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**The Price of Pain:
Studying Strategies Used by Women with Chronic Pain
Disability to Sustain Worker Identity**

A thesis
submitted in partial fulfilment
of the requirements for the degree
of
Master of Social Sciences in Labour Studies
at
The University of Waikato
by
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THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

2017

Abstract

Chronic pain is pain that persists longer than would be expected for healing to occur. It is an invisible disability for 20% of people worldwide, affecting a higher percentage of women than men. It is defined as an invisible disability because it has no immediate physical expression. In the workplace, employers, supervisors and colleagues may not know that work needs to be reconfigured to enable a person with chronic pain to function effectively. This thesis investigates how women with invisible pain disability are able to be successful at work. The research questions as set out in Chapter One are: What is the experience of women in chronic pain who are involved in paid work? How does suffering chronic pain force women to relate to their 'space' differently in the workplace? What kind of strategies are put in place to enable women to thrive in the workplace?

Chapter One sets out the initial qualitative research design. Its main elements were solicited photo diaries and qualitative semi-structured interviews. Five participants were recruited. However, after three months none of them had completed any diary entries. Chapter Two outlines the modified research methodology that was then developed. A variety of ways of interviewing and questioning participants was used and additional participants were recruited. Information was collected from seven women.

Reflections on participants' responses led to the discovery of the significance of the role of identity in their lives. Two of the significant identities for the women in this project were those of worker and of a person in chronic pain. Chapter Three includes a discussion of how participants manage the clash between these by prioritising their identity as worker over their pain identity.

In Chapter Four, seven strategies are identified as the main methods used by participants to maintain their worker identity in the face of their chronic pain. These have been identified through thematic analysis of what the participants reported. The strategies are: modifying the work space, managing their workload, establishing and maintaining positive relationships with employers, developing supportive relationships with colleagues and family, receiving and asking for help when required, disassociating themselves from pain, and managing life outside of work.

The conclusion, Chapter Five, summarises the project's findings about the salience of worker identity and how strategies are used by women to maintain their worker identity. It also includes the methodological insight that the failure of participants to complete solicited diaries arose out of the disruption to identity salience caused by having to focus on their chronic pain disability.

Acknowledgements

To Craig, Dorothy, Gemma, Dawn, Ben, Anthony, Lissa, Pip and Tracey.

This thesis is about living and working with chronic pain; a strong theme of which is having supportive colleagues to make it possible. You have become so much more than that to me and I know that I wouldn't be where I am without your support.

This thesis is dedicated to you.

To Craig - Our conversations over the last few months have not only shaped my thinking about these issues but also this thesis itself. By articulating to you how I felt about my life and experiences, you have helped me to move beyond one of the most difficult stages of my life. I have realised that I can be me and still be disabled and in pain and that has truly helped me move forward.

To my work mum Dorothy - Your never-ending support makes me believe I am capable of anything. A block basement will always hold a special place in my heart. Thank-you for your outstanding help with editing, you have helped me turn in a better thesis.

To Gemma - Thank-you for always being there in person and on the end of the phone, for talking me down, for talking me through and believing that I was capable, academically, physically and emotionally. I would be lost without you and your constant support.

To Dawn - Thank-you for helping me to discover the thesis that wanted to be written, for helping me pick up the pieces when the research methods failed and

for making me see that this story is one that needed to be told. You have been the most incredible sounding board and your endless advice on all aspects of writing this thesis is truly appreciated.

To Ben - Thank-you for fighting the fires so that I could concentrate on completing this thesis. When you told me, “If your life was a sitcom, everyone would stop watching”, it made me feel totally validated. I appreciate all your support.

To Anthony - Thank-you for taking monkey for many weekends so I could work on this thesis. You learn a lot about writing when you learn to grade student assessments, and working with you taught me to write better and to reference better. You have also shown me what a good boss is really like.

To my subject librarian Jillene Bydder - Thank-you for your help with formatting the final thesis document. You were always quick to respond to my questions and I appreciate your gentle encouragement and advice.

To Amber - You and I are the best team I will ever know. Thank-you for your patience as I worked nights and weekends. ‘Thesis mum’ is now on hiatus ☺. I look forward to taking the silver linings into our future.

To Hayden - Thank-you for all your help and support over the last two years.

To Michael - You constantly amaze me with your compassion and skill as a Doctor. You sometimes saw me as a “medical mystery to solve” but you always managed to get me the help I needed. I wouldn’t be here and able to write this thesis without your help and support.

To Luke and Emma - You are both an inspiration. It makes me proud that I have two siblings who are committed to working with the sick and injured. You always took my pain and health seriously and I am honoured that my experience and research has changed your practice.

To Holly - You will always be my second daughter. I would like to believe I can do everything on my own but I can't. This thesis would not be possible without all your help and support at home.

To my supervisor, Dr John Paterson (Social Science Research, School of Social Sciences) - You are the most wonderful supervisor I could ever ask for. Your patience and compassion as you guided me through the many 'milestones' in this project has been amazing. I appreciate your insight, knowledge and direction as you helped me to write this thesis in a way that was not only academically rigorous but also true to my own thoughts, beliefs and experiences. I have learnt so much through this process. Your guidance and insight helped me to turn in a thesis I am proud of and for that I will be forever grateful.

And lastly, to my participants: Thank-you for sharing your lives with me. Your stories have helped me understand my own story and so much more. Writing this thesis has often been painful for me in many ways but you have shown me courage, strength, tenacity, hope and spirit. You have inspired me to believe I can succeed. I am proud to call you comrades in arms. The aim of this thesis is to do your stories justice.

Table of Contents

Abstract	ii
Acknowledgements	iv
Chapter One - Personal Pain and Paid Work: Designing a Study of Invisible Pain Disability and Women's Paid Work	1
Introduction	1
The Dimensions of Pain	2
Chronic Pain as an Invisible Disability	6
Invisible Pain Disability in the Workplace.....	9
The Research Questions	11
Overview of Thesis	14
Methodology	15
Qualitative methods.	17
Methods used to find participants.	21
Abrupt Hiatus: Non-Appearance of the Solicited Diaries	23
Chapter Two - "I'm No Good at Keeping a Diary": Using Qualitative Interviews to Gain Insight into Women's Experiences of Pain at Work	24
The Diaries Didn't Work: Arriving at an Insight	24
Participants' diary challenges.	27
Using Personal and Online Interviewing and Email Questioning to Understand Women with Invisible Pain Disability	28
The seven participants: Data collection.	28
Auto-ethnography and research blog.	30
The Research Participants: An Introduction.....	31
The Research Participants' Responses to Being Women with Invisible Pain Disability at Work	32
"This isn't a proper disability."	33
"I don't want to be treated differently."	40
"It's stupid advice anyway."	43
"The fact that it changes - I think it's very difficult to live with."	45
"Find your own rhythm and beat your own drum."	47
Being at Work and Having a Worker Identity	49
Chapter Three - "I Don't Want to be <i>That Crippled Girl</i> ": The Clash between Pain Identity and Worker Identity	51
Pain and Identity at Work.....	51

Identities: Individual Social Being	52
Significant Identities.....	55
Disabled identity.	56
Pain identity.	57
Worker identity.	58
Managing Multiple Identities	59
Salient identities.....	59
Disability and identity.....	61
Giving Priority to Worker Identity	64
Clashing Identities	66
Clashing Identities and the Health System	69
Clashing Identities and the Failure of the Research Diaries	72
Clashing Identities and Coping Strategies.....	73
Chapter Four - “Faking Normality is Like Black Magic, There is always a Price to Pay”: Strategies Used by Women to Maintain Worker Identity	74
The Priority of Worker Identity.....	74
Workspace	75
Managing Work.....	80
Employer Relationship	83
Relationship with Others	84
Receiving and Asking for Help	86
Disassociation.....	87
Managing Life Outside of Work	90
The Divide Between Rich and Poor	93
Chapter Five - The Price of Pain: How Women with Invisible Chronic Pain Sustain their Worker Identity	95
Work and the Power of Pain.....	95
Question One: Women Experiencing Chronic Pain in the Workplace	97
Question Two: Relating to Space in the Workplace	99
Question Three: Strategies for Thriving in the Workplace	99
Methodological Findings.....	102
A Personal Conclusion	104
References	106
Appendix A: Application for Ethical Approval	121

Appendix B: Poster Requesting Participants	149
Appendix C: Project Information Sheet	150
Appendix D: Diary Guidelines.....	154
Appendix F: Consent Form for Interviews	160
Appendix G: Consent Form for Email Questioning	163
Appendix H: Interview Guide	166
Appendix I: Email Questions	169
Appendix J: Project Information Sheet	171

Chapter One - Personal Pain and Paid Work:

Designing a Study of Invisible Pain Disability and

Women's Paid Work

Introduction

I come to this study from the personal perspective of a woman who experiences chronic pain and who is employed full-time as a university Senior Tutor.¹ Eight years ago, I began to experience chronic pain. Despite eventually having surgery to remove a spinal cyst, I have continued to experience chronic pain and other neurological symptoms regularly. Although I had a short period of time off work to recover from the surgery, I have not taken significant time out of the paid workforce despite the debilitating effects of pain that I experience. My situation has led me to take a keen interest in research on chronic illness and chronic pain, and how they affect women in paid work.

In the research literature on women in chronic pain and employment, the focus tends to be on women who are unable to be in paid employment as well as those who face significant challenges or frustrations in work. There are very few studies that narrate the positive stories of women who are living and working while correspondingly experiencing chronic pain. I started this research project² with an aspiration to uncover the success stories, the stories of strength and resilience of women with an invisible pain disability who succeed in paid work no matter what life throws at them. I believe that these stories also need to be told.

¹ A “confessional” style of research writing (Van Maanen, 2011 and Boeije, 2010) is used in places in this thesis as is appropriate for a project based in the researcher’s personal experience and using a qualitative methodology.

² This thesis is a three-paper thesis, equivalent to three-quarters of a year’s full-time study.

Prior to embarking on this research project, I realised that my personal experience of chronic invisible pain was more permanent than I previously thought. Consequently, I came to identify as someone who was living with chronic invisible pain. The literature conveyed the difficulties faced by women like me in maintaining employment, implying that failures were much more common than successes. Work was important to me, however, and it was not something I was going to give up easily. In the course of undertaking this project, I wanted to understand how it would be possible to continue working with this new chronic pain identity. I have come to understand that I can be in pain and still be me, through configuring a different way of being; if I can do this, I can succeed in this body. Listening to the stories of my research participants has given me these insights.

The Dimensions of Pain

Pain is a subjective experience (Bendelow & Williams, 1995; Jackson, 2011; Malleson, Connell, Bennett, & Eccleston, 2001).³ “Pain in particular resists objectification: One’s extremely real pain remains unreal to others” (Jackson, 2011, p. 167). Because pain does not exist outside of the individual, it is invisible to those around them. Kugelmann (1999) argues that pain is ‘private property’ and other people cannot experience an individual’s pain (Davis, 2005; Jackson, 2011; Bendelow & Williams, 1995). People often expect that others experience pain in ways that are similar to their own, and therefore assume that they have the same understanding of what that experience is like. It is also easy for the individual to forget the experience of pain, until they experience pain again. Correspondingly, it can be difficult for people to understand what someone is experiencing when they

³ American Psychological Association (APA) style is used throughout this thesis for both formatting and referencing.

try to explain their pain to others (Jackson, 2011). At times, pain is difficult to describe. An individual can say that they feel pain or that something is sore, but there are few linguistic alternatives to describe the sensation of pain to others, though metaphors are often used by those experiencing chronic pain (Jackson, 2011). No one can tell a person what pain feels like, or alternatively, what no pain feels like. In my view, pain is one of the most subjective experiences, as it is impossible to see or measure objectively. Consequently, those who experience chronic pain often feel as though they must prove that their pain is real in order to be believed or for their pain to be acknowledged (Kugelman, 1999; McClusky, Brooks, King, Burton, 2011; Richardson, Ong, & Sim, 2007; Sturge-Jacobs, 2002).

Pain is experienced differently between individuals (Health Navigator New Zealand, 2016). If an individual accepts chronic pain as part of life, his or her ability to cope with the situation is significantly improved (Doran, 2014; Hancock, Hughes, Jaggar, Paterson, Russell, Tulle-Winton & Tyler, 2000; Jackson, 2011; Silverman, Nutini, Musa, Schoenberg & Albert, 2009; Afrell, Biguet & Rudebeck, 2007). The learned ability to cope with pain is also an important aspect of how pain is experienced, an individual used to pain is better able to function when they are in pain (Jackson, 2011). A positive state of mind enables a person to tolerate the pain that they experience better (Doran, 2014, Jackson, 2011). There can be no assumptions made about the pain that someone else is feeling. It is essential to that person to try and understand the psychological state, the belief systems and social context which shape that individual's coping mechanisms (Davis, 2005).

Additionally, pain is not only characterised by location and quality but also by its psychological and emotional aspects, as emphasised by Covington (2000) and a number of other pain researchers. Although the biological basis to pain may sometimes be successfully treated, pain itself is also a psychological and emotional experience (Bendelow & Williams, 1995; Hancock, et al., 2000; Jackson, 2011) and these aspects may be more difficult to treat, especially when that pain has become chronic.

Pain, after all, is both ubiquitous and elusive: *ubiquitous*, because it can emerge in virtually every area of the body – and thus cuts across virtually every specialty in the fractured practice of medicine, and *elusive* because of the way pain so frequently resists biomedicine's efforts to render it objective, both directly observable and reliably measurable (Crowley-Matoka & True, 2012, p. 697).

Furthermore, there is an important sociological dimension to pain – it is situated, communicated and formed in a wider cultural and social context (Bendelow & Williams, 1995; Käll, 2013). Part of this social context is the socially constructed way in which gender is related to pain. Traits and attributes that are traditionally considered feminine influence the way that women in pain are seen by others. Women are expected to behave in ways that are consistent with their gender; which often has negative effects as women are seen to be weak and less able to deal with pain than men. On the other hand, if they are seen to be too strong, too assertive or possess other traditionally male-associated traits, their pain is not taken seriously and they are not believed (Werner & Malterud, 2003; Weitz, 2017). However, if a man exhibited the female-associated traits and behaviours, their pain would be taken more seriously because it would be assumed that they

experience more pain if they speak of their pain to others (Werner & Malterud, 2003).

In addition to gender, another sociological dimension of pain is the area of work and employment. Judgements can be made if a woman is not working due to experiencing an invisible disability such as chronic pain and she may be seen to be lazy and avoiding work (Pfizer, 2012; Glenton, 2003; Werner, Isaksen, & Malterud, 2004). Consequently women are under additional pressure to be in paid employment. Women with an invisible pain disability may opt for part-time employment, however, this often does not provide enough income so welfare support may be sought. Other individuals, not understanding the significance of an invisible pain disability, may be critical of the woman and see her as 'scamming the system' (Glenton, 2003). Fulltime employment avoids these problems, but poses a range of difficulties in the management of pain in the work context. One of the initial motivations for this thesis was to find out what made it possible for some women with a chronic pain disability to maintain a successful work life. Any answer to this question needs to be contextualised within an understanding of the nature of chronic pain.

Individual experiences of chronic pain and illness are discussed substantially in the literature (Afrell et al., 2007; Charmaz, 2002; Charmaz, 2008; Kugelmann, 1999; Jackson, 2011; Moore, 2013; Richardson et al., 2007; Seear, 2009; Silverman et al, 2009; Sturge-Jacobs, 2002; Vickers, 2001; Vickers, 2009a; Vickers 2009b). As suggested by Silverman et al. (2009), the experience of illness and pain differs among those who have the same condition. This means that the experience of illness and pain is unique to the individual. Many of these stories and experiences are recounted in the literature on chronic pain and illness. They

are told not only from the perspective of those experiencing pain, but also from the perspective of the people in their lives who are close to them (Afrell et al., 2007; Charmaz, 2008; Kugelman, 1999; Moore, 2013; Richardson et al., 2007; Sturge-Jacobs, 2002; Werner et al., 2004). The literature often focuses on the negative side of living with chronic pain and the challenges of dealing with chronic pain in everyday life (Afrell et al., 2007; Kugelman, 1999; Moore, 2013; Sturge-Jacobs, 2002). The difficulties and barriers to being involved in the paid work force are also discussed in-depth (Antao, Shaw, Ollson, Reen, To, Bossers & Cooper, 2013; Braden, Zhang, Zimmerman & Sullivan, 2008; Ordóñez-Hernández, Contreras-Estrada & Soltero-Avelar, 2015; Marhold, Linton, & Melin, 2002; Oakman, Kinsman, & Biggs, 2016; Patel, Greasley, & Watson, 2007; Seear, 2009; Sturge-Jacobs, 2002). The identification of barriers faced by those attempting to re-enter the labour market is discussed as well (Marhold et al., 2002; Patel et al., 2007; Braden et al., 2008).⁴

Chronic Pain as an Invisible Disability

It is estimated that chronic pain affects 20% of people worldwide (Marcus, Cope, Deodhar & Payne, 2009; Patel, et al., 2007; Treede et al, 2015). One in six New Zealanders are effected by chronic pain (Pfizer, 2012; Dominick, Blyth & Nicholas, 2011). Internationally chronic pain accounts for 40% of visits to doctors surgeries every year and it has huge economic implications for the individual and society (Pfizer, 2012; Antao et al., 2013; Dominick, et al., 2011; Patel et al., 2007; Weitz, 2017). There is also a higher percentage of women than men that experience chronic pain (Marhold et al., 2002).

⁴ This section has drawn on some of the literature on the dimensions of pain. This thesis does not include one separate section reviewing the literature on its topic but rather refers to relevant literature at different points where it is appropriate.

Chronic pain is described as pain that persists longer than would be expected for healing to occur (Marcus et al., 2009; Dominick et al., 2011; Weitz, 2017). It is often defined as pain that has been present for at least three to six months and adversely affects an individual's well-being (Marcus et al, 2009; Antao et al., 2013, Pfizer, 2012; Dominick et al., 2011). Chronic pain falls in the space between disability and chronic illness (Weitz, 2017). It is an invisible disability (Davis, 2005; Glenton, 2003; Pfizer, 2012) and the often unpredictable nature of chronic pain can make it difficult for others to understand what it is like to live with it (Moore, 2013; Richardson et al., 2007; Sturge-Jacobs, 2002). This can make work challenging because colleagues and employers do not understand how the person is affected by this disability. In this way it is similar to other chronic illnesses on which there is a substantial body of research (Charmaz, 2002; Charmaz, 2008; Doran, 2014; Hoppe, 2013; Moore, 2103; Moss & Dyck, 1996; Rakovski, Zettel-Watson & Rutledge, 2012; Seear, 2009; Silverman et al, 2009; Sturge-Jacobs, 2002; Vickers, 2000; Vickers, 2001; Vickers, 2009a; Vickers, 2014).

Chronic pain remains invisible unless those experiencing it announce its existence to those around them (Jackson, 2011). Vision is a vital sense in understanding the world around us (Hockey & Allen-Collinson, 2009). As vision is valued above the other senses, (Davis, 2005; Hockey & Allen-Collinson, 2009; Jackson, 2011) this can cause issues in the working environment. Colleagues and employers are often unaware of invisible disabilities unless they are told about them by those who experience them (Wilton, 2008) or unless they pick them up through indirect visual cues (Jackson, 2011). The invisible nature of pain can be made visible by the ways in which bodies move through space (Riach & Wilson,

2014). For example, it is possible to see that someone is in more pain if they are limping, hunched over, or moving more slowly than they usually would.

Pain is more visible to those close to the person (Kugelmann, 1999; Richardson et al., 2007). Those who also experience chronic pain can see when others are in pain because they are more attuned to the ways in which the body moves when one is experiencing pain (Jackson, 2011). This may be one of the reasons why people in chronic pain feel that they are able to talk to and confide in others who share similar pain experiences. Such people not only notice the pain that others are in but understand its significance and the challenges that it represents.

Although there are challenges associated with the invisible nature of chronic pain, there are times when it is advantageous that the disability experienced by those in chronic pain is hidden. People may choose to hide their disability for fear of discrimination. There are also stigmas associated with being disabled (Antao et al., 2013; Fine & Asch, 1988; Goffman, 1963; Hancock, et al., 2000; Shilling, 2008). People may also be surprised when those with disabilities refuse to play the 'victim' role, and could assume that the individual is in denial (Fine & Asch, 1988).

Those in chronic pain are often not well understood even by the medical profession (Crowley-Matoka & True, 2012; Jackson, 2011; Kralik, Koch, Price & Howard, 2004; Sturge-Jacobs, 2002; Werner & Malterud, 2003; Werner et al., 2004). They may be judged by others for being in pain and for complaining about the pain they experience (Crowley-Matoka & True, 2012; Davis, 2005; Glenton, 2003; Ordóñez-Hernández et al., 2015; Jackson, 2011; Sturge-Jacobs, 2002; Werner & Malterud, 2003). They are told that they need to be stronger, to rise

above it, and that they should be able to cope better with their pain. Pain is therefore seen as a sign of weakness (Crowley-Matoka & True, 2012; Davis, 2005; Jackson, 2011; Hancock, et al., 2000). If those who experience chronic pain complain too often they will be referred to as hypochondriacs rather than acknowledged for the pain that they feel (Crowley-Matoka & True, 2012; Davis, 2005; Glenton, 2003; Werner & Malterud, 2003; Werner et al., 2004). Women in chronic pain will often hide the reality of their pain to avoid the gender stereotype of the constantly complaining woman. They must balance the need to not appear too sick or too well in order to receive appropriate treatment for their condition (Werner & Malterud, 2003; Werner et al., 2004; Weitz, 2017).

Invisible Pain Disability in the Workplace

The implications for workplace participation for those people experiencing invisible chronic pain are complex. In New Zealand society, as in all modern capitalist societies, significant value is placed on being involved in productive paid work outside the home (Melchin, 2008; Edgell, 2011). One of the first questions that is asked when people meet is what job a person does. What a person does for work is internalised by individuals and becomes part of their identity (Saayman & Crafford, 2011; Strangleman, 2012). This personal identity as a worker is challenged when they become chronically ill.

The invisibility of chronic pain means that a person can choose the people in the workplace to whom they disclose their disability. The fact that disclosure is a choice means that the individual can make strategic decisions about disclosing a disability. This choice empowers women in chronic pain to make strategic choices about who they disclose to so that they are not only supported in their work but also not disadvantaged as well.

The decision about whether to disclose an invisible disability during the hiring process is one that many women who experience chronic pain find challenging (Oakman et al., 2016; Wilton, 2008). Many people with disabilities choose not to disclose their disability to their prospective employer for fear that they may not be employed if they do. There is also the risk that they might not get the job because there may be someone else who is qualified and does not have an invisible and unpredictable disability. However, if they do not disclose their disability during the interview process, they often feel as though they are unable to ask for assistance later (Wilton, 2008). If women in chronic pain choose to disclose their disability, then there is the potential for them to get the support and assistance that is needed once they are employed in the job (Antao et al., 2013; Munir, Leka, & Griffiths, 2005).

Choosing whether or not to disclose chronic pain or illness in the workplace is a challenge (Goffman, 1963; Oakman et al., 2016; Vickers, 2000). Vickers (1997) discusses how people with stigmatised chronic illnesses often do not disclose them in the workplace. This could also be the case for people with invisible pain disability (Munir et al., 2005). The literature indicates that there is often a particular reason why women in chronic pain choose to disclose their pain for example: they may not think that they need to hide it, they may require time off from work to attend medical appointments, or they may need extra support or assistance in order for them to be effective at work (Vickers, 1997). There was often a reason why people in chronic pain disclosed their invisible disability at work (Munir et al., 2005; Vickers, 1997). Needing assistance or special equipment was the most likely cause of disclosure in one study, however, this depended on the occupation of the people involved (Munir et al., 2005).

If women in pain choose to disclose their disability then accommodations can be made. However, there is the potential for those with invisible disabilities to be treated differently once their employer and colleagues know of their situation (Ordóñez-Hernández et al., 2015; Munir et al., 2005; Oakman et al., 2016; Rakovski et al., 2012; Vickers, 1997; Vickers, 2000; Vickers 2009b; Vickers, 2014). There is also a fear about whether they will lose their job once their employer knows about their invisible pain disability (Charmaz, 2002; Munir et al., 2005; Oakman et al., 2016; Vickers, 2009b). Charmaz (2002) argues that “chronically ill and disabled people often become masters at reading cues about how much to tell and when to tell it” (p. 317). This was also discussed by Wilton (2008) who explained that employees often “feel out” (p. 368) supervisors and colleagues by giving a little information about their illness and seeing how others will react. They can then discern which people it would be acceptable to share their experiences with and who it would be best to approach when assistance or help is required.

The Research Questions

The purpose of the research project for this thesis was twofold: firstly, to examine the experience of women with chronic invisible pain so that they can be better understood and therefore accommodated at work; and secondly, to examine the strategies that women with chronic invisible pain use to enable them to thrive at work and maintain a work/life balance.

The following questions were developed after an initial review of the literature on chronic illness, chronic pain and work.

1. What is the experience of women in chronic pain who are involved in paid work?

- a. What are the challenges of experiencing chronic pain and being involved in paid work?
 - b. What sacrifices are made because of chronic pain?
 - c. How does the invisible nature of chronic pain (as a disability) contribute to the experience that women have at work?
2. How does suffering chronic pain force women to relate to their ‘space’ differently in the workplace?
 - a. What aspects of the traditional work space create challenges for women in chronic pain?
 - b. How do women experiencing chronic pain reorganise their workspace to meet their needs better?
 - c. In what ways do workers with chronic pain re-orient their bodies in the workplace?
3. What kind of strategies are put in place to enable women to thrive in the workplace?
 - a. What tools and/or equipment make it possible for women in chronic pain to undertake paid work?
 - b. What kind of help and support do they need from others?
 - c. What kind of arrangements do they put in place to ensure they do not fail?

As previously suggested, “chronic pain” is defined as pain that persists longer than would be expected for healing to occur (Pfizer, 2012; Dominick et al., 2011; Malleson et al., 2001). It is often an invisible disability, the physical appearance of the disability being missing so that employers, supervisors and colleagues do not know that work needs to be reconfigured to enable a person to function effectively (Charmaz, 2002; Davis, 2005). Charmaz (2002) argues that

this is further complicated by the fact that women often try to hide their disability because they want to retain their job or not appear to need “special” treatment.

Once women become chronically ill, their identity and sense of self changes (Ashbring, 2001; Audulv, Asplund & Norbergh, 2012; Charmaz, 1983; Charmaz, 2008; Kralik et al., 2004; Seear, 2009; Werner et al., 2004). They often struggle with their new identity which is complicated by the fact that illness or pain can make their lives feel out of control (Antao et al., 2013; Charmaz, 2002; Moss & Dyck, 1996; Shilling, 2008; Sturge-Jacobs, 2002). There is also extra pressure on women with chronic illness because of their traditional roles and responsibilities in the home (Ashbring, 2001; Mijoo, 2009; Ordóñez-Hernández et al., 2015; Moss & Dyck, 1996; Richardson et al., 2007; Seear, 2009). This is compounded by the need for more concrete changes, for example, their physical environment or working conditions may need to be altered so that they are able to pursue their everyday tasks (Fritz & Lysack, 2014; Moss & Dyck, 1996; Oakman et al., 2016; Rakovski et al., 2012). However, the workspace is the domain of the employer and women may not have control over how their workspace is set up.

There is a variety of literature on chronic pain and invisible disability, with some of it also concerned with the workplace (Charmaz, 2002; Davis, 2005; Jackson, 2011; Glenton, 2003; Vickers, 2001; Vickers, 2009b; Oakman et al., 2016). One significant area is the research on people with idiopathic pain conditions and these people’s ability to participate in the paid workforce (de Vries, Reneman, Groothoff, Geertzen & Brouwer, 2012; Marhold et al., 2012; Patel et al., 2007). Much of this literature is focused on the patients’ ability to undertake work and the obstacles and struggles they face while attempting to do so (Charmaz, 2002; Marhold et al., 2012; Moss & Dyck, 1996; Patel et al., 2007;

Sturge-Jacobs, 2002). This project looks to address the gaps in the literature by focusing on the achievements and successes of women in chronic pain who are engaged in the paid workforce.

Overview of Thesis

After considering the various methods used by researchers to study similar topics, I decided to use solicited diaries and follow-up qualitative interviews to find out how pain influenced the working lives of women with this invisible disability.

After piloting the diary myself, I recruited six women who agreed to participate in the research and I sent them guidelines for completing a daily diary about their work experiences. These diaries were to form the basis for the qualitative interviews. Despite their expressed willingness to do so, none of these participants were able to complete the daily diary activity, and there were few responses to my follow-up emails. Because the first stage of data gathering was unsuccessful, it undermined the basis of the follow-up interviews, causing significant disruption to the project timeline. After a number of weeks of attempting to understand why this might be the case, I realised that the inability of the participants to complete the diaries told me something important about these women and about how research could be conducted on women experiencing chronic pain.

The main method of data collection used for this study was seven qualitative interviews. Of the six women I initially contacted, two never responded to my requests for information, two answered a number of questions by email, and two were interviewed by me, one face-to-face and one online via Facebook Messenger. I also recruited three further participants with whom I conducted interviews, one online conducted via Zoom and two face-to-face.

Thematic analysis of the interviews led to the identification of seven significant strategies used by the participants to sustain their ability to work. In reflecting further on why the women use these strategies, I identified the significance of two of their identities – a pain identity and a worker identity. I conclude that the strategies enabled the women to maintain the salience of their worker identity.

The rest of this chapter details the initial methodological design for this research. In Chapter Two I outline the failure of the solicited diaries method and then describe how I went on to use a variety of questioning methods. The rest of that chapter discusses five issues that were identified as significant to the participants when dealing with their workplace experiences as women with invisible pain disability. In Chapter Three I examine how women's pain and worker identities often clash in the workplace and how this influences their lives. Chapter Four presents the seven strategies used by participants to sustain their worker identity. These strategies were identified through thematic analysis of the information provided by participants. In Chapter Five I conclude by addressing the thesis objectives and considering the methodological lessons arising from this study of women with chronic invisible pain.

Methodology

I take a critical position with respect to issues of women and work. The critical perspective in social research largely focuses on the structural context within which individuals experience social life (Bryman, 2008; Sarantakos, 2013; Jackson & Verberg, 2006; Neuman, 2006). However, I argue that structuralism over-emphasises the degree to which individual human experience is determined by social structures. There is a significant non-structuralist critical perspective that

pays attention to individual social experience (May, 2011; Sugden & Tomlinson, 1999). Individual experience is shaped by aspects unique to the individual and their context as well as structural forces. A critical social science perspective can provide a voice for the individuals who are oppressed by social structures at both the individual and structural level (Crotty, 1998). At the individual level, this means listening to people, understanding their challenges, frustrations and successes and validating their experiences (Jackson & Verberg, 2006; Neuman, 2006). Qualitative research enables the critical researcher to encounter the lived realities of women as they manage their multiple identities at home, in society and in the workplace. This research project is viewed as a contribution to “emancipatory disability research” (Henn, Weinstein & Foard, 2009) from a critical interpretivist perspective (Jones, 2014). I wanted to make sure I understood the experiences of women with chronic pain in their work context, focusing on the details of their lives, so that this research could become the basis for a more structural analysis undertaken in another project by myself or other researchers. It was also important to me that I not only focus on the frustrations and the barriers that these women face, but also that I gain insights into the successes of these women, because successes can be seen as instances of resistance to the hegemony of a capitalist work context that tries to fit everyone into the same mould of “productive worker.”

The focus of this project is on the experiences of individual women who experience chronic pain. By taking a critical stance and understanding the wider issues at play (Averett, 2009; Neuman, 2006) this project identifies some strategies that women who live with chronic pain as an invisible disability use to enact autonomy and identity through work.

Qualitative methods.

Qualitative researchers may gather participants' stories as the basis for understanding and analysis. Researchers who use this approach are often interested in learning about the social world through understanding the individual realities of their research participants (Bryman, 2008; Rubin & Rubin, 2005; Sarantakos, 2013). Such an approach does not provide representative findings in a statistical sense but it does provide significant insight into how certain groups of individuals experience societal reality. Such insights assist us to understand other similar individuals. This project used a qualitative methodology to gain an in-depth understanding (Darlington & Scott, 2002) of women's experiences of chronic pain in the workplace and the context in which these experiences are shaped. I planned to use four methods in this project: Auto-ethnography, solicited diaries (which included the use of photographs), in-depth interviews, and a research blog.⁵ The following is a description of the research design for the project as approved by the University of Waikato, Faculty of Arts and Social Sciences, Human Research Ethics Committee. The approved Application is in Appendix A.

Auto-ethnography design.

Auto-ethnography is a research method that is autobiographical in nature (Averett, 2009; Denzin, 2006; Ellis, 1999; Ellis, Adams & Bochner, 2011; Moore, 2013; Popovic, 2010). In this method, the researcher records their own experiences as a resource for the project. I believed that this method would be a useful means of investigating how my own experiences might influence and shape this project.

⁵ Uerata's (2011) thesis on the experiences of four people with chronic health conditions in finding and keeping work solely used qualitative in-depth interviews. Her approach was to collect and re-tell the biographical stories of her participants whereas my concerns are more specific and focussed, requiring a slightly different methodology.

Reflecting on their experiences also enables researchers to connect their personal experience to cultural and social structures around them (Averett, 2009; Denzin, 2006; Ellis, 1999; Ellis & Bochner, 1996; Moore, 2013; Popovic, 2010). “To write individual experience is, at the same time, to write social experience” (p. 216, Sparkes, 2002).

The main auto-ethnographic element of this project would be my personal development and trialling of the solicited diary method that I was intending to use with my participants. This would help to deepen my own understanding of the topic in the light of my experiences of chronic pain, invisible disability and work. By positioning myself at the centre of the project, I acknowledge my dual role as both researcher and participant and treat my personal position as a resource for this research (Ellis & Bochner, 1996; Moore, 2013). This reflexive approach (Denzin, 2006) enables me to be both an “insider and an outsider” in this project, allowing me to gain valuable insights into the lived experience of women with an invisible pain disability (Moore, 2013, p. 202).

Solicited photo diaries design.

The second method I decided to use was solicited photo diaries (Fritz & Lysack, 2014; Harper, 2002; Jacelon & Imperio, 2005; Kenton, 2010; Latham, 2016; Milligan, Bingley, & Gatrell, 2005; Zepeda & Deal, 2008). Daily diaries counteract problems of recall that can sometimes be encountered through interviewing participants and enable participants to record the taken-for-granted aspects of their lives (Alaszewski, 2006; Milligan et al., 2005; Kenton, 2010; Fritz & Lysack, 2014; Jacelon & Imperio, 2005). Solicited diaries have also been used in researching chronically ill people because the method is relatively unobtrusive (Alaszewski, 2006; Fritz & Lysack, 2014; Jacelon & Imperio, 2005; Kenton,

2010; Latham, 2016; Milligan et al., 2005; Richardson et al., 2007). I believed that the diaries would be an effective method to use for researching chronically ill women in pain because they could complete the diary “at their own pace” (Milligan et al., 2005, p. 1889).

I decided that, for a four week period, I would write a daily diary focussing on my work and the effect of chronic pain on my working life. I would take photographs of my work space as part of this process. I would regularly meet with my supervisor during this time to discuss both the method and the insights that arose from the daily diary activity. From this experience I would refine the daily diary and follow-up interview methods to be used later with my participants.

I planned for participants to write out their diary entries electronically and email them to me regularly. They were also able to use other media to record their diary entries if they would be more comfortable in doing so. Participants in this project would also be asked to consider including photographs of their work space in their diaries. This method would enable participants to become more aware of taken-for-granted aspects of their daily lives and work (Fritz & Lysack, 2014; Harper, 2002; Zepeda & Deal, 2008). I planned for the diaries and photographs to provide me with material for further discussion and analysis with each participant in the context of follow-up interviews.

Written guidance about the type of information to include in the diaries would be provided to participants before they started the daily diary activity. This method was suggested by Latham (2016) as a way of assisting participants to understand the type of information that would be useful to include in their diary entries. I would keep in contact with the participants throughout the data gathering period to provide support and advice.

In-depth interviews design.

The third method that I planned to use was in-depth follow-up interviews. These interviews were to be conducted after the diaries had been completed. They were to be conducted face-to-face with participants who lived in or not far from Hamilton, or using Skype or another similar web-based software with participants who were located further away. The interviews were to be used to explore, in greater depth, points that the participants had raised in their diaries and photographs (Jacelon & Imperio, 2005; Kenton, 2010). In-depth interviews are important to make sure that the participants' voices are heard and their stories are not misunderstood. It is especially important for women in chronic pain because they are often misunderstood in their everyday lives.

The follow-up interviews were to be semi-structured. A semi-structured interview is one where the researcher prepares an interview guide that contains a list of questions or topics that will be covered during the interview with participants (Bryman, 2008; Neuman, 2006; Sarantakos, 2013). With semi-structured interviewing, the researcher often asks additional questions throughout the interview process to clarify points that the participant has raised or probe further in order to get more information on an issue (Bryman, 2008; Sarantakos, 2013). Some of the interview questions were to be tailored to each research participant based on the issues arising from their diaries. The rest of the questions were to be prepared beforehand and were to be based on the literature as well as my own experiences in relation to the topic.

Both the face-to-face and online interviews were to be audio-recorded with the consent of each participant. Interview recordings were to be transcribed. If a participant declined to be recorded, notes would be written during the interview

and these were to be written up and sent to the participant in order for them to check for accuracy and make any required modifications. Participants were to be given the choice about whether to remain anonymous. This choice was to be revisited especially for those who initially decided to use their real name in the thesis. Those choosing anonymity would be asked to select a pseudonym for themselves. Each participant would be able to choose to be sent the transcript of her interview so that she could check that she was happy for the material contained within it to be used in the thesis and that it did not identify her if she had chosen to remain anonymous.

Research blog design.

The fourth method was to be a research blog written by the researcher about the research project (Jackson et al., 2015; Olive, 2013; Olive, 2015). This was to be public, to be started after the diaries had been completed, and was to function as a way of sharing issues and findings with those who were interested in the research project. It was also to be a means of collecting advice, views and contributions from other people, thus providing an additional source of information (Jackson et al., 2015).

Methods used to find participants.

In order to obtain participants for this project I created a poster (Appendix B). I attached this poster to pin boards in the General Practitioners' surgery, the physiotherapist's office and I took one copy of the poster to the pain clinic at the Waikato Hospital. I spoke with the administrator from the pain clinic who said she would discuss my project at an interdisciplinary meeting later that afternoon. A copy of the poster was also emailed to many not-for-profit organisations asking if they would be happy to send out my poster to their members (For example:

Arthritis New Zealand and Pain Action New Zealand). I also shared the poster on my personal Facebook page, on the *Who's That Lady Facebook group* (a support group for people living with chronic illness), and many of my friends and family members shared the poster with people that they knew. The poster provided information for people who met the research criteria and invited them to contact me to discuss the possibility of participation in the research project.

I was contacted by six potential participants to whom I sent a copy of the Information Sheet (Appendix C). For the participants that resided in the Waikato area, I arranged to meet with them over coffee to discuss my project. One of the women contacted me a few days after I set up the meeting to say she was no longer able to participate in the research due to upcoming surgery. I met with three other women in person and discussed the project and their experiences at length. Two of the other women lived outside of the Waikato area so discussing the project and what would be involved on Skype was suggested as an alternative. However, both participants preferred to discuss the details of the project via email. Each of these six women agreed to participate in the research project. Appendix D contains the guidelines for keeping a diary that were provided to the participants. These guidelines were developed after my own experience in keeping a similar daily diary. None of the participants wanted to take photographs as part of the diary exercise. One week later, one participant contacted me to let me know that she was unable to participate in the project because her grandmother had passed away. There were four participants who were undertaking the task of completing the diary activity. All participants agreed to complete diary entries for one week and email these through to me (or the number which they had completed during this time period).

Abrupt Hiatus: Non-Appearance of the Solicited Diaries

I was surprised when the diary entries did not eventuate soon after our agreement on the process. I did not want to place too much pressure on the participants because I knew they had a number of other demands on their time and may be struggling with the daily challenges of their invisible pain disability. However, I did send them reminder emails and text messages to encourage them to complete their diary entries. After three months, without the appearance of any diary entries, I had to accept that they were not going to eventuate. A well-intentioned design that aimed to be participant-driven had not worked. Chapter Two begins by examining the reasons for this, noting that, in a sense it is due to the price of pain. Chapter Two goes on to discuss how a number of interviews were then conducted without the diaries. Finally in Chapter Two, an introduction is made to the participants whose experiences form the basis for the accounts in Chapters Three and Four of how women with an invisible pain disability sustain worker identity.

Chapter Two - “I’m No Good at Keeping a Diary”:

Using Qualitative Interviews to Gain Insight into

Women’s Experiences of Pain at Work

The Diaries Didn’t Work: Arriving at an Insight

The failure of research participants to produce daily diary entries reveals a lot about women’s experiences of invisible pain at work. I initially believed that solicited daily diaries would be a useful method to research women in chronic pain because they are often used to research chronically ill people. Strengths of the method are that it is relatively unobtrusive and participants can complete diary entries in their own time (Alaszewski, 2006; Milligan et al., 2005; Kenton, 2010; Fritz & Lysack, 2014; Jacelon & Imperio, 2005). I also thought that the flexibility of being able to complete the diary in their own time and at their own pace would make participating in the research accessible for women who already face a significant number of challenges. However, I found that asking participants to diary their experiences was resisted and potentially had negative rather than positive effects. It forced them to confront the price they were paying for pain at work.

This reaction contrasted with reports of food diaries where people record what they eat so as to become more aware of what they are consuming. Daily diaries in this instance are a positive intervention because awareness in this context has the potential ability to change behaviour (Zepeda & Deal, 2008). What I failed to understand is that the women I am studying have competing demands on their time and energy. The tasks and activities that take priority in their lives are the ones that have deadlines, and the ones where they have committed to meeting in person at a specific time or place. This is why the initial

meeting, where the participants discussed the project and their experiences at length, was successful. They had committed to meeting me at a specific time and place. Consequently, even if they were in pain or were tired, they came to meet me anyway. The solicited daily diaries were different because participants were always able to put off completing the diary until some other time. It was the flexibility of the research design that allowed other priorities to take over, as the difficulties of these women's daily lives meant that other activities and tasks took precedence.

I had not anticipated this problem, in spite of piloting the method myself beforehand. When I kept a pain diary as part of trialling the method, I found that writing about it made the experience of pain more real. I did not anticipate that reflecting on my work and pain would be such a challenging experience. There were times that I felt depressed and as the weeks wore on, completing the activity daily became increasingly difficult. At the time, I did not see this as a flaw with the methodology itself; I saw this as a failing on my part and scolded myself for not being able to do better. Because I blamed myself, I did not follow my initial plan and use this experience to refine the methodology. I made no changes to the solicited diary activity as part of the research design and I proceeded to advertise the research project and identify potential participants.

After reflecting on this experience and after the participants were unable to complete the diaries, I realised there was a reason why participants were not completing the diary activity. Writing about their daily experiences of pain at work focussed participants' minds on the taken-for granted aspects of pain. Paying attention to pain at work in order to record it, appears to have given pain a more significant place in their lives than these women wanted. Just like the food

diaries, recording experiences of pain had made these women more aware of something that they were trying to ignore. However, in this instance it was not a constructive process. The effect was negative because women in chronic pain appear to deliberately avoid thinking about the pain they experience on a daily basis. The diaries became a physical representative of the pain that they faced. It was a physical manifestation of what was happening in their daily lives and they did not want to see this trauma written on the page, highlighting the difficulties of the pain they experience. It is therefore likely that this led to avoidance of completing the daily dairy activity.

It is also likely that the emails and contact from me further compounded their negative experiences. My prompts would have reminded participants not only about the pain that they were facing and trying desperately to ignore, but also of their failure to complete something they said they would do. Ignoring the emails from me became a strategy of avoidance as well.

Solicited daily diaries become detrimental in this context because they have the potential to make people experience pain more intensely. It is likely that thinking about, focusing on and writing down their experiences of pain made these women feel more pain, because thinking about pain leads to experiencing a higher level of it. Pain is not something that people want to notice more, they usually want to avoid it (Jackson, 2011). The taken-for-granted aspects of their lives which daily diaries bring to light may be best hidden as there is no benefit to feeling more pain.

I came to understand that women with invisible chronic pain face significant challenges to participate in the paid workforce and one of their coping mechanisms is not to confront the significance of their situation. Keeping a daily

diary made them confront how much their pain holds them back. I also began to wonder if the very notion of them agreeing to participate in the project was a kind of denial in terms of how much disability affects their lives.

Participants' diary challenges.

Participants' comments help to shed light on the challenges posed by the diary requirement. Two of the participants stated that the reason why they did not complete the daily diary was that they did not have the energy at the end of the day to complete each diary entry. Jackie said that she had tried to complete the diary the following morning as the mornings were when she could concentrate most effectively. However, when she attempted to write the diary entries in the morning, she struggled to remember what had happened the day before. Judith mentioned that it was her own time management skills which meant she did not complete the diary entries. She blamed herself and her own inadequacies (as did I) for not being able to complete the daily diary. However, she did cite her pain levels as the other reason for not completing the diary entries.

The interview participants who joined at a later stage of the research project were asked about how they would feel about keeping a diary if they had joined the research project at an earlier stage. Amy suggested that completing the diary may have been difficult for herself and other participants because "I don't think we like writing down how bad it is." Acknowledging pain by writing down experiences of it can make pain more real and more difficult to manage. This was echoed by Helen who acknowledged that she would have been hesitant to keep a daily diary about her pain and work experiences. "You'd be asking me to think about and notice when I'm in pain and when it fucks up my life...and that's what

I'm trying to be in denial about...I don't know that I'd want to, for a whole week, be consciously aware of all the times my pain is ruining my life."

Women who are in paid employment, especially those who are juggling family responsibilities have many competing demands on their time. Amy thought that this could be an issue for women in the project and mentioned that "in the triage of managing things, something falls off." Completing the daily diary entries for this research project was a task that was unmanageable for women in chronic pain who were balancing work and the other aspects of their lives.

Using Personal and Online Interviewing and Email Questioning to Understand Women with Invisible Pain Disability

The seven participants: Data collection.

This thesis is based on the experiences of seven women. Four of these were among the six originally contacted to participate in the research.⁶ I had asked these six initial participants if, despite being unable to produce any diary entries, they would agree to an interview or answer some questions by email. The email contained six questions and invited the participants to reply via return email (Appendix I). One of these women was interviewed by me face-to-face,⁷ two provided answers to questions over email, and the fourth used Messenger online chat via Facebook both to send answers to a set of questions and to respond in an interview-like manner to follow-up questions I asked of her. A further three participants were recruited after I realised the diaries would not work. Two of

⁶ The method of recruitment of these initial six participants is described towards the end of Chapter One.

⁷ This participant had agreed to take part in the project at the initial solicited diary stage of the research. However, she was unable to begin the daily diary because her health deteriorated and she had surgery before the project began. When I decided to recruit additional interviewees, I contacted her to ask if she was still interested in participating in the research project and would consider being interviewed. She agreed.

these were interviewed face-to-face and one online using Zoom technology. Additional questions were added to these three interviews to find out what the participants thought about the failed solicited daily diary method (Appendix H). One of these additional participants saw the poster about the project in the physiotherapist's office and contacted me about participating. The second noticed the research poster on my personal Facebook page and contacted me. The third additional participant was a fellow graduate student who fit the criteria and, after I had discussed with her about how I was having some difficulties with my research project, she realised that she fitted the criteria for participation and volunteered to take part.

Each of the four semi-structured interviews was conducted in the place that best suited the participant. Two interviews took place in the individual's workplace, one was conducted in a café, and one was conducted online via Zoom technology. The interviews were between 57 minutes and one hour 40 minutes in duration. The participant who answered some follow-up questions in an interview-like manner on Messenger online chat via Facebook chatted with me for three hours and 40 minutes. The three face-to-face interviews and the Zoom online interview were audio-recorded and later transcribed by me using Dragon Speech Recognition software. I used this software to transcribe the interviews because it was too painful to type for extended periods of time. I applied for, and received a WorkBridge disability support grant to purchase the software. It took significant time to transcribe the interviews. I verbalised the interviews to the software as it is tailored to understand the user's voice. Transcription was done in segments, stopping to correct errors and omissions from the voice recognition transfer. The Facebook chat material was already in text form and could be copy-and-pasted, as were the responses to the email questions.

Thematic analysis was used to analyse the transcripts of the interviews and email questioning. The process of thematic analysis involves identifying themes in the data that are relevant to the research (Bergman, 2010). In this instance a bottom-up approach was used where the themes were identified through looking for patterns in the data (Bergman, 2010). Ryan and Bernard (2003) suggest that thematic analysis often involves reading through transcribed texts and marking repetitions. This method was used in this project. When undertaking the thematic analysis, attention was paid to the meaning of what participants said, not simply to the transcribed or recorded words in isolation. The depth of my understanding of what participants meant varied, depending on whether I interviewed them face-to-face, online or considered their views by email. After the themes were identified, they were copied into new documents so they could be considered and analysed further. The themes that were identified formed the basis for the rest of this thesis.

Auto-ethnography and research blog.

As noted in Chapter One, the key auto-ethnographic component of the project was my trialling of the daily diary method. Following my supervisor's advice, I kept a daily diary about my workplace and my experiences of pain at work for four weeks. I had initially planned to do this for three weeks but extended it for another week to make sure I had explored its strengths and weaknesses and was in a good position to develop guidelines for my participants. I also took photographs of my workplace as part of the diary-

I planned to start the research blog once the research diaries had been completed. As noted in Chapter One, it took three months before I accepted that the diaries would not appear. I then focused on setting up interviews and finding additional participants. I also needed to develop alternatives to face-to-face

interviewing. As a result, a decision was made not to spend time on the research blog.

The Research Participants: An Introduction

Amy (a pseudonym) has a neurological condition which causes her back pain and other neurological symptoms. She also has osteoporosis which was caused by the medication that she was taking for her neurological condition in her younger years. She is a clinical psychologist and works full-time supporting young people who go into homes as support workers and is part of a larger on-call crisis team. She is Pakeha, in her late 40s and lives by herself.

Helen (a pseudonym) has had three surgeries to correct a curvature of the spine that was caused by scoliosis. This has left her with significant back pain and mobility issues. She works full-time as a Senior Tutor in a university. She is in her early 40s and lives at home with her partner. She has two adult children, one of whom has left home, the other is a full-time student and lives at home in order to complete his studies. Helen is Pakeha, in her 40s and is currently a PhD candidate.

Amelia (a pseudonym) has Adenomyosis which she has had since the age of 16 and has also recently been diagnosed with Crohn's disease. She also experiences chronic pain from an injury to her wrist nine years ago. She currently works part-time as a Consumer Advisor at a Mental Health Support service. She works two days a week, eight hours each day. She is in her early 30s and lives on her own. Amelia is Pakeha and has obtained a Certificate from a Polytechnic.

Leanne (real name) has Chronic Regional Pain Syndrome which was caused by an injury to her finger in December 2011. She works full-time in home-based childcare. She currently has four children in her care. She is in her 30s and

lives with her seven year old son. Leanne is Pakeha and is a qualified early childhood teacher.

Devangi (real name) has had Fibromyalgia since she was eleven years old. She then developed Arthritis in her early twenties. The most difficult part of her illness is the muscle spasms she experiences in her back and neck and more recently in her hips. She also experiences pain in her hands and feet. She works full-time as a receptionist in a spa salon. Currently this means that she works six days a week and works between five and ten hours per day. She is South African, 44 years old and lives with her partner.

Jackie (real name) has Chronic Regional Pain Syndrome which was caused by an injury to her ankle in 2008. It was then exacerbated by an injury to her wrist. She works part-time from home as a nail technician. Her hours of work are flexible because she can book in clients when she able to manage them. She is Pakeha, in her early 50s and lives at home with her husband.

Judith (real name) has Rheumatoid Arthritis which is primarily in her hips. She developed this condition 11 to 12 years ago. She works between 35 and 60 hours per week as a shift manager at McDonalds. She is in her early 30s, is currently single and flats with a group of friends. Judith is Pakeha and has a Post-graduate qualification.

The Research Participants' Responses to Being Women with Invisible Pain Disability at Work

When reflecting on how participants discussed their workplace experiences as women with invisible pain disability, there were five issues they identified as significant. These were responses to what they encountered in the workplace. These five are: Others' views that an invisible disability was not a proper

disability; the inclination of others to seek to provide special treatment to them; the tendency of others to offer advice that was unhelpful; the unpredictability of participants' chronic pain; and the participants' assertion of their own autonomy and independence. The following few pages provide an account of each of these, with reference to how other researchers have found similar themes.

“This isn’t a proper disability.”⁸

Firstly, women who experience chronic pain often feel as though their disability is not seen as legitimate. Because of the invisible nature of their pain, others can think it is not real or that their disability is not significantly affecting their lives; they therefore feel they need to prove their pain and justify its existence (Crowley-Matoka & True, 2012; Davis, 2005; Glenton, 2003; Jackson, 2011; Kugelmann, 1999; Moss & Dyck, 1995; Moore, 2013; Wilton, 2008). All of the participants experienced the challenges associated with the invisible nature of chronic pain. Helen mentioned the looks she received when she had not been able to carry out a task and had asked for help. “They look at you and they are like, why aren’t you doing that yourself? You know, because you look normal.” Individuals commenting on the visual appearance of a person in pain saying “You don’t look sick,” is a common occurrence and makes the person feel delegitimized in their disability (Pfizer, 2012, p. 9; Werner & Malterud, 2003; Werner et al., 2004). Conversely, Helen found it also occurred when people asked her for assistance, and she had to admit she was unable to help them. This has made her especially uncomfortable because it gives the appearance of being unhelpful, despite requiring help yourself at other times. “You feel like you’re this horrible person, that doesn’t want to help people that doesn’t do things for people...and that

⁸ The discussion of the first issue is longer than the other four because it has a number of elements to it and it has been noted much more in the literature.

doesn't do things for themselves...because they're some precious little princess." Feeling lazy for not contributing, or feeling as though others think this of you, is an issue that is discussed by Charmaz (2008). This contributes to the stigma and marginalisation that those with invisible disabilities face. They do not fit the able-bodied ideals that society has imposed on them (Charmaz, 2008). This is something that they have internalised as they often place this judgement on themselves as well.

Vickers (2012) discusses the challenges of working in teams for those with chronic illnesses. Teambuilding activities can present challenges for those who experience invisible chronic pain. Amy jokingly remarked that "I don't work anywhere that team-builds" because of the difficulties and the lack of understanding in many workplaces. She commented that now she suggests activities that she can do which has made for some more positive experiences. Helen also spoke of some of her negative experiences of teambuilding activities at a previous work place.

"I had that once at a job before... and they had one of these teambuilding things...and they did that whole let's do that knot your hands-up and get them out of the thing and I was like I can't do that, I'm not doing that, you know...because that's like bending...and contorting and [Researcher: It's not possible] I'm not doing that...and then it's like, well then, you're not really a team player then, are you."

Leanne also gets frustrated when people make judgement calls about what they believe she should be able to do. "And people go, oh but you look fine." The nature of her invisible pain condition is what makes people assume she is capable of undertaking physical tasks that she is not. The invisible nature of chronic pain

is an issue that has also been discussed in the literature on chronic illness and work (Vickers, 1997; Charmaz, 2008).

Another situation in which invisible pain is not seen by others to be a ‘proper disability’ is in relation to mobility parking. Some of the participants have used mobility parking permits in the past and people have questioned whether they should be parking in disabled parking spaces. Amy mentioned this when she spoke of people approaching her to make comments such as “you don’t need that.” Helen has experienced this when her colleagues made similar comments while she had a mobility parking permit before her surgery. She found it especially interesting that her pain was acknowledged after her surgery even though she was in less pain after the surgery had taken place. It was almost as if the surgery had made her condition more visible and therefore a more acceptable disability.

“Because then after I had surgery it was a thing [laughs] you know...It was a thing that was acknowledged...so they were sort of more accommodating after I’d had surgery, than before I had surgery but, before I had surgery I was in more pain and coping less well.”

The challenges faced by people with invisible disabilities in relation to the use of mobility parking is discussed in the literature on chronic illness and pain (Davis, 2005; Vickers, 2000).

As previously suggested, there is an expectation that able-bodied people will be involved in paid work. Those with invisible disabilities can struggle with society’s expectations about what they are capable of because their condition is not always seen as a ‘proper disability’ (Charmaz, 2008; Pfizer, 2012; Werner & Malterud, 2003; Werner et al., 2004). Amelia discussed the expectation to be

involved in full-time paid work. “Yep and...I guess the other thing is expectation...Because you do have what you call invisible illnesses which people can’t fathom...So you’re expected to be out there and doing things.” Other participants discussed the expectations that they felt that people they knew had put on them. Although Helen felt less pain and was more mobile after her surgery, others assumed that after an appropriate recovery period she should resume her ‘normal life.’ She should function like an able-bodied person and resume her role in the paid workforce. However, because of the pain she continues to experience she stated “I am better and I’m not worse and so in that sense it fixed me...but I am not able-bodied and I am not pain free.” She also discussed the ways in which she has been treated by others which made her feel as though chronic pain was not always considered a legitimate disability.

“Well you know, this isn’t a proper disability” [Researcher: It’s only pain!] Yeah [Researcher: It’s invisible! No one can see it] [Laughs]...I feel like it’s, and I don’t know how much of this is me projecting onto other people and how much of this is other people, but I feel like...saying that [if] you have chronic pain, [it] kind of doesn’t count as a disability [Researcher: To you? Or to other people?] I think to other people...They kind of didn’t think it was legitimate.”

Helen found the delegitimising of her condition difficult to manage. She talked about the “constant undermining” and “delegitimising of it” being a challenge. “Um, and all you’ve got is pain...But you can still walk, you can still carry things...And you can still study so it’s not really a disability if you’re having a normal life.” These challenges are discussed in the literature. For example, Davis (2005) discusses the idea that those who experience chronic pain and other

invisible disabilities face a number of challenges because they “appear to meet able-bodied standards” (p. 210). Those in pain must therefore prove that their disability is real in order to be believed and for assistance to be accessed (Davis, 2005; Glenton, 2003).

The comparison of those with invisible disabilities to those with visible disabilities was also something that was noticeable. People assume that if they cannot see the disability that a person is able-bodied. The image of a person in a wheelchair as a symbol of disability may be part of the issue (Vickers, 2000). Amy talked about when her invisible pain disability was not always taken seriously in the workplace. Because of the pain and the associated mobility issues, she struggled to climb stairs. This issue was not always taken seriously and her colleagues and managers sometimes booked meetings in a room that she could not access because of the stairs that led to the room. Although she had mentioned it several times, her inability to get to the meeting room was not seen as legitimate and she was seen to be overly dramatic because there were only three stairs. Amy commented on whether the situation would have been seen in such a way if she was in a wheelchair and was unable get up the stairs and access the room; or if those in wheelchairs would not be able to obtain or maintain their position in that place of employment. Davis (2005) argues that “persons with disabilities continue to be stigmatized and disadvantaged” (p. 192).

The notion that an invisible disability is not a ‘proper disability’ creates concerns around disclosure. Participants may choose not to disclose their disability to their employer if they think that they may not be believed or that their disability may not be taken seriously. Disclosing an invisible disability may lead to stigmatization or discrimination if asking for assistance or their disability is not

believed (Davis, 2005; Genton, 2003; Munir et al., 2005; Vickers, 1997; Vickers, 2000). Those with chronic pain may not want the label of 'chronic pain' because of the negative associations and judgements that people place on those who experience chronic pain. Helen did not want all of her colleagues to know about her invisible chronic pain disability, because of this label and how it may affect employment opportunities in the future. "And I don't want to be that crippled girl that always needs special this and extra that and can't do this...[and] needs someone else to do this for her." Amelia experienced this kind of attention and had been treated differently by her employer once she had disclosed her condition to her manager. This not only changed the working relationship between herself and her manager but also her working relationships with her colleagues. This made her apprehensive about disclosing her condition to others in the future.

"It didn't really feel like I was talking to my manager, it sort of felt like I was talking to somebody...with a lot of power, and a lot of...I don't know how to describe it...very influential on the situation...whereas I thought I was trying to disclose something that, I thought, would allow me to get more support [Researcher: right, ok] but that changed how others started treating me."

This is more of an issue for those with invisible disabilities, as the legitimacy of the disability is called into question, unlike with a visible disability. According to Helen, employers would prefer to hire those with visible disabilities, "I think it [the organisation] likes more high-profile things [Researcher: What do you mean high-profile things?] So that it can be seen to be hiring people with disabilities. It's a good thing to be seen to have people in wheelchairs."

Leanne has experienced something similar to Helen when applying for full-time positions in early childcare centres. She feels that she must disclose the nature of her chronic pain because there may be times it could affect her ability to do the job, or if she needs time off or to take rest breaks when she is fatigued. She believes that this affects her ability to obtain a job in a childcare centre which is why she undertakes home-based childcare. “They are not gonna choose me over someone else... who is fully capable.” Amy also feels as though there are difficulties with working in the paid workforce. She has experienced difficulties with taking annual leave when she needs to for health-related reasons. “They had to go all the way up to HR for them to give permission for me to use my annual leave...to look after myself.” She feels as though there will always be difficulties with employment because managers do not always understand the needs of employees with chronic illness and chronic pain conditions. She states “I think that’s the reality, if you are gunna work...unfortunately you’re bumping your head regularly.” This problem is reflected in the literature. For example, Richardson et al., (2007) observe that “The invisible nature of chronic widespread pain, coupled with the desire neither to talk about it nor to show it, exacerbates the potential for misunderstanding” (p. 360, Richardson et al., 2007).

Although there are challenges associated with the invisible nature of chronic pain, participants indicate that there are times that it is advantageous that the disability is hidden. Leanne appreciates that she could hide her pain and disability at times, and that she could choose when she disclosed this, and to whom. She liked that people did not treat her differently because of her disability if she chose to hide it. “You know, like people don’t look at you as some cripple.” This was especially important when she met new people or was with people she did not know. Amy also appreciated her ability to hide her chronic pain if she

chose to. She also appreciates that at times, she could push herself to do the things she wanted to, even if it will cause significant pain and would take a long time to recover. Helen and Leanne also thought this was one benefit of having a disability such as chronic pain, compared to more disabling conditions over which there is less control.

“I don’t want to be treated differently.”

The second issue that the research participants encountered in the workplace was that other people wanted to give them special treatment. They did not want to be treated differently to their colleagues or be given preferential treatment. In this sense, the invisible nature of their pain could sometimes be seen as a benefit. Helen discussed the desire to be treated like everyone else when she said “I feel like I don’t want to let my colleagues or my employers [to] know how much it affects me because I just want them to treat me like everybody else.” This was a very strong theme amongst the participants. They did not want their colleagues or supervisors to pity them or to make unnecessary sacrifices to assist them. Wilton (2008) has discussed how pity plays a role in this way. This desire to appear “as normal as possible” and be treated like everyone else may be due to the notion that being able-bodied is considered the norm (Davis, 2005; Hancock et al., 2000; Shilling, 2008).

This specific desire to be treated the same as everyone else was mentioned by Devangi who did not want her employer to understand how bad her pain was. Devangi was concerned that her boss may treat her differently if she knew more about how pain affected her. “I think if she understood more about my pain she might feel sorry for me and I don’t want that.” This is echoed by Moore (2013), when she also discussed the desire for people to not feel sorry for her because of

her chronic illness. Leanne also did not want people to feel sorry for her and so she would often “pretend to be fine.” She commented that people made their first impressions based on an initial meeting and it was important that their first impression was not “oh...you’re sick, I feel sorry for you.” Vickers (2000) suggests that people want to make a good impression in public situations, and avoid the stigma associated with invisible disabilities.

Devangi did not want others to know how much pain she experienced, as she did not want them to treat her differently because of her chronic pain. “I have been doing it for so long I have mastered wearing a mask to hide the pain - most of the time.” She commented that “most people who meet me have no idea how much pain I am in.” She believed that “it is easier that way, because you get treated normally.” There are multiple accounts in the literature of people being treated differently once their disability and pain are known to others, therefore many people with chronic illnesses and disabilities choose not to disclose them (Sturge-Jacobs, 2002; Vickers, 2000).

Amelia had similarly strong feelings and our conversation highlighted the tension between not wanting her employer to know more about her situation because of the way that people had treated her in the past after disclosure, and her desire to seek more support and assistance.

“But again, I don’t want to be treated differently than anybody else”

[Researcher: It kind of sounds like you are saying that there’s this interesting kind of mix between, it’s really hard because people don’t know because it’s invisible...but you don’t want to be treated differently?]

Yeah, yeah [Researcher: And that kind of clashes?] Yeah it does, yeah. I

guess, like I'm open to telling people, like...it's not a secret...Yep...but I guess it comes down to people's attitudes.”

She had shared her story with people in the past and it had changed the way that she was treated so she was apprehensive to disclose this again because of a fear of being treated differently in the work environment. Vickers (2009b) discusses the bullying that has occurred in workplaces as a result of disclosing chronic illness at work. Some participants were also nervous about disclosing their chronic pain for fear of discrimination, bullying or marginalization.

A conflict exists for women in chronic pain because they want their pain to be acknowledged, while at the same time they want to hide the reality of the pain they experience. While there are many reasons why women in pain may want others to know about the extent of their pain, they often do not talk about their experiences because they do not want to be seen as constantly complaining (Werner et al., 2004). This tension existed in the interview data where many of the participants appeared to be sending mixed messages about wanting others to understand their pain and how difficult it could be to live and work with chronic pain while not wanting to share the intimate details of their story with all of their colleagues.

Some of the participants did not want to burden their colleagues by not carrying their share of the workload. Helen discussed this when her colleagues offered assistance that she did not always want to accept. Often the desire to be treated the same as everyone else came at a personal and painful cost to these women as not accepting help when needed could cause additional pain later on. “My colleagues are quite good and they'll say ‘do you want me to carry that’ but I tend not to want to let them...because I can manage and so I do and then later on

I'll be in pain." Helen also mentioned that she did not get extra assistance as often as she should due to feeling self-conscious about appearing different. "I don't want to be seen as different, and so I probably put up with things that I could do something about...because I don't want to make a fuss." This desire to fit able-bodied standards and appear normal can mean that women in chronic pain do too much and experience more pain as a result (Davis, 2005).

"It's stupid advice anyway."

The tendency of others to offer advice that was unhelpful was the third issue the research participants encountered in the workplace. Offering advice to those who experience chronic pain is something that many people do. Although well intentioned, this advice can be challenging to listen to because of the nature of the advice that is given. It can often be seen as patronising assuming that the person experiencing chronic pain has not thought of attempting to manage their pain in this way. As mentioned by Amy, its "really obvious advice and it probably works for ordinary people" and so it can be frustrating. It could also be another reason why some people in chronic pain choose not to disclose their condition to others.

Amy mentioned that people had suggested strategies such as seeing a chiropractor or taking over the counter medications to manage her pain better. When people offered advice they usually had little idea about her condition and what would be of benefit. "I tried telling [them] and then people start giving you advice, telling you what you should do...and they don't know... it's stupid advice anyway." People have also suggested that she start going to the gym which is not something that she is able to do and this would exacerbate her pain further.

Helen also had this issue, with people suggesting what had worked for their pain, "I'm on this medication...or I'm taking Panadol that works really

well.” Consulting a physiotherapist was another suggestion that was often recommended by others. At times, the participants felt offended when people made comments such as this because it was as if they were implying the participant had not thought about taking Panadol or seeking professional advice to manage their pain better. This is another example of how their invisible disability was not seen as legitimate because it was not perceived (Crowley-Matoka & True, 2012; Davis, 2005; Glenton, 2003; Jackson, 2011; Kugelmann, 1999; Moss & Dyck, 1995; Moore, 2013; Wilton, 2008).

The challenge of others’ perceptions was voiced by Helen when she discussed the difficulties with experiencing chronic pain and how it would be difficult for others to comprehend, “I just don’t think people understand how hard it is to be in pain all the time.” Others have commented on how they obtained a sore back from gardening, but as Helen pointed out, the difference is “that yours will GO AWAY!” This lack of understanding could contribute to both the volunteering of advice as well as the unhelpful nature of the advice that other people offer. Part of the reason it is difficult to understand the pain that others experience is because of a lack of common language to describe pain (Jackson, 2011).

Using mindfulness to manage pain is another strategy that is suggested to those managing chronic pain. This strategy is one that is now being recommended by the medical profession, the effectiveness of which has been researched in the academic literature (Doran, 2014; Jackson, 2011). Mindfulness is a method of meditative practices that assists the person to bring themselves into the present by focusing on specific aspects of the world around them (Doran, 2014). Using mindfulness as a strategy to manage pain was not one that was supported by the

research participants. Amy noted this when she said “those damn people that say... [just] mindfully reduce your pain.” She discussed how mindfulness may work for people that do not experience pain to the same extent as someone in intense pain all of the time.

“The fact that it changes - I think it’s very difficult to live with.”

The fourth issue the research participants needed to deal with in the workplace was the unpredictability of their chronic pain. The unpredictable nature of chronic pain makes this a disability that is difficult to manage both at home and in the workplace (Richardson et al., 2007). It can be challenging for those who work with people experiencing chronic pain to know when they may need support and when they can manage on their own. This is further complicated by the fact that the level of pain experienced can change on a daily basis. As previously suggested, the ability of chronically ill women in pain can change as well and also depends on the emotional state of the person at the time (Jackson, 2011).

Amelia discussed the difficulties that she has encountered with the changing nature of her pain at work. “Some days are like all good for me but other days my wrist could be worse or my stomach might be playing up... but people don’t know that.” This is related to the invisible nature of chronic pain because others cannot know the level of pain that the individual is experiencing at any given time.

There are other challenges associated with the changing levels of chronic pain. Amy found it difficult that she did not know when the pain was going to change and become more intense. “The fact that it changes, I think it’s very difficult to live with so there’s some times [when] the pain is worse than others.”

Helen also experienced varying pain levels and commented on how she was always in pain but the level of pain she experienced differed.

“I just wonder what it would be like to wake up and not be in pain
[Researcher: Yea, I dream of that!] Like I don’t know, I don’t remember
what that feels like because every day since I was 12, I’ve had some pain.
It’s either a little bit of pain or a lot of pain, but it’s some pain.”

Amy commented on how difficult it was to manage her chronic pain condition herself rather than rely on doctors or tests to help determine what the most effective treatment would be. “I sometimes wish I had like a diabetes thing where you could test my blood and know what’s going on.” Leanne also experienced changes in her pain levels. However, she was better attuned to knowing what would help her to deal with the “flare” and avoiding the pain escalating as she had learnt to manage her condition over time.

Helen noticed significant changes in the level of pain she experienced from day-to-day; some days she had a significantly higher level of pain than she did on other days. These fluctuations in pain levels created an emotional burden because there were times where she would wake up and the pain had reduced significantly overnight. This caused her concern that there may be further damage to her spine and that she may lose the ability to walk.

“So I’d sort of be in that state and I go oh can’t feel my feet, and then I’d be going, well maybe it’s because I can’t feel my feet or maybe it’s because I’m just waking up and then I’d be lying there going, I will try and wiggle my toes just to make sure that I can... I was in so much pain yesterday and I woke up thinking, ‘what if today is the day? What if today is the day I can’t walk.’”

This could mean that the unpredictability of the pain experienced by these women can cause emotional harm which creates further difficulties for those who experience chronic pain.

Another issue that women in chronic pain encounter is the lack of ability to notice when they experience other issues or illnesses. As Amy mentioned “because I’m used to feeling like a bag of bones, I’m not noticing.” Helen noted that doctors often describe symptoms to be aware of and when to seek medical advice. These symptoms were ones that she experienced daily and it concerned her that she may not notice when she was ill and that medical attention should be sought. “Ohhh maybe it’s that [laughs] and then I’ve heard this thing and people say if you have symptoms get in early... but those are symptoms that I have every day to varying degrees.” If she experiences aches and pains in her body she would always “put it down to having a bad back day” rather than some other illness even though in some instances there were other medical reasons for her symptoms.

“Find your own rhythm and beat your own drum.”

The assertion of the participants’ personal autonomy and independence in the workplace is the fifth issue apparent in the data. The participants enacted autonomy at work by choosing what tasks they were capable of carrying out and what tasks they were unable to do. At times this came at a personal cost to the women themselves and they ended up suffering more pain because of the decisions they made. Making decisions about the tasks they were capable of, or wanted to do was important and empowered these women by giving them influence over their lives. This was important, not only because autonomy is essential to all individuals, but also because the unpredictable nature of chronic pain can make these women feel like they do not have control over their lives

(Moore, 2013; Richardson et al., 2007; Sturge-Jacobs, 2002). Unpredictability can be difficult to manage because they can never be sure what will cause their pain to flare.

The unpredictability of chronic pain can also be challenging for the people who work with those experiencing it. However, those in chronic pain are the best ones to judge their own capabilities. Helen stated that she wanted it to be her decision about what she was capable of. It is important that these decisions are not taken away from those experiencing chronic pain. “The days that I can lift a chair, I will...I can self-manage that thanks...I don’t need you infantilising me.” Oakman et al., (2016) suggest that those who experience chronic pain can best manage their situation and can put strategies in place to function effectively at work. Therefore women in chronic pain should be the ones to educate others about what assistance they require.

Devangi also wanted to be the one to make decisions about her body. She experienced pain whether she was at home or at work so being in paid employment meant she could be “as close to normality as... [she could] manage.” Being able to make these types of decisions is discussed in the literature by Audulv et al., (2012). These decisions may even include not taking medication which would help to manage their pain better (as was the case with two of the participants) as this would mean that they would be unable to work. Devangi mentioned that it was important to “find your rhythm and beat your own drum nobody else's.”

Both Leanne and Amy appreciated having autonomy over their work because it gave them the ability to make decisions that positively affected their lives and wellbeing. As Amy mentioned managing her own schedule allowed her

to look after herself “and so if I’m having a bad afternoon I can just go, [Amy] can I have time off, yes you can, and I do.” Leanne believes that prioritising important tasks is vital and allowed her to achieve what she set out to do “but if it is important then you’ve gotta choose to have a quiet day.” This meant she could participate in important activities later that evening. Having autonomy over their work schedule is an important aspect in aiding those in chronic pain to remain in the paid workforce (Oakman et al., 2016).

It was also evident that the participants valued their independence and the opportunities that participating in paid work provided. Amelia had decided that it was important to her that she did not entirely depend on government assistance. She valued her ability to be able to work and support herself. “I guess for me also the feeling of having to rely on other people is quite hard...I’d probably take it quite personally if I were to leave work... and then have to rely on the government.” Devangi mentioned that she appreciated going back to work to earn a wage because she could contribute financially to the household again. “Going to work and earning a salary definitely made me feel like I was contributing again.”

Being at Work and Having a Worker Identity

It is contended that these five issues reveal a struggle between the participants’ pain identity and their worker identity. The research participants placed priority on being good workers, on contributing in meaningful ways to the work they were involved in. Their worker identity was very important to them and they wanted to be able to make full contributions as valuable workers. They did not want the perception that they had a pain disability to undermine their identity as workers. They did not want to be treated as different even though they experienced invisible pain as an unpredictable and, at times, overwhelming disability. Their

salient identity was that of worker and they did not want their pain identity to undermine that. Chapter Three discusses the nature of and clash between these two identities, while Chapter Four describes the strategies that are used by the participants to maintain their worker identity.

Chapter Three - “I Don’t Want to be *That Crippled Girl*”:

The Clash between Pain Identity and Worker Identity

Pain and Identity at Work

When thinking about why participants were unable to complete the daily diaries, I considered whether avoidance, distraction and denial could be strategies adopted by them to maintain effectiveness at work. The task of completing diary entries may have made the participants focus on their pain more than they would have otherwise. Women in chronic pain often avoid tasks that cause pain, or activities that make them think about their pain. Writing in the diary would have made them think about their pain and this may have led them to avoid completing the diary entries. This outcome made me consider whether the failure to complete the diary was part of an overall denial that pain is a significant part of their lives. Work distracted them from the challenges of chronic pain and the diaries undermined that distraction.

Upon further reflection, discussion and re-examination of the interview transcripts, I decided that these women do not deny their pain; pain is part of their identity. I realised then that the participants had multiple identities. The two most important are the pain identity and the worker identity. These identities must be carefully managed in the work context. As I noted in Chapter Two, my participant Helen stated that when at work she did not want to be viewed as “that crippled girl” that always needed extra help. When at work, she wanted her identity to be understood primarily as that of a worker. The failure of the diaries as a research method, led to an understanding of how the participants manage their pain in the workplace.

Identity is how people see themselves, as well as how they would like to be seen by society and by the people around them. People's different identities define who they are, which influences how they behave in different settings (Deaux, 2015). The participants in this project often did not want people to see their disabilities or pain. They needed to balance the way they hide a body that is in pain with the reality that it cannot always be hidden. Denial of that part of their identity would be denying part of themselves. Therefore, the pain aspect of their identity is taken into consideration when managing their lives and becomes part of who they are. Failing to acknowledge their pain would significantly impact on their ability to implement strategies to succeed at work and maintain the salience of their worker identity

Identities: Individual Social Being

Identities are socially constructed (Callero, 2003; Shen & Dumani, 2013). There are many different influences on identity such as power and social relationships (Howard, 2000). They are also shaped, changed and communicated via language, social interaction and the media (Howard, 2000). These influences shape how identities are formed on an individual level and affect how people see themselves, thereby influencing how they choose to present themselves to the world. The identities that people form are constructed and maintained through cognitive processes (Howard, 2000). Therefore, the formation of personal identities is deliberate.

Personal identities are fluid and dynamic. They are unstable and can and often do change over time (Callero, 2003; Howard, 2000; Shen & Dumani, 2013). Howard (2000) argues that social identity theory has two components, one encompassing a social aspect, the other containing a personal element. These two

components sit at opposite ends of a spectrum. A person's personal identity is who they see themselves to be, but this is also shaped by social interaction with others (Callero, 2003; Howard, 2000). The individual characteristics of a person are only part of what constitutes their identity, it is also influenced by society, other people and the power relationships between them. Because society has an influence on an individual's identity, what is shown to others is important because identities are influenced through social interaction with others (Callero, 2003).

Identities influence how people perceive others in social groups. If a person has a known identity, they are expected to behave in a way that is consistent with that identity (Fine & Asch, 1988). Disability is one example of an identity where individuals are expected to behave in ways that fit what society expects. When people do not fit into predetermined expectations of their identity, it is confusing to other people. When individuals do not meet social expectations, others question the legitimacy of their identity (Charmaz, 2008; Pfizer, 2012; Werner & Malterud, 2003; Werner et al., 2004), and no longer know what to expect from the individual. Participants often wanted to hide their chronic pain and were reluctant to ask for help or assistance; this was referred to in Chapter Two and is an example of how their worker identity was called in to question. They were also nervous that asking for assistance in one circumstance would mean that others would assume that they would always need help because of their chronic pain disability.

Over time the social definition of an identity may change because of the cultural and social context in which it exists. Homosexuality was once classed as a disability (Shen & Dumani, 2013). Hysteria was classed as a mental health disability and in the past women have been institutionalised for hysteria.

Hysterical neurosis was deleted from the DSM-III in 1980 (Tasca, Rapetti, Carta & Fadda, 2012). An individual's self-perception of their identities can also change over time. An individual may identify as a musician, but may not be able to perform when they become ill. They may also take on a pain or illness identity when they become sick. These identities may change over time as individuals accept that illness and pain are part of their life.

Some identities are acquired (e.g. dancer or athlete) and some are prescribed (e.g. gender, sexuality) (Hodgetts, Drew, Sonn, Stolte, Nikora & Curtis 2010). Social identities also change depending on the context. If an identity is not seen as the important one in that setting, it will not be enacted at that time (Roccas & Brewer, 2002). Roccas & Brewer (2002) argue that with compartmentalization, "in certain contexts, one group membership becomes the primary basis of social identity, whereas other group identities become primary in different contexts. At the office, for instance, one's professional identity may be the only relevant basis for ingroup-outgroup distinctions; shared identities based on sex, ethnicity, religion or recreational group memberships are irrelevant and not activated in this setting" (p. 91). An individual's pain identity is not often one that is activated in the work setting. It is more commonly activated at home or in the health setting. There may be situations where more than one identity is enacted at the same time, however, this does not usually happen with a pain identity and a work identity.

Reynolds (2015) suggests that talking with others within the social group helps to validate members' views and experiences. Women in chronic pain often find that talking to others with similar experiences is beneficial and helps them to understand their own situation (Jackson, 2011; Oakman et al., 2016; Werner et al., 2004). The participants in this project found that talking to others was beneficial,

however, they did not benefit from participating in support groups as they had found them to be too negative. As the main reason a support group exists is to discuss pain, this could cause individuals to focus on their pain more than they would do so otherwise.

Significant Identities

Most people have more than one identity. For each of these identities, they can belong to a social group consisting of other people who share the specific characteristics of that identity (Hodgetts, et al., 2010; Reynolds, 2015; Roccas & Brewer, 2002; Shakespeare & Watson, 2002; Shen & Dumani, 2013). These characteristics define the person and have an influence on their behaviour (Roberts & Donahue, 1994). Each identity can be seen as a role that is played and these roles will be performed in different contexts. The role or identity that is chosen depends on the situation. However, the role that the individual is most committed to will be enacted more often due to that commitment. Individuals will take on that identity more than other identities as they will be more satisfied when taking on the role that is most important to them (Roberts & Donahue, 1994).

Because people have multiple identities with varying traits and attributes, they can become members of various social groups as they are drawn to others who share similar characteristics (Roccas & Brewer, 2002; Reynolds, 2015). People identify with a group and can see how it differs from other groups in society (Howard, 2000; Roccas & Brewer, 2002). People identify with a social group if they are emotionally invested in it, they see the value in it or it is significant to them (Deaux, 2015; Reynolds, 2015). This emotional link means that they are drawn to others in the group because of their shared identity, rather

than the individuals possessing a personal connection developed over time (Roccas & Brewer, 2002).

Disabled identity.

A person with a disability is defined as “any person who (i) has a physical or mental impairment which substantially limits one or more of such person’s major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment” (Fine & Asch, 1988, p. 5).

When considering people with disabilities “it is assumed that disability is central to the disabled person’s self-concept, self-definition, social comparisons, and reference groups” (Fine & Asch, 1988, p. 11). This misperception may be because disability is something that is important for those who are not disabled and is something that is often feared (Anastasiou & Kauffman, 2013). “Because disability is clearly salient for the nondisabled, it is assumed that the marked person incorporates the mark as central to a self-definition” (Fine & Asch, 1988, p. 11). Assuming that people with disabilities always define themselves by that disability is incorrect (Shakespeare & Watson, 2001). This remains consistent whether the disability is a visible or an invisible one. People with disabilities may not see it as their defining feature and may choose other characteristics to define themselves and use them to identify with others (Roberts & Donahue, 1994).

When a pain or disabled identity is not the one that is most valued by the individual, and therefore not normally seen by others, people do not understand when the behaviour of the individual reflects that identity. It is assumed that the person experiencing chronic pain is exaggerating their pain or being outright dishonest. Society cannot understand why the disabled or pain identity is not chosen as the salient one, if it is truly part of the individual’s identity.

Pain identity.

When people become unwell, their identity and sense of self changes (Ashbring, 2001; Auduly et al., 2012; Charmaz, 1983; Charmaz, 2008; Kralik et al., 2004; Seear, 2009; Werner et al., 2004). A pain identity is fluid and changes over time. This may be in relation to the experience of pain itself or the degree to which the person experiencing pain has accepted their diagnosis and its long-term effect on their life. Some people who experience chronic pain struggle with this change in identity (Antao et al., 2013; Charmaz, 2002; Moss & Dyck, 1996; Shilling, 2008; Sturge-Jacobs, 2002). This may be caused by a variety of factors such as the degree that the person's life has been affected by pain and whether they can engage in the activities they previously enjoyed, enacting any of their other multiple identities.

A pain identity differs from other identities due to the invisible nature of chronic pain. If an individual has an identity as a sportsperson, people can see the activities they engage in and know that this is one of their multiple identities. As previously suggested, pain is a subjective experience, it is not seen, it is not social and people can go to extreme lengths to hide their pain from others. Because of the invisibility of chronic pain, it is often not seen as a legitimate disability and therefore, it could be disputed whether it is a legitimate identity. Because vision is valued above the other senses (Hockey & Allen-Collinson, 2009) and society places huge value on what can be seen, a pain identity is not always beneficial because a person can be judged for having an identity that cannot be quantified. This is one reason why the pain identity is often hidden at work. People must be sure that those who know about chronic pain will not treat them any differently once a pain identity is known. Because of the stigma, discrimination and the potential to be treated differently at work, managing who to tell and who to keep it

from can be difficult to manage. Once known, there is a high chance that individuals experiencing chronic pain will be treated differently in relation to the identity that has been recently disclosed (Davis, 2005; Glenton, 2003; Munir et al., 2005; Sturge-Jacobs, 2002; Vickers, 1997; Vickers, 2000).

Worker identity.

A significant proportion of a person's identity centres around work (Saayman & Crafford, 2011; Strangleman, 2012). This becomes more relevant when a person holds strong beliefs about the work that they do and are committed to their job. For people experiencing chronic pain and illness, it is therefore important not to leave paid employment when they are diagnosed with chronic pain despite the challenges that they experience with managing pain at work. Due to the onset or change in chronic pain or illness, some of the identities that an individual once had may no longer be viable (Ashbring, 2001; Audulv et al., 2012; Charmaz, 1983; Charmaz, 2008; Kralik et al., 2004; Seear, 2009; Werner et al., 2004). It then becomes important that they maintain any of their identities that they can. Before people experience chronic pain, a work identity is often a significant one. It is therefore important that this identity is maintained after a pain identity has been adopted.

Undertaking paid work also made participants feel as though they were living productive lives despite their chronic pain disability. These women want to be successful despite the significant pain they experience. Therefore, it is not only the way in which other people see them that matters, it is also about the way they see themselves.

Managing Multiple Identities

Salient identities.

The different identities that people have are hierarchical and these are ordered based on how important the identities are to the individual (Deaux, 2015; Howard, 2000; Roberts & Donahue, 1994; Shen & Dumani, 2013; Shakespeare & Watson, 2001). The identity that is the most important is the salient identity. Different identities may become salient at different times. For example, office parties may be problematic for an overweight person as there is usually a significant amount of food there. The individual may find this difficult as they could expect to be judged, or consider their weight to be more noticeable at the time (Shen & Dumani, 2013). Sport or teambuilding activities may be an issue for people with disabilities. Their pain identity may become salient when they are unable to participate in these activities, or their job requires them to do manual tasks such as heavy lifting.

The salient identity is the one that is most obvious to others (Callero, 2003; Roberts & Donahue, 1994; Shen & Dumani, 2013). People are usually more committed to the salient identity and are often drawn to others who share this same identity. Which identity is salient depends on the context and what is most important to the person (Howard, 2000).

A pain identity is one that is acquired, often the result of injury or illness. In many instances, it is not an identity that an individual chooses as most people try to avoid pain (Jackson, 2011). Some people who experience chronic pain choose the pain identity as the salient identity and in this instance the pain identity often takes over their lives (Chronic Illness is a Journey, 2013; Counting My

Spoons, 2015; Patel et al., 2007; McCluskey et al., 2011; MycuppaJo.com, 2016; Sturge-Jacobs, 2002; The Mighty, 2016).

The identity change that occurs when an individual first experiences chronic pain and illness is well documented in literature as internet blogs, forums and other mediums (Chronic Illness is a Journey, 2013; Counting My Spoons, 2015; MycuppaJo.com, 2016; The Mighty, 2016). People who have experienced a change in identity after being diagnosed with chronic pain, have written about their experiences online. The pain identity discussed in these contexts, is referred to negatively, having replaced other identities that individuals previously saw as important. Their pain identity has become the salient identity, visible in the way these women discuss their pain experience. This is echoed in the academic literature, where the difficulties faced by those who experience chronic pain are discussed in-depth (Afrell et al., 2007; Ordóñez-Hernández et al., 2015; Kugelmann, 1999; Moore, 2013; Seear, 2009; Sturge-Jacobs, 2002). As previously suggested, it is also an identity that is fluid and changes over time. It may not be the salient identity as people learn to accept that pain is part of their life. Research suggests that people who accept their chronic pain and illness are more content than those who deny its effect on their life (Doran, 2014; Hancock et al, 2000; Jackson, 2011; Silverman et al, 2009; Afrell, et al, 2007).

A pain identity therefore, can be one that people choose to distance themselves from (Howard, 2000). Howard (2000) argues people are ambivalent towards some identities. However, the participants in this project accept their pain identity and do not show ambivalence towards it. They cared about the effect that pain has on their life and attempt to manage it so that it does not affect either themselves or their work negatively. However, they choose for their pain identity

not to be their salient identity. In this way, their experience of accepting a pain identity differs from many of those who have written their stories in the literature.

Based on the experiences that the participants shared, I argue that they chose for their worker identity to be the salient identity. Work is important to these women and this is echoed in the literature on chronic pain and work (Ashbring, 2001). For the participants in this project, not choosing their pain identity as the salient identity does not mean that it was rejected, as this would mean that they deny that pain had an influence on their life. However, these women chose not to let their disability and their pain identity take over and rule their lives. Placing less value on this part of themselves ensures that their experiences of disability, pain and illness does not define who they are. This is illustrated by the lengths participants went to in order to ensure their pain identity did not surpass their worker identity. This could be another reason why participants in this project did not find support groups helpful. Participating in support groups may have made their pain identity more salient than they wanted it to be, thus threatening the salience of the worker identity. Different identities are shown in different contexts and in this instance the pain identity is suppressed at work. However, if it is not taken into consideration, women experiencing chronic pain may make the pain worse, which in turn would threaten the position of the worker identity in the hierarchy of identities.

Disability and identity.

Society often considers disability to be an individual issue and therefore many subscribe to the medical model of disability. The medical model sees disability as “a personal tragedy, with the difficulties experienced by the disabled person being caused directly by their impairments” (Harris & White, 2013). Those who

subscribe to this way of thinking see disability as intrinsic to the individual, that it is important to their self-concept. It will hinder them and hold them back. They see disability as solely an individual physical problem that will disadvantage those with disabilities in some way.

An able-bodied identity is considered the dominant identity and society is set up in such a way to meet the needs of those who do not have disabilities (Howard, 2000). This is true of many different spaces in society including the workplace. Although this is unintentional, workplaces are often set up to sanction disabled bodies. When those who are disabled struggle with the way that the workplace is set up, it is the person's disability that is assigned blame rather than the environment or workplace. Discriminatory work practices are another example of the way that people's bodies are blamed rather than considering ways in which processes, practices or the environment could be changed to better meet the needs of those with disabilities (Fine & Asch, 1988). It is often expected that people with disabilities should accept the current situation rather than challenge the status quo or set up the work space in a way that meets their needs better (Fine & Asch, 1988).

Another issue that people with disabilities face is that any difficulty they experience is assumed to be caused by the disability (Fine & Asch, 1988). It is also assumed that people with disabilities are unable to assist others and are unable to work or be productive members of society (Haufe, 1997). As argued by Fine and Asch (1988) "disability is assumed tantamount to incompetence and helplessness [and this] has been investigated and supported in laboratory research" (p. 12, Fine & Asch, 1988). However, society has fixated on the idea that people with disabilities are always in need, while able-bodied people are

never in need of help or support (Fine & Asch, 1988). If society thinks that it is not possible to have any identity except that of a disabled person, then it will be challenging for people with disabilities to be successful at work. This perception may be another reason why women in this project were tentative about disclosing their chronic pain disability to others because it may be assumed that they will always be in need of help and support and may not be seen as competent in their field.

Some people reject the medical model of disability because they see the challenges that those with disabilities face are not entirely the result of biology; but that there are also social influences that create challenges for those with disabilities (Anastasiou & Kauffman, 2013). The social model of disability considers the social treatment of people with disabilities as the biggest issue and considers the ways in which their lives are effected by those around them (Anastasiou & Kauffman, 2013; Harris & White, 2013; Hancock, et al., 2000). Those who believe in this model think that it is society that “disables physically impaired people.” (p. 442, Anastasiou & Kauffman, 2013). The argument is that such a view is politically driven and advocates for there to be change in society. Although this model has often been critiqued for ignoring the personal issues that those with disabilities face, it is relevant to consider the ways in which those with impairments are disadvantaged by an able-bodied normative culture (Anastasiou & Kauffman, 2013; Harris & White, 2013; Shakespeare & Watson, 2001).

While the environment is an important consideration and causes part of the struggle of living with a disability, the disability itself remains the central element in the difficulties faced by women living with chronic pain. These women must take their pain identity into consideration or their worker identity may be less

salient. Managing the work environment is important and helps to maintain the salience of the worker identity and suppress the pain identity. Therefore, considering aspects of the social model of disability and the medical model of disability is most appropriate because both the environment and the body need to be taken into consideration. Therefore, the individual must manage their pain and environment in order to succeed at work. For that to occur, the impetus must come from the individual during or after the onset of their disability. Because of the challenging nature of chronic pain, this individual determination is what stops the pain identity from becoming the salient identity.

The disability or pain identity is not the only one that an individual has, it is only one of the many identities they possess. The idea that the disability is not a defining feature of a person is one that is valued by the participants. Their disabilities do not define them and do not describe who they are. Although they acknowledge that their pain has a significant impact on their lives, they do not let it take over and become the defining feature of their identity.

Giving Priority to Worker Identity

Chronic pain has not become a defining feature of the participants' identities. Although their identity and sense of self changed when they became ill, these women work hard to ensure that it does not become the first or only thing that people see about them. Although chronic pain is a significant part of the participants' lives, their pain identity is not their most valued identity, especially in the work context. Choosing which one is the most salient can only be defined by the person themselves; their beliefs, values and social interactions have a role to play in determining which one is the salient identity (Reynolds, 2015). They manage their multiple identities and make sure that the salient worker identity is

the one that is seen most often at work. This is not only important because of how they would like to be seen by others, but also because they would not like for their pain to be the most important thing that they see about themselves (Callero, 2003).

The literature surrounding chronic illness and chronic pain is significantly focused on the idea that individuals should rest to recover from their illness or injury or engage with rehabilitation in order to return to work (Antao et al, 2013). There is the underlying assumption that the patient will get well and return to their previous place of employment. There is less focus on living and working with chronic pain or chronic illness (Antao et al, 2013). This rehabilitation focus is present in society as well and living and working with chronic illness for many people is a perplexing concept. In society, value is placed on the concept of wellness. However, the definition of wellness is considered within an able-bodied frame of reference. For those who experience a temporary disability or illness they may be able to rest and engage with rehabilitation while they recover so they are able to return to work.

However, it is difficult for most people to imagine experiencing pain as a long-term problem (Fine & Asch, 1988). As argued by Howard (2000) “the handicapped role, like the sick role of which it is an extension, compels the occupant to suspend other activities until recovered, to concentrate on getting expert therapy, to follow instructions, to get well, and only then to resume a normal life” (p. 12). It is therefore difficult for able-bodied people to understand how someone can be unwell or in pain for a significant period of time (Howard, 2000). When someone does not recover from illness or their pain does not improve, it is assumed that they are at fault and they are not trying hard enough to

get well. Society does not accept that people play the role of the sick person long term (Kugelman, 1999). On the contrary, it is thought that they must recover and only then may they return to work and their previous life. While recovering, and overcoming chronic pain is not possible in order to be involved in paid work, the women in this project have proven that the absence of pain is not necessary in order to be successful in the workplace. Furthermore, involvement in the paid workforce while experiencing chronic pain has many benefits for women's lives (Antao et al., 2013; Oakman et al., 2016; Rakovski et al., 2012).

Because the worker identity is the salient identity, the pain identity is often suppressed at work. This suppression enables them to function as an effective worker and be productive in the work environment. Although it may appear that these women deny their pain identity, it is not their salient identity, especially at work. As previously suggested, if they deny that pain is part of their lives, they may undertake tasks that exacerbate the pain thus making involvement in the paid workforce difficult. Women in chronic pain make strategic choices about the tasks they need to undertake to ensure that they are successful. These women also make strategic choices about when they need assistance to ensure that their pain identity is not shown too often in the work environment. There are times when women in chronic pain 'take the hit' and engage in tasks that cause them more pain in order to keep their pain identity hidden. The more that their pain identity is shown, the less likely that their worker identity will remain salient in the work environment.

Clashing Identities

The women in this project possess dual identities of a worker and a person in chronic pain. Although their pain identity is often hidden, it does not mean it is any less a part of who they are or who they see themselves to be. The pain identity

is not hidden from work because it needs to be taken into consideration in terms of the way that work is organised. However, it is often hidden from the people they are working with. In this way there is a distinction between being someone in chronic pain and telling someone about a chronic pain identity.

Striving to live as normal life as possible may have ramifications for woman who experience chronic pain. These woman often take on more than they should in order to keep up this façade. At times, this choice can have damaging consequences and can cause significant pain. Because of the salience of their worker identity, their work is often prioritized which may come at a significant personal cost. This pain could be avoided if these women asked for more help or assistance at work. This strategy shows that maintaining their worker identity is more important than avoiding pain. When making decisions about who to tell about how pain influences their life and work, an individual must trust that they will not be treated any differently because others are aware of their pain identity.

The more that people's multiple identities are similar the less complex their social identity is (Roccas & Brewer, 2002). There are some identities that fit comfortably (e.g. PE teacher and runner) and some that do not (e.g. junior doctor and runner, working long hours and not having enough time and energy). At times, the multiple identities that people have, have contradictory goals (Howard, 2000). Balancing the goals can be challenging, especially when each identity is significantly different. A pain identity and worker identity are two that often have competing goals because of the nature of each identity. Therefore, the participants in this project have a complex social identity as their identities do not match and each has competing goals. The goals of each must be managed, which sometimes means that the pain identity is shown at work.

As argued by Roccas and Brewer (2002) “when group identities do not converge [like work and pain], there are different ways in which the individual may structure his or her perception of the in-groups to reconcile the potentially competing implications for defining the social self” (p.89).

This may mean that the participants reorganised how they saw themselves. Their pain identity did not always match with others version of a pain identity; either those in support groups or those who were not involved in paid work because of their pain.

People who understand that there are multiple complex identities, are often able to balance the conflicting goals of each and meet the needs of both of their identities successfully (Roccas & Brewer, 2002). This may mean that the participants in this project had a greater understanding for the complexity of social identities. There has been little research into the relationships between peoples’ multiple identities and how these are enacted in the work setting (Roccas & Brewer, 2002; Shen & Dumani, 2013).⁹ This is especially relevant in terms of how a pain identity and a worker identity are managed in the work environment.

As argued by Charmaz (1995) (as cited in Howard, 2000) “many of the tactics they used to accomplish one goal conflict with the accomplishment of the other” (p. 379). This presents a challenge as the goals of different identities may conflict and if the task is not possible, women in chronic pain must ask for assistance in order to complete tasks at work (Howard, 2000). However, succumbing to the pain identity and letting it become the salient identity at work is considered as failure and this was not reported as an option for women in this

⁹ There is a literature on parent identity and worker identity (e.g. Daymon & Surma, 2012; James, 2009; Johnston & Swanson, 2007), but the focus of this thesis is on pain identity and worker identity.

project. Therefore the pain identity cannot be shown for too long. When struggles such as this arise, women in pain must decipher[ing] the authentic identity” (p.386, Howard, 2000) and for them this must be the worker identity.

Clashing Identities and the Health System

Those experiencing chronic pain are often treated sceptically by many medical professionals. There is often a fear that those seeking medical treatment for ongoing pain are drug seekers and do not need assistance in order to manage their daily lives (Crowley-Matoka & True, 2012; Werner & Malterud, 2003; Werner et al, 2004). Because of the fear of opioids and addiction, pain is one area that is not being medicalised in the same way as other areas in medicine. Because of the invisibility of pain, it resists being objectively measured which may be one reason why pain management is going in the opposite direction and not being medicalised in the same way as most other fields in medicine. Many other fields are being medicalised, and treated biologically and chemically, however, this is often not the case with chronic pain (Crowley-Matoka & True, 2012). As argued by Crowley-Matoka and True (2012);

The fear with opioids is always that the patient will respond too well, will want them too much - and to do so immediately reinvigorates doubts about the authenticity of the illness itself... Yet here what seems striking is instead a persistent failure of understandings of pain (and, in a deeply related vein, of addiction) as disease to take fully hegemonic hold. In this context, opioids are simultaneously - and inextricably - both imperfectly medicalized and ineffectively medicalizing (p. 705).

Because the worker identity is the salient identity for participants in this project, there are complications for how they manage other aspects of their lives.

In order to focus on work, the types of medication that they take to treat their pain are significantly limited due to the side effects that the medication will cause as they often disrupt productivity at work.

When women in pain are engaged in full-time work outside the home, the hours that are available to seek medical treatment are limited as well. From my experience, in Waikato, New Zealand, there is also a lack of access to other forms of support when the patient is involved in full-time paid work. For example, there is the assumption that if a patient is involved in paid work that the pain that they experience cannot have a significant effect on their life, therefore the treatment options available to them are limited. In this way the health system delegitimises the pain that these women experience. This is an issue for women who are working because medical professionals cannot understand how they are in paid work as well as in need of assistance because their pain is significant. If someone presents as a functioning, employed member of society it is assumed that they do not need treatment and assistance which is an incorrect assumption. Therefore, the health system and the workplace threaten the women's multiple identities as medical professionals assume that an individual cannot be a worker and experience chronic pain. This further delegitimises women's position within the health system because their pain is not acknowledged and little support or assistance is offered to them.

When someone does not play the sick role, it is assumed that the person is disingenuous and may mean that they do not get the help that they need (Werner & Malterud, 2003). In order to get assistance, an individual must play the role of a credible patient (Hancock, et al., 2000; Werner & Malterud, 2003). Women in this project do not fit into the mould in which medical professionals expect. In order to

be taken seriously women must take on a sick and pained identity while at the doctor's surgery, which creates challenges because of the very notion that they are employed. If they present their pain identity within the health system they must give up their salient worker identity which may change the importance of its role in their life over time. However, because they have a worker identity, it diminishes the fact that their pain identity exists.

The opposite is true for the workplace. At work certain behaviours are rewarded; these are different from the behaviours that are required within the health system. If these women disclose their pain identity at work it could be perceived that they are incapable which may mean that they are not given advancement opportunities. Roberts and Donahue (1994) discuss that meaningful differences should be found in the different ways that people behave depending on the role that they have in different settings. For most people, acting out the expected role in the appropriate setting, can ensure success in each of the roles that they undertake. However, when the goals of each identity clash, this can be difficult to achieve in practice.

Woman who are living and working with chronic pain do not fit in a predetermined box within the health system or the workplace. The multiple identities they have clash and these women must balance the goals of each on a daily basis. This clash means that these woman must manage their lives where little help can be accessed from the public health system or at work and they must make trade-offs every day. They must ensure that they balance the goals of each identity so that their pain does not become unmanageable and influence their well-being, therefore negatively affecting their work. At the same time they must not internalise the persona of a sick person so that it affects their worker identity

therefore effecting their work and disadvantaging their careers. They must make strategic decisions at work about what tasks to undertake and who to ask for assistance in order to balance the goals of both of these identities in the workplace.

Clashing Identities and the Failure of the Research Diaries

The daily diary activity forced the participants' pain identities and worker identities together in ways that they have intentionally tried to keep apart. The more an individual thinks about pain the more pain they feel (Jackson, 2011), which will have an effect on their work. By paying more attention to the taken-for-granted aspects of how pain effects work, keeping a daily diary may have brought pain to the forefront of these women's consciousness and lives. It may have highlighted their pain and meant that they enacted their pain identity more often in the workplace and made the two identities more entwined than they usually are.

Because their pain identity is less salient in the workplace, these women often do not place great emphasis on this identity while they are at work. However, writing about their experiences of pain may have made their pain identity more salient than it otherwise would be. This may have also made them experience more pain within the work environment. When participants attempted to write in the daily diary and considered how pain had affected them at work, it may have disrupted their ability to use work as a distraction from pain. This disruption to identity salience may have influenced the completion of the daily diary activity.

The process of writing a daily diary may have made these women consider the ways that pain holds them back. Considering the ways in which pain

influenced their lives may have made them reluctant to complete the diary activity. During the interview process, some of these women had not previously considered how much their pain held them back. This may have been a problem as they may not have realised that writing daily diary entries would be challenging until they came to write at the end of each day.

Clashing Identities and Coping Strategies

At times women in chronic pain struggle with feelings of failure. Because of their experience of pain and the way they have been treated by people, women in chronic pain are scared of being accused of laziness or questioned for their perceived lack of achievement. For Helen, this was the fear of being identified as “that crippled girl” at work. Such women are too scared of ever using their pain as an excuse that they rarely let it be the reason; so they seldom rest or take a break and this often does them a disservice.

They strongly believe that their worker identity is their most important identity and that their work should be prioritised. Because of this, they believe they should have accomplished more at work and in their careers. They place huge pressure on themselves to achieve in the work environment. Embracing the salience of the worker identity is therefore vital so that the pain identity cannot win and failure is not possible. The pain identity must also be acknowledged so that pain does not become overwhelming and make work impossible. Therefore, these women do not deny that pain affects their lives and work as it must be taken into consideration in order to succeed at work. However, they are prepared to pay the price of pain and not let it take over because the worker identity is more important to them than the pain identity. Chapter Four discusses the strategies used by women in chronic pain to maintain the salience of the worker identity.

Chapter Four - “Faking Normality is Like Black Magic,

There is always a Price to Pay”:

Strategies Used by Women to Maintain Worker Identity

The Priority of Worker Identity

My research participants were all significantly stretched by the demands of work, family and personal life while at the same time seeking to successfully manage their invisible chronic pain. In the workplace, they wanted to be treated the same as everyone else, but their disability often did not allow this to happen easily. Ignoring their disability or significantly minimising it would have detrimental effects on their health and wellbeing, in turn negatively affecting their work. As Helen put it, “Faking normality is like black magic, there is always a price to pay.”

The participants have developed a range of strategies to maintain the salience of their worker identity while managing their pain. Some of these strategies are echoed in the literature on chronic pain, some in relation to work and others solely in relation to managing pain conditions. The themes in the literature centre on the workspace, having a supportive employer (Oakman et al., 2016) scheduling work and managing life outside of work (Kralik et al., 2004; Nes, Ehlers, Whipple, & Vincent, 2013; Doran, 2014). The purpose of this chapter is to outline the strategies that participants use to maintain the salience of their worker identity.

The participants discussed the strategies they use to balance their worker identity and pain identity.¹⁰ Through thematic analysis, I identified seven similar strategies that were reported by the participants. The strategies the participants used are modifying the work space, managing their workload, establishing and maintaining positive relationships with employers, developing supportive relationships with colleagues and family, receiving and asking for help when required, disassociating themselves from pain and managing life outside of work.

Workspace

The first strategy that women in chronic pain use to maintain the salience of their worker identity is modifying their work space. The workplace set-up has a direct impact on these women's ability to do their jobs. All participants indicated that their workspace significantly affected their day-to-day work. The ability to adjust their workspace was something that impacted their pain and made it possible for them to work effectively. Participants reported on a range of different workplace modifications that they had made. Amy mentioned that she had altered her work station to make it more comfortable. "I've got a big screen there that I've adjusted with books to fit so that when I'm like this, it's at the right height." Devangi felt privileged to not only have a large desk, but also to be able to bring in small items from home which helped manage her pain. She utilised some of the equipment after work which she found beneficial as well. "There is also a massage chair in the reception area and a spa bath/sauna which I am welcome to use in the evenings." Modifications to workspaces is also something that is discussed in the

¹⁰ This chapter has been edited back by one-third due to word count limitations. This means that the voice of each participant is not heard in each section.

literature on chronic pain and work (Antao et al, 2013; Munir et al., 2005; Oakman et al., 2016; Rakovski et al., 2012; de Vries et al., 2012).

In addition to making modifications to their workspace, participants also identified the benefits of having their own office. An individual office enabled some of the women to use their own space when they needed to rest. For example, Amy mentioned she “was lucky that I had an office to myself because I would go and lie down.” By contrast, not having the ability to set-up the workspace to meet their needs caused significant difficulties for participants. This challenge was exacerbated when the workspace was shared because there was less flexibility in the way the workspace was set up. The responses indicated that employees can reduce their pain and be more effective at work if they can control their workplace set up. The flexibility to move around and utilise the space was advantageous. For instance, Judith stated that she would be unable to work if she was confined to a chair all day. She mentioned that “being able to stand at work” was great because “sitting is the worst thing I can do.” Likewise, Helen also appreciated the flexibility of being able to stand when she needed to noting that, “if I wanted to I could sit, if I want to stand I could stand.” This was also echoed by Jackie who struggled with sitting continuously. Although her job required her to sit for long periods, she developed a solution with the assistance of an Occupational Therapist. “My workplace has improved...with an Occupational Therapist assisting with chairs and pillows to help...which was a major issue beforehand, with sitting [for] a length of time.”

Being able to move around the workspace was important, whether this was moving around the immediate workspace or utilising the wider work area. Judith mentioned how important being active was in enabling her to stay at work and

remain productive. “I generally find that the more I move the more able I am to keep moving.” Most participants found that movement was beneficial, however, Amy preferred not to move once she was in a comfortable position. “I hear that you’re meant to get up every ten minutes, you know, but I’ve just got comfortable.” Participants who did not have the flexibility to move around noticed that this caused them more pain. Amelia, who had a frontline administrative position found that “sitting for a long time does make things a bit worse.”

Another reported way of managing the workspace was by opting to work from home. This practice provided other benefits for participants experiencing chronic pain, including the ability to change their work location in order to minimize their pain. Amy found this helpful and often moved location, “sometimes that’s at my desk but if it’s a bad day, it’s on my bed.”

Many of the participants did not share the reasons why they had set-up their workspace in a particular way with their colleagues. This was often due to the stigma and discrimination that they had experienced in the past. At times, this meant they re-purposed their environment to suit their needs. Amy mentioned a setup where she used the type of work and the people she worked with as a way of creating a work space to meet her needs. “Well for the young people I would have a bean bag which would also mean that I could lie on it, or have a chair set up.” Using objects present in the work environment was another strategy used by some of the participants, especially those who had little control over their work environment. Judith particularly noticed that she leaned on the equipment and counters when the pain became difficult to manage.

Many of the participants used specialist equipment to minimise the pain that they experienced. Using specialist equipment to minimise pain is a strategy

that is discussed in the literature and is explained by Oakman et al., (2016) as a strategy that can be utilised to assist people in chronic pain to counteract some of the negative effects of paid work. Using special equipment can be a challenge because each employee will have different needs and these must be addressed on an case-by-case basis (Oakman et al., 2016). This challenge became evident when discussing the use of specialist equipment with the participants. Jackie worked as a nail technician and over time had purchased different pieces of machinery which improved her ability to work despite her chronic pain.

“I also have purchased things like good expensive machinery to make the stress less on my wrists, like the e-file, I had to get a good one that would not vibrate as much in my wrist, it also assists in filing, so I have to hand file less.”

Some participants utilised other pieces of equipment that assisted them in their work; such as special chairs or standing desks. The need for special equipment can be an issue as employers do not always understand what is required for employees who experience pain at work (Messing, 2014). This is often more of an issue for people who experience invisible disabilities such as chronic pain as there is no outward sign that they need special equipment in order to be productive at work (Kralik et al., 2004). Some of the participants discussed having to advocate for their own needs. Amy drew attention to this when she discussed how the invisible nature of chronic pain means that the individual has to communicate what they need, “at the end of the day you have to manage it and no one else can do it for you.”

Accessing equipment can come at a cost to women in chronic pain as in order to access equipment, their condition must be disclosed to their employer.

This may be an issue for those women who do not want their employer to know about their chronic pain (Oakman et al., 2016). Some women counteract this by purchasing special equipment themselves. For example, Amy recently purchased a new lazy-boy chair. “Yeah I just splashed out on a Danske Mobler chair...yeah it’s amazing! It was pretty expensive...it means...that without using any muscles I can change the positions, so I’m not squashing on one place or anything.”

Purchasing one’s own equipment is an option that is only available to women who have the financial means to purchase the equipment they need, creating a division between those who can afford special equipment and those who cannot. For instance, Amelia spoke of how difficult it was for her to handwrite notes at meetings, only to digitize them later. She could not afford to purchase a laptop and her employer did not see purchasing this piece of equipment as a necessity.

More generally the use of technology and the flexibility that this creates has made a substantial difference to participants and their ability to work from different locations. For Amy this means that she is able to work from home. She is a strong advocate of how technology has enabled her to participate in the paid workforce, “technology helps heaps as well, it’s changed the world.” She commented on how beneficial it is to attend meetings online and stay in contact with her colleagues.

Technology can be used to assist women in chronic pain to attend conferences that they would otherwise not be able to attend. Many people with chronic pain struggle with travel due to the potential pain it can cause. Helen commented on how she had missed important conferences that were relevant to her job because of the travel required. The use of technology has the potential to

assist women in chronic pain to participate more fully in the workforce so they are not excluded from opportunities that would be beneficial to their careers.

Managing Work

The second strategy that women in chronic pain use to maintain the salience of their worker identity is to manage their working lives carefully. One of the key features of this strategy is building flexibility into their work schedules. This management includes the scheduling of tasks and when breaks are taken. Amy argues that having “heaps of freedom” has been important for her and was a key determinant in succeeding at work. She also discussed how moving to more flexible schedules in the future would benefit those in chronic pain.

“I hope for the future...how they talk about flexi-hours...and letting people work from home...I think that will open the door for people with chronic pain much more...cause we never under work...we’re hard workers...we’re almost over compensating...so they could trust us.”

Autonomy over individual work schedules was also important to other participants. Having control over the type of work that is completed was important as well. This was frequently mentioned by Amelia who spread difficult tasks over a period of time. “If I know I’m having to do a lot of writing, spreading it out over a period of time [is beneficial].”

The timing of work was important and although different participants mentioned being effective at different times, each appreciated the flexibility to do cognitively-demanding tasks when they were most able. As suggested by Amy “I work at my computer desk, in [the] mornings...because that’s when I am at my best.” This flexibility was also useful in regards to the hours worked as some participants changed the number of hours they completed depending on the day.

The flexibility to take breaks when required is important for managing the work day. Some participants had more flexibility to decide when breaks could be taken; but regular breaks were important to manage the demands of participating in the paid workforce. Helen took regular short breaks throughout the day, as this gave her the opportunity to move around which helped her pain and assisted her to focus on her work. “I’m sure people here think that I have far too many cups of tea...tea is an excuse to get up and walk around...I tend to have a shorter lunch break...and get a cup of tea in between things.” When participants did not feel comfortable to communicate that regular breaks were required, they would find a reason to excuse themselves to take a break. Amy had excuses that she would use so that she did not have to explain her chronic pain, “I’ve just got to ring home, or I’ve just got a bit of work to do and I make some random excuse to go back to the motel room...and lie down and then go.” The flexibility to manage an individual’s work schedule is discussed in the literature on chronic pain and illness (Antao et al., 2012; Oakman et al., 2016; Rakovski et al., 2012). This enables people in chronic pain to manage their work and pain so they are able to complete tasks when they are most able as this makes them more productive in the work environment.

Many participants mentioned the different strategies they used to pace themselves throughout the work day. These strategies included organising days where less activities or meetings were planned, scheduling a decent amount of time between clients or ensuring that work is completed well in advance of deadlines. Rakovski et al., (2012) discussed the importance of pacing in assisting women in chronic pain to manage their pain at work. Leanne was also an advocate of pacing and discussed this often throughout the interview. Jackie also found this

helpful and would ensure that her workload was manageable by scheduling a reasonable number of clients.

“I do make sure though if I have a late night client, I get an afternoon sleep-in. I also make sure to give myself an hour break after each client, where I use a TENS machine or do some gentle wrist exercises.”

Participants found that booking their own travel arrangements was useful as travel can be problematic for women experiencing chronic pain. Those in chronic pain may need to check access to the accommodation and the furniture in the room to determine whether it is suitable. Amy mentioned that booking her own accommodation close to the venue was important so that she could rest if she needed to. She also stayed the night before the conference so that she was not in too much pain before it began. “I do that and even if the company is not going to pay, there’s no budget for me to stay the night before, sometimes I choose to because it’s easier for me.”

Balancing the volume of work that needs to be completed can be a challenge. Amelia has found that this can be difficult because people put pressure on her to complete specific tasks. “I’m not good at saying no, so it’s like, ‘yup, I’ll get that done’ and then I don’t think about the consequences til later.” Sometimes women place this pressure on themselves. They can also put pressure on themselves to be as efficient as possible, as Helen found, “the temptation is that you overload yourself because you don’t want to make two trips.” Managing tasks and workloads so that these women do not cause themselves more pain is a strategy that is advocated by Kralik et al., (2004).

Employer Relationship

Establishing and maintaining a supportive relationship with their employer was the third strategy that women in chronic pain used to maintain the salience of their worker identity. Devangi mentioned that having a supportive boss had motivated her to put in extra effort at work. Allowing women with chronic pain to take leave when needed was one way an employer could be supportive and this was discussed by some of the participants. This could be planned sick leave for medical appointments or sick leave taken at the last minute due to the unpredictable nature of invisible chronic pain. Annual leave was utilised as well when participants had used their sick leave entitlements. Amy appreciated her employer's flexibility in this regard. "They have always been very good about when I can't do stuff...they don't say that your leave should be for anything...I take my leave when I need my leave."

Another important aspect of having a good working relationship was the employer not making assumptions about the limitations of the employee. Two of the participants felt strongly that they did not want to be excluded from promotion or other opportunities because of their condition. Amy mentioned appreciating this aspect of her relationship with her current employer.

"I just say I'd like leave at da da da and [they] go, do whatever I need to do and I like that...even when they know what's been going on, they don't baby me. They say, okay, you're back, can you do this stuff? Let us know if you can't and I like that cause I don't want to be baby'd or miss out on opportunities."

Participants mentioned that being honest with their employer about their health situation made the working relationship a positive one. This meant any

issues could be resolved and special equipment or work arrangements could be organised. Amelia contrasted her experiences between her previous and current employer and appreciated the relationship she had with her previous boss whom she had discussed her needs with. Being open with her boss meant they could work out solutions to the challenges together. “Although I did have a previous manager who I was quite close with and she knew quite a bit about me...um, my current manager, probably not...so much.” The literature also discussed the benefits of having a supportive employer in assisting women in chronic pain to remain in the paid workforce (Antao et al, 2012; Oakman et al., 2016; Ordóñez-Hernández et al., 2015; Rakovski et al., 2012).

Another way that the employer can be supportive was mentioned by Leanne where she discussed the flexibility of the families that she worked with. “I haven’t had a day off in a long time...because I’ve got such...flexible families...they are very understanding and are quite happy to adapt.” Becoming a contractor or setting up a business was another solution to the issue of managing the working relationship with an employer. Two of the participants had found the flexibility that this offered was beneficial.

Relationship with Others

Developing supportive relationships with co-workers and family was the fourth strategy used by women experiencing chronic pain and was important in assisting them to maintain the salience of their worker identity. Amelia mentioned that support from her mother was invaluable and one of the most important factors in her ability to remain in the paid workforce. Richardson, Ong and Sim (2007) discuss the importance of family support in assisting women in chronic pain to manage their lives better (Ordóñez-Hernández et al., 2015). Devangi mentioned

that she is appreciative for the help and support she receives from her partner, “I am truly blessed to have the most understanding and supportive partner I could wish for. I find myself wondering how I managed all those years on my own.”

Supportive colleagues were an important factor in managing pain and maintaining the worker identity. Support from colleagues was discussed by Oakman et al., (2016) and was seen as an important factor in assisting people in chronic pain to be productive at work. Although the participants often mentioned this assistance in relation to physical tasks, colleagues offered emotional support as well. Amelia appreciated this support from her colleagues, “I don’t think the managers actually notice, it’s my colleagues...I’m downstairs in the open plan office and so it’s my colleagues that think, oh, you’re not having such a good day today.” Sharing experiences with colleagues and therefore receiving support depends on whether women in chronic pain are comfortable with their colleagues knowing of their condition and how it affects them at work. Because of some negative experiences, Amy does not always disclose her chronic pain to those she works with. “It’s just a self-protection mechanism where I don’t necessarily talk about it with the people I work with.”

Participants mentioned that some of the most useful support, was the support received from other women in chronic pain. This was consistent with the literature discussing how useful it is to talk with others who share illness and pain experiences (Haufe, 1997; Hoppe, 2013). Leanne discussed how much she appreciates the support she receives from a client. “One of the...care kids I have, his mum has CRPS too...that’s how I met her...she just messaged me this morning she was like, I’m sore today, Carter’s staying home...and I’m like yep, totally get it.”

Receiving and Asking for Help

Receiving or asking for help when required is the fifth strategy that enables women in chronic pain to maintain their worker identity. This can be challenging as participants often struggled to ask for help because they did not want to disclose their condition to their colleagues. Some participants found it easier to ask someone they did not know for assistance.

After experiencing a wrist injury, Amelia found many people offered to help her with heavy lifting. However, after the visible cue had been removed, colleagues often forgot about the injury, or that she experienced other chronic pain and did not offer the same level of assistance. This became a challenge because colleagues did not always know “how it affects you and so...sometimes its back to you to kind of ask people to help you...which is a bit harder.”

Accepting help when it is offered is more difficult for some women than others. Helen often did not accept help when it was offered but sometimes she would regret doing so, “I’ll be like ‘I really should have let that person carry that [laughs] and then I might not feel like this.’” At times participants asked for help when they were in pain or there was a difficult task they were unable to complete. If they asked for help once it may be assumed they always need help with similar tasks. As Helen mentions:

“They’re like you shouldn’t be doing that cause you’ve got a bad back, and I’m like I can lift a chair right [laughs]...the days that I can’t...lift a chair I won’t...the days that I can lift a chair, I will...I can self-manage that thanks...and I don’t need you infantilising me.”

For women in chronic pain in supervisory roles, delegating more difficult or physically demanding tasks was particularly important, especially during times

when more pain is felt. Judith found this beneficial, as “being able to delegate some more physical duties when pain is bad” was useful so pain can be avoided.

There were other creative ways that participants sought help when it was needed. Amelia discussed some of the ways in which she sought help to take notes during meetings as handwriting was a task that she found particularly challenging.

“There’s like little things that I try to do to help myself...if I’m going to a meeting with a couple of other people and I know that minutes or notes need to be taken...I’ll try to creatively get out of doing that.” [She was prompted to continue]. “Sometimes it’s just the truth, you just say hey, I’ve got this wrist injury...other times you just kind of go, you know, bags not.”

Disassociation

Another strategy that participants use to maintain the salience of their worker identity is disassociating themselves from the pain that they experience.

Disassociating themselves from pain assists participants to focus on the work that they need to accomplish throughout the day. As mentioned in Chapter Two, deliberately avoiding thoughts about pain can also assist individuals to feel less pain (Jackson, 2011). Amy discussed using disassociation to manage the pain that she felt. Other participants described their use of this technique. Helen mentioned:

“Sometimes I choose to not let it, not attend to it, so when I’m working with the student and I’m in the moment with them, it’s not that I’m not in pain, because at any point if I someone said are you in pain? I would know that I was.”

For women in chronic pain, paid work can be used to disassociate themselves from pain. Several participants, including Helen, mentioned that having a cognitively challenging job was beneficial as their attention was focused on their work. “Full-time work is quite good for that because I’m actually distracted for several hours a day and I get to feel vaguely like a human so...I’m just not noticing the pain.”

Although work itself can be a distraction, other smaller tasks were often used to distract the participants from their pain. As discussed in the literature, distraction can be utilised as a technique to control pain (Jackson 2011; Kralik et al., 2004; Oakman et al., 2016). The participants were committed to the work that they did and saw this as important. Leanne discussed the difficulties she faced but was committed to her work. “It becomes mind over matter... I’ve gotta do what I’ve gotta do...and that becomes the bigger picture.”

Undertaking difficult and physically demanding tasks has the potential to cause significant pain. This must be considered by women in chronic pain as they decide whether the task is one they want to undertake and therefore accept the potential consequences. This is further complicated by the unpredictability of their bodies, because they are often unsure whether undertaking a task will cause pain. This was discussed by Helen. “With pain there’s probabilities, you know, like, will I get away with this, will this just cause a bit of a twinge or will this cause a full on migraine, and will I not function for a week?”

Women in chronic pain may choose to ignore pain if there is something they want to participate in or attend. Pain is often ignored when women are stressed or trying to meet important deadlines as well. Overriding the pain mechanism assists women in chronic pain to achieve work-related goals. Amelia

discussed making poor decisions when managing her own health and wellbeing during times of stress at work. “I tend to, obviously neglect my own needs in that time...I’m really bad at taking lunch breaks.” Amy had more awareness of the effect that work events would have on her body and would not make plans for that evening. “If I work all day cause it’s something I really want to do or it’s a conference I want to sit at, then that evening’s just not going to be, it’s going to be a write-off.”

Women in chronic pain may choose to push through their pain because of their desire to be perceived as normal (Shilling, 2008). Helen made reference to this on a number of occasions “I just do things that I probably shouldn’t do...because then I’m normal and then no one knows, so then I just crash when I get home.” This idea was also discussed by many other participants. Devangi mentioned that her pain does not change at work or at home so she chooses to be employed. “I am in pain if I work or if I stay at home, so I choose as close to normality as I can manage - if that makes sense.”

Although women in chronic pain use different strategies to disassociate themselves from their pain, once they think about pain, it becomes difficult not to focus on it. This was expressed by Helen during the interview:

“Once I’ve noticed it gets worse and worse and worse...acknowledging the pain is there makes it worse...so I need to do something to get distracted [Researcher: So what effect does that have, like, on work?] Ha! Now I’ve mentioned it, now it’s sore...[Researcher: Well probably an interview about pain is probably making it worse too] It possibly is [laughs].”

Managing Life Outside of Work

The final strategy women in chronic pain use to maintain the salience of their worker identity is managing their life outside the work context. As work takes priority, their non-work lives are affected because they focus on being capable of attending work. Other activities must be planned around looking after themselves so they can be productive in the work environment (Doran, 2014; Kralik et al, 2004; Seear, 2009; Oakman et al., 2016). Undertaking paid work can have negative consequences for women who experience chronic pain. The participants all spoke of how they managed their lives outside of the work environment so that they were able to continue in paid employment. Helen discussed how full-time employment and appearing “normal” had consequences for life outside of work. “Faking normality is like black magic, there is always a price to pay.” Managing the conflicting demands on their time and energy was often negotiated through trial and error as not looking after themselves had detrimental effects on their health and wellbeing, thus negatively affecting their work. Amy discussed how she had learnt to manage her life by making better decisions over time. “It is taking control of those things and I’ve made mistakes. I’ve done it and gone ugh...or I re-make the mistake a year later and I go damn it.” She described managing the competing demands on her time and energy as “a constant juggling act.”

Balancing pain management and work also places extra pressure on women because of their traditional roles and responsibilities in the home (Ashbring, 2001; Mijoo, 2009; Ordóñez-Hernández et al., 2015; Moss & Dyck, 1996; Richardson et al., 2007; Seear, 2009). As argued by Seear (2009), chronic illness can be seen as a third shift. Women who are employed in paid work outside the home must manage their work and domestic responsibilities as well as

managing their health and the many different demands that this places on them. It can become exhausting as the task of managing their health is never complete. As Amy mentioned: “I think you’re forever practically putting that into where you go on holiday, where you work, what you do, how am I going to do this, so there’s always part of your brain navigating for you.”

If women in chronic pain do not engage in self-care, it is not possible for them to meet the demands of paid work. By taking the opportunity to rest at home, their work days become more manageable. The need to rest came as a surprise to some of the participants. As Amy mentioned, “the more pain has become part of my life, the less energy I have...and that’s something I never fully appreciated before...how tiring pain is.” Experiencing fatigue as a result of pain is discussed by Wilton (2008). Helen mentioned this as well and discussed how getting enough rest on the weekends was important. The importance of rest was also discussed by the other participants, some of whom went to bed early when necessary. As Leanne said, “busy days mean that I am in bed at 6 o’clock.” Some participants noticed an increase in pain when they did not rest. This became noticeable for Amelia as she felt more pain when she was stressed and tired. “When I get stressed I get fatigued...and when you’re fatigued you feel a lot more pain...and then you can’t sleep cos you’re in so much pain and the cycle continues.”

Taking annual leave when needed to recover from periods of pain or stress is another strategy that is used by some of the participants. Helen used this strategy when the pain became unmanageable. “Occasionally it just builds and builds so I’ll take some annual leave and have a little ‘codeine holiday.’” Amelia planned to utilize this strategy in the near future. “I’ve got enough annual leave

and I feel like it's time that I should probably use it...hopefully it's going to...help me get through the next couple of months.”

Most of the participants discussed prioritising what was important and scheduling time for activities they valued. These activities differed between participants but included spending time with family, undertaking activities they enjoyed or attending important events. Jackie found that she prioritised rest and scheduled her time around activities if she had events planned. Amy mentioned that she would often consider:

“What do I enjoy the most and what can I miss out on...so I don't miss out on the good stuff as well... I've made those mistakes too and it was just work...what's the point of putting up with it if you don't have enjoyable stuff as well.”

Balancing the competing demands on their time and energy is important in terms of managing life outside of work. Leanne found that listening to her body was beneficial. “Yeah, it all comes down to getting that balance...knowing your limits...being flexible...and also understanding your body...and being okay with that.” Taking life at a slower pace allowed some participants to better manage their work and daily lives. Devangi used the story of the tortoise and the hare to illustrate how taking life at a slower pace had enabled her to achieve more at home and at work.

Limiting the number of social functions that they attended assisted women in chronic pain to rest on the weekend. At times this was intentional and no social engagements were planned. However, there were times when plans were cancelled as the participants were in too much pain. Although not attending social

functions could be a negative consequence of being involved in paid work, Devangi appreciated the time and energy she did have.

“Going to work and earning a salary definitely made me feel like I was contributing again - but now with work I have no energy to do anything else, so yes my personal life has taken a knock in some ways, and in others we appreciate my one day off a week that much more and make the best of it.”

The Divide Between Rich and Poor

The most significant difference between the participants was their financial ability to implement these strategies. This was often evident in relation to purchasing specialist equipment when needed. When an employer did not pay for equipment that was required, participants paid for the equipment themselves. This solution has the potential to create inequalities as people who could afford to buy required equipment may have more opportunities in the workplace. Being able to afford the equipment that is needed influences whether some women in chronic pain are able to be employed in full-time or part-time positions or potentially whether they are able to be employed at all. Some participants did not understand that there were others who could not afford to buy the equipment that they needed because of financial constraints. As Amy mentioned, “If you are sore do something about it. Don’t sit for weeks thinking gee I’m sore, try other things, experiment. Ok, you might buy something, a cushion that doesn’t work, but donate it.” Having the financial means to book their own travel arrangements and accommodation for conferences or meetings is also beneficial for those who can afford it. This is not something that all participants have the financial means to do, especially those working in part-time positions.

In this chapter, I have outlined the conclusions generated by a focused thematic analysis. Taking the words of what the participants told me, I looked for the ways they sought to maintain the salience of their worker identity in the face of their chronic pain. In the next chapter, the concluding one, I return to the research questions posed at the beginning of the thesis to highlight the price of pain in the workplace for these women.

Chapter Five - The Price of Pain:

How Women with Invisible Chronic Pain Sustain their Worker Identity

Work and the Power of Pain

The women I encountered in this project were all strong individuals with positive attitudes. They could be called ‘kick-ass’, strong women who push through debilitating pain in order to achieve their goals. They value their identity as professional workers very highly. They believe strongly in the work they do and that they are making a positive contribution to the lives of others. Work not only takes the lion’s share of their time and energy but it extracts a significant price from them personally because they often experience more pain as a result of their involvement in the paid workforce.

My participants were a self-selected voluntary sample of women with the motivation and opportunity to contact me and provide answers to my questions. These women were also able to influence the organisation of both their physical work environment and their work schedule. All had personal characteristics and values which placed significance on work. Employment was a means to gain personal and financial autonomy. They were also women who had flexibility in their home environment which allowed them to rest, recover and go back to work. Not all women with a chronic pain disability have these characteristics and opportunities. Many are unable to be involved in paid work at all. Therefore, the insights arising from this project are applicable primarily to a particular type of women with a chronic pain disability in a particular type of work context. For these women, being able to suppress their pain identity at work, making it less

salient, means that there is a sense in which their pain is not given “its power” (p. 155, Jackson, 2011).

These insights arose out of a consideration of three sets of research questions. These questions, as introduced in Chapter One, were:

1. What is the experience of women in chronic pain who are involved in paid work?
 - a. What are the challenges of experiencing chronic pain and being involved in paid work?
 - b. What sacrifices are made because of chronic pain?
 - c. How does the invisible nature of chronic pain (as a disability) contribute to the experience that women have at work?
2. How does suffering chronic pain force women to relate to their ‘space’ differently in the workplace?
 - a. What aspects of the traditional work space create challenges for women in chronic pain?
 - b. How do women experiencing chronic pain reorganise their workspace to meet their needs better?
 - c. In what ways do workers with chronic pain re-orient their bodies in the workplace?
3. What kind of strategies are put in place to enable women to thrive in the workplace?
 - a. What tools and/or equipment make it possible for women in chronic pain to undertake paid work?
 - b. What kind of help and support do they need from others?

- c. What kind of arrangements do they put in place to ensure they do not fail?

Despite a significant change in methodology with the solicited diaries not eventuating, the research still focused on these initial questions. In addition, the research ended up exploring an issue that was not present in the initial questions, this was the concept of identity and the significance to the participants of their worker identity in relation to their pain identity. The next three sections discuss the answers that have emerged to the research questions, noting how identity has also emerged as a relevant concept.¹¹

Question One: Women Experiencing Chronic Pain in the Workplace

The participants in this project shared the frustrations and challenges they experienced while remaining in paid work. As I noted in Chapter Three, balancing pain and the demands of paid work was something that many participants found challenging. Work often took priority because of their desire to maintain the salience of their work identity. However, the constant juggling act could be difficult to manage and women in chronic pain used a variety of strategies to ensure they were productive at work.

All of the participants had developed creative strategies to be effective at work. These are set out in Chapter Four. As a consequence of these creative strategies, others may assume that their pain is not real or that their disability is not significantly affecting their lives. Additionally, as I noted in Chapter Two disclosing an invisible disability may lead to stigmatization or discrimination.

¹¹ How the answers emerged did not always follow the neat sequencing or categorising reflected in these questions and sub-questions. For example, the sacrifices made by my participants referred to in Question 1b will be discussed below in relation to Question 3 because they better fit the topic of Question 3c.

Participants may choose not to disclose their disability to their employer if they think that they may not be believed or that their disability may not be taken seriously.

The participants in this project did not want to be treated differently to their colleagues or be given preferential treatment. This is an example of their worker identity being given priority over their pain identity. For some, as I discuss in Chapter Two, prioritising this had influenced whether they chose to disclose their chronic pain to their employer or colleagues. While there are many reasons why women in pain may want others to know about the extent of their pain, they often do not talk about their experiences because they do not want to be seen as constantly complaining women. Another reason was that some participants did not want to burden their colleagues by not carrying their share of the workload.

I also observe in Chapter Two that participants were often offered unsolicited advice. Although well intentioned, this advice can be challenging to listen to because of the nature of the advice that is given. It can often be seen as patronising, assuming that the person experiencing chronic pain has not thought of attempting to manage their pain in the suggested way. As it is difficult to comprehend how other people experience chronic pain, it can be difficult to give helpful advice.

The unpredictable nature of chronic pain makes it difficult to manage at home and in the workplace. It can be challenging for those who work with people experiencing chronic pain to know when they may need support and when they can manage on their own. This is further complicated by the fact that the level of pain experienced can change on a daily basis. The ability of chronically ill women to cope with pain changes as well and can depend on their emotional state at the time.

Question Two: Relating to Space in the Workplace

Because of the non-appearance of the solicited diaries and associated photos, it was not possible to examine the issue of space in the workplace to the extent anticipated. However, Chapter Four does contain some material that relates to this issue. All participants mentioned their workspace as something that significantly affected them in their day-to-day work. Reorganising their workspace was more difficult for some participants than others. This was often because the workplace is the domain of the employer who has control over it. When a participant shared her workspace with others, it gave her less flexibility to set up the workspace in a way that met her needs. Having some control over the way in which the work space is set up means that pain can be reduced and the worker can be more effective.

Participants appreciated having space at work to re-orient their bodies. This could be in relation to moving to more comfortable positions, or moving around in space. Autonomy or flexibility over individual work schedules was also important to participants in managing their work. Another significant factor was being able to pace daily activities as this helped them to manage their pain and maintain the salience of their worker identity.

Question Three: Strategies for Thriving in the Workplace

I point out in Chapter Three how participants experience a clash of identities, particularly between their pain identity and worker identity. The topic of identity does not appear in the initial research questions for the project as the subject arose in the course of developing an understanding of the context and meaning of the strategies used by participants to thrive in the workplace. They choose to make their worker identity the most salient one in the workplace. In order to achieve this, seven main strategies have been used by them. In Chapter Four, I draw on

participants' own words to describe each of these strategies. Note that not all participants used every strategy, though two did and the rest used most of them. However, even if it had been discovered that a strategy was used by only one participant, it would have been an important finding as such a strategy is potentially available to women with invisible pain disability in the workplace. This is a key difference between quantitative and qualitative analysis.

The first strategy is the use of specialist equipment to minimise the pain that participants experience at work. Some participants did not use special equipment because it was not provided by their employer or they could not afford to purchase it themselves. I initially thought that having access to special equipment and setting up the workspace would be one of the most important strategies to assist women in chronic pain to be successful at work, but this did not turn out to be the case.

The second strategy that participants used is the careful management of their working lives. One of the key features of this strategy is building flexibility into work schedules. Although different participants mentioned being effective at different times, each appreciated the flexibility to complete tasks when they were most able. The flexibility to take breaks when required is important for managing pain throughout the work day, as well as balancing the volume of work that needs to be completed.

Working with a supportive employer was the third strategy participants used in maintaining effectiveness at work. Allowing them to take time off when needed was one way in which employers can be supportive. Participants also mentioned that their employer not making assumptions about their limitations was beneficial to creating a positive working relationship. Participants found that

being open with their employer about their health situation meant issues could be resolved and special equipment or work arrangements could be organised.

The fourth strategy was drawing on relationships with others. Support from family was a significant factor in managing chronic pain and work. Supportive colleagues were also important. Although this was often mentioned in relation to the more physical tasks where help was offered, colleagues offered emotional support as well. Women in chronic pain also received a significant amount of moral and emotional support from other women who were also experiencing chronic pain and working, some who were colleagues and some they had found through social networks.

Receiving or asking for help when required was the fifth strategy that assists women in chronic pain to maintain the salience of their worker identity. Participants struggled to ask for help because they often did not want to disclose their condition to their colleagues. They would ask for help when they were in pain or there was a difficult task they were unable to complete. They made strategic decisions about the tasks they engage in and who they involve to effectively fulfil their aspirations.

The sixth strategy for the women in this project was disassociating themselves from pain in order to focus on the work that they need to accomplish. Although work itself can be a distraction, other smaller tasks were often used to distract the participants from their pain. Women in chronic pain must decide whether a task is one worth undertaking and accepting the pain that results. This is further complicated by the unpredictability of their pain and its effects on their bodies.

The seventh strategy that participants used was carefully managing their lives outside of work. Looking after themselves is important and enabled them to

be productive while they were at work. This includes resting when possible and taking annual leave when needed to recover from periods of stress or pain. Taking life at a slower pace allowed some participants to better manage their work and pain. Limiting the number of social functions that they attended assisted women in chronic pain to rest. Many of the women in this project also discussed prioritising what was important and ensuring that they scheduled time for activities they valued.

Methodological Findings

There were two surprising methodological ‘findings’ that arose in the course of this project, one relating to the solicited diaries and one relating to the analysis of the information supplied by the participants. The former is the most significant. I observed in Chapter One that the solicited diary research method had been used to research chronically ill people because it is unobtrusive and can be relatively flexible. In theory the research is easily accessible for those who already face a significant number of challenges thus making it easier for them to participate in the research. However, participants ability to postpone writing diary entries until later meant that they were not completed.

Furthermore, focusing on pain in order to write in the diary had a negative effect on these women’s lives. The taken-for-granted aspects of daily life that solicited diaries draw attention to are better ignored because women in chronic pain do not want to focus on their experience of pain. Suppressing the pain and therefore the pain identity is important because these women want to maintain the salience of their worker identity in order to be successful at work. The failure of the solicited diaries as a research method revealed key insights about the clash of identities and how these women focused on maintaining the salience of their

worker identity. Therefore, their pain must be carefully managed in the workplace and there are times when their pain identity must be shown so they can get help to ensure that their pain does not become unmanageable. Kenton (2010) argues that solicited diaries are “an empowering method” (p. 18). But for the women in this project, this method was detrimental to their wellbeing. This shows that the context needs to be taken into consideration when selecting a methodological design for research.

After accepting that the solicited diary method had failed, I decided that the best method to utilise was different types of interviewing as it was important to maintain a qualitative participant-driven methodology. Another reason for this was because the initial group of participants had spoken to me at length during our initial meeting to discuss the research project and their participation. I came to the conclusion that I needed to match the method to the participants and so different types of interviewing were developed for different participants. I could be flexible in relation to their needs while gaining commitment about participation in a way that was more manageable for them. Participants only had to consider their pain once rather than a number of times at regular intervals when writing diary entries. Data was therefore gathered via face-to-face interviewing, online interviewing and through Facebook Messenger chat.

The participants in this project often felt like failures because they believed they should be achieving more at work and in their personal lives. Dealing with an invisible pain disability limited the time and energy they had. However, when their achievements are considered it is clear that they are developing creative strategies to succeed at work. There is a parallel between the temptation for them to consider their work life as a failure and the temptation for

the non-appearance of the solicited diaries to be considered a failure for this research project. However, there was an important lesson to be learned from this about the participants and their attitude towards their invisible pain disability. It revealed insights into how women in chronic pain successfully manage their personal and work lives.

The second surprising methodological finding that arose over the course of this project related to data analysis. After I had used qualitative thematic analysis to identify the strategies used by women to be successful at work, I realised that I needed to understand why these strategies were used. Discussing the results of the thematic analysis with others, reflecting on the ideas in the published literature, and developing a conceptual framework to make sense of my participants' experiences all led me to consider the notion of clashing identities. The analysis leading to the insights about clashing identities was not simply the thematic analysis of the participants' words. There is a role for more creative and reflective analysis to complement thematic analysis because restricting insights solely to thematic analysis is too limiting.

A Personal Conclusion

“The process of writing about illness is often painful as the body remembers the journey it has negotiated to be where it is today...my body is surviving, as I am. Through the reliving of pain comes the knowledge I survived and continue to survive this ‘empowering’ experience of illness” (p. 1421, Defenbaugh, 2008, as cited in Moore, 2013).

I am a woman who experiences chronic pain. Similar to my participants, I found that writing about illness and pain was a challenging experience. Vickers (2009a) also found this when studying participants who had a disability similar to herself.

Before this project, I was not aware of these challenges as I had not previously investigated a topic so personal and significant to my own life. This thesis has taught me more about myself than I ever thought possible. Holding this mirror to my own life was very difficult. But the insights I have gained from what my participants shared with me have been significant, cathartic and rewarding. I agree with Charmaz (2008) when she writes “qualitative research can transform your discipline and your qualitative research can transform you” (p. 17). As Moore (2013) states, “for me on a personal level, writing my illness narrative helped me to find clarity in my world as it allowed me to ‘gain insight into the meaning of my own life [and] come to know my own story’” (p. 206, McAdams, 1993, as cited in Moore, 2013). I have come to know more about myself through writing this thesis.

I started this project to focus on the success stories of women in chronic pain who are involved in the paid workforce. But I have learnt that it is not an accident that the literature is focused on the failures, challenges, difficulties and impossibilities of being involved in paid work when suffering from chronic illness and chronic pain. I have found that it takes a courageous, inspirational and determined women to push through the challenges and succeed. I have seen a lot of my own experience mirrored in all the stories I have heard. Although writing this thesis has been a painful in many ways, if I can show half as much courage, tenacity, hope and positivity as my participants, I will believe that I have succeeded. I am grateful they chose to share so much of themselves with me.

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Appendix A: Application for Ethical Approval

UNIVERSITY OF WAIKATO
FACULTY OF ARTS & SOCIAL SCIENCES

HUMAN RESEARCH ETHICS COMMITTEE

REVISED APPLICATION FOR ETHICAL APPROVAL

1. NAME OF RESEARCHER

Charlotte Ferry-Parker

2. PROGRAMME OF RESEARCHER(S)

Labour Studies – School of Social Sciences

3. RESEARCHER(S) FROM OFF CAMPUS

No researchers from outside the University are involved in this project.

4. TITLE OF RESEARCH PROJECT

Experience of paid work of women with an invisible chronic-pain disability

5. STATUS OF RESEARCH PROJECT

Master of Social Science in Labour Studies - LBST593-14C (HAM)
(Part-time, started October 2014)

6. FUNDING SOURCE

Only minor expenses will be involved with this research and these will be met personally by the researcher

7. NAME OF SUPERVISOR(S)

Dr John Paterson – Social Science Research Programme

8. DESCRIPTION OF RESEARCH PROJECT

The purpose of this research is twofold: firstly, to examine the experience of women in chronic pain caused by chronic illness so that they can be better understood and therefore accommodated at work; and secondly, to examine the strategies that women in chronic pain use to enable them to thrive at work and maintain a work/life balance. Different types of workplaces offer challenges and opportunities – those women on wages or salaries who are required to work in an office away from home face different situations than those women who work from home or are self-employed.

This topic arises out of my personal situation as a woman who experiences chronic pain and who is employed fulltime as a university evaluation administrator.

Chronic pain is pain that persists longer than would be expected for healing to occur (Dominick, Blyth & Nicholas, 2011; Malleson, Connell, Bennett & Eccleston, 2001 – see page 11 below for List of References). Experiencing chronic pain can significantly affect a person's productivity at work and may prevent some people from being involved in paid work at all. The literature on invisible disability itself is broad due to the number of conditions that fit into this category. Workplaces are often not set up with disabled bodies in mind. People with invisible disabilities have to navigate a work space and/or work schedule that is not set up to meet their physical needs.

Davis (2005) outlines many of the issues that those with invisible disabilities face. With conditions that are invisible the physical appearance of disability is missing so people do not know that work needs to be reconfigured to enable them to function effectively (Charmez, 2002; Davis, 2005). This is further complicated by the fact that women often try to hide their disability because they want to retain their job or not appear to need "special" treatment (Charmez, 2002).

Once women become chronically ill, their identity and sense of self changes. They often struggle with their new identity which is complicated by the fact that illness or pain can make their lives feel out of control (Moss & Dyck, 1996; Charmez, 2002; Sturge-Jacobs, 2002). This is compounded by more concrete changes, for example, their physical environment may need to be altered so that they are able to pursue their everyday tasks (Fritz & Lysack, 2014; Moss & Dyck, 1996). There is also extra pressure on women with chronic illness because of their traditional roles and responsibilities in the home (Moss & Dyck, 1996; Mijoo, 2009).

a) Justification in academic terms

There is a variety of literature on chronic pain and invisible disability, with some of it also concerned with the workplace. One significant area is the research on people with undiagnosed chronic lower back pain and their participation in the paid workforce (see de Vries, Reneman, Groothoff, Geertzen & Brouwer, 2012; Marhold, Linton & Melin, 2012). Much of this is focused on the patients' ability to undertake work and the obstacles and struggles they face while attempting to do so (Marhold, Linton & Melin, 2012). Often the focus is on the obstacles and challenges that chronically ill people face (Sturge-Jacobs, 2002; Charmaz, 2002; Moss & Dyck, 1996; Marhold, Linton & Melin, 2012). This project looks to address the gaps in the literature by focusing on the achievements and successes of women in chronic pain who are engaged in the paid workforce. The positive effects that being involved in paid work can have on these women's lives will be

considered. This project will also analyze how the invisible nature of their condition forces these women to relate to the work space and the people around them in different ways.

b) Objectives

The focus of this project is on the experiences of individual women; it also recognises the significance of the wider issues that influence chronically ill women's experience at work and the social structures that contribute to the struggles that they face throughout their working lives. Being aware of the role of power in the workplace and the ways that women are often treated with prejudice can also help to understand how women in chronic pain can be further disadvantaged at work. By taking a critical stance and understanding the wider issues at play, this project hopes to identify some solutions to the problems experienced by women in chronic pain (Averett, 2009; Neuman, 2006).

The following research questions will be addressed:

1. What is the experience of women in chronic pain who are involved in paid work?
 - a. What are the challenges of experiencing chronic pain and being involved in paid work?
 - b. What sacrifices are made because of chronic pain?
 - c. How does the invisible nature of chronic pain (as a disability) contribute to the experience that women have at work?
2. How does suffering chronic pain force women to relate to their 'space' differently in the workplace?
 - a. What aspects of the traditional work space create challenges for women in chronic pain?
 - b. How do women experiencing chronic pain reorganise their workspace to better meet their needs?
 - c. In what ways do workers with chronic pain re-orient their bodies in the workplace?
3. What kind of strategies are put in place to enable women to thrive in the workplace?
 - a. What tools and/or equipment make it possible for women in chronic pain to undertake paid work?
 - b. What kind of help and support do they need from others?
 - c. What kind of arrangements do they put in place to ensure they do not fail?

c) Method(s) of information collection and analysis

This project will use a qualitative methodology to gain an in-depth understanding of women's experiences of chronic pain in the workplace and how social structures shape their experiences. Participants' stories will

become the basis of analysis for this project. The experiences that they share will shape the research and through sharing their stories, I aim for “participants’ meanings and metaphors [to become] the starting point of analysis rather than forcing our narrative frames on them” (p. 305, Charmaz 2002). I aim to use four methods in this project: auto-ethnography, solicited diaries (which will include the use of photographs), in-depth interviews, and a research blog. I have not previously undertaken auto-ethnography nor have I used solicited photo diaries or a research blog before, although I have already undertaken extensive reading on these methods and their use by social researchers. My honours research project in Labour Studies involved the conduct of qualitative interviews with a small number of participants. I have also successfully completed graduate courses in ethnography and qualitative interviewing.

i) Auto-ethnography

Auto-ethnography will be undertaken in order to deepen my own understanding of the topic in the light of my own experiences of chronic pain, invisible disability and work. It positions myself at the centre of the project in acknowledgment of my dual role of both researcher and participant and treats my personal position as a resource for the research. It enables me to make explicit to myself what would otherwise be implicit and may be overlooked. Secondly, the process of auto-ethnography will enable me to develop and trial the solicited diary method to be used with participants.

Auto-ethnography is a research method that is autobiographical in nature. In this method, the researcher draws on their own experiences as resources for the project. Reflecting on their experience also enables the researcher to connect their personal experience to cultural and social structures around them (Denzin, 2006b; Averett, 2009). “To write individual experience is, at the same time, to write social experience” (p. 216, Sparkes, 2002).

It is proposed that, for a three week period, I will write a daily diary focussing on my work and invisible disability. I will use photographs as part of this. During this time, I will meet regularly with my supervisor to discuss both the method and what insights arise from it. Out of this experience I will refine the daily diary and follow-up interview methods to be used with my participants.

Photos may be taken of areas inside and outside of my own work office and immediate work-space, e.g., of areas I transverse in the course of my daily work, and of meeting rooms and so on. It may be that some of these photos will be used in the thesis to demonstrate or illustrate the methodology or the findings. See Sections 8d(i) and 10c below for

comments on the issue of informed consent and anonymity in relation to this method.

ii) Solicited photo diaries

The second method that will be used is solicited photo diaries (Harper, 2002; Jacelon & Imperio, 2005) compiled by three or four participants. Participants will record their diary entries online and make them available to the researcher for analysis. Secure web-based software will be used for this purpose.

Solicited diaries involve participants recording their experiences and reflections in relation to the research topic at the request of the researcher. Participants in this project will also be asked to consider including photographs of their work space in their diaries (Zepeda & Deal, 2008; Harper, 2002; Fritz & Lysack, 2014). This method enables participants to become more aware of taken-for-granted aspects of their daily lives and work. The diaries and photographs also provide the researcher with material for further discussion and analysis with the participant.

Solicited diaries have been used in researching chronically ill people because the method is relatively unobtrusive (Kenton, 2010) which is good for chronically ill women in pain because they can fill in the diary “at their own pace” (Milligan et al., 2005, p. 1889). The solicited diary method also counteracts the problem of recall that is sometimes an issue when conducting in-depth interviews (Alaszewski, 2006; Milligan et al., 2005). This makes it an appropriate method for this project because women in chronic pain are often forgetful.

Written guidance about the type of information to include in the diaries will be provided to participants before they start (see, for example, Appendix A). I will keep in contact with the participants throughout the data gathering period to provide support and advice.

iii) In-depth interviews

The third method that will be used is in-depth interviews. These interviews will be conducted after the diaries have been completed and considered by the researcher. They will be conducted face-to-face (if participants live in or not far from Hamilton) or using Skype or another similar web-based software which enables the researcher to communicate with the participants at a distance. The interviews will be used to explore in greater depth points that the participants have raised in their diaries and photos (Kenton, 2010). This is important for this project in order that the participants’ voices are heard so that their stories are not misunderstood by the researcher. It is especially important for women in chronic pain because they are often misunderstood in their everyday lives.

The follow up interviews will be semi-structured. Some of the questions in the interview can be prepared beforehand, covering the issues of interest to the researcher based on the literature and her own experiences in relation to the topic. Some of the interview questions will also be individually tailored to each research participant based on issues arising from their diaries (see Appendix B).

Both the personal and virtual interviews will be audio-recorded. This will be with the consent of the participants and all recordings will be kept confidential (see Appendix F). Recordings will be transcribed. If a participant declines to be recorded, notes will be written during the interview of his or her responses. These will then be written up and sent to the participant for them to add, delete or clarify anything.

iv) Research blog

The fourth method will be a research blog written by the researcher about the research project. This will be public, will be started early in the project, and will function as a way of sharing issues and, later, finding with anyone interested. It will also be a means of collecting advice, views and contributions from other people, thus being an additional source of information (Jackson et al., 2015). It will be made clear that the blog is linked to a research project, details of the project will be provided, and people who make comments will be made aware that they may be included in the research. Any sensitive or personal material contained in comments will be checked with the source before being used in the thesis to make sure the person is happy for it to be used in this way.

d) Procedure for recruiting participants and obtaining informed consent

i) Auto-ethnography

One of the important ethical issues for the auto-ethnography is that of third parties. My own research diary and fieldnotes could conceivably refer to the people I work with, including members of the Teaching Development Unit (TDU) and other academic staff (and possibly students) elsewhere in the University. The diary and fieldnotes will be kept confidential. There are two ways this material may be made available to others – I will be discussing them with my supervisor, and I may refer to parts of them in the thesis. The supervisor will sign a form agreeing to maintain confidentiality (see Appendix A), and anything used in the thesis will either be made anonymous (by not using names or identifying information) or, if there is a possibility of the third party being identifiable (e.g., because they are a member of the TDU), then they will be approached for their written consent for such material to be included in the thesis (see Appendix G). Otherwise such material will not be included in the thesis.

Members of the TDU will be informed of my thesis project and that it involves me undertaking a daily diary and fieldnotes for a specific period – this enables them to be aware that the research is being conducted, and avoids covert research insofar as it relates to them. Other members of the University will not be so informed as this would be “inappropriately intrusive or impractical” (as foreseen by Section 11, Clause 3 of the University’s “Ethical Conduct in Human Research and Related Activities Regulations”).

Photos may be taken of areas outside of my own office and immediate work-space, e.g., of areas I transverse in the course of my daily work, and of meeting rooms etc. Such photos will not include images of anyone – they will be taken when people are not present. Where appropriate, such as when a space is more private than public, or when taking a photo may be intrusive in some way, consent will be sought from any managers having control over such areas as well as anyone present. Any photos used in the thesis will not include images of people, and if they might otherwise be able to be linked to anyone then that person’s written consent will be sought. If consent is not given, such photos will not be used in the thesis.

ii) Solicited photo diaries and iii) In-depth interviews

Voluntary and snowball sampling will be used to identify possible participants. Only three or four participants will be required. I will advertise the research topic and ask people who meet the research criteria to contact me to discuss the possibility of them providing the solicited diaries and taking part in follow-up interviews. At this stage, the best ways and places to advertise, virtual and non-virtual, have not been determined – this will be discussed further with my supervisor and with people who may have some suggestions (these may include, e.g., the Pain Clinic at Waikato Hospital, CCS, a couple of people I know with invisible chronic-pain disability). Once one or more potential participants have contacted me, they may themselves know of others who may fit the sample criteria.

The criteria for participants will be that they experience chronic pain as a result of chronic illness that contributes to an invisible disability and are involved in some kind of paid work either outside or inside the home. Participants from New Zealand will be sought as this social and policy context is best understood by me. See Appendix D for the Project Information Sheet, Appendix E for the Consent Form for the solicited diaries, and Appendix F for the Consent Form for the follow-up interviews.

iv) Research blog

As noted above, it will be made clear that the blog is linked to a research project, details of the project will be provided, and people who make comments will be made aware that they may be included in the research. The researcher will use the blog setting available to check comments before they are posted publicly so that issues of privacy and consent can be monitored. Any sensitive or personal material contained in comments will be checked with the source before being used in the thesis to make sure that the person is happy for it to be used in that way.

e) Procedures in which participants will be involved

i) Auto-ethnography

For a three week period, I will write a daily diary focussing on my work and invisible disability. I will use photographs as part of this – taking photos of my personal work-space and maybe other areas involved with my work. During this time, I will meet regularly with my supervisor to discuss both the method and what insights arise from it. Out of this experience I will refine the daily diary and follow-up interview methods to be used with my participants.

ii) Solicited photo diaries

I will ask participants to keep a daily diary over a period of about three weeks. It is important to keep in mind that participants may experience pain and fatigue from time to time. They will be told that a sentence or two would be ok on any days where they may struggle to do much, but that more detailed entries would be appreciated on other days, with the aim of such detailed entries being to cover at least a week at work. These diaries will include the photos and their written thoughts and reflections. Participants will record their diary entries online and make them available to the researcher for analysis. Google forms or similar web-based software will be used for this purpose.

iii) In-depth interviews

Participants will be asked to participate in follow-up semi-structured interviews personally (face-to-face) or conducted online via Skype or similar technology. Both the personal interviews and online interviews will be audio-recorded. This will be with the consent of the participants and all recordings will be kept confidential.

It is anticipated that interviews could last between about 30 minutes and one hour in duration. However, the researcher will be sensitive to the comfort of the interviewee and it may be that an interview will be much shorter as a result. If either the researcher or interviewee wants

to discuss more than can be covered in one interview, then another will be conducted at another time.

iv) Research blog

Once the blog begins, the researcher will post something about the research at least every week and at times may post more often. Research participants will be able to follow the blog and post comments to it. As the blog will be public, anyone else can also post comments and contribute to discussion about any issue raised there. The researcher will use the blog setting available to check comments before they are posted publicly so that issues of privacy and consent can be monitored.

- f) Provide a copy of any research instruments to be used for, or any guidelines relating to, the collection of information from or about people, e.g., questionnaires, interview schedules, structured observation schedules, topics of questions to be covered in qualitative interviews, lists of types of behaviour to be observed in participant observation.**

See Appendices A and B for the drafts of the solicited diaries guidelines and the semi-structured interview guide.

9. PROCEDURES AND TIME FRAME FOR STORING PERSONAL INFORMATION AND OTHER DATA AND MAINTAINING CONFIDENTIALITY OF PERSONAL INFORMATION

All information gathered will remain secure at all times. Digital information will be stored in a password protected computer and any hard copy material will be stored in lockable drawers in my University office and at home. Only my supervisor and myself will be viewing the participant diaries and interview transcripts. The recordings of the interviews will be destroyed at the end of the project (some transcription may initially be selective and the researcher may need to go back to the recordings later). Signed consent forms will be stored securely and then destroyed one year after the thesis has been passed, in case consent ever becomes an issue upon the thesis becoming publically available. Participants' diaries and photos will not be destroyed for up to five years following the completion of the thesis. After this time, all digital files will be deleted and hard copy material will be shredded in a confidential bin. Auto-ethnographical material will be kept by the researcher.

10. ETHICAL AND LEGAL ISSUES

- a) Access to participants**

No issues anticipated apart from those normally associated with conducting voluntary and snowball sampling with sensitivity to potential participants.

b) Anonymity and informed consent

Participants will be given the choice about whether to remain anonymous or not – this is set out on the Information Sheet and Consent Forms (Appendices D, E and F). This choice will be re-visited, especially for those initially decided not to be anonymous, after the interview, for instance, by which stage the participant will be more aware of the information and views they are sharing. Those choosing anonymity may select a pseudonym for themselves. I may remind participants identified through snowball sampling that the person who referred them may be able to guess that they are a participant in this project. Each participant will be sent the transcript of her interview so that she can check that she is happy for the material in it to be used in the thesis and that it would not identify her if she has chosen to remain anonymous. If during the interview (or at any other time in the project) it becomes apparent that a participant would wish to clarify, modify, or change any part of their diary, such revisions will be made. I have also decided, in consultation with my supervisor, that I will also inform participants that they can withdraw from the project up until the thesis is about to be finalised, that is, until it is not practical to do so.

c) Third party issues

Auto-ethnography – As noted above in Section 8d(i), my research diary and fieldnotes might refer to the people I work with, including members of the TDU and other academic staff (and possibly students) elsewhere in the University. The diary and fieldnotes will be kept confidential. There are two ways this material may be made available to others - the researcher will be discussing them with her supervisor, and she may refer to parts of them in the thesis. Firstly, my supervisor will sign a form agreeing to maintain confidentiality (see Appendix A). Secondly, any reference to identifiable third parties in a diary or interview, if I wish to use it in the thesis, will either be made anonymous (by not using names or identifying information) or if there is a possibility of the third party being identifiable (e.g., because they are a member of the TDU) then they will be approached for their written consent for such material to be included in the thesis (see Appendix G). Members of the TDU will be informed of my project and that it involves me keeping a daily diary and fieldnotes for a specific period. Other members of the University will not be so informed as this would be “inappropriately intrusive or impractical” (as foreseen by Section 11, Clause 3 of the University’s “Ethical Conduct in Human Research and Related Activities Regulations”).

Participants' Solicited Diaries – I will discuss with each participant whether it would be appropriate for them to get consent from their manager and/or work colleagues. In some cases, one or more of the participants may be in a workplace which has a manager (i.e., not in self-employment or working from home). It might therefore be appropriate for such participants to advise, or even gain consent from, their manager, and/or their work colleagues, to take part in this project.

It is possible that a participant may not wish to seek such consent from managers – for example, some people with invisible chronic-pain disability may wish to keep it confidential or may wish to keep confidential from managers or colleagues the nature of effects on them. In such cases, where the participant does not wish to seek consent, if it is determined that their participation in the research is not intrusive, can be actioned in the personal time of the participant, and where the participant and workplace are kept anonymous, it will be deemed appropriate for such participation on the basis of the significance of the topic for advancing the interests of women in work with invisible chronic-pain disability.

I will discuss with participants the need to avoid identifying third parties in their diaries and photographs. This may not be a straightforward matter so I will take special care when writing up the research to consider whether any material would identify someone. I will also consult with participants regarding such matters should I consider identifiability to be a potential problem.

d) Potential risk to participants

A possible risk to participants is the extra burden that participating in the research process could place on them due to their health conditions. The information sheet will provide potential participants with an indication of what participation in the research will mean for them. They are thus able to make their own judgement on its likely impact on them.

e) Publication of findings

The project will be written up in a thesis which will be lodged with the University Library and made available online. The blog will make public at least some of the findings from the project. The findings may also be made public in conference presentations or academic journal articles. The main ethical issue associated with these is anonymity for those participants wishing it, and for third parties. At various places above, how such anonymity will be achieved has been set out – see especially Sections 8d and 10b above.

e) Conflict of interest

No conflicts of interest has been identified.

f) Intellectual and other property rights

The diary entries, original photos and interview recordings remain the intellectual property of the participants. All other intellectual property rights will remain with the researcher (e.g. blog entries, interview transcripts, thesis document, and any resulting publications).

g) Intention to pay participants

There is no intention to pay participants

h) Any other ethical or legal issue

No other ethical or legal issues have been identified

i) The Treaty of Waitangi/Cultural Sensitivity

Should one or more of the participants be Māori, I will seek appropriate cultural advice in consultation with my supervisor. I will follow the same procedure should any participant have a different cultural background from my own.

ETHICAL STATEMENT

The researcher believes that social research should be conducted in such a way that it respects the interests of all parties involved, and that the purpose of research is to advance people's knowledge, understanding and wisdom. More specifically, the researcher will follow the letter and spirit of the University of Waikato's regulations concerning the ethical conduct of research.

.....

Signature of **Applicant**

Date

.....

Signature of **Chief Supervisor**

Date

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Appendix A – Participant Guidelines for Daily Diaries and Photos

Note: These Guidelines will be further developed in the light of what I learn from my auto-ethnography which includes the keeping of a daily diary and the use of photos. What follows is an draft of initial thoughts to indicate the type of guidelines possible.

Masters of Social Science Thesis Research Project
**“Experience of Paid Work of Women with an Invisible Chronic-Pain
Disability”**
Charlotte Ferry-Parker

GUIDELINES FOR YOUR DAILY DIARY

YOUR WRITTEN DIARY

The aim of this diary is to get you to reflect on how your work is affected by your experience of chronic pain. A daily diary is a useful research method because it gets the research participants to think about the topic and their own experiences over an extended period of time. The problem with a one-off interview is that it relies on the interviewee having a good memory as well as being aware of what they do in their everyday life. Keeping a daily diary helps you to pay attention to things you might otherwise not note.

I would be grateful if you would set aside some time each day for the following two to three weeks, outside of your work context, to write about what happened at work and what you noticed about your work in relation to the issues looked at in this research project. If something occurs to you during the day, it might be a good idea to take a quick note of it to help remind you about it later, when you are writing your diary.

It doesn't matter if you don't write much on any particular day, especially if you are busy or tired.

Please also remember what we discussed about the protection of third parties. The aim of the research is to understand your experience – the personal details about people you work with are not relevant to the research, even though your interaction with people is relevant. Also, it is important that people not be part of a research project if they have not given their informed consent. This is a matter we will discuss again in your follow-up interview.

Please contact me if you are unsure about what to do or what to include in your diary. Don't worry if you think that what you are writing might not turn out to be of use to the research project – we can always discuss this in the follow-up interview.

YOUR PHOTOGRAPHS

Taking photos adds another dimension to your diary about your workplace, the challenges you face at work, and the strategies you use to be an effective worker. A picture can sometimes be better than a thousand words. It's not always easy or possible to describe something adequately in words. Furthermore, in your follow-up interview, we can discuss in greater depth why you took a photo and what it shows.

Whenever you take a photo, note it in your diary and write down why you took it and what it shows. It may be that a photo you take may not be very well framed or very clear. That's ok – your diary entry can explain it and we can discuss it during your follow-up interview.

Remember to be aware of the issues we discussed about respecting any managers and co-workers in your workplace, about being unobtrusive when taking photos, and keeping other people non-identifiable. If in doubt anytime about whether it's appropriate to take a photo, please don't take it. You could maybe discuss it with me and we can work out what is the best thing to do – you can always write about it in your diary instead.

TOPICS TO THINK ABOUT

It may help you to think about the following issues:

- * What have I had to modify about my workspace or work-station?
- * What different/extra equipment or resources have I needed?
- * What do I have to put extra effort into?
- * How much do I have to rely on someone else for some things?
- * What do I find most challenging about my work?
- * How might my experience of chronic pain actually be helpful or positive in my work?
- * What strategies do I use to be successful?
- * What kinds of things have I done that have not proved to be very useful?
- * How do the actions of other people either help or hinder me being successful at work?
- * How does the invisible nature of my pain affect how I do my job and how I interact with other people in my workplace?

Appendix B - Draft Semi-Structured Interview Guide

Part I – Discussion of Participant’s Solicited Diary and Photographs

NOTE: In the initial part of the interview, I will go over the material provided by the participant and clarify its relevance to the research topic. It is not possible to anticipate at this stage the nature of this material.

Part II – List of Topics of Interest to Researcher

NOTE: In this part of the interview, I will check to see if the following questions have been covered in Part I. If not, I will ask them of the participant. It is possible that these questions will be modified or developed in the light of my auto-ethnography.

Experience

1. What do you enjoy about being involved in paid work?
2. What are the challenges of having a paid job when you have an invisible chronic-pain disability?
3. What sacrifices do you have to make in order to stay at your job?
4. Are there other parts of your life that you feel you neglect because of your involvement in paid work? If so, what are they?
5. In what ways do you think the invisible nature of chronic pain is a blessing or a curse?
6. Is it worth it? How do the benefits of work outweigh the challenges?
7. How does your involvement in paid work affect your home and family life?

Space

1. How does the lay-out of your work space affect your ability to do your job?
2. What changes, if any, have you made to this space to enable you to undertake your job better?
3. In what other ways do you think your work space helps or hinders your daily life?

Strategies

1. What special tools or equipment enable you to do your job?
2. What types of support or help would enable you to do your job better?
3. What other arrangements have you put in place to ensure that paid work does not affect your health negatively?
4. What have you told your boss and work colleagues about your invisible chronic-pain disability? What issues did that or would that raise?

Appendix C - Confidentiality Agreement With Supervisor

I am the supervisor of Charlotte Ferry-Parker's MSocSc thesis project, "Experience of paid work of women with an invisible chronic-pain disability". I undertake to keep confidential the material in Ms Ferry-Parker's ethnographic fieldnotes and diary, especially any reference to her co-workers and any other third parties. I also undertake to support and abide by Ms Ferry-Parker's promises of confidentiality to all her research participants in relation to all ways she collects information for her thesis and in the manner she writes up her findings.

Signature: _____

*John L. Paterson
Social Science Research
School of Social Sciences
University of Waikato*

Appendix D - Project Information Sheet

On University Letterhead

Masters of Social Science Thesis Research Project
**“Experience of Paid Work of Women with an Invisible Chronic-Pain
Disability”**
Charlotte Ferry-Parker

PROJECT INFORMATION SHEET

The Research Project

This research project seeks to explore the experience of women in paid work with an invisible chronic-pain disability. I am interested in this topic because I share this challenge, working as an administrator at the University while dealing personally with chronic pain. My degree is in Labour Studies so I have an interest in people’s experience of work and workplaces. It is my hope in this research project to identify useful ideas and strategies that will be of use to other women sharing the same challenges.

The purpose of my Masters thesis project is twofold: firstly, to examine the experience of women in chronic pain caused by chronic illness so that they can be better understood and therefore accommodated at work; and secondly, to examine the strategies that women in chronic pain use to enable them to thrive at work and maintain a work/life balance. The project will focus on the achievements and successes of women in chronic pain who are engaged in the paid workforce and the positive effects that being involved in paid work can have for women’s lives. It will also analyze how the invisible nature of chronic pain can force women to relate to the work space and the people around them in different ways. The research will collect information from about three or four women and consider their experiences in depth. Participants can choose to be anonymous, if they wish. It is important to me that you are comfortable with every aspect of your participation in the project, and you may withdraw from it at any stage. The project has been given ethical approval by the Human Research Ethics Committee of the University’s Faculty of Arts and Social Sciences.

What Participation in This Research Project Involves

The researcher will ask you to keep an online daily work diary over a period of up to three weeks. The aim of this diary is to record what you notice about how your work is affected by issues arising from invisible chronic-pain. Maybe you do things differently from your fellow workers or from someone else without invisible chronic-pain. Maybe you have come up with strategies to overcome certain challenges that other people could benefit from knowing. Maybe there are

some things you just can't do. You will be given the opportunity to take photos as a means of recording the nature of your workspace, how you have shaped it and how you interact with it. These photos can also illustrate your diary entries.

After the diaries have been completed, you will be asked if you would like to participate in a follow-up interview with me to discuss the things you have noted in your diary and photos. This interview is likely to last somewhere between 30 minutes and an hour, and it could be done in two or three stages at different times if you would prefer. If you live near Hamilton, the interview will be conducted in person. If you live further away, the interview will be conducted via Skype or a similar technology. Please note that you need not answer any question in the interview if you do not want to. You may also choose to withdraw from the interview or project at any stage. The interviews will be recorded so that I can later transcribe them and think about the issues raised in them. All recordings and transcripts will be kept confidential – no-one except my supervisor and I will have access to them. However, I may quote some parts of your interview in my thesis to illustrate key points. Your diaries and photos will be kept securely for five years following the completion of the thesis in case the University wishes to review the conduct of the research during this period. After that, they will be destroyed.

Anyone who wishes to consider participation in this project will be shown a Consent Form which sets out various aspects of participation in more detail and provides them with a means to stipulate the conditions under which they would agree to take part. Such conditions are open to discussion and negotiation.

How the Research Findings will be Made Public

The project will be written up in a thesis which will be lodged in the University Library and made available online so that anyone can access it on the Internet. Please take note that there will be only three or four participants in this research project and so the research findings will refer in some detail to these individuals and their experiences. If you choose to remain anonymous, material that identifies you will not be used, but it is not always possible to achieve full anonymity. I will consult you about this at the writing up stage of the thesis. I am also going to be writing a Blog about the research project and the issues faced by women with an invisible chronic-pain disability in their workplaces. I will post blog entries about various parts of the research, although any participants choosing anonymity will not be referred to in an identifiable way. It is also possible after the successful completion of my thesis that I may present conference papers on the research and/or write academic articles about it, in order to advocate for and advance the interests of women with invisible chronic-pain.

Your Rights

If you agree to take part in this research project, you have the following rights:

- a) To decline any part of the research that you are uncomfortable with and, when being interviewed, you may decline to answer any particular question, and to terminate the interview at any time.
- b) To ask any further questions about the research project that occurs to you, at any stage.
- c) To remain anonymous, should you so choose - anything that might identify you will not be included in the thesis, conference presentations, academic articles or any other report about the findings of the research.
- d) To withdraw your consent at any time up until one month after viewing the transcript of my interview.
- e) To take any complaints you have about the research project to the University's Faculty of Arts and Social Sciences' Human Research Ethics Committee (University of Waikato, Te Whare Wananga o Waikato, Private Bag 3105, Hamilton 3240, or you can email its secretary at fass-ethics@waikato.ac.nz).

Contact Information:

Should you be interested in finding out more about this project or in discussing your possible participation, please contact me as follows:

Researcher:

Charlotte Ferry-Parker
Labour Studies Programme
School of Social Sciences
Faculty of Arts and Social Sciences
Email cferryparker@gmail.com
Phone 021-02748861

Supervisor:

Dr John Paterson
Social Science Research
School of Social Sciences
Faculty of Arts and Social Sciences
Email johnp@waikato.ac.nz
Phone 07-8379361

Appendix E - Consent Form for Solicited Diaries

On University Letterhead

Masters of Social Science Thesis Research Project

“Experience of Paid Work of Women with an Invisible Chronic-Pain Disability”

Charlotte Ferry-Parker

CONSENT FORM FOR PHASE ONE: SOLICITED DIARIES

Please read the “Project Information Sheet” and raise any questions you have about the Project with the researcher. If you decide you are interested in becoming a research participant, please consider the following issues and indicate your choices. Please feel free to mention any concerns you might have about any of these issues. Note that if you change your mind about your participation or any of the issues below, you are able to contact the researcher and either withdraw or re-negotiate the conditions of your participation.

This Consent Form relates to the first phase of the project, solicited photo diaries. Guidelines have been provided to you relating to the keeping of a daily diary and taking photos of your workspace. Should you decide to be involved in Phase Two, Follow-Up Interview, issues of consent, anonymity, etc. will be discussed again with you.

Name of Participant: _____

Please indicate your responses below by circling Yes or No:		
I have had an opportunity to discuss this Project with the researcher	Yes	No
I understand that I may ask any questions at any time about the project and my participation	Yes	No
I understand that I may withdraw from the Project at any time by contacting the researcher	Yes	No
I understand that I may request any changes, deletions or additions to the diary material I send to the researcher, and that the researcher will respect such requests	Yes	No
I understand that all the material I provide to the researcher will be confidential and kept securely either on a password-protected computer or in a locked filing cabinet	Yes	No
The issue of third parties and the protection of their identities has been discussed with me	Yes	No
I wish to be kept anonymous	Yes	No
I am happy to be identified in the thesis and in any presentation or publication about this research project	Yes	No
I am happy to consider taking part in a follow-up interview and understand that I will have the chance to review my consent at that stage	Yes	No

“I consent to take part in Phase One of this research project on the above conditions”

Signature of Participant: _____ *Date:*

“I undertake to abide by the above conditions stipulated by the Participant”

Signature of Researcher: _____ *Date:*

Researcher:

Charlotte Ferry-Parker
Labour Studies Programme
School of Social Sciences
Faculty of Arts and Social Sciences
Email cferryparker@gmail.com
Phone 021-02748861

Supervisor:

Dr John Paterson
Social Science Research
School of Social Sciences
Faculty of Arts and Social Sciences
Email johnp@waikato.ac.nz
Phone 07-8379361

Appendix F - Consent Form for Follow-Up Interviews

On University Letterhead

Masters of Social Science Thesis Research Project

“Experience of Paid Work of Women with an Invisible Chronic-Pain Disability”

Charlotte Ferry-Parker

CONSENT FORM FOR PHASE TWO: FOLLOW-UP INTERVIEWS

This Consent Form relates to the second phase of this project, the first phase having involved you keeping and submitting a solicited photo diary. As was noted in the Project Information Sheet (copy attached in case you misplaced your previous copy), this follow-up interview is likely to last somewhere between 30 minutes and an hour, and it could be done in two or three stages at different times if you would prefer.

Please note that you need not answer any question in the interview if you do not want to. You may also choose to completely withdraw from the interview at any stage. I will ask for your permission to record your interview so that I can later transcribe it and think about the issues raised in it. I will send you the transcript of your interview so that you can check that you are happy for the material in it to be used in my thesis. You can also think about how any material in the transcript might identify you if you have chosen to remain anonymous.

If during the interview (or at any other time in the project) it becomes apparent that you would wish to clarify, modify, or change any part of your diary or interview, such revisions will be made. All recordings and transcripts will be kept confidential – no-one except my supervisor and I will have access to them. However, I may quote some parts of your interview in my thesis to illustrate key points.

Your interview recording will be destroyed at the end of the project and the transcript will be kept securely for five years following the completion of the thesis in case the University wishes to review the conduct of the research during this period. After that, it will be destroyed. You may request a copy of your interview recording. The researcher is happy to discuss any aspects of consent and anonymity at any time.

Name of Participant:

Please indicate your responses below by circling Yes or No:		
I understand that I may decline to answer any question in the interview and that I may terminate the interview at any time	Yes	No
I understand that all the material I provide to the researcher will be confidential and kept securely either on a password-protected computer or in a locked filing cabinet	Yes	No
The issue of third parties and the protection of their identities has been discussed with me	Yes	No
I wish to be kept anonymous	Yes	No
I give permission for my interview to be recorded	Yes	No
I understand that the researcher will send me any transcript of my interview and that I may request any deletions, modifications or additions	Yes	No
I am happy to be identified in the thesis and in any presentation or publication about this research project	Yes	No
I wish to be provided with a copy of the recording of my interview	Yes	No

“I consent to take part in Phase Two of this research project on the above conditions”

Signature of Participant: _____

Date: _____

“I undertake to abide by the above conditions stipulated by the Participant”

Signature of Researcher: _____

Date: _____

Researcher:

Charlotte Ferry-Parker
 Labour Studies Programme
 School of Social Sciences
 Faculty of Arts and Social Sciences
 Email cferryparker@gmail.com
 Phone 021-02748861

Supervisor:

Dr John Paterson
 Social Science Research

School of Social Sciences
Faculty of Arts and Social Sciences
Email johnp@waikato.ac.nz
Phone 07-837-9361

Appendix G – Consent Form for Third Parties regarding the Use of Photographic Images

I consent to the use of a photographic image of myself in Charlotte Ferry-Parker's MSocSc thesis project, "Experience of paid work of women with an invisible chronic-pain disability". I have been given a copy of the Project Information Sheet which sets out details about the research. I agree to the following, as indicated:

Please indicate your responses below by circling Yes or No:		
I agree to my photographic image being used in a research participant's solicited diary	Yes	No
I agree to my photographic image being used in the researcher's thesis	Yes	No
I agree to my photographic image being used in presentations and publications by the researcher	Yes	No
I wish to be kept anonymous (for my name not to be used)	Yes	No
I wish my facial features to be masked	Yes	No
Any additional conditions (<i>to be written in</i>):		

Name of Photographed Person: _____

Signature of Photographed Person: _____

Date: _____

"I undertake to abide by the above conditions stipulated above"

Signature of Researcher: _____

Date: _____

Researcher:

Charlotte Ferry-Parker
Labour Studies Programme
School of Social Sciences
Faculty of Arts and Social Sciences
Email cferryparker@gmail.com
Phone 021-02748861

Supervisor:

Dr John Paterson

Social Science Research

School of Social Sciences

Faculty of Arts and Social Sciences

Email johnp@waikato.ac.nz

Phone 07-837-9361

Appendix B: Poster Requesting Participants

RESEARCH PROJECT: WOMEN LIVING AND WORKING WITH CHRONIC PAIN

DO YOU LIVE WITH CHRONIC PAIN?

HAS CHRONIC PAIN INFLUENCED YOUR WORK-LIFE?

RESEARCH PROJECT:

This research project is a Master's thesis at the University of Waikato and seeks to explore the experience of women in paid work with invisible chronic pain.

It is my hope that through this research project I will be able to identify useful ideas and strategies that will be beneficial to other women in similar situations.

I am also interested in the positive effects that being involved in paid work can have for women's lives.

I am seeking 3 or 4 women as participants in this research project.

The project will focus on the achievements and successes of women in chronic pain who work as employees or are self-employed either in a part-time or full-time capacity.

PURPOSES OF THE PROJECT:

To examine the experience of women in chronic pain so that they can be better understood and therefore accommodated at work.

To examine the strategies that women in chronic pain use to enable them to thrive at work and strive towards some kind of work/life balance.

IF YOU ARE INTERESTED IN PARTICIPATING IN THIS RESEARCH, PLEASE CONTACT:

Charlotte Ferry-Parker

Labour Studies Programme

School of Social Sciences

Faculty of Arts and Social Sciences

University of Waikato

Email cferryparker@gmail.com

Phone 021-02748861



Appendix C: Project Information Sheet

Faculty of Arts and Social
Sciences

School of Social Sciences

Te Kura Kete Aronui

The University of Waikato

Private Bag 3105

www.waikato.ac.nz



THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Masters of Social Science Thesis Research Project

Experience of Paid Work of Women with Invisible Chronic Pain

PROJECT INFORMATION SHEET

The Research Project

This research project seeks to explore the experience of women in paid work with invisible chronic pain. I am interested in this topic because I share this challenge, working as a Senior Tutor at the University while dealing personally with chronic pain. My degree is in Labour Studies so I have an interest in people's experience of work and workplaces. It is my hope that through this research project I will be able to identify useful ideas and strategies that will be beneficial to other women in similar situations.

The purpose of my Master's thesis project is twofold: firstly, to examine the experience of women in chronic pain so that they can be better understood and therefore accommodated at work; and secondly, to examine the strategies that women in chronic pain use to enable them to thrive at work and strive towards some kind of work/life balance. The project will focus on the achievements and successes of women in chronic pain who work as employees or are self-employed either in a part-time or full-time capacity. I am also interested in the positive effects that being involved in paid work can have for women's lives. The project will also analyse how the invisible nature of chronic pain can force women to relate to the work space and the people around them in different ways.

The research will collect information from three or four women and consider their experiences in-depth. Participants can choose to be anonymous, if they wish. It is important to me that participants are comfortable with every aspect of their participation in the project, and they may withdraw from it at any stage. The project has been given ethical approval by the Human Research Ethics Committee of the University's Faculty of Arts and Social Sciences.

What participation in this research project involves

As the researcher, I will ask you to keep a daily work diary over a period of two to three weeks, (the time length dependant on what suits you). The aim of this diary is to record how your work is affected by issues arising from invisible chronic pain.

Questions to keep in mind include:

- How might you do things differently from your colleagues without invisible chronic pain?
- What strategies have you come up with to overcome challenges that other people could benefit from?
- What are the things that you are unable to do because of the effects of chronic pain?

I will ask you to consider taking photos to record the nature of your workspace, how you have shaped it and how you interact with it. These photos can also illustrate your diary entries.

After your diaries have been completed, I would like to conduct a follow-up interview to discuss your diary and photos. This interview is likely to last between 30 minutes and an hour, and it could be done in two or three stages if you would prefer. If you live near Hamilton, the interview will be conducted in person. If you live further away, the interview will be conducted via Skype or a similar online technology. You do not need to answer any question in the interview if you do not want to. You may also choose to withdraw from the interview or this project at any stage. The interviews will be recorded so that I can later transcribe them and think about the issues that have been raised. All recordings and transcripts will be kept confidential – no-one except my supervisor and I will have access to them. However, I may quote some parts of your interview in my thesis to illustrate key points. If you wish, you may of course keep a copy of your diaries, photos, recordings and transcripts. I will keep a copy of your diaries, photos, recordings and transcripts in a secure manner for five years following the completion of the thesis – this is standard practice in case the University wishes to review the conduct of the research during this period. After that, the researcher's copies will be destroyed.

If you are considering participation in this project I will show you a Consent Form which sets out various aspects of participation in more detail and provides the means for you to stipulate the conditions under which you agree to take part. Such conditions are open to discussion and negotiation at any time.

How the Research Findings will be Made Public

This project will be written up in a thesis which will be lodged in the University Library and made available online by the university so that it can be easily accessed by anyone who is interested in it. Because there will be only three or four participants in this project the research findings will refer in some detail to each person and their experiences. If you choose to remain anonymous, material that identifies you will not be used, however, it is not always possible to achieve full anonymity. I will consult you about this when writing-up the thesis. Attention will also have to be given to the anonymity of people you refer to in your diaries.

After the successful completion of my thesis, I may present conference papers on the research and/or write academic articles about the subject, in order to advocate for and advance the interests of women with invisible chronic pain.

Your Rights

If you agree to take part in this research project, you have the following rights:

- a) To decline to participate in any part of the research that you are uncomfortable, with including declining to answer any question when being interviewed, and you may terminate the interview at any time.
- b) To ask any further questions about the research project that occur to you, at any stage.
- c) To remain anonymous, should you so choose to do so; this means that anything that might identify you will not be included in the thesis, conference presentations, academic articles or any other report about the findings of the research.
- d) To withdraw your consent at any time up until one month after viewing the transcript of your interview.
- e) To take any complaints you have about the research project to the University's Faculty of Arts and Social Sciences' Human Research Ethics Committee (University of Waikato, Te Whare Wananga o Waikato, Private Bag 3105, Hamilton 3240, or you can email its secretary at fass-ethics@waikato.ac.nz).

Contact Information:

If you are interested in finding out more about this project or in discussing your possible participation, please contact me as follows:

Researcher:

Charlotte Ferry-Parker

Labour Studies Programme

School of Social Sciences

Faculty of Arts and Social Sciences

University of Waikato

Email cferryparker@gmail.com

Phone 021-02748861

Supervisor:

Dr John Paterson

Social Science Research

School of Social Sciences

Faculty of Arts and Social Sciences

University of Waikato

Email johnp@waikato.ac.nz

Phone: 027-3818247

Appendix D: Diary Guidelines

Faculty of Arts and Social
Sciences

School of Social Sciences

Te Kura Kete Aronui

The University of Waikato

Private Bag 3105

www.waikato.ac.nz



THE UNIVERSITY OF
WAIKATO

Te Whare Wānanga o Waikato

Masters of Social Science Thesis Research Project

Experience of Paid Work of Women with Invisible Chronic Pain

GUIDELINES FOR YOUR DAILY DIARY

YOUR WRITTEN DIARY

I would be grateful if you would set aside some time each day for the following two to three weeks, to write about what happened in your workplace and what you noticed about your work in relation to chronic pain. Don't worry too much if you don't write much on any given day, especially if you are busy or tired. At the end of each week, please email me your diary entries. Remember the aim of the diary is for you to reflect on how your experience of chronic pain affects you in the workplace, the challenges you face at work, and the strategies you use to be successful.

A daily diary is a useful research method because it allows participants to think about their experiences in relation to the topic over an extended period of time. It also means that you do not have to rely on your memory as much as you would have to with a one-off interview. Keeping a daily diary also helps you to pay attention to things you might otherwise not think about and write them down.

When I wrote a daily diary, I found it useful to write a quick note of something when it happened so I didn't forget about it and could write about the event in more detail later. I used Google docs because the app was easy to access on my phone and ipad. I sometimes used post-it notes and sent a text or email to myself as well. These are only suggestions and any way you can think of to record your notes is fine. I then copied the notes into a word document and

wrote the rest of the story so it could be sent by email. You are welcome to write your diary by hand and I will collect it from you when you are finished if you would prefer.

Please remember what we discussed about the protection of third parties. The aim of the research is to understand *your* experience and even though your interaction with people is relevant, it is important not to identify anyone who has not given their informed consent to be part of this research project.

Please contact me if you are unsure about what to do or what to include in your diary. You are welcome to email me at any stage to check whether what you are doing is on the right track as well. Don't worry if you feel that what you are writing might not be useful, we can always discuss it further in the follow-up interview.

YOUR PHOTOGRAPHS

Taking photos adds another dimension to your diary. A picture can sometimes be better than a thousand words especially because it's not always easy or possible to describe something adequately through text. During your follow-up interview, we can discuss in more detail why you took a photo and what it shows.

When I took photos for this project, I used my cellphone and then emailed the pictures to myself. This method was easy as I always carried my phone with me and it was easy to use. You are welcome to use any digital camera that you have instead. If you are unable to take photos on your phone and you do not have a camera, I will arrange for you to borrow one to use while you are completing your daily diary.

Whenever you take a photo, note it in your diary and write down why you took it and what it shows. Don't worry if your photo is not very well framed or is unclear because your diary entry can explain it in more detail and we can discuss it during your follow-up interview.

Remember to be aware of the issues we discussed about respecting any managers and co-workers in your workplace, about being unobtrusive when taking photos, and not taking any identifying pictures of other people. If you are unsure about whether it's appropriate to take a photo it is best not to take it. Please do write about it in your diary and we can discuss the best thing to do later.

TOPICS TO THINK ABOUT

It may help to think about the following issues:

- * What have I had to modify about my workspace or work-station?
- * What different/extra equipment or resources have I needed?
- * What do I put extra effort into?
- * How much do I have to rely on someone else for some things?
- * How do the actions of other people help or hinder my success at work?
- * What do I find most challenging about my work?
- * How might my experience of chronic pain be helpful or positive in my work?
- * What strategies do I use to be successful?
- * What kinds of things have I done that have not proved to be very useful?
- * How does the invisible nature of my pain affect how I do my job and how I interact with other people in my workplace?

Appendix E: Consent form for Solicited Daily Diaries

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Masters of Social Science Thesis Research Project

Experience of Paid Work of Women with Invisible Chronic Pain

CONSENT FORM FOR PHASE ONE: WORK DIARY AND PHOTOS

Please read the *Project Information Sheet* and raise any questions you have about the project with the researcher. If you decide you are interested in becoming a research participant, please consider the following issues and indicate your choices. Please feel free to raise any concerns you have about any of these issues. If you change your mind about your participation or any of the issues below, please contact the researcher and either withdraw or re-negotiate the conditions of your participation.

This *Consent Form* relates to the first phase of the project, *Work Diary and Photos*. Guidelines have been provided to you relating to keeping of a daily diary and taking photos of your workspace. Should you decide to be involved in *Phase Two - Follow-Up Interview*, the issues associated with *Phase Two* will be discussed with you at that point.

Name of Participant:

Please indicate your responses below by circling Yes or No:		
I have had an opportunity to discuss this project with the researcher	Yes	No

I understand that I may ask any questions at any time about the project and my participation	Yes	No
I understand that I may withdraw from the project at any time by contacting the researcher	Yes	No
I understand that I may request any changes, deletions or additions to the diary material I send to the researcher, and that the researcher will respect such requests	Yes	No
I understand that all the material I provide to the researcher will be confidential and kept securely either on a password-protected computer or in a locked filing cabinet	Yes	No
The issue of third parties and the protection of their identities has been discussed with me	Yes	No
I wish to be kept anonymous	Yes	No
I am happy to be identified in the thesis and in any presentation or publication about this research project	Yes	No
I am happy to consider taking part in a follow-up interview and understand that I will have the chance to review my consent at that stage	Yes	No

"I consent to take part in *Phase One* of this research project on the above conditions"

Signature of Participant: _____

Date: _____

"I undertake to abide by the above conditions as stipulated by the Participant"

Signature of Researcher: _____

Date: _____

Researcher:

Charlotte Ferry-Parker

Labour Studies Programme

School of Social Sciences

Faculty of Arts and Social Sciences

University of Waikato

Email cferryparker@gmail.com

Phone 021-02748861

Supervisor:

Dr John Paterson

Social Science Research

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Faculty of Arts and Social Sciences

University of Waikato

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Phone: 027-3818247

Appendix F: Consent Form for Interviews

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Masters of Social Science Thesis Research Project

Experience of Paid Work of Women with Invisible Chronic Pain

CONSENT FORM FOR INTERVIEW

Please read the *Project Information Sheet* and raise any questions you have about the project with the researcher. If you decide you are interested in becoming a research participant, please consider the following issues and indicate your choices. Please feel free to raise any concerns you have about any of these issues. If you change your mind about your participation or any of the issues below, please contact the researcher and either withdraw or re-negotiate the conditions of your participation.

Name of Participant:

Please indicate your responses below by circling Yes or No:		
I have had an opportunity to discuss this project with the researcher	Yes	No
I understand that I may ask any questions at any time about the project and my participation	Yes	No
I understand that I may withdraw from the project at any time by contacting the researcher	Yes	No
I am happy for the interview to be recorded	Yes	No
I would like to receive a copy of the interview transcript	Yes	No

I understand that I may request any changes, deletions or additions to the interview transcript and the researcher will respect such requests	Yes	No
I understand that interview transcript will be confidential and kept securely either on a password-protected computer or in a locked filing cabinet	Yes	No
The issue of third parties and the protection of their identities has been discussed with me	Yes	No
I wish to be kept anonymous	Yes	No
I am happy to be identified in the thesis and in any presentation or publication about this research project	Yes	No

“I consent to take part in this research project on the above conditions”

Signature of Participant: _____

Date: _____

“I undertake to abide by the above conditions as stipulated by the Participant”

Signature of Researcher: _____

Date: _____

Researcher:

Charlotte Ferry-Parker

Labour Studies Programme

School of Social Sciences

Faculty of Arts and Social Sciences

University of Waikato

Email cferryparker@gmail.com

Phone 021-02748861

Supervisor:

Dr John Paterson

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Appendix G: Consent Form for Email Questioning

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Experience of Paid Work of Women with Invisible Chronic Pain

CONSENT FORM FOR EMAIL INTERVIEW

Please read the *Project Information Sheet* and raise any questions you have about the project with the researcher. If you decide you are interested in becoming a research participant, please consider the following issues and indicate your choices. Please feel free to raise any concerns you have about any of these issues. If you change your mind about your participation or any of the issues below, please contact the researcher and either withdraw or re-negotiate the conditions of your participation.

Name of Participant:

Please indicate your responses below by circling Yes or No:		
I have had an opportunity to discuss this project with the researcher	Yes	No
I understand that I may ask any questions at any time about the project and my participation	Yes	No
I understand that I may withdraw from the project at any time by contacting the researcher	Yes	No
I am happy for the interview to be conducted via email	Yes	No

I understand that I may request any changes, deletions or additions to the interview material and the researcher will respect such requests	Yes	No
I understand that the email interview material will be confidential and kept securely either on a password-protected computer or in a locked filing cabinet	Yes	No
The issue of third parties and the protection of their identities has been discussed with me	Yes	No
I wish to be kept anonymous	Yes	No
I am happy to be identified in the thesis and in any presentation or publication about this research project	Yes	No

"I consent to take part in this research project on the above conditions"

Signature of Participant: _____

Date: _____

"I undertake to abide by the above conditions as stipulated by the Participant"

Signature of Researcher: _____

Date: _____

Researcher:

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Appendix H: Interview Guide

General

1. **Can you tell me a little bit about yourself and what you do in your work?**
2. **What kind of pain do you experience?**
(What is the nature of your chronic pain condition?)
3. **Who do you live with?**
(What is the nature of your household situation?)

Experience

8. **What do you like about your job?**
(What do you enjoy about being involved in paid work?)
9. **What makes it difficult?**
(What are the challenges of having a paid job when you have an invisible chronic-pain disability?)
(Is it the invisible nature of chronic pain a blessing or a curse?)
10. **How does your work affect your personal life?**
(How does your involvement in paid work affect your home and family life?)
(What sacrifices do you have to make in order to keep your job? or stay at work?)
(What things in your personal life have you had to give up in order to keep working?)
(Are there other parts of your life that you feel you neglect because of your involvement in paid work? If so, what are they?)
11. **Is it worth it? Why do you keep working?**
(How do the benefits of work outweigh the challenges?)

Space

1. **What does your workspace look like?**

Get interviewee to draw their workspace or describe it if they don't want to / or can't draw

(What do you like about it? What do you not like about it?)

(How does the lay-out of your work space affect your ability to do your job?)

(What changes, if any, have you made to this space which help you to do your job better?)

2. How does the way that your workspace is set up help or hinder you?

(In what other ways do you think your work space helps or hinders your daily life?)

Strategies

5. What would be the ideal way for you to do your job?

(What types of support or help would enable you to do your job better?)

(What special tools or equipment enable you to do your job?)

6. What have you done to make sure that work doesn't negatively affect your health?

(What other arrangements have you put in place to ensure that paid work does not affect your health negatively?)

7. What have you told your boss about your pain? What issues did that / or would that raise?

(What have you told your boss and / or your work colleagues about your invisible chronic-pain disability?)

Stage 1 – Work diary and photos (focus on methodology rather than what they have or haven't done)

When I was setting up this research project I thought that the diaries were a good idea because you could do it when you were able to, but it required more from participants than I expected. I didn't think about it enough and so now I'm wondering if doing an interview is better.

How did you find the daily diary?

I found it hard and it made me depressed. Were either of these things an issue for you as well? (Note: Access if they are open to being led)

General

1. Scenario question – Have you had a bad day at work recently? Tell me about it

(You've come home from a bad day at the office, what are the kinds of things that have led to that being a bad day?)

- 2. If someone with your condition were to take on the kind of job you have what would you tell them?**
- 3. Is there anything else that you would like to add?**
- 4. Is it ok if I email you in a week to see if you have noticed anything else about your work that you'd like to share?**

Appendix I: Email Questions

Dear [insert participants name here]

I've reached the stage of my thesis project on The Experience of Paid Work of Women with Invisible Chronic Pain when I need to start the writing process and so I am sending you this email to see if you would like to take this last opportunity to provide a brief written contribution about your experience with chronic pain in the workplace.

I have included six questions below and if you choose to do so, you can share your experiences by answering these questions by return email. Alternatively, if you would like to talk about your experiences, you are still able to contact me to set up a time for a short interview. As it turned out, none of my research participants were able to complete the diary activity. It intrigues me why this happened and so Question 6 below asks about this.

If you would like your responses to be included in the project, I would need to receive your email reply by Wednesday 30th March 2016 (the Wednesday immediately after Easter).

I would like to take this opportunity to thank you for your participation in my project. I have very much enjoyed our conversations and have learnt a lot from listening to your stories.

Ngā mihi maioha

Charlotte

- 1. What is the nature of your current chronic pain and how long have you experienced it?*
- 2. What is your current employment situation?*
- 3. What are the key things that help you to do your job as a person living with chronic pain?*
- 4. What are the main challenges or barriers to doing your job well?*

5. In terms of your workspace, what is helpful and what is problematic in assisting you to do your job well?

6. What, if anything, would have made it difficult for you to keep a diary for a week?

Appendix J: Project Information Sheet

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Masters of Social Science Thesis Research Project Experience of Paid Work of Women with Invisible Chronic Pain

PROJECT INFORMATION SHEET

The Research Project

This research project seeks to explore the experience of women in paid work with invisible chronic pain. I am interested in this topic because I share this challenge, working as a Senior Tutor at the University while dealing personally with chronic pain. My degree is in Labour Studies so I have an interest in people's experience of work and workplaces. It is my hope that through this research project I will be able to identify useful ideas and strategies that will be beneficial to other women in similar situations.

The purpose of my Master's thesis project is twofold: firstly, to examine the experience of women in chronic pain so that they can be better understood and therefore accommodated at work; and secondly, to examine the strategies that women in chronic pain use to enable them to thrive at work and strive towards some kind of work/life balance. The project will focus on the achievements and successes of women in chronic pain who work as employees or are self-employed either in a part-time or full-time capacity. I am also interested in the positive effects that being involved in paid work can have for women's lives. The project will also analyse how the invisible nature of chronic pain can force women to relate to the work space and the people around them in different ways.

The research will collect information from three or four women and consider their experiences in-depth. Participants can choose to be anonymous, if they wish. It is important to me that participants are comfortable with every aspect of their participation in the project, and they may withdraw from it at any stage. The project has been given ethical approval by the Human Research Ethics Committee of the University's Faculty of Arts and Social Sciences.

What participation in this research project involves

As the researcher, I will ask you participate in an interview. This interview is likely to last between 30 minutes and an hour, and it could be done in two or three stages if you would prefer. If you live near Hamilton, the interview will be conducted in person. If you live further away, the interview will be conducted via Skype or a similar online technology. You do not need to answer any question in the interview if you do not want to. You may also choose to withdraw from the interview or this project at any stage. The interviews will be recorded so that I can later transcribe them and think about the issues that have been raised. All recordings and transcripts will be kept confidential – no-one except my supervisor and I will have access to them. However, I may quote some parts of your interview in my thesis to illustrate key points. I will keep a copy of your transcript in a secure manner for five years following the completion of the thesis – this is standard practice in case the University wishes to review the conduct of the research during this period. After that, the researcher's copies will be destroyed.

Some of the topics I will ask you about in the interview include:

1. What you enjoy about your job
2. What some of the challenges are with living and working with chronic pain
3. What your workspace is like
4. How working and living with chronic pain affect your personal life
5. How you balance your health and work demands

If you are considering participation in this project I will show you a Consent Form which sets out various aspects of participation in more detail and provides the means for you to stipulate the conditions under which you agree to take part. Such conditions are open to discussion and negotiation at any time.

How the Research Findings will be Made Public

This project will be written up in a thesis which will be lodged in the University Library and made available online by the university so that it can be easily accessed by anyone who is interested in it. Because there will be only three or four participants in this project the research findings will refer in some detail to each person and their experiences. If you choose to remain anonymous, material that identifies you will not be used, however, it is not always possible to achieve full anonymity. I will consult you about this when writing-up the thesis. Attention will also have to be given to the anonymity of people you refer to in your diaries.

After the successful completion of my thesis, I may present conference papers on the research and/or write academic articles about the subject, in order to advocate for and advance the interests of women with invisible chronic pain.

Your Rights

If you agree to take part in this research project, you have the following rights:

- a) To decline to participate in any part of the research that you are uncomfortable, with including declining to answer any question when being interviewed, and you may terminate the interview at any time.
- b) To ask any further questions about the research project that occur to you, at any stage.
- c) To remain anonymous, should you so choose to do so; this means that anything that might identify you will not be included in the thesis, conference presentations, academic articles or any other report about the findings of the research.
- d) To withdraw your consent at any time up until one month after viewing the transcript of your interview.
- e) To take any complaints you have about the research project to the University's Faculty of Arts and Social Sciences' Human Research Ethics Committee (University of Waikato, Te Whare Wananga o Waikato, Private Bag 3105, Hamilton 3240, or you can email its secretary at fass-ethics@waikato.ac.nz).

Contact Information:

If you are interested in finding out more about this project or in discussing your possible participation, please contact me as follows:

Researcher:

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