthritis: “they seem to think it’s old age, don’t they?”**

Respondents possessed certain beliefs regarding the cause of arthritis. Women implicated a range of factors including accidents and falls, playing sport and having sporting injuries, dancing as a child, as well as repetitive strain from physically demanding occupations and gender roles as some of the reasons for their arthritis. For example, “I used to do highland dancing when I was a child. I sometimes wonder if my bung knees are something to do with that too” [Participant 5]. A number of women had a family history of arthritis “I have a feeling the arthritis has been passed on” [Participant 12], “well actually arthritis runs within my family” [Participant 19] and as such viewed arthritis as a consequence of “genetic garbage” [Participant 11].

Although women attributed arthritis to the above mentioned issues, the majority of participants also described arthritis, particularly OA, as simply a “wearing out” disease, and thus was a natural part of the ageing process. For example, “… what arthritis I’ve got is simply related to my age” [Participant 4]. Women accepted that this process would be ongoing, with the aches and pains a signal of “another bit break[ing] down” [Participant 3].
Acknowledging arthritis as natural was buoyed by knowing others with the disease. “most of our, my friends are now, they’ve reached this, the similar age to me have got some sort of problem with it” [Participant 6], “it is the commonest I’m told, osteoarthritis in women … It’s so common with a lot of my friends and we just get on with it” [Participant 11]. Despite the negative nature of arthritis, group membership may be an adaptive mechanism in terms of disease acceptance and psychological adjustment.

7.4.5 Help-seeking and support-based approaches to coping with pain and limitation: “a good network around you helps”

Some women made active attempts to seek advice or support in order to cope with pain and limitations. A few women were able to seek both physical and emotional support from their spouses. One participant remarked:

my partner who is now my husband, he’s always been very supportive about it, um even to the extent of um he’s had to slow down various things that he would have liked to of done because he has very good joints … he is [also] very happy to talk things through with me and to give me um advice … [Participant 10].

However, this was the exception rather than the rule. A number of women described having husbands who, while supportive in the respect of providing physical assistance, were unavailable to provide emotional support, “he’s not a person who you can cry on his shoulder or anything …” [Participant 5]. This generation of women found their support from alternate sources such as family, friends, trusted health professionals and older women within the community. This was especially true for a number of women who described their husbands as “difficult” or “abusive”, for example “he’s not very helpful or empathetic about that at all” [Participant 4]. Women often used a variety of sources of support in order to share the emotional burden. Despite this, women were conscious of the emotional burden associated with discussing their arthritis with others. One participant indicated that although she might discuss some things with her daughter she didn’t want to “put too much on her” as she had two children and still worked as a nurse. She restricted her arthritis-related conversations to things that you “mighten ask someone that’s not in the medical bit” [Participant 12]. Alternatively, she would seek emotional support from a couple of “true friends”.

While women displayed a tendency to seek social support, this process was required to be adaptive across the life course. For one participant who had previously sought
support from her late husband, she had to shift and expand her sources of support to her close friend who also had arthritis, as well as drawing upon additional cognitive approaches such as prayer to fill the void following his sudden death “… prayer and family and particularly one good friend, we’ve been friends since we were twelve so um and she and I can share anything ….”[Participant 14].

Coping with arthritis pain and limitation was facilitated by a number of approaches. Passive cognitive strategies aimed at pain minimisation and perceptions surrounding the cause and severity of arthritis proved particularly pertinent. The role of these factors in the long-term adjustment to arthritis is described in Section 7.4.6.

### 7.4.6 The process of adjusting to arthritis over time: “you learn to live with it and … that’s basically it”

The previous sections (see Sections 7.4.1-7.4.5) examined factors that assisted with coping with pain and arthritis limitation. However, specific coping strategies appeared to facilitate the long-term psychological adjustment to arthritis. A particular focus of this section is on strategies and beliefs important to the long-term adjustment to a deteriorating body over the disease course. These primarily concerned personal beliefs about the disease, in conjunction with cognitive strategies that facilitated the acceptance of pain or the reappraisal of arthritis in the context of their lives as a whole.

Despite fears regarding increasing arthritis-associated disability, the majority of women interviewed expressed a degree of acceptance with having the disease. It was suggested that despite it all, they had to “learn to live with it” [Participant 4]. This concept emerged as an important contributor to the long-term psychological adjustment of the disease. However, while the notion of “you’ve got to accept it. It’s a part of life” [Participant 9] was a common thread throughout the interviews, the acceptance of increasing limitations and disability appeared to be a dynamic ‘day by day’ process. This consisted of grieving physical losses and increasing dependence whilst managing daily chronic stressors such as pain, followed by a period of psychological readjustment. One participant described this as “reluctant acceptance”[Participant 14].

Over time, this balancing process was facilitated by a number of factors. Women indicated that the gradual onset of symptoms and limitations fostered a sense of resilience against the potential deleterious impact of the disease. Described as a “slow creeping disease” [Participant 14], this allowed women to incrementally manage this
chronic stressor as the disease progressed. The gradual increase in pain intensity further assisted the participants cognitively in terms of developing pain-coping strategies and by extension aided psychological adjustment through allowing a tolerance to pain to be constructed over time:

If this had leapt on me straight up, I probably wouldn’t of known what hit me, I would of gone to the doctor and said, you know I’m dying [laughs] because it’s a gradual thing and that the intensity has increased as I’ve gotten older, um I think I’ve built up a tolerance to the level of pain and as I said it’s only when it’s excruciating now that it really stops me from doing things, or otherwise I work through it … [Participant 19].

Personal beliefs and attitudes were also identified as significant to women coming to terms with their deteriorating body. Beliefs surrounding the permanence of the condition, viewing arthritis as an uncontrollable entity reflective of the ageing process and perceiving resistance to physical changes as futile were important. In spite of the reality of the situation, women chose not to focus on the inevitable disease progression and remained stoic in their approach to life.

Long-term acceptance of arthritis was primarily facilitated by cognitive processes. These revolved around focusing on the positive and being grateful for what could still be achieved as well as having someone to measure their arthritis against (i.e. making downward comparisons). Despite the uncertain future associated with arthritis, one participant who had been quite physically active suggested that maintaining a meaningful existence and a sense of independence for as long as possible by findings “something else to become passionate about” [Participant 15], as well as constantly adapting to circumstances was paramount to adjustment. Other women presented similar views regarding adapting to circumstances as they arise and living life while you still can “I'm conscious, that time is limited …” [Participant 13]. Additionally, although arthritis-associated disability caused early retirement for a number of women, women spoke about the opportunities this life stage presented, particularly appreciating having the time to focus on themselves:

I think it probably was a bit harder to find that bit of space because you don’t say to yourself I’m just going to ah um sit here for half an hour and concentrate on my own thoughts, you don’t do it when you’re busy you don’t have the time to do that [Participant 10].

16 While the concepts around arthritis development being a natural and gradual process was conducive to better psychological adjustment it must be noted that these perceptions also presented a barrier to early detection and effective treatment management, with some participants conveying reluctance to seek treatment.
Ultimately, psychological adjustment to arthritis was facilitated by redefining perceptions about specific life stages and self-concepts whilst maintaining control over arthritis symptoms. Despite the significant emotional burden associated with the physical aspects of the disease, the participants found ways in which to mitigate the daily concerns associated with arthritis, and developed strategies over time in an attempt to integrate the disease into their identity. Adjustment and coping particularly concerned relinquishing perceptions about past abilities and ‘creating a new normal’ “you can go back to your normal life ... you just have to learn to live like that ...” [Participant 12].

7.5 Discussion

Arthritis is considered one of the most pervasive chronic conditions affecting middle-aged and older adults [131]. This study aimed to examine the lived psychosocial experience of women with arthritis during the transition from midlife to older age. Overall, the findings from the qualitative analysis indicate that the emotional burden of arthritis is considerable, and the process of psychological adjustment complex. The findings of this study add important information to the wider body of knowledge surrounding arthritis-related psychosocial challenges for women as they age.

Considerable evidence exists to suggest that arthritis and mental health are intimately intertwined [329,338,345,422-430,432,681]. Findings from this study indicate that for women, poor mental health was not a global response to being diagnosed with a chronic disease, but was reflective of specific disease-related characteristics. For these women, the emotional burden of arthritis was found to primarily involve the experience of pain, coupled with increasing loss of function and resultant disability. Pain and increasing disability have previously been reported as the prime psychosocial stressors confronting middle-aged and older individuals with arthritis [451,452,490,682,683]. It has been suggested that arthritis-related pain and limitation presents a significant challenge to the individual’s sense of self, impacting upon the way in which they perceive themselves, interact with others, as well as their ability to carry out valued roles [684-688]. This notion is supported by the findings of the current study. Women with arthritis reported varying levels of distress surrounding increasing limitations around the performance of household duties, the maintenance of nurturing roles and participation in leisure activities. Particularly for women transitioning from midlife to older age, significant distress was associated with the decreased ability to run the household, care for ailing spouses and parents, and participate in the care of
grandchildren. Restrictions in these life spheres facilitated feelings of loss, inadequacy and anxiety surrounding increasing dependence. Lutze and Archenholtz [447] in their RA-focused study found that fears regarding the long-term impact of the disease presented early. For women in this study who predominantly reported OA, fears regarding the loss of independence appeared later, coinciding with disease progression.

Participants described their emotional reaction to pain on a spectrum. Some women expressed being unaffected by the pain describing it as a ‘niggle’. Others, described being annoyed or frustrated, while a minority of women conveyed feelings of depression, helplessness and wanting to escape chronic pain. The severity of emotional distress often coincided with the perceived intensity and chronicity of the pain. This finding is consistent with those found in other arthritis and pain samples [447,689]. Baird [445] on the other hand noted in her qualitative study of older women with OA (aged 65-92) that arthritis pain was reported by the majority of participants as persistent and severe, and as such was assimilated into the participants’ identity. The disparity in findings may be reflective of disease progression as the majority of women in Baird’s [445] study reported having arthritis for more than twenty years. The midlife transition may present a critical period for pain-related psychological intervention.

Self-management of arthritis symptoms appears to be a common theme for individuals with either RA or OA across adulthood [446,447,472,491,690-692]. In this study, a combination of approaches were utilised to assist with coping with the immediate symptoms of arthritis. These concerned behavioural strategies (e.g. physical activity and rest), in conjunction with cognitively-driven strategies (e.g. distraction, pain minimisation and positive self-talk) as well as prayer and social support. Physical activity in particular is accepted within the literature as an important factor in the maintenance of joint function and strength [693]. The benefits of other coping resources are less well-established and were primarily attributed to psychological adjustment to chronic pain and functional limitations. Traditionally, emotion-focused approaches in coping with pain have been associated with poorer psychological adjustment [323,324]. In the current study, approaches such as prayer served as a form of emotional release, often when all other avenues had been exhausted. The way in which this coping approach is utilised may be critical for not only psychological adjustment but also HRQoL outcomes.
Social support has been suggested as particularly important to pain-coping and by extension, psychological adjustment [446,453,498,694]. Although social support was accessed as a coping resource in the current study, it was used less often than other approaches. This may have been due to the inconsistent nature of this resource. Emotional support was generally sought from female counterparts, with husbands often unresponsive to emotional cues. This finding has particular implications for the long-term psychological adjustment of women with arthritis. Karaaimaat et al. [495] found that the provision of social support from a spouse was effective in reducing arthritis-related depression and anxiety. In the current study, the denial of support within this intimate relationship often resulted in increased distress despite receipt from alternate sources.

Coping with arthritis over the long-term was revealed as a dynamic ‘day to day’ process involving a constant struggle between grieving physical losses and increasing dependence amidst symptom management. This process of ‘reluctant acceptance’ has also been reported in relation to the long-term psychological adjustment to RA [493,695] and ankylosing spondylitis patients [696]. Iaquinta and Larrabee [695] in a small (n=6) phenomenological analysis of women aged 47-67 described the struggle associated with this process in terms of ‘grieving whilst growing’. Grieving promoted personal growth by allowing individuals to rise above their personal circumstances. Losses were reconciled, with the grief attached to those losses not impinging on future desires or achievements. Coping with arthritis did not represent an endpoint of adjustment, but revolved around ongoing cognitions in which the participant had to reframe their self-concept at each stage of the disease process. Focusing on the positive and what still could be achieved, in conjunction with constantly adapting tasks in order to maintain independence for as long as possible were seen as important. Plach et al. [449], in a sample of adults aged 39-86 years indicated that the process of relinquishing was an important concept in providing women with a sense of control that offset such losses. Over the course of the disease, participants relinquished not only activities but also began unburdening themselves from social roles. The findings of this OA-dominant study, coupled with previous research focused on RA, suggest that the process of adaptation does not appear to be contingent on the type of arthritis experienced by women.

While cognitive mechanisms were pivotal to the reconciliation of perceptions associated with dependence and independence, psychological adjustment to arthritis over time was often facilitated by ingrained belief systems and attitudes. Notably, the
majority of participants minimised their symptoms, viewing arthritis as a natural and permanent artefact of the ageing process. Arthritis was simply labelled as a consequence of “wear and tear”. This notion is supported in other qualitative studies primarily involving older individuals with severe OA symptoms [684,697-700], and contrasts with the view of Ailinger and Schweitzer [682] who argued that the cause of the disease was not important to arthritis patients. Possessing such views has been found to provide a barrier to seeking treatment [701]. Gignac and colleagues [684] suggested that this perception was perpetuated by health professionals, with physicians dismissing arthritis-related symptoms. With perceptions surrounding arthritic symptoms as ‘normal’ pervasive, this may have contributed to feelings of a lack of entitlement in participants, and as such resulted in the minimisation of pain. Maintaining a stoic attitude and making downward comparisons about their condition or functionality with other individuals may have been an adaptive mechanism in this instance. The results of this study extend the current understanding regarding coping with arthritis that have primarily focused on emotion and problem-based efforts and have failed to consider personality-based coping practices.

Therefore, the findings of this study add significant information to the wider body of knowledge surrounding the psychosocial impact and psychological adjustment to arthritis for women transitioning from midlife to older age, particularly for women with OA. The complexities surrounding coping and adjustment to OA have been a relatively under-researched phenomenon using qualitative methods. While RA is commonly viewed as a more insidious disease due to its inflammatory component, these findings suggest that the psychosocial impact for women with OA is similar to that of RA in terms of pain, functional impairment and loss of self-identity. These findings have the potential to inform clinical interventions and alter disease trajectories for women with arthritis transitioning from midlife to older age. The results suggest that focusing on clinical interventions aimed at assisting women with arthritis come to terms with increasing disease-related disability are warranted (see Section 9.4 of the General Discussion).

While this qualitative analysis was able to examine the emotional burden and adjustment to arthritis in-depth, it must be considered in light of a few limitations. Firstly, while this study examined the psychosocial experiences of women with arthritis transitioning from midlife to older age, the findings are driven by diagnoses of OA. Therefore, the results may not be generalisable to women with RA at a similar life stage. However, findings from this study are supported by previous RA-focused
research, particularly in terms of the transformative process required for psychological adjustment to the disease [e.g. 493]. Additionally, due to the delay between symptom onset and diagnosis of arthritis, the length of time since arthritis diagnosis could not be determined. Likewise, these findings must be evaluated within the context of participants’ lives as a whole. The experience of psychosocial stress in other life spheres may have potentially contaminated their experiences of arthritis. The psychosocial challenges confronting women with arthritis are explored in Chapter 8. Further, previous research has suggested that men and women use different coping strategies, with women using more emotionally and support-based approaches than men. Niu et al. [690] also noted that when these approaches are used, men and women elicit them differently. As this study focused on an in-depth analysis of women from the 1946-1951 cohort of the ALSWH, the findings may not be representative of the psychosocial experiences of men. However, with women in this age group twice as likely as men to develop arthritis, and the psychosocial sequelae for women significantly higher, this cohort is appropriate [144,702,703].

7.6 Conclusion

The findings of this qualitative study add to the current understanding of the psychosocial impact of arthritis and the complex processes involved in the psychological adjustment over time. Importantly, the findings indicate that women transitioning from midlife to older age have psychological difficulties associated with pain and functional impairment. The results suggest that coping requires the implementation of a myriad of strategies in order to deal with pain and limitation, including a strong focus on self-management. Psychological adjustment over time was attributed primarily to cognitive and attitudinal factors. This process was a dynamic ‘day to day’ process involving a constant struggle between grieving physical losses and increasing dependence amidst symptom management. Developing accurate quantitative measures to assess the complexity involved in coping and adjustment are required to confirm these findings at a population level. Further qualitative research surrounding psychosocial stress in other life spheres is required in order to provide context regarding the psychosocial impact of arthritis. The psychosocial challenges confronting women with arthritis are explored in Chapter 8.
Chapter 8

Making sense of stress

Qualitative results from the ALSWH

Findings from Chapter 5 of this thesis highlight the detrimental impact of chronic stress perception on future health. Women experiencing minimal and moderate to high levels of perceived stress were found to have significantly increased odds of developing arthritis later in life. While this finding adds significantly to the arthritis literature, it is important to understand the appraisal process for these women. The following chapter will extend the findings from the quantitative analyses and focus on a qualitative exploration of stress and coping over the life course. Specifically, pertinent literature will be discussed, in conjunction with the presentation of the study results and a discussion of the findings within the broader context of stress and coping within arthritis.

8.1 Introduction

As highlighted in Chapter 1, a wide body of evidence exists regarding the negative psychological and physical consequences associated with the exposure to psychological stress [50,51,53-58,62,704-706]. Within arthritis populations, the majority of stress-related research has focused on the occurrence of chronic major and minor life events [330,333,453,454,457] (see Chapter 2). However, not all disease associations have been consistent. Current approaches to stress such as the transactional theory of stress and coping [67] (see Section 1.4 of the General Introduction) highlight the stress appraisal process as critical to adjustment following stress exposure. Studies primarily focused on RA sub-populations have consistently demonstrated that coping strategies employed by an individual in response to a stressful event have a significant impact on psychological as well as physical outcomes [318-320]. Maladaptive coping efforts (generally referred to as passive coping) have been found to be associated with increased arthritis pain, disability and depression in comparison to those who employ active (problem-based) coping strategies [318,321-324]. With significant variability in the adjustment to stress being noted, further research surrounding stress and appraisal processes are warranted. It is important to
understand the meanings attributed to stress, how life events are perceived, the processes involved in coping with stress, and how the relationship between stress and health is perceived (see Chapter 2 for review).

Findings from Chapter 5 of this thesis indicate that perceived stress is a critical modifiable risk factor for arthritis onset for women transitioning from midlife to older age. Other psychosocial processes including ongoing stress in terms of having a family member or close friend with a chronic illness, using functional forms of social support most of the time, and a history of depression, also moderately and independently increased disease onset. The results from these quantitative analyses, while pertinent to the discussion on arthritis, are limited in their ability to explain the intricacies associated with the appraisal process and perceptions surrounding the impact of stress on health. It has been argued that the use of a qualitative approach is essential to capture the personal meaning associated with stress and the complexities surrounding cognitive appraisal \[707\]. Quantitative approaches lack the ability to explore these concepts in-depth. Such information may assist with the development of preventive strategies and screening tools in order to mitigate arthritis onset in women.

In Chapter 7, findings from the qualitative analysis revealed that pain and increasing disability presented as specific arthritis-related sources of stress for women with arthritis. However, limited qualitative evidence exists regarding non-disease specific stress in arthritis populations. In one study involving focus groups of men and women aged 45-78 (mean age=64.2 years) from a Canadian self-management program (n=26), it was found that stress played a major role in their lives (e.g. “stress in my opinion is the biggest factor”). Non-arthritis specific coping efforts concerned either “just getting through the day” or participating in leisure-time activities in order to achieve “enjoyment” or “balance” \[335\]. Findings from semi-structured interviews conducted with a convenience sample of Dutch women with generalised OA (mean age=64 years), indicate that of the 20 women interviewed, all had described some sort of negative life event, particularly around gynaecological issues and difficulties with conception. Others reported experiencing either a depressive episode or unhappiness at the time their arthritis symptoms first emerged \[304\]. Meanwhile, in an examination of daily stress, coping strategies and social support resources (n=13) in older U.S. adults (mean age=72.8 years) with arthritis (>1 year), interpersonal relationships were identified as a source of non-arthritis related stress. Coping efforts such as cognitive, behavioural or social diversion-based activities and assertive actions (e.g. directly addressing the problem by seeking a solution or talking to someone) were found to
reduce the effect of stress [336]. However, these studies were primarily focused on understanding arthritis-related stress and coping and do not provide an in-depth account of the meanings attributed to stress, how life events are perceived over the life course, the processes involved in coping with stress, and how the relationship between stress and health is perceived by women with arthritis. The following study will clarify and expand upon the findings from Chapter 5 surrounding the role of stress by qualitatively exploring the stress appraisal process and perceptions regarding its role in arthritis in a subset of women from the ALSWH 1946-1951 cohort (n=19) using semi-structured telephone interviews (see Chapter 6 for an overview). A realist-oriented framework was employed in the development and coding of the interviews (see Section 6.1).

8.2 Thematic structure

Based upon the aims of the thesis (see Section 2.6), one overarching theme, 'making sense of stress' emerged from the data during analysis. This theme encompassed aspects related to the perception and adjustment to psychosocial stress. Within this overarching theme, two major themes were identified. These were stress and its perception, and coping with stress. The thematic structure highlighting both the major and corresponding sub-themes is located in Figure 8.1. The results will be presented using the following format: the major theme will be described in relation to its sub-themes. Sub-themes will be provided with an example quote that illustrates an aspect of the content. This will be followed by a description with supportive evidence from the transcripts that best illustrated each theme/sub-theme.
Figure 8.1. Thematic map for the overarching theme ‘making sense of stress’
8.3 Stress and its perception

This theme describes participants’ perceptions of, and meanings attributed to stress. Included in this section is a description of the language and context with which the women used to define stress, along with reasons for being stressed (“the perception and meaning of stress”). Participants’ perceptions regarding the role of stress in mental and physical health were also discussed. This related particularly to perceived signs and symptoms of stress and thoughts regarding its role in physical health outcomes (“perceptions regarding the impact of stress on health”).

8.3.1 The perception and meaning of stress

The following sub-theme describes the nature and context of stress appraisal for women with arthritis. This included how women with arthritis defined stress and the degree of pervasiveness of stress within their lives.

**The language of stress: “I suppose it is stressful um but I call it worrying”**

The majority of participants were conscious of experiencing some form of stress, describing it in terms such as ‘anxiety’, being ‘under a lot of pressure’, or more simply as ‘worry’. Although a large portion of women acknowledged experiencing stress and possessed a degree of knowledge regarding its manifestation, a few women denied ever feeling stress, or had specific definitions of stress. One participant possessed a distorted view of what constituted stress, suggesting that she was not a “stressful person” [Participant 9] despite being diagnosed with a stress-related stomach ulcer (according to her long-time GP who was privy to her life circumstances)\(^7\). For her, stress was conceptualised as having catastrophic consequences involving “nervous breakdowns” and referenced her daughter as an example “she was stressed because she was in tears and, and, yeah having panic attacks and things like that”. Anything below this threshold was not considered as stress. Additionally, a number of women openly described themselves as “chronic worriers”. This involved going on “worrying … trips … about things you don’t have to” [Participant 12].

\(^7\) While the helicobacter pylori bacteria was discovered as a risk factor for stomach ulcers in 1982, recent evidence suggests that psychological stress may still play a role in its pathogenesis via enhancing the colonisation of the helicobacter pylori bacteria in the stomach [708].
**The context of stress: “life is full of stress and worries”**

Stress was accepted as a common and natural occurrence by a number of women with the only differences related to the source of stress and the extent to which they worried, “I don’t think I’m out of the ordinary um everybody has it, some have a lot more worry than others um and some people probably have as much worry hence maybe on a different subject” [Participant 17]. Participants identified the onset of worrying behaviour with a specific life event such as the illness of a family member or single motherhood. One participant suggested that stress and worry were gender-specific issues indicating that “most women are worriers” [Participant 11]. Worrying was identified as a key factor associated with the hypervigilant behaviour required for mothering, “if you’re a mother you worry, you know you get a kid you worry, you know [you] have gotta have radar and so forth …”[Participant 11].

Women who described themselves as chronic worriers indicated that the worrying process particularly focused on ruminating about “silly things” [Participant 6] including not wanting to let others down “ah they weren’t disastrous but I don’t like to let people down, when you’re supposed to be there, you’re supposed to be there” [Participant 6], time pressures associated with what’s “gotta get done” [Participant 1], doing the right thing as a parent or an accumulation of ‘pressures’ “depending upon the situation at work … and what’s going on with family” [Participant 13]. A few women indicated that stress revolved around the perception of the event, “it’s not about the facts, it’s about how you see them” [Participant 11] and that stress is “just goin’ on in your head” and that “a lot of the time … a lot of the stress you create yourself” [Participant 1]. Concerns about the controllability or uncertainty of a future event were particularly evident “I do try and think ahead um that okay this situation may arise so if it does um what are the options um I could do this, this or this. I just like to be prepared” [Participant 12].

Worrying also extended beyond work and family and included larger world issues around poverty and natural disasters.

**8.3.2 Perceptions regarding the impact of stress on health**

This sub-theme describes participants' thoughts regarding the manifestation of stress in terms of signs and symptoms. Also discussed are perceptions around the impact of stress on physical health, paying particular attention to the role of stress in arthritis.
Signs and symptoms of stress: “… you feel like you’re backed into a corner sometimes with stress”

Women with arthritis reported that stress could manifest psychologically and physically. Participants described the impact of stress in terms of making them feel “uptight and emotional” [Participant 5], being “agitated about things” [Participant 1], being “down in the dumps” [Participant 9] or having bouts of depression, feelings of powerlessness, as well as having a loss of appetite and experiencing panic attacks. The effects of stress were often attributed to sleep disturbance. Women described lying awake at night with a head that’s “going crazy” [Participant 15]. A number of women reported a cyclical pattern between stress and sleep disturbance, with a lack of sleep found to be a catalyst for feelings of fatigue “ahh it makes me tired because, because it stops me sleeping” [Participant 15], depressed mood or ‘weepiness’ and anger. Meanwhile, one participant indicated that stress could have widespread symptoms, particularly those revolving around mood swings and “brain fog” [Participant 1]. The internalisation (e.g. depression) and externalisation (e.g. anger) of stress-related feelings was often perceived by the women to be incongruent with their natural character. For instance, one participant indicated “I’ve always been a very cheerful, happy person and I still am as long as I’m not feeling stressed …”[Participant 10].

The perceived role of stress in physical health: “the mind is such a powerful thing”

The majority of women suggested that stress had not only emotional consequences such as contributing to depression or anxiety, but also had influence over physical health domains. Some women suggested that “the mind is such a powerful thing” [Participant 8] and psychological stress could have a global influence on health. Some participants posited that stress could possibly exert influence over physical health through the disruption of homeostasis:

I’m a firm believer that stress is very, very bad for your health … I think it um just puts your body out of balance, and when your body’s out of balance then it doesn’t function properly and things go wrong [Participant 6].

When the conversation turned to the role of stress in arthritis, the participants were less assured of this relationship. Participants most commonly attributed arthritis-related symptom exacerbations to extraneous factors such as physical exertion “I notice the thing that really stresses my arthritis is activity” [Participant 19] and the weather “I can
tell when it’s going to rain, ah [laughs], it certainly, it’s a lot worse just before it rains, a few days before it rains” [Participant 5]. Arthritis onset was also viewed as a natural part of the ageing process (see Section 7.4.4 of the previous chapter). One participant in particular found it extremely difficult to consider the relationship between stress and arthritis. She indicated that although she could accept that stress is a “killer” and was connected with other health problems such as cancer, she had been able to cope effectively with the stresses experienced throughout her life despite being a chronic worrier, “you name it I worry about it” [Participant 4], and that her arthritis was a result of either genetics or ageing.

A few participants did contemplate the possibility of a stress-arthritis connection. Some women commented that stress and decreased mood played a role in increased pain sensitivity. One participant observed that like the flu, emotional stress “brings out all your little aches and pains everywhere” [Participant 1], while another reported that when she felt “down” her “aches and pains …seem[ed] worse” [Participant 5]. Likewise, one participant who reported a greater awareness of stress in relation to her arthritis expressed that at the height of her son’s clinical depression that it “aged [her] terribly” and that she was “aware of being uncomfortable and in pain” [Participant 14]. This participant believed that “negativity increases the acid in your system and makes [arthritis] worse” [Participant 14]. Meanwhile, another commented that stress “deteriorates you mentally” and “deteriorates your confidence” and that this “must go somewhere” [Participant 17].

Some women began to question the relationship between stress and arthritis during the process of the interview. After indicating that “I don’t think that’s got much to do with arthritis really” one participant who had previously lived in a violent relationship uttered “… who knows what it affects who knows er what the interrelationships are between stress and arthritis …” [Participant 8]. She further remarked that upon reflection with her current partner she came to the realisation that her primary life philosophy had been rooted in not making a “fuss” and being “invisible”. She admitted that “you do hold it in” and that “… kind of the holding it in and not talking about things” can affect you physically in a form of “life messages”[Participant 8].

8.4 Coping with stress

Women with arthritis described experiencing stressful life events revolving around issues such as death, illness and relationship strain. Further, a number of women
reported an accumulation of stress over the life course. Despite the exposure to such stressors, the expression of stress-related symptoms was often reported to be the consequence of the appraisal process, with factors such as the perceptions of the event identified as critical to this process (see Section 8.3.1). However, the adjustment to stress is often complex, with some coping better than others. Coping has been identified as important in the mitigation of the stress response, and facilitation of psychological adjustment following stress exposure. This theme provides a discussion surrounding the coping strategies employed by participants in dealing with stress, the patterns of coping that emerged over time, and factors that influenced psychological adjustment to stress.

8.4.1 Approaches to coping with stress

Women with arthritis identified a number of strategies involved in minimising the immediate effects of stress. Notably, behavioural approaches such as physical activity were often used sparingly by the participants “If I go to the gym and feel absolutely buggered I always come out of there feeling energised and it’s easy to put things back into perspective then” [Participant 15]. Likewise, only one participant described making active attempts to remove the stressor, in this case ongoing work stress “I just thought, oh look I just want out of this I’m yeah I can’t handle this any longer. This isn’t worth it. Life’s you know worth more than this. Money’s not everything” [Participant 9]. Women with arthritis most often utilised either help-seeking practices, cognitive-based coping or drew upon personal belief systems and attitudes in order to deal with stress. The following contains a discussion of these particular approaches.

Help-seeking and support-based approaches: “my social network was hugely important at the time”

A number of women reported that seeking support from others was particularly important as a means of coping with life stress. This played a more significant role than for coping with arthritis specific concerns. For example, one participant indicated that when she had undergone significant stress surrounding her divorce, having a supportive network was a key factor in getting through the situation:

*It was very important to me to have my friends and my yeah my social network was hugely important at the time, I think, I think that’s what largely got me through it and certainly my new relationship with my now husband, it was very...*
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Important to me, yeah and it gave me a life outside um work and home which was very important [Participant 10].

While some women sought emotional support from a number of sources, other women described being more constrained in their choices. For women who valued this coping approach and had difficult or generationally stereotypical relationships with their spouses, this involved seeking informal support from individuals outside the marital union. Children, siblings, friends or other women within the community were identified as key sources. For instance, one participant described her husband as “useless” when it came to providing the support she needed, suggesting that although her husband was a wonderful man, “he would no sooner talk about his feelings than fly to the moon” [Participant 5]. She described his response to stress in primitive terms suggesting that it was often a case of “it’s happened, let’s get on with it, [I] don’t want to talk about it”. She confided in her “two girls” or female friends. Additionally, women sought support from other women within the community, particularly those older women who were “full of wisdom” regarding the trials and tribulations associated with life.

Despite this, some women relied upon their husbands for emotional support, often to the exclusion of others. One participant indicated “no [it’s] just [my husband] and I, that’s all we need” [Participant 2] while another suggested that although having support was important, for her having people to confide in wasn’t as important as it was “to most other people”. Reflecting on a recent “breast cancer scare” she indicated that during the three week period where she underwent two exploratory operations she “actually only spoke to one person” and suggested that “I suppose that tells the story a bit”. Consequently, she described herself as “a bit of a closed box” and often needed prodding to talk about things. Notably, her husband who is experienced in active listening techniques and providing feedback acted as a “sounding board” when she was “very upset about something” and assisted her with “looking at things um ah more rationally” [Participant 15].

A number of women also spoke about receiving professional help regarding their problems and sought counsel from psychologists, psychiatrists, grief counsellors, GPs or other alternative and complementary health practitioners, as well as attending self-development courses through Women’s Health Centres. For one participant, seeking the support from her “personal trainer” assisted her with identifying behaviour patterns and strategies to cope with her husband’s abusive behaviour “I feel like I’ve made good progress with … dissociating from it, labelling the conversations. You’re like ahh that’s
the money one, or that’s the … feral insult one, you know you just ‘butt’ your ears and move away” [Participant 11].

Seeking help from others facilitated emotional release, a factor that was seen as pivotal to the maintenance of good mental health:

*I think the main thing is to be able to talk about it. I think you have to talk to people about these things. You don’t bottle it up and try to deal with it yourself. Um talk about it and yeah open up about it and just get other people’s opinions. I think that’s the main thing. You know some people sort of, they clam up and they don’t talk about it, well they’re the ones that really have the breakdowns aren’t they?* [Participant 9].

However, for some women, seeking support was only viewed as beneficial when it came from like-minded individuals. Having the “same temperament” and being on the “same wave length” in terms of emotional expression was seen as crucial for these women.

A few women with arthritis also used ‘information seeking’ practices in order to reduce the impact of a stressor. This was particularly useful when the stressor related to the illness of a spouse or family member. For one participant whose husband was possibly in the early stages of Alzheimer’s disease, the ability to source information from the internet was viewed as a “God send” for her and others that live in “fairly um less developed parts of the countryside”. For her, having information readily available either dispelled concerns regarding the source of stress or provided a sense of control over the situation in which plans to combat the issue could be outlined. Being educated about the source of stress was also supported by others, “the more you know, it does stop you worrying” [Participant 12].

**Cognitive approaches: “put it back where it belongs”**

Women often spoke about using cognitive approaches to modify their thoughts surrounding the stressor. Similar to coping with arthritis pain and limitation, these practices included mind blocking strategies or distraction in order “to not dwell on all th[e] kind of crap that happens” and “put [the stress] back where it belongs” [Participant 11]. Activities that provided distraction included reading, watching television, listening to music, bird watching, paid work, playing with a pet and being involved in craft activities. These activities were reported to have a calming effect and facilitated relaxation. Women also employed positive self-talk techniques, although to a lesser
extent. These techniques allowed for the participant to either minimise or discount the stress they were experiencing:

> sometimes you know you can be feeling down and, and you’ve, and you have to say to yourself well come on it’s in your mind, you’re, it’s not as bad as you think it is. It’s just the way you’re feeling … [Participant 5].

Other cognitive processes which paralleled arthritis specific coping efforts included the use of comparative coping in order to normalise stress.

**Faith-based approaches: “ah the power of prayer”**

As with coping with arthritis, religious or faith-based coping was identified by a number of women as pivotal to coping with stress “…even though I’m not a church goer now I still have very strong faith and I do think that … has helped me right through life face things”[Participant 5]. This type of coping not only related to formal prayer and belief in Christianity, but also included engagement in meditation and the assistance of crystal therapy in order to promote emotional expression. Formal prayer methods were often used by participants when all earthly avenues were exhausted and the participant could no longer carry the burden.

**Stoicism: “oh I bottle up everything”**

Being stoic and repressing emotions “Oh I bottle up everything probably [laughs]. I’m one of those”[Participant 12] was consistently chosen as a coping strategy by the participants. While women employed this type of coping in order to adjust to arthritis, this strategy appeared to play a more significant role in terms of life stress. This type of coping was particularly noted in response to traumatic stress or the compounding of life events “you know things like that they make you bottle it up”[Participant 3]. In response to dealing with her daughter and husband having cancer at the same time, one participant commented “… that’s the sort of person I am I just cope. You have to do it and I had to be there for her because there was no one else and you just do it” [Participant 18]. Other women provided a similar analysis of the stress they experienced often simply suggesting that “I just had to get on with it, there was no time to dwell on things”[Participant 4].
8.4.2 Origins of coping responses: “we were brought up to be strong”

Although the participants reported coping with stress through either cognitive, help-seeking, attitudinal or faith-based practices (see Section 8.4.1), coping with stress did not appear to be a dynamic process. Throughout the course of the interviews, distinct patterns regarding the ways in which women with arthritis approached stress over the life course emerged. Coping responses particularly during times of intense stress were often a result of unconscious mechanisms that emerged early in life. Women with arthritis often indicated that the ability to cope was either an intrinsic quality “[I] was probably born like that” [Participant 12], a result of a “survival” [Participant 7] mechanism or the influence of parent-driven coping characteristics taken on at an early age “we were brought up to be strong” [Participant 10]. For instance, one participant noted that having been brought up by a single mother she learned to “just get on with things”:

Well we got taught when we were quite young ‘cause mum had to bring the two of us up on her own to you know, you’ve got to just get on with life no matter what happens to you you’ve got to just pick yourself up and get on with things. You don’t dwell on things or else you’ll go under. Yeah it’s just the way we were brought up [Participant 2].

Another participant described a lack of closeness within her family and having a mother “that was concerned about what people thought” created “a lot of pressure to um put on a show so everything looked really good”. For her this type of upbringing provided a “hopeless situation in learning how [laughs] to cope with the world ...” [Participant 15]. She indicated that living with her mother she learned to “never put yourself first ... and did what people expected of you even if you didn’t want to”. As a result, her early adult life involved “a lot of trial and error and a lot of error” where she had to learn to be “resourceful” [Participant 15].

Women with arthritis appeared to repeatedly choose coping mechanisms developed in childhood across the life course. This concept was most aptly illustrated by Participant 18. Despite having loving parents, being exposed to poverty as small child she modelled her coping practices on her mother and as such developed a “very strong sort of character”:

Oh I think my mother was a very strong person. I think she had to be to get through our childhood and you know with what they had, the little that they had
and um yeah she had quite a few setbacks in her life but I think that’s where I get it from. I am a lot like her … [Participant 18].

It was this coping mechanism that she indicated assisted her when faced with having her daughter and husband diagnosed with cancer at the same time.

Another participant indicated her “very unusual upbringing” that involved being sent to boarding school at five and a half shaped her ability to cope with life as she “either had to learn to get on with it or you know sink or swim” [Participant 4]. For one participant, the ability to “soldier on” in the face of stress was described as an admirable and necessary quality that she modelled from her mother, suggesting that it was “very common” with people of her mother’s “era” [Participant 19]. Thus, coping with early experiences had long-term implications, shaping the way in which the women approached not only future stressful life experiences, but their view of life in general.

8.4.3 Changes in coping with stress over time: “I think I’ve lost some of my ability to manage my stress”

As noted in the previous section (Section 8.4.2), the coping responses employed by the participants were often developed early in life and persisted across the life course. Consistently coping with psychosocial stressors using the same strategies, although adaptive in the short-term, were described as being detrimental to both physical and mental health over the long-term. The persistent use of attitudinal-based coping resources such as the “just get on with it” mentality were reported to coincide with a reduced ability to cope with ongoing stress. This process was often described by participants as a “loss of resilience”. For the majority of participants, new coping strategies were sought only when strategies used in the past began to fail. For some participants, the quest for new and effective coping strategies was a difficult process. As one participant indicated “I think I’ve lost some of my ability to manage my stress and I haven’t found … something that works”[Participant 10].

8.4.4 Perceived factors associated with reduced resilience: “it seems to just be something that goes missing”

As indicated in the previous section (Section 8.4.3) a number of women described an erosion of “mental resilience” in response to stress over time. The following describes the factors perceived by participants as catalysts in the reduction of coping abilities and
by extension, adjustment to stress. These factors were diverse and spanned the areas of relationship conflict, role responsibility, ageing and reproductive health, as well as cognitive factors such as ingrained attitudes and unresolved feelings, among others.

One participant who had experienced a range of adverse events including parental issues (e.g. having a domineering father and being a caretaker for her mother), single motherhood, marriage to an abusive man with psychiatric and alcohol concerns, as well as the illness and subsequent death of a young child, perceived chronic stress surrounding her marital relationship as key to the erosion of her ability to cope over time “37 years of personal abuse about how dumb you are, stupid this that whatever, it takes its toll … and just when you’re ageing [sobs] and you are more vulnerable” [Participant 11].

A large portion of participants indicated that age proved to be detrimental to the maintenance of resilience. As one participant noted “… it seems to just be something that goes missing as you get older” [Participant 15], while another suggested:

I think the older you get I think your coping mechanisms let you down a bit. I think I coped a lot better with things when I was younger and I find I don’t cope as well now that I’m older [Participant 19].

Further, some women attributed increased difficulty with coping with the onset of menopause:

… a friend later said that just wasn’t like you, I’ve seen you through all these hard times, it’s not like you to be like that, she said go off and have a test and see if you’re menopausal because you should have been coping … and I was [Participant 10].

One participant noted that her decreased coping ability may have been a result of a number of factors including the stress associated with increased arthritis symptoms, a greater use of internalisation as a coping response, or simply an artefact from having “more time to actually worry about things”. This concept of barrelling through life was expressed by the majority of women, and while the burden of responsibility and expectations associated with being a woman allowed women to get through difficult and often traumatic times, over time this method of coping was ineffective and detrimental to both their physical and mental health. For instance, “I had teenage kids, I was studying and I was cleaning and um we were quite poor so I just know there’s no way you can drop the balls really you know” [Participant 8]. One participant described
going into “a clinical mode” [Participant 7] and trying to detach from the situation when dealing with her mother’s illness and trying to maintain normalcy in her own family. Having “no options” was suggested by a number of participants as being beneficial in dealing with stress at the time of its occurrence “Oh if you think too far ahead you end, you end up getting bogged down in a big quagmire” [Participant 19]. It was often reductions in responsibility as well as having more time to worry that was detrimental to coping. As one participant indicated:

When you’ve got no option and there’s absolutely nothing you can do about something um you either completely collapse under it all which most people don’t tend to do actually, most people tend to oh well let’s you know, yes I’ve been worried about it but let’s get on with it. It’s when you are left with options that you have more stress [Participant 13].

She further expressed that during times of great stress, particularly when the focus was on the welfare of others she “didn’t increase any um de-stressing activities” indicating that “there was no time to even say the word de-stress”. A lack of time promoted the use of survival coping, with the effects of this process only evident once chronic stressors were removed. This self-sacrificing mentality facilitated some women remaining in stressful situations despite their own needs and health “I guess I just pressed on regardless of my own health needs” [Participant 4]. For one participant her gender stereotypical beliefs surrounding the care of children facilitated her returning to an abusive marriage. Apart from not being able to effectively provide for them and their education, she indicated “I chose to have them … you know” [Participant 11].

For another participant who had spent time as a single mother and “kept going because [she] had [her] children to look after and nobody else could do that” [Participant 10], her beliefs surrounding the stigma associated with depression and the need to be perceived as being “on top of things” provided a further barrier to coping with the effects of stress. Likewise, unresolved feelings surrounding previous life events affected a number of participants’ ability to cope with ongoing stress. Negative experiences revolving around parental figures and particularly those pertaining to mental illness were reported to have ongoing implications for the participants. As Participant 4 explained, the processing of these experiences required an understanding beyond the capabilities of a child and as such had ongoing implications for their adult lives. Unresolved feelings towards the affected parent were prominent over the long-term. The persistent rumination associated with unresolved feelings about past experiences had the potential to act as an ongoing stressor with implications pivotal to
not only the loss of mental resilience, but also physical resilience. Therefore, while stoicism appeared to have benefits in the short-term, consistent coping with this strategy was ultimately detrimental to health.

8.4.5 Surviving stress: “it’s not easy having difficult experiences, but it certainly toughens you up”

As with arthritis specific coping, coping with stress appeared to be dualistic in nature. While the majority of women reported experiencing psychosocial stress over the life course, a number of women indicated that the ability to see the ‘silver lining’ in their experiences. This process of ‘stress-related growth’ was vital to long-term psychological adjustment. This section describes the factors participants perceived as important in the reappraisal of stress over time.

Stressful experiences were viewed by participants as character building and presented a learning experience. For instance:

*I think you don’t know what’s in you until you are solely tested, that’s what I tell my kids, we don’t know what strengths we have and it’s easy when you’re cruising along but that’s when you find out who you really are and how you grow I think* [Participant 11].

Another participant who was currently grieving the sudden loss of her husband suggested that although “it wasn’t always easy”, adversity “ended up affecting [her] for the better”. Particularly, she highlighted that adversity assisted in cultivating empathy for others. Accepting the process of life and being grateful for the positive experiences were also noted by a few women as key factors in facilitating personal growth. For instance:

*... I wouldn’t change anything. I mean the things that I’ve done in my life have been ah, some of them have been really great, and some of them have been you know absolutely terrible. Um but I put that down to being you know life and um I’m thankful for the things I’ve been able to do. I’ve had some great experiences, I’ve met some wonderful people and I’ve done some um, unbelievably fantastic things. I mean I wouldn’t change anything …* [Participant 4].

Another participant suggested that her life involved “a lot of trial and error, and a lot of error” particularly during her early adult years. This period was critical in the
development of resourcefulness and although she viewed the coping strategies developed as less than optimal, it created the platform for adjustment in later years:

*it was a lot of trial and error and a lot of error … throughout my young adult life things were not very easy, I made some poor decisions, … I learnt to be resourceful um I think I also learnt not to trust anyone which was a bad thing um to rely on myself and my own strength and um be tough … I guess now at this stage in my life um things are pretty easy, really the easiest it’s been my whole life …* [Participant 15].

The overarching sentiment flowing through the interviews revolved around “survivorship”. Despite whatever they had experienced, including abuse, significant loss, or having “nervous breakdowns”, the majority of women came to terms with their experiences, accepted them as a part of life and managed to get up ‘off the floor’ and kept moving forward. As one participant commented:

*I think I’m a survivor. I’ve, I have come through a very good marriage and a sad marriage and I’ve lost my parents um and I’ve always moved forward, I’ve always kept going forward it never occurred to me to give up and I think it’s the genes I have from my parents who were survivors as well* [Participant 7].

Coping over the life course was extremely complex. While coping with the immediate impact of stress involved similar practices to that of arthritis specific stress, a stronger focus was placed upon cognitive and attitudinal-based processes. These styles of coping were often developed early in life. Particularly, the persistence of attitudinal coping styles over time were detrimental to long-term adjustment with significant reappraisal required in order to process life events.

### 8.5 Discussion

This study aimed to qualitatively explore aspects of the stress appraisal process in women with arthritis during the transition from midlife to older age. The findings suggest that while participants experienced stressful life events of varying intensity and chronicity across the life sphere, these women attributed particular meanings to the experience of stress and its role in chronic disease. Likewise, the adjustment to stress over the life course for participants was complex, with coping strategies often developed early in life. The findings add important information to the wider body of knowledge surrounding stress and coping in arthritis.
Women who participated in this study described being conscious of experiencing some form of stress throughout their lives. This finding is consistent with the limited qualitative research surrounding perceived stress in arthritis populations [e.g. 335]. While the participants acknowledged that stress was an ever-present entity in their lives, they tended to minimise its role by describing it in terms of ‘worry’. Women worried about specific issues surrounding the illness of a family member or chronically worried about how they were perceived by others, as well as the uncontrollability or uncertainty of a future event. Women often attributed stress with gender-specific caring roles in which hypervigilance was required to protect children from potential harm. Consequently, stress was suggested to be “not about the facts”, but self-created. This finding may have important implications for arthritis prevention. By understanding the types of stress women encounter and the language women use when describing stress, the development of arthritis screening tools may assist with health practitioners identifying women ‘at risk’ of arthritis.

Similar to the findings from focus groups of middle-aged and older Canadian adults from a self-management program (n=26) [335], women from this community sample suggested that stress could present itself both psychologically and physically. This often revolved around feelings of agitation, depression, anxiety-driven panic attacks and rumination-related sleep disturbance. Despite this, only a few women attributed stress to increased arthritis symptoms. This finding is supported by the reverse lagged analyses in Chapter 5 and that of previous research such as Treharne et al. [453]. Although a relationship between perceived stress and mental health outcomes at six month follow-up for individuals with RA was found, psychological stress was not related to key physical markers including inflammation, pain and functional disability. This finding however contrasts with that of Zautra et al. [709] who found in a ten week longitudinal study that increased interpersonal stress was associated with increased disease activity for RA patients with active disease. As such, perceived stress may have a more subtle impact on arthritis symptomatology that requires shorter measurement periods (e.g. weekly). Alternatively, this lack of association may be contingent upon the individual’s level of knowledge about stress. While women in this study suggested that stress was a “killer” and could affect physical health, particularly in terms of the onset and exacerbation of cardiovascular disease, cancer and asthma, they were less assured of its relationship with arthritis. Participants in this study possessed specific beliefs surrounding the cause of arthritis. Arthritis was primarily associated with genetics or a consequence of the ageing process, as has been found in past research [697]. Individuals with chronic illness construct a narrative around past
experiences in order to adjust psychologically [701]. This notion was reflected in the current study. Framing chronic illness in this manner has implications for coping with, and the prognosis of arthritis, with strategies employed selected based upon this belief system. As such, public health campaigns are required in order to dispel the myths surrounding the causes of arthritis in conjunction with highlighting the negative long-term impact that stress may have on the body. Likewise, educational programs aimed at assisting individuals in the identification of stress symptoms, its role in arthritis and the promotion of early intervention seeking practices may also provide the key to the prevention of arthritis.

While the perception of stress was extremely important to stress-related outcomes, it must be noted that participants also described experiencing a number of life events that varied in intensity and chronicity. For a large number of women a pattern emerged whereby women reported experiencing considerable ongoing stress across the life course. Stress often began in childhood with either the death or mental illness of a parent and persisted during adulthood. The experience of adversity prior to adulthood has been associated with adult onset arthritis in previous research [301,303]. The experience of significant stress during the formative years has the potential to disrupt early brain development and contribute to dysregulation of the HPA axis in conjunction with the nervous and immune systems [602]. This process may create a kindling-type effect whereby persistent maladaptive coping patterns developed in response to the processing of complex stimuli during a period of emotional immaturity may provide the impetus for increased response to decreasingly intense stimuli [603,710,711]. Zautra and colleagues [712] have provided support for the kindling hypothesis in relation to increased pain expression by individuals with RA and a past history of multiple depressive episodes experiencing perceived stress. Although this pathway would have to be examined longitudinally in relation to disease onset, it may have implications for clinical interventions.

In contrast to Lazarus and Folkman’s transactional model of stress and coping which posits that coping is a dynamic process involving a transaction between the threat, the appraisal and the response [67], coping with stress by women in this study appeared to involve static attitudinal coping processes that were developed early in life. This included stoicism, in conjunction with more stressor-dependent cognitive and support-based coping responses such as positive self-talk and help-seeking. These results are partially supported by Tak [336] and Isawasaki and Butcher [335]. However, in this study, educational help-seeking practices were related only to non-arthritis associated
stressors. In particular, Iwasaki and Butcher [335] found that middle-aged and older women with arthritis used spiritual-based coping, social support, physical activity, altruistic endeavours, maintaining a positive attitude, and educational help-seeking practices (although this was described specifically in relation to arthritis) in order to cope with stress. The use of a stoic attitude in order to cope with stress among women with arthritis is unique to the current study. The findings add to the current understanding surrounding coping with stress and highlight the detrimental long-term effects of such coping practices. As such, the expansion of quantitative coping inventories beyond currently recognised problem-focused and emotion-focused approaches are required.

Social support and seeking help were found to be particularly important for the women in this study. Some women sought support from a number of sources, while others were constrained in their choices and chose to seek emotional support from outside the marital union. It must be noted that there is potential for seeking social support to act as a double-edged sword (in terms of increased emotional distress), particularly in relation to the denial of emotional support within the marital union or intimate relationship. The expectation surrounding the source of support was pivotal to its efficacy, with women resigned to accept gender stereotypical behaviours. In the absence of social support, the women relied heavily on their own personal resources (e.g. cognitive approaches such as distraction or stoicism) in order to cope.

The employment of ingrained coping styles over the life course appeared to be detrimental to long-term psychological adjustment to stress in the current study and previous research [713], with women describing a loss of resilience over time. Emotional repression, characteristic of a stoic attitude, has been found to be associated with the reporting of low levels of distress despite high levels of physiological reactivity [714-716]. This may have particular implication for stress and coping over the life course and arthritis. For women in this study, changes to their coping approach were only made following significant impact on either their emotional or physical health. However, participants attributed the loss of resilience to the physiological challenges associated with ageing and menopause, rather than to stress. Evidence exists to suggest that the ageing process may contribute to reduced HPA axis feedback sensitivity in older age, particularly for women [717,718]. The sex hormone, oestradiol, reduced at menopause has been implicated in an altered HPA axis response in women (i.e. less pronounced cortisol response to psychological stressor) [719,720], however this finding has not always been consistent [721]. As
such, while these factors may play a modulatory role in contributing to allostatic load via HPA dysregulation, these perceptions may also be representative of an external health locus of control in which there is a tendency to attribute health and disease to uncontrollable external factors as opposed to those of an internal nature [722].

The process of coping with stress over the life course appeared to be dualistic. While the participants described experiencing a reduction in their ability to cope with ongoing stress over time, this was coupled with a degree of personal growth. Participants described implementing cognitive reappraisal techniques that allowed them to see the silver lining in their experiences. Stress was viewed as character building and provided women with the ability to cultivate or increase the depth of existing qualities such as empathy. The development of greater empathy has been reported in studies involving other chronic conditions [723-727]. The notion of co-occurring positive and negative psychological states in response to chronic stress is supported by Zautra [728]. Importantly, for these women the diagnosis of, and increasing disability associated with arthritis may have provided the impetus for the re-evaluation of pre-existing schemas surrounding stress [729]. It has been suggested that the ability to find benefit in a negative experience assists the individual with reinstating valued beliefs about themselves in relation to a world that is orderly, predictable, meaningful and benevolent [730]. This finding provides evidence for widening the scope in which to view stress and coping in arthritis. As such, this finding has important clinical implications (see Section 9.4 for discussion).

Although the depth of the findings surrounding the stress appraisal process in women with arthritis is a particular strength of the study, it must be considered in light of a few limitations. Firstly, while the aim of this study was to examine stress and coping in women with arthritis transitioning from midlife to older age, the findings are driven by diagnoses of OA. Thus, the results may not be generalisable to women with other rheumatic conditions such as RA. Likewise, studies have shown gender differences in stress reactivity and approaches to coping [622-624]. As this study focused on an in-depth analysis of women from the 1946-1951 cohort of the ALSWH, these findings may not be generalisable to perceptions surrounding stress and coping in males with arthritis. However, with women in this age group twice as likely as men to develop arthritis [144], and perceived stress in this cohort found to contribute to increased arthritis risk (see Chapter 5), understanding stress and coping processes in this cohort is appropriate.
8.6 Conclusion

The findings of this qualitative study add to the current understanding of stress and coping in arthritis. Importantly, the findings indicate that while women transitioning from midlife to older age experienced stressful life events varying in intensity and chronicity over the life course they attributed particular meanings to the experience of stress and its role in chronic disease. Coping with stress appeared to involve both static attitudinal coping processes developed early in life, coupled with stressor-dependent cognitive and support-based responses. Coping with stress over the life course was complex with women describing a dualistic process involving both reduced resilience and personal growth. The findings of the study have the potential to inform clinical interventions (see Section 9.4 for further discussion). These findings may also have implications for coping with the stress associated with arthritis. The following chapter provides a synthesis of the findings contained within this thesis and discusses these within the broader context of stress and psychosocial factors in arthritis and more generally, chronic disease.
Chapter 9

General Discussion

From psychology to biology revisited: perceived stress and psychosocial factors in women with arthritis

The overarching aim of this thesis was to examine in-depth the role of perceived stress and psychosocial factors in arthritis in a cohort of women transitioning from midlife to older age. As indicated in Chapter 1, this specific life stage presents as a critical period in terms of increasing psychosocial stress associated with physical changes and increased carer responsibilities. This period often culminates in the manifestation of chronic disease, most notably arthritis [2,15,16]. With significant variability associated with arthritis-related disability, the identification of extraneous factors contributing to the burden of disease has become particularly pertinent. Little attention has been given to the role of psychosocial factors and more importantly psychological stress in this process.

The findings from this thesis add significant information to the wider body of knowledge surrounding arthritis in women. Particularly, the findings add to our current understanding of the burden associated with arthritis, and highlight the important role psychosocial factors play in this process. Additionally, findings from this thesis provide the strongest and most convincing empirical evidence to date regarding the role of perceived stress as a risk factor for arthritis in women. This final chapter provides a contextualised and integrated synthesis of this work, and the implications for clinical interventions and policy are discussed. The limitations and strengths of this research are acknowledged and directions for future research are proposed.

9.1 The burden of arthritis for women: the entanglement between arthritis and mental health

Against a backdrop of literature that provides support for a general improvement in the mental health of women as they age (or at least until very old age), the findings of this thesis highlight the detrimental impact of arthritis on mental health [731-734]. The findings from this research indicate that the emotional burden of arthritis for women
during the midlife transition is substantial. The results from the quantitative and qualitative analyses (see Chapter 4 and Chapter 7) suggest that in this cohort of women, arthritis coincides with the increased reporting of anxiety and may also result in a spectrum of depressive symptoms. The results provide additional support for previous research conducted on mental health and arthritis in middle-aged and older adults [329,338,401,423-425,428,430,432]. However, the majority of previous arthritis-related research has focused on the role of depression or generalised psychological distress, and not anxiety [338,579,735]. The findings from Chapter 4 suggest that anxiety may be a primary and somewhat overlooked concern in women with arthritis, with the diagnosis of an anxiety/nervous disorder the only significant psychosocial factor associated with arthritis following the adjustment for demographic characteristics and HRQoL. This finding is supported by previous case-control and clinic-based research [428,430,736,737], in conjunction with the recent population-based study conducted by Murphy and colleagues [738] using data extracted from the CDC. While one-third of respondents with arthritis reported experiencing either anxiety or depression, the authors noted that depression was contingent upon the presence of anxiety (84%).

However, the findings from Chapter 4 of this thesis were the first to report the role of anxiety in arthritis for women in a large population-based study (n>10,000), controlling for various aspects of the stress process, along with risk/protective factors and health perceptions that may influence the arthritis experience within the one model. This study extends previous research by suggesting that in women with arthritis, anxiety extends beyond a direct relationship with pain expression and may be related to issues related to stressor control. Findings from the cross-sectional analyses in Chapter 4, coupled with those from the longitudinal time lag analyses in Chapter 5 suggest that anxiety in women is a consequence of the disease process and not a precursor to arthritis, although the long-term impact of anxiety on arthritis would have to be confirmed via longitudinal analyses. This finding was also extended by the qualitative analysis described in Chapter 7. In this study, women reported that the experience of anxiety was associated with a lack of control over the disease and in particular, the loss of control surrounding pain chronicity. This may have implications for arthritis management [739] (see Section 9.4).

Anxiety, like depression, has been found to heighten the perception of pain and contribute to functional limitations [580,583,740-742]. It has been suggested that mood may impact upon pain through similar biological pathways [741,743]. Using event-
related functional MRI, Ploghaus et al. [744] found that anxiety-induced pain sensitivity was associated with activation of the hippocampal network, particularly the entorhinal cortex of the hippocampal formation. Using the Gray-McNaughton theory of anxiety [745], the authors posited that during the experience of anxiety the hippocampal formation increases the response to aversive stimuli by behavioural priming responses to consider the worst possible outcome. This may result in a chronic cycle of pain and anxiety for women with arthritis. This bi-directional relationship would have to be examined longitudinally. However, this may have implications for clinical interventions around the disengagement of the hippocampal formation.

Further, the findings from the qualitative analysis (Chapter 7) may provide some support for the consistent association between pain and increased disability in arthritis [440]. Psychological distress, although associated with pain and limitation was found to involve not only the chronicity of pain but primarily concerned the effects of pain-related sleep disturbance and the disruption to the participants’ sense of identity with increasing functional disability. Distress was perceived by participants to increase over the course of the disease and escalated in line with increasing disability. This finding contrasts with that found in RA sub-populations where distress was found to either decrease, or remain stable over time [438,439,441,442]. This difference may have been a consequence of the constant struggle between dependence and independence associated with this life stage. This concept was a major focus for participants in the qualitative interviews and was a key feature associated with the psychological adjustment process. The differences in findings from the quantitative (Chapter 4) and qualitative analyses (Chapter 7) regarding the role of depression (i.e. depression not contributing to the arthritis experience following control of current health perceptions in Chapter 4) in arthritis may be attributed to the methods employed, with variables containing shared variance being removed from the quantitative model. It may also suggest that the measures of depression in Chapter 4 (i.e. doctor-diagnosed or the Mental Health Index-5 Index of the SF-36) may be inadequate to capture factors relating to the loss of independence that was captured using the interview process in Chapter 7. The Mental Health Index-5 [746] subscale of the SF-36 in particular has been found to have better detection of current (4 weeks), as opposed to long-term (12 months) psychological distress [747].

While it is important for physicians to assess anxiety and by extension depression in conjunction with arthritis-related disease activity, anxiety has been suggested as a key reason individuals avoid seeking medical care [748]. Pain and the presence of physical
disease comorbidity have been associated with reduced recognition of depression [743]. This may have a similar impact on anxiety. These findings coupled with those from this thesis suggest that mental health problems, particularly anxiety may be under-recognised and under-treated in women with arthritis [739]. Further research focused on psychosocial barriers to treatment access and an in-depth analysis of doctor-patient relationships is warranted.

9.2 The power of the mind: the role of perceived stress in arthritis

Perceived stress emerged as the strongest risk factor for arthritis, with both minimal and moderate/high levels of stress contributing to the onset of arthritis three years later. Comparison of GEE models with and without a time lag component, coupled with the adjustment for traditional risk factors, provides evidence for perceived stress playing a causal role in arthritis onset. In particular, the findings indicated that the experience of moderate/high levels of perceived stress resulted in a higher risk of arthritis than that of being in the highest BMI category. As such, chronic stress is just as detrimental to arthritis as obesity.

Previously it has been more commonly accepted that stress may play a role in the onset and exacerbation of RA due to its relationship with systemic inflammation [596,597]. Although arthritis forms could not be distinguished in the current analyses, the numbers of women in this cohort were driven by diagnoses of OA. Thus, conducting sensitivity analyses (excluding women with persistent pain at previous surveys), as well as reversed lagged analyses with and without time lags, contributed to providing the most convincing evidence to date that supports the tenet that perceived stress plays a substantial role in the development of OA.

The acute stress response involves the initiation of key allostatic systems including central, autonomic, neuroendocrine, and immune systems as well as motor responses in response to real or perceived threats to homeostasis [604]. Particularly, the SAM-axis releases catecholamines and the HPA axis secretes glucocorticoids that mobilise the ‘fight or flight’ response [598,749]. This process is deemed adaptive and facilitates physiological resilience [604]. Chronic activation of the SAM and HPA axes results in a stress-related hormonal cascade into surrounding interconnected systems. Coupled with amplification of pro-inflammatory cytokines, these maladaptive processes may
result in lasting changes to these systems that is conducive to the onset of disease, such as those of an inflammatory nature [599, 612]. It has been argued that perceived stress may also influence joint degeneration and pain pathways through cellular ageing or altered mood [604, 605, 750]. Chronic inflammatory stimulation (through increased tumor necrosis factor-α and interleukin-6 production) has been found to have direct effects on key disease-related features including cartilage breakdown and heightened pain sensitivity [751, 752]. Increased levels of c-reactive protein, an inflammatory marker, has previously been associated with the prevalence and progression of knee and hip OA [753-755]. Likewise, it has been suggested that disease onset for arthritis, most notably OA, may occur through metabolic pathways as a result of adverse health behaviours such as obesity [607]. In light of the current thesis findings, the physiological pathways underpinning the role of perceived stress in the onset of arthritis require further examination.

Findings from the qualitative analysis in Chapter 8 offer support for the role of chronic stress perception, and provide information about the context of stress for this cohort of women. A large portion of the women interviewed expressed ‘worrying’ throughout their lives. Chronic stress was viewed as a natural occurrence, with women worrying about ‘silly things’ including whether they were doing the right things as a parent, what others have said or done or the anticipation of future events. A few women indicated that it wasn’t about the events themselves but was contingent upon how they viewed them. One of the biggest factors contributing to the perception of stress was the uncontrollability or unpredictability of the stressor (see Section 8.4.4). This finding although of a qualitative nature is consistent with Lazarus and Folkman’s transactional model of stress and coping [67]. Research has indicated that individuals experience less physiological and psychological effects of stressors when they can predict a negative event, or when they have sufficient personal resources to control and ameliorate the effect of the stressor [756, 757]. It has been hypothesised that the exposure to uncontrollable stressors alters later cognitive processes such as attention [758], thereby instigating a level of fear conditioning. What the individual learns about the stressor has the ability to set in motion a cascade of biological events. Psychological insult may instigate sensitisation of the central nervous system via the release of the stress-related hormones, adrenaline and cortisol. Cortisol feedback to the amygdala and the hippocampus has the ability to alter declarative memory [759]. As such, a response to decreasingly intense stress stimuli may occur [603]. This however would have to be confirmed through quantitative analyses at a population level.
Women from this thesis suggested that stress could present itself both psychologically and physically, as has been previously noted in other research [335]. This often revolved around feelings of agitation, depression, anxiety-driven panic attacks and rumination-related sleep disturbance. Despite this, only a few women attributed stress to increased arthritis symptoms. This finding is consistent with that of past research [453,463].

Women with arthritis possessed a degree of understanding of the effects of stress when it involved comprehending the relationship between stress and conditions such as cancer and cardiovascular and respiratory diseases (Chapter 8). When focused on the role of arthritis, women were less assured. This was facilitated by lay beliefs surrounding the cause of arthritis, most notably OA being a natural part of the ageing process. Holding beliefs such as arthritis being a non-preventable disease, are detrimental to long-term health. A potential consequence of these beliefs is that potentially less effective treatments might be used in order to cope (e.g. home remedies) [760].

The findings from this thesis add significantly to the wider body of arthritis literature. In conjunction with providing the most convincing evidence to date regarding the role of perceived stress in the onset of arthritis, this is the first study to provide comprehensive contextual information regarding the meanings attributed to stress, factors contributing to how life events are perceived and perceptions surrounding the role of stress and health for women transitioning from midlife to older age. While these findings require confirmation at a population level, they may have potential significance for public health strategies aimed at altering perceptions surrounding arthritis, and the detrimental long-term health effects of chronic stress in relation to arthritis onset.

Importantly, a number of women in the qualitative analysis reported experiencing adverse life events that generally began early in life, coupled with ongoing chronic stress. Smith et al. [611] found that perceived stress partially mediated the relationship between traumatic life events and mental, as well as physical health, in women with fibromyalgia. The authors concluded that exposure to trauma may have contributed to ongoing cognitive appraisals, leading to long-term dysregulation of stress response systems and increased sensitivity to ongoing life demands [69,612] (i.e. allostatic load). Women also spoke about the cumulative effects of stress, particularly in terms of mental health. Findings from Chapter 5 indicate that the diagnosis of depression was associated with a similar increase in risk of arthritis comparable to minimal levels of
chronic stress. Depression and chronic perceived stress may act synergistically in order to induce chronic arousal of key stress-related allostatic systems in order to facilitate health outcomes. Although the contribution of allostatic overload would have to be confirmed in future studies, the findings from this research appear to fit within an integrated biopsychosocial model of health that accounts for the physiological role of allostatic load [e.g. 69] with ongoing stress appraisals. This has implications for future public health research focused on understanding the role of stress in the aetiology of chronic disease. Further research is also needed in order to ascertain the cumulative psychosocial risk associated with arthritis onset in women. Studies focused on understanding the psychosocial profile of older women who do not go on to develop arthritis may assist with the development of arthritis-related prevention strategies (e.g. psychosocial screening).

It must be noted, that while perceived stress contributed significantly to the onset of arthritis in the longitudinal analyses contained in Chapter 5, chronic stress perception although the strongest predictor of arthritis at a univariate level in Chapter 4, failed to contribute to the multivariate model when adjusted for HRQoL. This unidirectional relationship was paralleled in the reversed lagged sensitivity analysis in Chapter 5 when adjusted for chronic health conditions and health service use. These findings suggest that stress may act differently in terms of disease manifestation and progression. Once the disease has been established, chronic stress may act as a precursor, that when coupled with an additional stressor such as arthritis, accelerates to a diagnosable state (i.e. anxiety) [761]. This hypothesis however would have to be examined in future longitudinal analyses.

9.3 Coping with arthritis and stress: two sides of the same coin?

Findings from Chapter 7 provide some insight into the complex processes involved in coping with arthritis symptoms and the psychological adjustment to the disease for women born 1946-1951. Coping was found to be highly individualised and often involved self-management strategies with a cognitive or behavioural focus. The findings from this qualitative study is supported within the arthritis literature [446,447,472,690,692]. Self-determined pharmacological approaches were primarily used by participants with chronic pain that could not be alleviated by other methods. Similar to previous research involving middle-aged and older individuals with RA [684],
women viewed medication as potentially harmful in terms of side effects. From their point of view, medicines only provide a mask to symptoms as opposed to a cure, with the benefits of such practices often not outweighing the potential costs. When pharmacological approaches were utilised, they were often over the counter sources of pain relief rather than physician prescribed, thereby taken without consultation from any healthcare professional. As such, the participants relied upon their own resources in order to cope with arthritis-related pain and limitation. This finding may have implications for HRQoL outcomes. Future prospective research is required in order to understand the role of psychosocial factors on the long-term HRQoL impact of arthritis for women.

Women used a combination of strategies including physical activity, distraction, activity restriction, pain minimisation, and positive self-talk. Additionally, some women used prayer and social support as a source of comfort. While emotionally-based approaches to coping have been suggested as maladaptive, in this study, prayer served as a form of emotional release particularly when all other avenues had been exhausted. This finding is congruent with that of Smith and Wallston [482] who found that prayer when combined with low levels of catastrophising (such as hopelessness) was negatively correlated with functional impairment and depression in RA. In contrast, Niu et al. [690] found that religion and prayer instigated passive approaches to arthritis management in terms of mitigating functional impairment and was solely focused on immediate symptom relief. In this study, faith-based beliefs served the purpose of reinforcing the notion that arthritis was a result of ‘God’s will’, and dealing with the symptoms was a ‘test of faith’. The way in which this faith-based coping approach is utilised may have implications for not only psychological adjustment, but also HRQoL outcomes.

Although social support has been suggested as particularly important for pain-coping [446,453,498,694], this type of strategy was emphasised less often than other approaches by women in this study. This may have been associated with the potential negative consequences of this approach for women of the ‘baby boomer’ generation. Interviewees expressed seeking informal support from family and friends in conjunction with professional sources such as a GP or psychologist. Support was generally received along gender lines as husbands were often perceived as unresponsive to arthritis-related emotional cues. Findings from the quantitative analyses in Chapter 5 found that perceived social support was unable to provide a buffer against the effects of perceived stress. Both factors acted as independent risk factors for arthritis. Hawkley and colleagues [762] provided evidence for the role of social factors (particularly
loneliness) in maintenance and reparative processes via pro-inflammatory cytokine mediators (interleukin-1β and tumor necrosis factor). Further research is required in order to elucidate the physiological processes underlying the stress associated with social support quality and sources. However, women with arthritis may benefit from extending their social support networks both formally, by joining arthritis support groups in order to address arthritis specific issues in an environment conducive to understanding the psychosocial burden, as well as informally by extending their social and community involvement. Such practices may not only have implications for psychological health but may also play a role in reduced pain perception.

Although minimizing the immediate effects of stress involved similar processes to that of coping with arthritis specific stress, these strategies were fewer in number and heavily focused on cognitive (e.g. positive self-talk), help-seeking (e.g. social support and stressor education), and faith-based practices (see Chapter 8). This is a novel finding as previous qualitative research using OA or RA samples have viewed coping with stress as a part of coping with arthritis [e.g. 336] and have not been able to provide an in-depth account of the subtle differences in coping with life stress as opposed to coping with an arthritis-related stressor. Further, the findings of this study have extended previous work by demonstrating that coping over the long-term, with either arthritis specific stress or life stress, may involve both static attitudinal coping processes in conjunction with more stressor-dependent strategies (see Section 8.4.1).

The employment of ingrained attitudinal coping responses was a significant finding of this study and extends the concept of coping involving emotion and problem-focused efforts [67]. These response styles (particularly the use of stoicism) were often developed early in life and although described as one of the factors driving the long-term adjustment to arthritis (see Section 7.4.6), they also appeared detrimental to long-term psychological adjustment to stress (see Section 8.4.3). Interviewees described a loss of resilience to stress over time with additions to stress-related coping repertoires only made following significant impact on either their emotional or physical health. While stoicism appeared to be adaptive in the short-term by mitigating an emotional response to the stressor, this was not representative of ‘true’ resilient (i.e. adaptive) behaviour. Continually responding to stress with a stoic attitude may have increased the physiological arousal associated with this passive style of coping and facilitated the onset of arthritis. This finding however requires further investigation at an epidemiological level.
The repression of emotion, a key factor associated with stoicism, has been found to have adverse health effects [763-765]. Women in the qualitative study reported significant stress early in life and a pattern of coping with stress and arthritis using stoicism (see Chapter 8). Diamond and colleagues [766] noted a relationship between attachment style developed early in life and coping patterns. Particularly, their findings demonstrated that attachment avoidance (i.e. a pattern of caregiver attachment which is characterised by the minimisation and suppression of negative emotions) [767,768] was associated with a pattern of physiological stress reactivity characteristic of repressive coping. As such, tasks that elicited negative thoughts and feelings were accompanied by heightened and escalating sympathetic nervous system reactivity in the absence of self-reported distress. This pattern was more pronounced in women. Thus, attachment styles may have implications for the onset of arthritis in women. While the attachment style of women with arthritis would have to be examined in future analyses, this finding may have implications for arthritis prevention.

In the qualitative analyses, psychological adjustment to arthritis was described as a ‘day to day’ process involving the constant struggle around the grief of physical losses and reappraisal of what could now be achieved (Chapter 7). Women responded similarly to coping with stress over the life course. Coping with stress appeared to be dualistic with reductions in the ability to cope with stress, coupled with a degree of personal growth. This notion of co-occurring positive and negative psychological states in response to chronic stress is supported by Zautra [728]. Further, the struggles associated with coming to terms with life stress may have provided the skills necessary in order to psychologically adjust to the physical changes associated with arthritis. Alternatively, for these women, the diagnosis of, and increasing disability associated with arthritis may have provided the impetus for the re-evaluation of pre-existing schemas surrounding stress [729]. This however, would require further investigation. Qualitative analyses using diary methods may assist with capturing the daily context of stress, and contribute to understanding the dynamic nature of coping over time.

The constant psychological readjustment over the long-term associated with these processes may have contributed to deleterious physiological effects through increased arousal of stress systems. The development of accurate quantitative measures in order to assess the complexity involved in coping and adjustment are required to confirm the findings from the qualitative analysis at a population level (including the expansion of coping inventories to encompass more attitudinal-based coping). Further research is also required in order to better understand the role of stoicism and the effects of
emotional repression on arthritis outcomes, and its role in the onset of chronic diseases more generally.

9.4 Implications

At the outset of this thesis, arthritis was described as a subset of diverse diseases with OA and RA the most prevalent forms. Cases of arthritis for this cohort of women are likely to be driven by OA. RA is commonly viewed as a more insidious disease due to its inflammatory component. The findings from the qualitative analysis (Chapter 7), coupled with previous research from other arthritis populations suggest that women with OA may have similar concerns with regard to the emotional burden associated with pain, functional impairment and loss of self-identity. The process of adjustment did not represent an endpoint but was a ‘day to day’ process. This process of ‘reluctant acceptance’ has been reported in other arthritis populations [493,695,696]. Additionally, the findings from Chapter 5 indicate that perceived stress may act through similar pathways to RA in order to induce OA. These findings have important implications for shared clinical interventions and policy.

Public health education strategies aimed at the general population are required to dispel misconceptions surrounding chronic joint symptoms and the ageing process. The synergy between the findings of this study and that of Gignac et al. [684] suggest that these perceptions are already present by middle age. Highlighting the destructive nature of arthritis (and in particular OA) as well as providing education regarding pain being unnatural and not a consequence of “wear and tear” may assist with increased early detection and treatment in middle-aged and older adults. Specialised public health educational programs targeted at young adults may also reduce the burden associated with arthritis in the future by facilitating the early detection of chronic joint symptoms or prevention through awareness of pertinent risk factors. Targeted programs may also have implications for reducing the culture around self-medication. By understanding the destructive and preventable nature of arthritis, this may facilitate increased uptake of appropriate treatment options for arthritis that not only provide symptom relief but have the ability to modify the disease trajectory, thereby promoting the maintenance of HRQoL. Public health campaigns are also required in order to inform individuals about the negative long-term health consequences of perceived stress, particularly with regard to arthritis development. Findings from this thesis indicate that the mitigation of the adverse effects of stress are required in childhood and adolescence as part of chronic disease prevention programs that focus on other
modifiable factors such as nutrition, physical activity and obesity prevention as coping patterns were shown to develop early and persist over time.

Additionally, the findings from Chapter 4 and Chapter 7 indicate that women with arthritis who are transitioning from midlife to older age may benefit from targeted clinical intervention in order to reduce the emotional burden associated with pain and increasing disease-related disability. The findings from this thesis provide support for a multi-staged, multidisciplinary (i.e. biopsychosocial) approach in order to address the psychosocial concerns of these women. Customisation of treatments according to patient characteristics (i.e. disease stage, functional impairment) have been posited as a way to optimise treatment efficacy [769]. Particularly, women with arthritis would benefit from improved psychosocial screening and evaluation methods. Sleath and colleagues [770] found that depressive symptoms are not often addressed in physician-patient communication consultations. It has been argued that patients should play a more active role in disease management [447,771], with such practices linked to an increased sense of independence [772]. While self-management of arthritis and gaining personal control over symptoms should be encouraged, this should not be to the exclusion of professional consultation. Such efforts may be detrimental to the maintenance of HRQoL.

Appropriate treatment of depression and anxiety may result in clinically significant reductions in pain, as well as improved functional outcomes [773]. GPs, who are at the coal face of chronic disease management, could be more actively involved in the care of arthritis patients, monitoring not only symptoms but also routinely screening for psychosocial concerns (e.g. depression and anxiety). Psychosocial assessments of risk for poor emotional outcomes using standardised self-report measures with defined cut-off scores may be key to assisting with clinical referrals and supplementary treatment options [774-776]. Particularly, cognitive-behavioural approaches targeted to the individual’s specific needs, such as pain-coping/pain-acceptance skills, are required. Engagement in complementary self-management practices (e.g. moderate physical activity) may assist in the improvement of not only functional ability but also in the reduction of poor mental health [777]. GPs however, need to be conscious of the language they use when assessing the psychosocial concerns of women with arthritis. Findings from this thesis indicate that these women tend to use stoicism and minimise the impact and use terms such as ‘frustration’ or ‘worry’. This may not be reflective of the true degree of burden.
Women of this generation may also require interventions associated with redefining self-concepts outside the confines of their caring responsibilities in order to reduce the risk of poor mental health. Sharpe and colleagues [450] found that a lack of coping skills significantly predicted depression in older adults with arthritis. Such efforts may assist in fostering resilience in the face of inevitable physical deterioration. Sturgeon and Zautra [778] suggested that resilient individuals adopt more adaptive strategies to pain, possess a greater belief in their abilities to effectively control pain, possess greater emotional knowledge and direct more attention to evaluating their own current emotional state. This type of therapy would also assist with reappraising and finding meaning in the arthritis experience and thus facilitate the acceptance of, or encourage appropriate control of pain. In light of concerns surrounding the use of pharmacological approaches to pain relief, women with arthritis would benefit from psychosocial interventions aimed at improving sleep quality in order to halt the pain-distress cycle. Likewise, education surrounding the appropriate use of pharmacology in mitigating functional impairment is warranted. The findings from this thesis also highlight the need to improve communication regarding the treatment and detection of arthritis in women.

The incorporation of stress-management practices such as biofeedback or mindfulness-based therapies may also assist not only in stress reduction but also in facilitating pain management. The framework surrounding mindfulness posits that individuals can learn to respond to stress as opposed to automatically reacting to it (i.e. eliciting the ‘fight or flight’ response). These practices have been shown to be comparably effective to traditional multimodal cognitive-behaviour therapies in terms of functional outcomes and physiological measures of stress (e.g. interleukin-6) [779,780]. These types of strategies may play an important role in long-term disease management. Women with arthritis that have stress vulnerabilities may also benefit from targeted interventions aimed at increasing emotional expression and increasing coping flexibility. Adopting a balanced or flexible coping approach may be the key to long-term adjustment to stress [781,782], particularly as women combat additional stressors associated with ageing. Such approaches may be supplemented by other promising self-management strategies such as computer-assisted therapies. This type of intervention has benefits for addressing issues surrounding not only perceived stress (including the role of stress in health), but also presents an opportunity for a flexible and integrated biopsychosocial approach to providing coping techniques (e.g. the development of pain-coping skills and psychological adjustment to arthritis) at low cost to governments and consumers. This type of approach would require further investigation.
The findings from this thesis are also of particular relevance to health policy. Given the global burden associated with musculoskeletal diseases, the period 2000-2010 was declared the ‘Bone and Joint Decade’ in order to address the worldwide burden associated with these conditions. Prevention and health promotion were highlighted by the United Nations, WHO and more than 60 countries around the world [76]. Within Australia, the prevention and treatment of arthritis has received particular attention as a National Health Priority Area [783]. Despite this focus, little attention has been given to examining the links between psychological and physical well-being in arthritis [3,784-786]. The findings from this thesis highlight the necessity of mental health being included as part of a national chronic disease strategy. A greater focus on arthritis prevention beginning in childhood may be required in order to mitigate the potential long-term effects associated with particular coping styles. In this thesis, women described experiencing stress early on in life and developed persistent patterns of coping that in the long-term proved maladaptive. Despite the achievements in advancing the area of arthritis, the dissemination of material to health professional and consumers regarding the role of psychosocial factors in arthritis onset and progression are lacking. The intersection between psychology and arthritis is required to be a part of a joint public health agenda.

9.5 Strengths and limitations

A major strength of this thesis lies in its design. A multi-method approach was applied in order to explore the depth and breadth of the phenomenon being studied. Knafl and colleagues [787] suggest that a multi-method design maximises the strengths and minimises the weaknesses associated with each study method (i.e. quantitative and qualitative methods). Initially, a quantitative approach was taken and explored the relative importance of psychosocial factors in arthritis (see Chapter 4) and the role of perceived stress in the onset of the disease (see Chapter 5). These analyses utilised a nationally representative cohort involving over 10,000 women. A cohort of this magnitude allowed for the examination of various aspects of the stress process within the one model as well as control for a comprehensive range of risk/protective factors and health perceptions. To date, no epidemiological studies examining perceived stress and psychosocial factors have been able to examine the factors of interest in such a comprehensive model. A further strength regarding the quantitative analyses related to the statistical techniques employed. Employing time lag modelling allowed for
the examination of causality between perceived stress and arthritis onset at the following survey. This has not been undertaken previously in women at this life stage.

While this approach allowed for the generalisation and prediction of outcomes [625,626], it did not allow for the lived psychosocial experience of arthritis to be examined. As such, a qualitative approach using a realist-oriented framework (see Chapter 6) was applied in order to gain a depth of understanding surrounding the emotional burden of arthritis and the context and meaning associated with stress. A major strength of the qualitative approach related to methodological rigour (see Section 6.6). Factors such as purposefully sampling participants, creating transparency at each stage of the process and systematically analysing the data contributed to the study’s rigour. Added to this, a systematic process was used in order to achieve data saturation [643]. These approaches allowed for the corroboration of previous arthritis research and generated novel findings that will provide avenues for further investigation. Finally, while qualitative research has generally relied upon face-to-face interviewing when conducting in-depth interviews, using a telephone approach presented several advantages. It has been suggested that qualitative telephone interviews provide rich, vivid and high quality data [788-791]. In addition to its cost effective nature, this method allowed the participation of women with arthritis from geographically diverse areas of Australia, particularly those living in rural areas [788,790-792]. Further, this method has been found to be effective in facilitating a relaxed anonymous environment conducive to the disclosure of intimate information [791-793]. During the interviews a number of women disclosed information, particularly regarding depressive episodes, that they had not expressed prior.

The current research must also be considered in light of its limitations. Firstly, the measure for arthritis was based on self-report. However, March and colleagues [589] have found good congruency between self-report physician diagnosis and clinician derived diagnoses. Additionally, due to the nature of the ALSWH survey, arthritis forms were not able to be distinguished. However, this has been found to be an acceptable method of case definition for epidemiological research [542-544]. In fact, the CDC strongly discourages the use of specific arthritis forms in analyses from self-report surveys, due to the inherent difficulties associated with labelling less prevalent forms [794]. Likewise, the heterogeneity associated with arthritis diagnosis in the ALSWH survey presents potential issues regarding the lag times between symptom onset and diagnosis. In the analyses contained in Chapter 5, sensitivity analyses were conducted in order to account for potential reverse causality.
Further, in the quantitative analyses conducted in Chapter 4 and the qualitative analyses in Chapter 7 and Chapter 8 there was no accurate information regarding the time since diagnosis. Further, this research was focused on the role of psychosocial factors in arthritis among women. These findings may not reflect the experiences of men. With women in this age group twice as likely as men to develop arthritis [144], this is an appropriate cohort to study.

Although a purposive sampling frame was applied to the qualitative studies, the sample of participants was largely homogenous in terms of OA diagnosis. Also, although the coding in the qualitative analyses in Chapter 7 and Chapter 8 were verified by peer review, primary coding was conducted by the candidate and did not involve a second independent coder. However, Morse [795] suggests that only the interviewer has true insight into the material that is presented. The maintenance of meticulous notes and the creation of an audit trail allows for the trustworthiness of the study to be examined by a third party. Moreover, only a sub-sample of the women approached agreed to participate in the semi-structured interviews. It is possible that the participants may not be representative of the women who declined to participate. Future qualitative research should involve purposeful sampling with representation of the arthritis forms similar to current prevalence rates.

9.6 Conclusion

The findings from this multi-method thesis add to our current understanding of the burden associated with arthritis and highlight the important role of psychosocial factors in this process, particularly for women as they transition from midlife to older age. Findings from this thesis also provide the most convincing evidence to date regarding the role of perceived stress in the onset of arthritis. Women with arthritis have widespread psychosocial concerns related to chronic stress perception and poor mental health (Chapter 4), as well as psychological difficulties associated with pain and functional impairment (Chapter 7). Coping with pain and functional limitation was found to involve a number of strategies, with a strong focus on self-management.

In addition, this thesis has provided insight into the processes associated with the psychological adjustment to arthritis over time. For these women, the adjustment to arthritis involved a daily struggle against the grief associated with threats to the participant’s sense of identity. Unlike the strategies used to cope with the immediate effects of arthritis symptoms, coping over the long-term was largely contingent upon
cognitive and attitudinal factors. The particular role of attitudinal factors such as stoicis

This thesis adds significantly to arthritis research in terms of the relationship between perceived stress and arthritis. Chronic perceived stress has significant health consequences for women, with the effects of these cognitions evident years later (Chapter 5). While the connection between stress and the onset of RA has been more readily accepted, the results of this thesis suggest that perceived stress may also play a substantial role in the onset of OA. Findings from Chapter 8 extend this finding by providing a context for the stress experienced by the women, the meanings attributed to stress, and the process of coping and adjustment over time. The findings from the qualitative analysis provide support for coping strategies identified in previous studies primarily focused on the stress of arthritis, and extend the findings in terms of coping with the immediate effects of non-arthritis-related stress. Likewise, the findings related to the effects of ingrained coping patterns developed early in life on later psychological adjustment is particularly novel. Additionally, the dualistic process of adjustment to stress involving reduced resilience and personal growth and its similarity to the process of adjusting to arthritis over time for women with arthritis is also a novel finding.

These findings have important implications and suggest that stress and psychosocial factors should form part of a public health agenda aimed at reducing the incidence of arthritis in women. Recommendations from this thesis are that perceived stress should be considered alongside other modifiable risk factors such as obesity and physical activity. Public health education strategies are required in order to inform individuals of the long-term negative health consequences associated with stress, as well as dispel myths associated with the onset of arthritis, notably OA (i.e. a natural part of the ageing process). Additionally, the development of clinical interventions targeting both stress and arthritis specific psychoeducation in conjunction with cognitive-behavioural techniques may prove effective in the minimisation of not only stress but improve arthritis-related outcomes. For widespread generalisability, the findings of this thesis would require replication in a cohort of similarly aged men. Future research should focus on understanding physiological pathways underpinning the role of perceived stress in the onset of arthritis as well as the indirect pathways in which perceived stress may induce arthritis in OA and RA. Likewise, studies aimed at elucidating the cumulative psychosocial risk associated with arthritis onset in women and their long-term impact on HRQoL are also required.
Thus, the findings of this thesis highlight the insufficiencies associated with viewing arthritis within a biomedical model, both in terms of pathophysiology and disease management. Due to the significant role of psychosocial factors in disease onset and progression, arthritis should be viewed within a biopsychosocial framework. Primary and secondary intervention strategies should have a strong psychosocial focus. A collaborative approach in which healthcare practitioners, health policy makers and the community are cognisant of the detrimental impact of stress and the benefits of its reduction, may see fewer women diagnosed with arthritis. Taking a top-down approach, changes to the health framework and national guidelines based upon the findings of this research are pivotal to future generations of women ageing well.
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The following appendix contains additional material relevant to Chapter 2: Literature Review. Included are tables relating to the ACR classification criteria for both OA and RA.
### A.1 Disease classification: osteoarthritis

Table A.1. ACR classification criteria for hand, knee and hip osteoarthritis

<table>
<thead>
<tr>
<th>Classification of OA</th>
<th>Criterion</th>
<th>Sensitivity</th>
<th>Specificity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Classification of OA of the hand</strong></td>
<td>Hand pain, aching or stiffness and 3 or 4 of the following features:</td>
<td>94%</td>
<td>87%</td>
</tr>
<tr>
<td></td>
<td>• Hard tissue enlargement of 2 or more of 10 selected joints(^a);</td>
<td>92%;</td>
<td>75%</td>
</tr>
<tr>
<td></td>
<td>• Hard tissue enlargement of 2 or more DIP joints</td>
<td>91%;</td>
<td>86%</td>
</tr>
<tr>
<td></td>
<td>• Fewer than 3 swollen MCP joints</td>
<td>95%;</td>
<td>69%</td>
</tr>
<tr>
<td></td>
<td>• Deformity of at least 1 of 10 selected 10 joints</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Classification of idiopathic OA of the knee</strong></td>
<td>Knee pain and at least 5 of 9:</td>
<td>92%;</td>
<td>75%</td>
</tr>
<tr>
<td></td>
<td>• Age &gt;50 years</td>
<td>92%;</td>
<td>75%</td>
</tr>
<tr>
<td></td>
<td>• Stiffness &lt;30 min</td>
<td>92%;</td>
<td>75%</td>
</tr>
<tr>
<td></td>
<td>• Crepitis</td>
<td>92%;</td>
<td>75%</td>
</tr>
<tr>
<td></td>
<td>• Bony tenderness</td>
<td>92%;</td>
<td>75%</td>
</tr>
<tr>
<td></td>
<td>• Bony enlargement</td>
<td>92%;</td>
<td>75%</td>
</tr>
<tr>
<td></td>
<td>• No palpable warmth</td>
<td>92%;</td>
<td>75%</td>
</tr>
<tr>
<td></td>
<td>• ESR &lt;40 mm/hour</td>
<td>92%;</td>
<td>75%</td>
</tr>
<tr>
<td></td>
<td>• RF &lt;1:40</td>
<td>92%;</td>
<td>75%</td>
</tr>
<tr>
<td></td>
<td>• SF OA</td>
<td>92%;</td>
<td>75%</td>
</tr>
</tbody>
</table>

| Classification of idiopathic OA of the hand | Knee pain and at least 1 of 3: | 91%; | 86% |
| | • Age >50 years | 91%; | 86% |
| | • Stiffness <30 min | 91%; | 86% |
| | • Crepitis + osteophytes | 91%; | 86% |

<table>
<thead>
<tr>
<th>Clinical and Laboratory</th>
<th>Clinical and Radiological</th>
<th>Clinical[^b]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Combined clinical (history, physical examination, laboratory and radiographic classification of OA of the hip)</strong></td>
<td>Hip pain and at least 2 of the following 3 features:</td>
<td>89%;</td>
</tr>
<tr>
<td></td>
<td>• ESR &lt;20 mm/hour</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Radiographic femoral or acetabular osteophytes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Radiographic joint space narrowing (superior, axial and/or medial)</td>
<td></td>
</tr>
</tbody>
</table>

Note: OA = Osteoarthritis; DIP = Distal Interphalangeal; MCP = Metacarpophalangeal; ESR = Erythrocyte Sedimentation Rate (Westergren); RF = Rheumatoid Factor; SF = Synovial Fluid signs of OA (clear, viscous or white blood cell count <2,000/mm\(^3\)).

[^a]: The 10 selected hand joints are the second and third distal interphalangeal, the second and third proximal interphalangeal, and the first carpometacarpal joints of both hands.

[^b]: Alternative for clinical category would be 4 of 6 with sensitivity = 84% and specificity = 89%.
## A.2 Disease classification: rheumatoid arthritis

Table A.2. The 1987 revised criteria for the classification of rheumatoid arthritis$^a$ [124]

<table>
<thead>
<tr>
<th>No.</th>
<th>Criterion</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Morning stiffness</td>
<td>Morning stiffness in and around the joints, lasting at least 1 hour before maximal improvement</td>
</tr>
<tr>
<td>2</td>
<td>Arthritis of 3 or more joint areas</td>
<td>At least 3 joint areas simultaneously have had soft tissue swelling or fluid (not bony overgrowth alone) observed by a physician. The 14 possible areas are right or left PIP, MCP, wrist, elbow, knee, ankle, and MTP joints</td>
</tr>
<tr>
<td>3</td>
<td>Arthritis of hand joints</td>
<td>At least 1 area swollen (as defined above) in a wrist, MCP, or PIP joint</td>
</tr>
<tr>
<td>4</td>
<td>Symmetric arthritis</td>
<td>Simultaneous involvement of the same joint areas (as defined in 2) on both sides of the body (bilateral involvement of PIPs, MCPs, or MTPs is acceptable without absolute symmetry)</td>
</tr>
<tr>
<td>5</td>
<td>Rheumatoid nodules</td>
<td>Subcutaneous nodules, over bony prominences, or extensor surfaces, or in juxtaarticular regions, observed by a physician</td>
</tr>
<tr>
<td>6</td>
<td>Serum rheumatoid factor</td>
<td>Demonstration of abnormal amounts of serum rheumatoid factor by any method for which the result has been positive in &lt;5% of normal control subjects</td>
</tr>
<tr>
<td>7</td>
<td>Radiographic changes</td>
<td>Radiographic changes typical of RA on posteroanterior hand and wrist radiographs, which must include erosions or unequivocal bony decalcification localized in or most marked adjacent to the involved joints (OA changes alone do not qualify)</td>
</tr>
</tbody>
</table>

Note: RA = Rheumatoid arthritis; OA = Osteoarthritis; PIP = Proximal Interphalangeal; MCP = Metacarpophalangeal; MTP = Metatarsophalangeal.

$^a$ For classification purposes, a patient shall be said to have RA if he/she has satisfied a least 4 of these 7 criteria. Criteria 1 through 4 must have been present for at least 6 weeks. Patients with 2 clinical diagnoses are not excluded. Designation as classic, definite, or probable RA is not to be made.
Appendix B

Chapter 4

Supplementary data analyses and material

The following appendix contains additional statistical analyses relevant to Chapter 4: The relative importance of psychosocial factors in arthritis. Chi-square and univariate logistic regression analyses are presented for each of the predetermined covariates.

B.1 Health behaviours

Table B.1. Chi-square analysis for health behaviours for women born between 1946 and 1951 according to arthritis diagnosis

<table>
<thead>
<tr>
<th></th>
<th>Missing n (%)</th>
<th>No arthritis n (%)</th>
<th>Arthritis n (%)</th>
<th>Unadjusted odds ratio (95% CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BMI</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Healthy weight [ref]</td>
<td>3135 (43.9%)</td>
<td>881 (29.8%)</td>
<td>--------</td>
<td></td>
<td>--------</td>
</tr>
<tr>
<td>Under weight</td>
<td>93 (1.3%)</td>
<td>31 (1.0%)</td>
<td>1.2 (0.8, 1.8)</td>
<td>0.407</td>
<td></td>
</tr>
<tr>
<td>Overweight</td>
<td>2373 (33.2%)</td>
<td>1034 (35.0%)</td>
<td>1.6 (1.4, 1.7)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Obese</td>
<td>1539 (21.6%)</td>
<td>1008 (34.1%)</td>
<td>2.3 (2.1, 2.6)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td>317 (3.0%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Alcohol consumption</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-drinker [ref]</td>
<td>477 (6.9%)</td>
<td>207 (7.4%)</td>
<td>--------</td>
<td></td>
<td>--------</td>
</tr>
<tr>
<td>Low risk</td>
<td>5925 (86.2%)</td>
<td>2422 (86.7%)</td>
<td>0.9 (0.8, 1.1)</td>
<td>0.484</td>
<td></td>
</tr>
<tr>
<td>Moderate risk</td>
<td>400 (5.8%)</td>
<td>144 (5.2%)</td>
<td>0.8 (0.6, 1.1)</td>
<td>0.150</td>
<td></td>
</tr>
<tr>
<td>High risk</td>
<td>69 (1.0%)</td>
<td>21 (0.8%)</td>
<td>0.7 (0.4, 1.2)</td>
<td>0.155</td>
<td></td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td>746 (7.2%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Smoking status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-smoker [ref]</td>
<td>4532 (62.0%)</td>
<td>1738 (58.1%)</td>
<td>--------</td>
<td></td>
<td>--------</td>
</tr>
<tr>
<td>Ex-smoker</td>
<td>1998 (27.3%)</td>
<td>920 (30.7%)</td>
<td>1.2 (1.1, 1.3)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Current smoker</td>
<td>783 (10.7%)</td>
<td>335 (11.2%)</td>
<td>1.1 (1.0, 1.3)</td>
<td>0.122</td>
<td></td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td>105 (1.0%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*a weighted for area.*
## B.2 Health-related factors

Table B.2. Chi-square statistics and unadjusted odds ratios with 95% confidence intervals (CI) for health-related factors for women born between 1946 and 1951 according to arthritis diagnosis

<table>
<thead>
<tr>
<th></th>
<th>Missing n (%)</th>
<th>No arthritis n (%)</th>
<th>Arthritis n (%)</th>
<th>Unadjusted odds ratio (95% CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Menopause status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre/peri-menopause</td>
<td>160 (2.2%)</td>
<td>44 (1.5%)</td>
<td>0.8 (0.6, 1.1)</td>
<td>0.182</td>
<td></td>
</tr>
<tr>
<td>Post-menopause [ref]</td>
<td>4959 (67.5%)</td>
<td>1731 (57.6%)</td>
<td>--------</td>
<td>--------</td>
<td></td>
</tr>
<tr>
<td>Surgical menopause</td>
<td>2224 (30.3%)</td>
<td>1230 (40.9%)</td>
<td>1.6 (1.5, 1.7)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>63 (0.6%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>HRT use</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td>6180 (84.2%)</td>
<td>2384 (79.4%)</td>
<td>--------</td>
<td>--------</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1160 (15.8%)</td>
<td>620 (20.6%)</td>
<td>1.4 (1.2, 1.5)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>67 (0.6%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*a weighted for area.
## B.3 Health-related quality of life

Table B.3. Means with standard deviations and unadjusted odds ratios with 95% confidence intervals (CI) for health-related quality of life for women born between 1946 and 1951 according to arthritis diagnosis\(^a\)

<table>
<thead>
<tr>
<th></th>
<th>Missing n (%)</th>
<th>No arthritis</th>
<th>Arthritis</th>
<th>(^b)Unadjusted odds ratio (95% CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M(SD)</td>
<td>86 (0.8%)</td>
<td>84.93 (17.01)</td>
<td>68.71 (24.13)</td>
<td>0.83 (0.82, 0.84)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Bodily pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M(SD)</td>
<td>3 (0.0%)</td>
<td>74.33 (21.45)</td>
<td>52.82 (22.99)</td>
<td>0.82 (0.81, 0.82)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Mental health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M(SD)</td>
<td>36 (0.3%)</td>
<td>77.46 (18.75)</td>
<td>71.41 (18.71)</td>
<td>0.91 (0.90, 0.92)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Social functioning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M(SD)</td>
<td>4 (0.0%)</td>
<td>86.38 (21.29)</td>
<td>75.35 (26.09)</td>
<td>0.91 (0.90, 0.92)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>General health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M(SD)</td>
<td>249 (2.4%)</td>
<td>75.54 (18.48)</td>
<td>61.45 (22.65)</td>
<td>0.85 (0.84, 0.86)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Vitality</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M(SD)</td>
<td>35 (0.3%)</td>
<td>63.59 (19.79)</td>
<td>51.88 (21.83)</td>
<td>0.88 (0.87, 0.89)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Emotional role functioning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M(SD)</td>
<td>61 (0.6%)</td>
<td>86.35 (30.06)</td>
<td>75.24 (38.29)</td>
<td>0.96 (0.95, 0.96)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Physical role functioning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M(SD)</td>
<td>40 (0.4%)</td>
<td>82.64 (32.68)</td>
<td>58.40 (42.93)</td>
<td>0.92 (0.92, 0.93)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

\(^a\) weighted for area.  
\(^b\) 5 point change in index.
Appendix C

Chapter 5

Supplementary data analyses and material

The following appendix contains additional statistical analyses relevant to Chapter 5: The influence of perceived stress on the onset of arthritis in women. Chi-square analyses related to the sample characteristics are presented in conjunction with univariate GEE analyses for each of the predetermined covariates for the arthritis onset, multinomial sensitivity analysis models with, and without a time lag.

C.1 Arthritis status sensitivity analyses

Table C.1. Chi-square analysis based on survey 3 arthritis status for women who completed survey 4 compared to women who did not complete survey 4

<table>
<thead>
<tr>
<th></th>
<th>Did not complete survey 4</th>
<th>Completed Survey 4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>No arthritis (survey 3)</td>
<td>811 (77.6%)</td>
<td>7,647 (77.7%)</td>
</tr>
<tr>
<td>Arthritis (survey 3)</td>
<td>234 (22.4%)</td>
<td>2,200 (22.3%)</td>
</tr>
</tbody>
</table>

χ²(1, N = 10892) = 0.001, p = 0.970.

Table C.2. Chi-square analysis based on survey 4 arthritis status for women who completed survey 5 compared to women who did not complete survey 5

<table>
<thead>
<tr>
<th></th>
<th>Did not complete survey 5</th>
<th>Completed Survey 5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>No arthritis (survey 3 and 4)</td>
<td>608 (66.3%)</td>
<td>6,628 (67.8%)</td>
</tr>
<tr>
<td>Arthritis (survey 3 or 4)</td>
<td>309 (33.7%)</td>
<td>3,143 (32.2%)</td>
</tr>
</tbody>
</table>

χ²(1, N = 10688) = 0.898, p = 0.343.
C.2 Longitudinal arthritis risk analyses

C.2.1 Psychosocial covariates

Table C.3. Unadjusted odds ratios with 95% confidence intervals (CI) for the relationship between psychosocial factors and arthritis during the period 2001-2007

<table>
<thead>
<tr>
<th>Negative life events experienced within the past 12 months</th>
<th>GEE Model without time lag</th>
<th>GEE Model with time lag</th>
<th>GEE Model with time lag (excluding persistent joint pain)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Odds ratio (95% CI)</td>
<td>P Value</td>
<td>Odds ratio (95% CI)</td>
</tr>
<tr>
<td>Death of a family member/close friend</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td>--------</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Yes</td>
<td>1.2 (1.1, 1.3)</td>
<td>&lt;0.001</td>
<td>1.1 (1.0, 1.2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1.2 (1.1, 1.3)</td>
</tr>
<tr>
<td>Major illness of family member/close friend</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td>--------</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Yes</td>
<td>1.4 (1.3, 1.4)</td>
<td>&lt;0.001</td>
<td>1.4 (1.3, 1.5)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1.4 (1.3, 1.6)</td>
</tr>
<tr>
<td>Interpersonal/relationship difficulties</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td>--------</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Yes</td>
<td>1.2 (1.1, 1.3)</td>
<td>&lt;0.001</td>
<td>1.3 (1.1, 1.4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1.3 (1.2, 1.5)</td>
</tr>
<tr>
<td>Financial strain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td>--------</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Yes</td>
<td>1.2 (1.1, 1.3)</td>
<td>&lt;0.001</td>
<td>1.2 (1.1, 1.3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1.3 (1.2, 1.4)</td>
</tr>
<tr>
<td>Psychiatric diagnoses</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Appendix C

<table>
<thead>
<tr>
<th></th>
<th>Reference</th>
<th>Unemployment stress</th>
<th>Anxiety/nervous disorder</th>
<th>Perceived social support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>No [ref]</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.9 (1.7, 2.1)</td>
<td>&lt;0.001</td>
<td>1.9 (1.7, 2.1)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Anxiety/nervous disorder</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.9 (1.7, 2.1)</td>
<td>&lt;0.001</td>
<td>1.9 (1.7, 2.2)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Perceived social support</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All of the time [ref]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most of the time</td>
<td>1.2 (1.1, 1.3)</td>
<td>&lt;0.001</td>
<td>1.2 (1.1, 1.3)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Some of the time</td>
<td>1.1 (1.0, 1.3)</td>
<td>0.021</td>
<td>1.2 (1.1, 1.4)</td>
<td>0.001</td>
</tr>
<tr>
<td>None/little of the time</td>
<td>1.4 (1.3, 1.7)</td>
<td>&lt;0.001</td>
<td>1.7 (1.5, 2.0)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

*weighted for area.*
### C.2.2 Health behaviours

Table C.4. Unadjusted odds ratios with 95% confidence intervals (CI) for the relationship between health behaviours and arthritis during the period 2001-2007

<table>
<thead>
<tr>
<th></th>
<th>GEE Model without a time lag</th>
<th>GEE Model with a time lag</th>
<th>GEE Model with a time lag (excluding persistent joint pain)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Odds ratio (95% CI)</td>
<td>P Value</td>
<td>Odds ratio (95% CI)</td>
</tr>
<tr>
<td><strong>BMI</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under weight</td>
<td>1.2 (0.8, 1.7)</td>
<td>0.371</td>
<td>1.1 (0.8, 1.6)</td>
</tr>
<tr>
<td>Healthy weight</td>
<td>--------</td>
<td>-----</td>
<td>------</td>
</tr>
<tr>
<td>Overweight</td>
<td>1.5 (1.4, 1.6)</td>
<td>&lt;0.001</td>
<td>1.5 (1.4, 1.6)</td>
</tr>
<tr>
<td>Obese</td>
<td>2.4 (2.1, 2.6)</td>
<td>&lt;0.001</td>
<td>2.5 (2.2, 2.8)</td>
</tr>
<tr>
<td><strong>Physical activity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nil/sedentary</td>
<td>1.5 (1.4, 1.7)</td>
<td>&lt;0.001</td>
<td>1.5 (1.4, 1.8)</td>
</tr>
<tr>
<td>Low</td>
<td>1.0 (0.9, 1.1)</td>
<td>0.903</td>
<td>1.0 (0.9, 1.1)</td>
</tr>
<tr>
<td>Moderate [ref]</td>
<td>--------</td>
<td>-----</td>
<td>------</td>
</tr>
<tr>
<td>High</td>
<td>1.0 (0.9, 1.1)</td>
<td>0.504</td>
<td>0.9 (0.8, 1.0)</td>
</tr>
<tr>
<td><strong>Smoking status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-smoker [ref]</td>
<td>--------</td>
<td>-----</td>
<td>------</td>
</tr>
<tr>
<td>Ex-smoker</td>
<td>1.1 (1.0, 1.3)</td>
<td>0.003</td>
<td>1.2 (1.1, 1.3)</td>
</tr>
<tr>
<td>Current smoker</td>
<td>1.2 (1.0, 1.3)</td>
<td>0.011</td>
<td>1.3 (1.1, 1.5)</td>
</tr>
</tbody>
</table>

[a] weighted for area.
### C.2.3 Demographic variables

Table C.5. Unadjusted odds ratios with 95% confidence intervals (CI) for the relationship between demographics and arthritis during the period 2001-2007

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>GEE Model</th>
<th>GEE Model with time lag</th>
<th>GEE Model with time lag (excluding persistent joint pain)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Odds ratio (95% CI)</td>
<td>P Value</td>
<td>Odds ratio (95% CI)</td>
</tr>
<tr>
<td>Age</td>
<td>1.14 (1.13, 1.15)</td>
<td>&lt;0.001</td>
<td>1.11 (1.09, 1.13)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/de facto [ref]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separated/divorced/widowed</td>
<td>1.2 (1.1, 1.3)</td>
<td>&lt;0.001</td>
<td>1.3 (1.1, 1.4)</td>
</tr>
<tr>
<td>Never married</td>
<td>1.4 (1.1, 1.7)</td>
<td>0.002</td>
<td>1.5 (1.2, 1.8)</td>
</tr>
<tr>
<td>Area of residence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban [ref]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural/remote</td>
<td>1.1 (1.0, 1.3)</td>
<td>0.070</td>
<td>1.1 (0.9, 1.3)</td>
</tr>
<tr>
<td>Educational attainment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tertiary/post graduate [ref]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trade/diploma</td>
<td>1.3 (1.1, 1.5)</td>
<td>&lt;0.001</td>
<td>1.2 (1.1, 1.4)</td>
</tr>
<tr>
<td>School/higher school certificate</td>
<td>1.3 (1.2, 1.5)</td>
<td>&lt;0.001</td>
<td>1.3 (1.1, 1.4)</td>
</tr>
<tr>
<td>No formal education</td>
<td>2.0 (1.7, 2.3)</td>
<td>&lt;0.001</td>
<td>2.0 (1.7, 2.4)</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Highly skilled [ref]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skilled</td>
<td>1.1 (1.0, 1.2)</td>
<td>0.158</td>
<td>1.1 (1.0, 1.2)</td>
</tr>
<tr>
<td>Less skilled</td>
<td>1.2 (1.0, 1.5)</td>
<td>0.030</td>
<td>1.4 (1.1, 1.7)</td>
</tr>
<tr>
<td>No employment</td>
<td>1.8 (1.6, 1.9)</td>
<td>&lt;0.001</td>
<td>1.7 (1.5, 1.9)</td>
</tr>
</tbody>
</table>

*weighted for area.
### C.2.4 Health-related factors

Table C.6. Unadjusted odds ratios with 95% confidence intervals (CI) for the relationship between health-related factors and arthritis during the period 2001-2007

<table>
<thead>
<tr>
<th>Health-related factor</th>
<th>GEE Model</th>
<th>GEE Model with time lag</th>
<th>GEE Model with time lag (excluding persistent joint pain)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Odds ratio (95% CI)</td>
<td>P Value</td>
<td>Odds ratio (95% CI)</td>
</tr>
<tr>
<td>Menopause status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre/peri-menopause</td>
<td>0.6 (0.6, 0.7)</td>
<td>&lt;0.001</td>
<td>0.8 (0.7, 0.9)</td>
</tr>
<tr>
<td>Post-menopause [ref]</td>
<td>--------</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Surgical menopause</td>
<td>1.5 (1.4, 1.7)</td>
<td>&lt;0.001</td>
<td>1.6 (1.4, 1.7)</td>
</tr>
<tr>
<td>HRT use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No [ref]</td>
<td>--------</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Yes</td>
<td>1.2 (1.1, 1.2)</td>
<td>0.001</td>
<td>1.3 (1.2, 1.4)</td>
</tr>
</tbody>
</table>

*weighted for area.
Appendix D

Chapter 6

Supplementary data and material

The following appendix contains additional material relevant to Chapter 6: Qualitative methods. Included is the letter of invitation, semi-structured telephone interview schedule, consent interview script, a copy of the ethics approval from the University of Newcastle and the systematic method of data saturation presented.
D.1 Letter of invitation/Participant information statement

Arthritis at midlife: The lived psychosocial experience
Participant Information Statement
Version 1.1; July 13, 2011

Dear (Title) Name,

Thank you for your continued participation in the Women’s Health Australia project. We appreciate how many demands are placed upon your time and your continued involvement is highly valued.

When you agreed to take part in the Women’s Health Australia project we mentioned that you might be invited to participate in projects on a range of health issues between the main surveys. We would like to invite you to take part in an important extra study concerning women’s experiences with arthritis. Your responses and experiences are important and will serve to influence decisions about arthritis care in Australia.

Who is conducting the study?
Researchers working on the Women’s Health Australia project at the University of Newcastle are conducting this study. Particularly, for this study we are collaborating with Melissa Harris, a PhD candidate from the School of Medicine and Public Health. This research will form part of Melissa’s thesis on psychosocial experiences of arthritis at midlife. Melissa is supervised by Dr Deborah Loxton, Deputy Director of the Women’s Health Australia project, Associate Professor David Sibbritt from the School of Medicine and Public Health at the University of Newcastle and Professor Julie Byles, Co-Director of the Women’s Health Australia project and Director of the Research Centre for Gender, Health and Ageing at the University of Newcastle.

What is the study about?
The purpose of this study is to explore the personal experiences of women living with arthritis.

Why was I chosen?
You were randomly selected from the Women’s Health Australia database because you indicated in a previous survey that you have arthritis.
What would I be asked to do?
If you would like to participate in this study you do not need to do anything. Melissa will call you in the next 2-4 weeks to arrange a time convenient to you in order to complete a telephone interview about your experiences of living with arthritis. In particular, we will ask you to talk about your thoughts and feelings surrounding being diagnosed with arthritis as well as your life experiences around this time and before you were diagnosed. The telephone interview will take about 60 minutes to complete and will be audio-recorded. Please note that during the interview you will have the right to at any time review the recording and ask for sections to be erased. You will also be given the opportunity to review, edit or erase a typed copy of the interview.

Do I have to participate?
Your participation is completely voluntary. If you do not wish to take part you are under no obligation to do so. You are entirely free to discontinue your participation at any time without reason or to decline to answer particular questions. Your decision to participate or not will have no bearing on your future participation in the Women’s Health Australia project.

What if I do not want to participate in this study?
If you would prefer not to participate, or if you have any questions about this study, please call Women’s Health Australia on our FREECALL number 1800 068 081. Alternatively, you can email us at the following address: whasec@newcastle.edu.au or tear off the slip at the end of this letter and return it in the enclosed replied paid envelope to Women’s Health Australia.

Are there any risks or benefits in participating?
We cannot promise you any benefit from participating in this research, however your contribution will help us to better understand how women are affected by arthritis. While we do not expect that there will be any problems or risks associated with participating in this study, some people may become upset when talking about their life experiences. If you become upset by any of the questions you may stop the interview or decide to take a break. If needed, counselling support will also be available through Lifeline. They can be contacted on 131 114 (local call). Alternatively you can consult your local GP.

How confidential is the information I give?
All the information you provide to us will remain confidential and will only be made available to the researchers. Your name and address will not be released and the results of the research will only be published in a form whereby you cannot be identified. This means that your name and other identifying information will not appear on your transcript. The results from this study will only be used for the purposes of publication in scientific journals and presentations at conferences as well as contributing to a thesis to be submitted for Melissa’s degree.

All information will be stored at the University of Newcastle in locked filing cabinets or on a password protected computer database for a minimum of five years after which time it will be destroyed. Please note however, that the audio-recorded interviews will be destroyed at the conclusion of the study, following checks for accuracy. Further, to save you re-answering many questions that you have already answered in previous surveys, we will link your responses from this interview to your answers from previous surveys.
How can I find out about the results of the study?
The results of the study will be published in the annual Women's Health Australia newsletter. If you would like to receive a summary of the results in the mail, these can be obtained from Dr Deborah Loxton from July, 2012.

Who can I contact about the study?
If you have any questions about the study, please call Women's Health Australia on our FREECALL number 1800 068 081. Alternatively you can contact one of the researchers.

Dr Deborah Loxton
Women's Health Australia
The University of Newcastle
Callaghan, NSW 2308, Australia
Tel: 02 4913 8872
Fax: 02 4913 8888
e-mail: Deborah.Loxton@newcastle.edu.au

Ms Melissa Harris
School of Medicine and Public Health
The University of Newcastle
Callaghan, NSW 2308, Australia
Tel: 02 4913 8872
Fax: 02 4913 8888
e-mail: Melissa.Harris@newcastle.edu.au

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2011-0191. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellory, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone 02 4921-6533, email Human-Ethics@newcastle.edu.au.

Thank you for your consideration.

Yours sincerely,

Dr Deborah Loxton
Primary Supervisor and
Deputy Director

Ms Melissa Harris
PhD Candidate

I do not wish to participate in the substudy "Arthritis at midlife: The lived psychosocial experience."

Name: __________________________ Date: ___/___/11 Signature: __________________________

Please mail this slip to: Women's Health Australia
Reply Paid 70
Hunter Region MC
NSW 2310

or return it in the reply paid envelope provided.
D.2 Semi-structured telephone interview schedule

<table>
<thead>
<tr>
<th>Question</th>
<th>Prompt</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychosocial impact of being diagnosed with arthritis (approx. 15 mins) – major focus: aim 1</td>
<td></td>
</tr>
</tbody>
</table>
| • Today I’d like to ask you about your life experiences and your experiences with living with arthritis. Firstly, could you describe your experience of being diagnosed with arthritis? | - You could start by describing how you came to be diagnosed?  
- What things were happening for you that led you to seek medical advice? |
| • What was going on for you in your life at the time of being diagnosed? | - Was there anything major happening in your life at the time or daily hassles such as issues with money?  
- How were things with your friends or family?  
- **What is going on for you in your life when your arthritis/symptoms are worse (e.g., when you have pain, fatigue or stiffness)?**  
- **What makes it harder for you to cope with having arthritis or dealing with your symptoms? What makes it easier?** |
| • How has your life been affected by arthritis?                         | - How has having arthritis affected you physically? Emotionally? With your relationships with friends or family? |
| • How has your ability to cope with arthritis changed from when you were diagnosed until now? | - How do you feel about how things have changed for you? |

| Psychosocial impact prior to arthritis diagnosis (approx. 15 mins) – major focus: aim 2 |                                                                                                                                          |
| • Now, I’d like to ask you about your life prior to being diagnosed with arthritis. Could you tell me what your life was like before you began experiencing symptoms? | - Thinking about your life growing up and in your early adult years, how would you generally describe the experiences in your life?  
- Have you experienced one or a series of stressful events or have they been on the whole positive?  
- What kind of things did you do to cope?  
- What kind of impact do you think this/these event(s) had on your health (physically and emotionally)?  
- What are your thoughts and feelings about this time in your life now? |
Understanding of the relationship between stress and health (approx. 15 mins) – major focus: aim 2

- Switching focus now, I’d like to ask you about experiencing stress in relation to your health. How do you think stress affects your health (physically and emotionally)?
- How often would you say that you get stressed?
- What is happening in your life when you feel stressed?
- How do you know when you are feeling stressed?
- What do you do to cope when you are feeling stressed?
- **How do you respond to feeling stressed now compared to before having arthritis? Compared to when you were younger?**

Looking to the future (approx. 10 mins) – major focus: aim 1

- To finish up, I’d like you to now reflect on how your life has changed since being diagnosed with arthritis. How is it different?
- Is there anything you would like to add that we haven’t already discussed?
D.3 Telephone interview script

Introduction

[With the tape recorder turned off]

Hello my name is Melissa Harris, I am calling from the Women’s Health Australia project at the University of Newcastle. Can I please speak to [name of participant]?

Is it still convenient for you to do the interview about your experiences with having arthritis? The interview will take about 60 minutes to complete. Just let me know at any point if you need to stop while we are talking.

Firstly, I would like to confirm that you have received the letter that we sent you regarding this project and ask if you have any questions about the study before we begin the interview.

I am about to read some statements when I turn the tape recorder on to confirm that you give consent to participate in this project. Before I do this, do you have any questions?

I am going to turn on the tape recorder now.

[With the tape recorder turned on]

The tape recorder is now running. I am going to ask you some questions about your willingness to take part in this interview.

I’d like you to answer either ‘yes’ or ‘no’.

- Do you acknowledge that you have read and kept a copy of the letter which invited you to take part in this research?

- Do you understand why this research is being conducted and have you had all of your questions about the research answered?

- Do you consent to participate in a telephone interview about your experiences with having arthritis?

- Do you understand that the interview is being recorded, and that information on this recording will be used for research which may be published, provided that you will not be identified in the research or publications?
Chapter 6: Supplementary data and material

- Do you consent to having responses you provided at previous surveys linked to information obtained from this interview?

- Do you understand that you can stop the interview at any time if you do not wish to continue, or would like to take a break, and that you do not have to give any reason for doing this?

Lastly, do you have any questions before we begin the interview?

[See interview schedule]

Ending the interview

I am now turning the tape recorder off.

[With the tape recorder turned off]

How are you feeling after talking about your experiences?

Is there anything else you would like to ask or discuss with me?

Before I go, I would just like to remind you that if you need to talk to anyone about anything that has been discussed today, you should either call Lifeline on 131 114 or consult your local GP.

Thank you very much for your time today. I really appreciate you taking the time to talk to me.
D.4 Ethics approval for project H-2011-0191

HUMAN RESEARCH ETHICS COMMITTEE

Notification of Expedited Approval

To Chief Investigator or Project Supervisor: Doctor Deborah Loxton
Cc Co-investigators / Research Students: Ms Melissa Harris
Associate Professor David Sibbritt
Professor Julie Byles

Re Protocol: Arthritis in women at midlife: The lived psychosocial experience
Date: 20-Jul-2011
Reference No: H-2011-0191
Date of Initial Approval: 20-Jul-2011

Thank you for your Response to Conditional Approval (minor amendments) submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under Expedited review by the Chair/Deputy Chair.

I am pleased to advise that the decision on your submission is Approved effective 20-Jul-2011.

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research, 2007, and the requirements within this University relating to human research.

Approval will remain valid subject to the submission, and satisfactory assessment, of annual progress reports. If the approval of an External HREC has been "noted" the approval period is as determined by that HREC.

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal Certificate of Approval will be available upon request. Your approval number is H-2011-0191.

If the research requires the use of an Information Statement, ensure this number is inserted at the relevant point in the Complaints paragraph prior to distribution to potential participants. You may then proceed with the research.

Conditions of Approval
This approval has been granted subject to you complying with the requirements for Monitoring of Progress, Reporting of Adverse Events, and Variations to the Approved Protocol as detailed below.

PLEASE NOTE:

In the case where the HREC has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University's HREC.

- **Monitoring of Progress**

Other than above, the University is obliged to monitor the progress of research projects involving human participants to ensure that they are conducted according to the protocol as approved by the HREC. A progress report is required on an annual basis. Continuation of your HREC approval for this project is conditional upon receipt, and satisfactory assessment, of annual progress reports. You will be advised when a report is due.

- **Reporting of Adverse Events**

1. It is the responsibility of the person first named on this Approval Advice to report adverse events.
2. Adverse events, however minor, must be recorded by the investigator as observed by the investigator or as volunteered by a participant in the research. Full details are to be documented, whether or not the investigator, or his/her deputies, consider the event to be related to the research substance or procedure.
3. Serious or unforeseen adverse events that occur during the research or within six (6) months of completion of the research, must be reported by the person first named on the Approval Advice to the (HREC) by way of the Adverse Event Report form within 72 hours of the occurrence of the event or the investigator receiving advice of the event.
4. Serious adverse events are defined as:
   - Causing death, life threatening or serious disability.
   - Causing or prolonging hospitalisation.
   - Overdoses, cancers, congenital abnormalities, tissue damage, whether or not they are judged to be caused by the investigational agent or procedure.
   - Causing psycho-social and/or financial harm. This covers everything from perceived invasion of privacy, breach of confidentiality, or the diminution of social reputation, to the creation of psychological fears and trauma.
   - Any other event which might affect the continued ethical acceptability of the project.
5. Reports of adverse events must include:
   - Participant's study identification number;
   - date of birth;
   - date of entry into the study;
   - treatment arm (if applicable);
   - date of event;
   - details of event;
   - the investigator's opinion as to whether the event is related to the research procedures; and
   - action taken in response to the event.
6. Adverse events which do not fall within the definition of serious or unexpected, including those reported from other sites involved in the research, are to be reported
in detail at the time of the annual progress report to the HREC.

- **Variations to approved protocol**

If you wish to change, or deviate from, the approved protocol, you will need to submit an *Application for Variation to Approved Human Research*. Variations may include, but are not limited to, changes or additions to investigators, study design, study population, number of participants, methods of recruitment, or participant information/consent documentation. **Variations must be approved by the (HREC) before they are implemented** except when Registering an approval of a variation from an external HREC which has been designated the lead HREC, in which case you may proceed as soon as you receive an acknowledgement of your Registration.

**Linkage of ethics approval to a new Grant**

HREC approvals cannot be assigned to a new grant or award (ie those that were not identified on the application for ethics approval) without confirmation of the approval from the Human Research Ethics Officer on behalf of the HREC.

Best wishes for a successful project.

Professor Alison Ferguson

**Chair, Human Research Ethics Committee**

*For communications and enquiries:*

**Human Research Ethics Administration**

Research Services
Research Integrity Unit
HA148, Hunter Building
The University of Newcastle
Callaghan NSW 2308
T +61 2 492 18999
F +61 2 492 17164
Human-Ethics@newcastle.edu.au

**Linked University of Newcastle administered funding:**

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<th>Funding project title</th>
<th>First named investigator</th>
<th>Grant Ref</th>
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### D.5 Data saturation

#### Table D.1. Process of data saturation

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<th>The psychosocial impact of disability</th>
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<th>Behavioural approaches to coping with pain &amp; limitation</th>
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Total: 19 participants
### Making sense of stress

#### Stress and its perception

- The perception and meaning of stress
- Perceptions regarding the impact of stress

#### Coping with stress

- Approaches to coping with stress
- Origins of coping responses
- Changes in coping with stress over time
- Perceived factors associated with resilience
- Surviving stress

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**Note:** symbols in bold indicate the first time the theme/sub-theme emerged. X = theme/sub-theme mentioned O = not mentioned; Distractions = Distraction; Accepting pain = Accepting pain & limitation; Pain minimisation = Pain minimisation; Comparative coping = Comparative coping; Positive self-talk = Positive self-talk; Cognitive reappraisal = Cognitive reappraisal; T = Total.