

**“If You Can’t See It, It Never Happened:”
The Legitimation Experiences of Women and Men
Living with Repetitive Strain Injuries of the Upper Extremities**

By Jennifer Werhun

**A Thesis
Submitted to the Faculty of Graduate Studies
In Partial Fulfillment of the Requirements
for the Degree of
Master of Arts**

**Department of Sociology
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Jennifer Werhun

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree**

of

Master of Arts

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ABSTRACT

Work-related upper limb disorders are widespread despite improved ergonomic awareness and practice (Gardiner, 1998). Women and men in today's workforce who sustain these disorders face the challenge of living with a contested condition. To date, there is little known about the legitimization experiences of persons with repetitive strain injuries (RSIs). This study is a qualitative examination of 12 women and men living with RSIs of the upper extremities. All participants were recruited from the Manitoba Federation of Labour Occupational Health Centre in Winnipeg. In-depth interviews were conducted in order to explore the legitimization of these conditions, and to show if and how the process differs by gender. Four main themes emerged from the interviews: the illness experience of RSIs, the presentation of symptoms, sources of legitimization and the recovery process. These themes revealed that women and men with RSIs negotiated definitions of their conditions in order to gain access to various forms of social support, and to confirm their identities in the eyes of physicians, employers, co-workers, friends, family members, and themselves. The strategies adopted by participants to facilitate the acceptance of their RSIs challenge the conception of ill persons as passive agents in the legitimization process. Comparison of the stories of female and male participants also revealed that gender shaped the experience of RSIs. The women and men in this study differed with respect to the value placed on the external and internal legitimization of RSIs, and rehabilitation outcomes. Their accounts contribute to the qualitative literature of RSIs, and provide insight into the impact of gender and context on the experience of a work-related condition that is contested.

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TABLE OF CONTENTS

Abstract	i
Acknowledgments	ii
Table of Contents	iii
List of Figures and Tables	vi
Chapter 1. Introduction	1
Chapter 2. Research Context	5
I. <u>Review of the Literature</u>	6
A. The Rise of RSIs: When and Why?.....	6
Defining the Problem	6
What’s In a Name?: The Issue of Terminology	8
The Relation of RSIs to Work	10
Women and Work	12
Workplace Safety: An Option or Requirement?	16
Medicine and the Diagnosis ‘RSI’	19
Clinical, Solicitude, and Psychological Frames of Diagnosis	19
Who’s in Charge Anyway? The Treatment of RSIs	24
B. The Social Control of RSIs	27
C. The Illness Experience of RSI	30
Physical and Social Consequences	31
D. The Legitimation Experience of RSI	37
‘Looks can be Deceiving’: The Invisibility of RSI	39
Presentation of Symptoms	42
The Evaluation of Illness	45
Physicians and other Health Care Professionals	46
Employers/Co-workers	48
Family members and Friends	50
E. The Importance of Legitimation	52
II. <u>The Conceptual Framework</u>	54
A Concept Map	54
Symbolic Interactionism	58
Impression Management	59
Public and Private Accounts of Illness	60
Phenomenology	63

III. <u>Research Questions</u>	65
Chapter 3. Research Methods	66
Research Process	66
i. Sample Selection	66
ii. The Interviews	69
iii. Data Analysis	74
Chapter 4. Participants in the Study	78
Summary of Participants	78
Profile of Female Participants	81
Profile of Male Participants	88
Chapter 5. Findings of the Study	96
I. Introduction	96
II. The Illness Experience of RSIs	97
Physical Consequences	97
Social Consequences	101
Economic Consequences	104
Gender Differences	107
III. The Presentation of Symptoms	109
The Invisibility of RSIs	109
Non-Verbal Communications	112
Verbal Communications	113
Complaining vs Disclosure	116
Gender Differences	118
IV. Sources of Legitimation	121
External Sources	122
Gender Differences	139
Internal Sources: The Self	143
Gender Differences	145
V. The Recovery Process	147
Gender Differences	152
Chapter 6. Discussion and Conclusions	156
The Process of Legitimation	156
The Importance of Context	166
Does Gender Matter in RSIs?	172
Limitations of the Study	183
Implications and Directions for Future Research	186

Bibliography192

Appendices204

Appendix A. Recruitment Letter205

Appendix B. Demographics Sheet206

Appendix C. Consent Form208

Appendix D. The Disabilities of the Arm, Shoulder and Hand Questionnaire211

Appendix E. Interview Guide212

Appendix F. Summary of Study Discussion 216

LIST OF FIGURES AND TABLES

Figure 1. The Process of Legitimation for Persons Living with RSIs	56
Table 1a. Age of Participants	78
Table 1b. Marital Status of Participants	78
Table 1c. Education History of Participants	79
Table 1d. Current Employment Status of Participants	79
Table 1e. Employment at Time of Injury	79
Table 1f. Form of RSIs of the Upper Extremities	80
Table 2a. Rating of RSI Symptoms by Male Participants	98
Table 2b. Rating of RSI Symptoms by Female Participants	99
Table 3. The Experience of RSIs for Participants	174

Chapter 1. Introduction

“If there is a single experience shared by virtually all chronic pain patients it is that at some point those around them...come to question the authenticity of the patient’s experience of pain.”(Kleinman, 1988 cited in Eccleston et al., 1997:706).

Repetitive Strain Injuries (RSIs) are referred to as “occupationally related pain in the upper limbs, lower back, and neck from tasks producing high static loads on neck and upper limbs” (Sikorski, 1988:81). Symptoms of the condition are vague and non-specific, and include general joint pain, inflammation, stiffness, and/or numbness of the affected limb (Kome, 1998). Currently there are women and men scattered across the globe dealing with the pain and disability of RSIs on a daily basis. The National Population Health Survey in Canada revealed that in 1996/1997 “nearly two million people aged 12 and older sustained RSIs that were serious enough to hamper their usual activities” (Statistics Canada, 1998). This figure translates roughly into one in 14 Canadians (Kome, 1998:7). In 1992, upper limb work-related musculoskeletal disorders constituted 24% of workers’ compensation claims for lost time in Ontario (WCB Ontario, 1993 as cited in Polyani et al., 1997). Similarly, there are a growing number of cases of RSIs in the United States. The U.S. Bureau of Labour Statistics reports that in 1996 “repeated trauma accounted for 61% of all illness in the workplace” (Baker, 1999:97). It was even predicted by the U.S. government that by the year 2000, 50 cents of every dollar will be spent on RSIs (Melhourn, 1998: 107). However, despite the high incidence of these conditions, RSIs remain a contentious issue (Gilbert et al., 1997).

While medical bodies recognize the existence of RSIs, they have yet to agree upon

a specific medical definition (Brown, 1995). RSIs challenge the medical model which has long dominated Western medicine. Within the biomedical paradigm, illness is 'proven' with physical evidence that meets medical criteria (Dodier, 1994). Those illnesses that do not readily fit into medical categories are discounted. Cooper (1997) points out that there are several conditions which have been denied the legitimate status of 'organic disease' in medicine. RSIs are one of these "non-diseases," due to their symptoms and uncertain aetiology (1997:186). Symptoms of RSIs are neither visible nor measurable (Schlesinger, 1993); they are a "hidden disability" (Stone, 1983: 618). RSIs are also difficult to define because they are associated with a multitude of factors, and cannot be easily related to one causative agent (Gilbert et al., 1997). Identifying the factors responsible for the development of RSIs becomes an even greater task when the condition is deemed work-related. Decisions must be made as to whether or not the root of the problem lies within the body and mind of the injured worker, or outside in the workplace. Disputes continue between medical practitioners, employers, unions, and the persons living with the condition on whether upper limb conditions should be regarded as work-related disorders (Gardiner, 1998). It must be noted that illness, injury, condition, and disease are concepts used interchangeably throughout the literature of RSIs.

While the medical and political aspects of RSIs are well documented, the personal dimensions of the condition are less understood. Cohn (1999) argues that persons living with contested conditions seek recognition for their subjective experiences, which are at odds with the medical discourse based on the principles of objectivity. Persons living with conditions like RSIs may find that others are reluctant to validate their experiences

when the physical signs of illness or injury are missing. As a result, women and men with RSIs are vulnerable to accusations and/or labels of malingering (Dembe, 1998), neurosis (Lucire, 1986), and even hysteria (Hocking, 1987). Legitimation is considered key to self-esteem and to the receipt of support, help, and information (Schlesinger, 1993). Thus, for persons with RSIs, being believed by those around them can mean having access to a diagnosis and treatment, compensation, task adjustments at work, and role negotiation in the home.

The legitimation of RSIs by others can also influence whether or not the person living with the condition is able to accept and legitimate its presence in her/his own life. When a person's complaints are met with doubt and suspicion, negative views of illness and self can result. In these circumstances RSIs have been related to social isolation, feelings of anger and helplessness, guilt and hopelessness, and even attempted suicide (Bammer & Blignault, 1998; Meekosha & Jakubowicz, 1986). There is relatively little known about the limits of tolerance within families and workplaces when it comes to chronic illness (Bury, 1991). Persons living with RSIs interact with physicians, employers, co-workers, friends and family, all of whom may evaluate whether or not the condition is 'real.' These interactions need to be examined from the perspective of the individuals living with the condition to determine how reactions to RSIs by those in the public and private sphere affect the meanings they give to pain. In turn, these interactions shape their experience of illness.

According to Thorne et al. (1997:2), the social experience of illness is "neither gender nor context neutral." Thus, the influence of gender on the experience of illness

cannot be overlooked. Studies indicate that women sustain RSIs twice as often as men (Doheny et al., 1995). In fact, Newport (2000) reports that carpal tunnel syndrome (CTS) is one of the few conditions that affect women in significantly greater numbers than men. However, the gendered experience of RSIs has not been explored. Consequently, it is not clear if and how gender influences the everyday lives of women and men living with these conditions. By giving a voice to women and men with RSIs, the legitimization and illness experiences of persons with these conditions can be understood, and the influence of gender on these processes can be uncovered.

The purpose of this study, then, is to explore the process used by women and men living with RSIs of the upper extremities to seek legitimization, and to determine if and how this process differs by gender. Chapter Two provides an overview of the literature on RSIs. It addresses the sociopolitical aspects of the condition, as well as the illness experience of RSIs. The conceptual framework and objectives of the study are also outlined in this chapter. Chapter Three describes the research design of study. This chapter reviews the qualitative methods used to collect data from the participants in the study. Strategies used in the analysis of data are also discussed. Chapter Four contains the summary of participant characteristics, and includes the individual profiles of the women and men in the study. Chapter Five features the experiences of women and men living with RSIs of the upper extremities. This chapter is divided into a number of sections, each of which represents an aspect of the legitimization experience of RSI. Chapter Six develops the findings of the study in the context of the literature, and examines the limitations of the study, directions for future research and conclusions.

Chapter 2. Research Context

According to Turner (1987:15), a sociological examination of RSIs requires the analysis of vested interests of conflicting professional groups and inquiry into the perceptions and interpretations of the disorder for those living with the condition. The issue of RSIs is not merely medical, but political and economic (Ranney, 1997). RSIs are related to struggles between doctors, lawyers, the media, compensation representatives, union leaders, and therapists of all kinds (Ranney, 1997). Each of these social groups has something to gain from the appearance or disappearance of the problem (Martin and Bammer, 1997), and will support or advocate one causal explanation over another. However, as much of the literature of RSIs lacks a qualitative focus, the impact of the various definitions and explanations of RSIs on the individuals living with the condition cannot be determined.

Understanding RSIs at the social and individual level will uncover the linkages that exist between macro and micro worlds. The interplay between society and its members cannot be underestimated. Thus, a socio-political examination of RSIs will not only provide the necessary background on *why* this occupational illness is disputed by managers and various medical practitioners; it will also demonstrate *how* the controversy affects the process of legitimation and illness experience for women and men with the condition.

I. The Review of the Literature

A. The Rise of RSI: When and Why?

Defining the Problem

It has only been in recent years that RSIs have reached “epidemic” proportions (Stone, 1983:616). As early as 1713, Ramazzini observed and documented the various disorders of scribes and trade workers as having what is known in this century as “writer’s cramp” (Gilbert et al., 1997:51). By 1888, it was recognized that the problem was present among workers in various occupations; in addition to writer’s cramp, there was also “piano player’s cramp,” “seamstress’ cramp,” and “telegraphist’s cramp” (Melhourn, 1998:108). Diagnoses became more specific with the growth of medicine and the increase in knowledge of the anatomical structures of the upper limb. In 1918, the term tenosynovitis was put forth by Troell to describe the pain and swelling that accompany inflammation of the tendon sheath (McDermott, 1986). By 1941, it was postulated by Woltman that pain in the upper limbs could also result from compression of the median nerve, particularly in the carpal tunnel (Stone, 1983).

History shows that conditions like carpal tunnel syndrome, tenosynovitis, and de Quervain’s disease are not new. Rather, it is the umbrella term ‘RSIs,’ under which they are placed that is new (Gilbert et al., 1997). Thus, although RSIs have in fact been in existence for a long period of time, they are still referred to as a new industrial epidemic (Gilbert et al., 1997).

RSIs are described as “musculoskeletal disorders created by repeated or sustained

stressors, physical and psychological, which are beyond the capacity of the body to withstand without damage” (McPhee, 1992:102). Symptoms of RSIs can range from general joint and muscle pain and inflammation, to loss of strength, feelings of clumsiness, and total numbness (Fraser, 1985; Kome, 1998). Symptoms become progressively worse over time and can lead to permanent disability if not recognized and properly managed (Kome, 1998). In the initial stages of RSIs, pain appears when doing work activities, but then disappears a couple of hours after work. If treatment is sought at this stage, the RSI can be treated promptly and corrected without after effects (Kome, 1998). However, as it is common to be sore and tired after work, most people will not contact a doctor until symptoms are more severe (what is referred to as stage two or three of the condition).

In stage two of RSIs, pain and discomfort persist during work and into the evening, where they disrupt sleep, but are gone before morning (Kome, 1998). If an individual has not seen a doctor by stage three, recovery becomes difficult. By this point, pain is present most of the time, especially when engaging in activities that involve the affected area (Kome, 1998). Muscle strength will have depleted to the point that everyday tasks such as turning a faucet and opening a jar are a challenge (Kome, 1998). Symptoms can last from several weeks to several years. Where an individual exists within the continuum of symptoms will depend on the severity of the RSI and her/his exposure to exacerbating factors.

RSIs can occur in “any muscle group where the muscle is used repeatedly for long uninterrupted periods with the posture in a relatively fixed position” (Doheny et al.,

1995:7). They are associated with a number of factors including rapid, repetitive movements, less frequent but more forceful movements, static loads (Stone, 1983), posture (Kome, 1998), and awkward positioning of hands and wrists (Fraser, 1985). Heavy work, vibration and direct pressure are also precipitating risk factors (Gilbert et al., 1997). Since these factors are likely to occur in combination with one another, it is difficult to isolate the precise source of a RSI. It is this absence of a single inciting event that makes RSI an “occupational illness, not injury” (Weinstein et al., 1997:16).

But if RSI is not an injury, why have the ‘I’ in RSI? It is this question, along with many others, that have led researchers and scientists from various disciplines to challenge the term and conclude that it is misleading and thus inappropriate.

What’s In a Name? The Issue of Terminology

Currently there is no international standardization of terminology for RSIs (Gilbert et al., 1997). In addition to ‘RSI,’ there are numerous vague terms circulating in and between countries, all of which describe similar disorders of the joints and soft tissue. The presence of the various terms is reflective of the lack of understanding that exists about them (Stone, 1983). The term “occupational cervicobrachial disorder” was established by the Japan Association on Industrial Health in 1972, in response to an outbreak of cervicobrachial disorders among workers between 1960 and 1980 (Melhorn, 1998:111). In Scandinavia and Sweden these disorders have been discussed as “tension neck,” and in Finland as “occupational disorder” (Melhorn, 1998:111). Canada uses the term RSIs. It may also appear as “repetitive stress,” “repetitive motion,” or “repetitive

bodily motion disorder” (Kome, 1998:4).

The acronym ‘RSI’ was coined in 1982 by Australian researchers in connection with a large incidence of upper-limb injuries in the 1960s and 1970s (Gilbert et al., 1997). While the term ‘occupational overuse syndrome’ has recently replaced RSI in Australia, during the peak of the ‘epidemic’ in the early 1980s the RSI acronym was in use. Hopkins (1990:367) believes that it was the presence of a “simple and universally used term” that facilitated the social recognition of RSIs in Australia, and not the United States. Americans have adopted the term “cumulative trauma disorder” to refer to musculoskeletal pain that an individual believes to be associated with activities performed at work (Melhorn, 1998:113). This term has been used interchangeably with RSI, musculoskeletal problems, and the more specific diagnosis of CTS (Hopkins, 1990). Hopkins (1990) postulates that this lack of uniform terminology has hindered the widespread awareness and acceptance of the problem.

The absence of a single term or phrase can, in part, be attributed to the difficulty in creating or locating a name that accurately represents the condition. While the term RSI is commonplace in the media and medical literature (Gilbert et al., 1997), it has received criticism from a variety of scientists and health care professionals (McDermott, 1986; Semple, 1991). The leading argument against the use of RSI is that the term implies the relation to particular work tasks, despite a lack of epidemiological evidence (Melhorn, 1998). Consequently, the name “work-related musculoskeletal disorders” is gaining popularity for “while indicating a relationship to work, it does not imply a sole cause” (Gilbert et al., 1996:52).

The term 'RSI' is used in this study, rather than 'work-related musculoskeletal disorders,' because it is widely used and thus is familiar among members of the public.

The Relation of RSIs to Work

While there are numerous explanatory models in the RSI literature, the "standard" view is the classification of the illness as work-related (Reid and Reynolds, 1990:164). Supporting this view is the growing documentation of the causative role occupational risk factors play in the development of RSIs (Gerr et al., 1991; Stock, 1991). Included in this literature are critical examinations of the changing structure of work, work environments, and the introduction of technology to the workplace.

Our society is distinguishable from others in the forces and relations of production. As a capitalist society, the prominent concern is "the expansion of markets and the reduction of costs" (Kelman, 1975:631). When a state is based on capitalism, economic productivity and profitability prevail, even if it is at the expense of the individual worker (Clarke, 1996). Profitability comes before human need; the construction of a safe working environment does not occur if it is a cost to employers. In comparison, a 'wise' investment is the introduction of machinery and other labour-saving devices to the workplace, to allow for greater productivity in a reduced amount of time. Semple (1991) points out that the presence of conditions like RSI has increased as the amount of physical effort required of workers has decreased. As a result, the contributions of machinery and factory work are not as impressive when production is "weighed against the disadvantages of repetitive movements and monotony, which lead to physiological

overuse and strain” (Mandel, 1987:87).

According to Kelman (1975), the nature of work, the level of technology, and the pace of automation all originate from the pursuit of profit. Consequently, the likelihood of developing a RSI is open to all workers. Economic restructuring and time-saving technologies in today’s workplace makes it a prime site for musculoskeletal injuries. With the domination of twentieth century capitalism by large corporations (Clarke, 1996), the negative impact of work on the human body persists and intensifies. Work has become increasingly segmented and mechanized, shifting the focus of work from the back to the eye, “where hands and arms are the most vulnerable structures” (Yassi et al., 1996:471).

RSIs are common among workers who spend extended periods of time in front of the computer and on the keyboard. The term “computeritis” has been used to describe the painful upper limb disorders of computer operators (Thompson and Phelps, 1990:143). While computers ease the retrieval of information, the physical risk factors associated with video display terminals include lack of forearm support and constrained neck postures (Evans, 1987). Although desk jobs allow for more sitting to take strain off the back, without proper ergonomic considerations, the body is put under physical stress. Assembly line workers may find themselves repeating motions thousands of times a day (Yassi et al., 1996). New tools designed for efficiency often require excessive force, twisting, and a strong grip, and thus contribute to the problem (Fraser, 1985; Melhorn, 1998). RSIs can also be found among those working under deadlines, facing job pressure, and experiencing inflexibility in tasks and break times (Polyani et al. ,1997).

The relationship of RSIs to occupational factors cannot be denied; high hand force, gripping, exposure to vibration, and/or awkward joint postures are present in most work activities (Sprout, 1997). Consequently, RSIs appear in many different kinds of industries and occupations. Yassi et al. (1996) examined the 1991 Workers Compensation Board injury claims data to determine high risk industrial sectors in Manitoba. Manufacturing was found to be the industry with the greatest prevalence of RSI claims; packing houses, meat products and poultry processing plants, and stock yards were high risk sectors, followed by such industry groups as bakeries, dairy products, tanneries, welding shops, and rolling mills (Yassi et al., 1996). Electronics assemblers, cashiers, nurses, clerical workers, seamstresses, and cleaner/janitors also work in jobs characterized by risk factors for RSIs (Fraser, 1985; Gilbert et al., 1997; Kome, 1998). Workers at risk of developing a more specific form of RSI, such as carpal tunnel syndrome include butchers, hairdressers, dental hygienists, and sign language interpreters (Kome, 1998). It should be noted that aside from the heavy manufacturing jobs listed, most women work in occupations where the risk of developing RSIs is high.

Women and Work

Since the industrial revolution, there has been an influx of women into the paid workforce. The introduction of machinery did not only affect and improve productivity, it also adjusted the profile of workers. Machines opened up the paid labour force to include both women and men; women could now perform those tasks that were previously segregated by muscle power. In 1901, only 13% of Canadian women were employed

outside of the home (Grabb, 1992). In 1999, Statistics Canada reports that this proportion has reached 58.9% (Statistics Canada, 1999). It has been estimated by the U.S.

Department of Labour that over the next 10 years (1999-2009), nearly nine million American women will be in the labour force (Biddle and Blanciforti, 1999). Yet despite the strong presence of women in the labour force, occupational segregation still exists.

Hyde (1996:198) considers occupational segregation a critical issue because it limits work options and contributes to the gender gap in wages. However, the relationship between occupational segregation and illness must also be considered. The proportion of injuries in Canadian women has increased every year from 1984 and 1992 in all industries (Clement, 1996:1). More specifically, women are at greater risk than men for developing work-related musculoskeletal disorders (Ashbury, 1995; Faucett, 1997; Kome, 1998; Sprout, 1997). In 1993, women sustained 64% of occupational disorders caused by repetitive motion (U.S. Bureau of Labour Statistics, 1995 as cited in Faucett, 1997). Feuerstein et al. (1998) examined 2,535 claims accepted by the Office of Workers' Compensation Programs in the U.S. Department of Labour and found that females accounted for 71% of all carpal tunnel syndrome diagnoses, while males only accounted for 29% of cases. With the higher proportion of women developing RSIs, it appears that the processes of work performed predominantly by women are less understood in terms of their impact on individual health (Ashbury, 1995).

Newport (2000) points out that over the last 30 years, women have increasingly entered jobs requiring repetitive tasks. The performance of computer work for extended periods of time is common among women employed in clerical and administrative

occupations (Clement, 1996). Without proper ergonomic work stations and flexibility in tasks, these women are likely to sustain injuries to the hand, wrist or fingers (Clement, 1996). With regards to sewing machine operators, poor posture and constant motion contribute to the development of RSIs. The risk of disability for garment workers increases with the number of years on the job (Brisson et al., 1992 as cited in Faucett, 1997). Supermarket cashiers are also likely to suffer from RSIs. Scanning up to 600 items per hour, prolonged standing, and an invariable keyboard contribute to an unsuitable working environment (Harber et al., 1993). Ergonomic problems also exist for women involved in electronics assembly. Muscles are strained due to upper limbs remaining in a fixed position, twisting, pulling and putting small parts together (Kome, 1998).

With the increase in educational and training opportunities, women have also entered occupational fields traditionally held by men. However, it should not be assumed that women who share the same job title as men will have similar working conditions (Messing, 1997). Evans (1987) distributed a survey to British video display operators involved in data processing, programming, and information retrieval, and found that female operators engaged in continuous, rapid, less varied tasks, while male operators worked for shorter periods of time at the terminal, and took breaks more often. In an analysis of train cleaners in France, Messing (1993) found a clear sexual division of labour. Male workers drove a water cart to fill bathroom reservoirs, swept aisles, or held the position of foreman, while female workers polished railings, and cleaned toilets, which forced them to bend and scrub for a significant amount of time in a small space. These examples are reflective of the general pattern of task assignment by gender; men

tend to perform physically strenuous work with greater task variety while women tend to do more rapid, repetitive tasks with less variety, often requiring them to stand motionless (Clement, 1996; Messing, 1997; Sprout, 1997).

A different problem exists for those women filling positions that were at one time solely filled by men. They must use the tools that were originally designed for male workers (Fraser, 1985). Tools and equipment tend to be unavailable in the right dimensions for women (Messing, 1997). They may be too large, too heavy, too awkward to hold, or too difficult to grasp, placing extra strain on the joints of women. Thus, it should not be assumed that the same tools and tasks interact the same way with women's and men's bodies (Messing, 1997:43).

Since the industrial revolution, the length of the work day has changed in order to equally divide time for work, leisure, and sleep (Dreidger, 1991). However, for most women, leisure time does not begin when they leave their jobs, i.e., women's participation in the public sphere has not replaced their responsibilities in the private sphere. In our society, "we have not yet achieved a system in which women have equal relationships with men at work and at home" (Hyde, 1996:207). Consequently, women return home from work to perform a 'second shift,' as they remain responsible for housework and childcare (Singer, 1991). Leisure time is further diminished for the increasing number of women who care for an elderly parent (Arber and Ginn, 1991).

Studies in the 1970s found that if the paid and unpaid dimensions of women's work are accounted for, "over the course of a year, women work an extra month of 24 hours" (Hyde, 1996:206). With the amount of physical energy and time spent working, it

is not unfair to say that women do so at the expense of their health. However, illness is a cost for both the workers and the owners/managers of the workplace. Workers suffer physically and emotionally, and owners/managers face the financial challenges of sick leaves, time loss claims, and compensation.

Workplace Safety: An Option or Requirement?

Each RSI claim filed represents a cost to employers. Costs include the loss of workers to disability, and thus a loss in overall productivity. In 1992, it was estimated that lost productivity in the United States amounted to \$7 billion (Kome, 1998). According to the Workers Compensation Board of British Columbia, in 1996 musculoskeletal injury claims amounted to \$143 million. When RSIs are deemed work-related, employers face “fines, increased insurance levies...as well as additional indirect costs through employee retraining and replacement, production losses and reduced morale” (Gardiner, 1998:4). A growing number of employers have encountered a 100% to 300% rise in worker compensation premiums (Stone, 1983), and in 1987, Ontario workers received compensation for RSIs which accounted for 600,000 lost days of work (Gilbert et al., 1997).

While these figures are startling, they are small in comparison to the costs that would be incurred if all claims were filed and compensated. Kome (1998) comments on the difficulty people face having their RSIs deemed work-related by Workers Compensation Board case managers. She points out that when work-relatedness is the question, it is the claimant, not the employer who is on trial (Kome, 1998:95). A history

of activities the claimant participates in will be documented and scrutinized, to identify any non-work factors that may have caused the RSI. A worker may have her/his claim refused if s/he engages in sports (particularly those that involve swinging the arm, such as golf or tennis), sewing, knitting, housework (especially vacuuming and ironing), as well as writing, gardening, and driving (Kome, 1998). As many of these activities are a part of daily life, workers are put in a vulnerable situation from the beginning when trying to obtain compensation. Without access to compensation, workers can either return to work, find a new job with lighter duties, or leave the workforce altogether.

The problem of RSIs is taken more seriously when the number of injured workers is large, and employers find it difficult to replace them (Ranney, 1997). This situation will force an employer to take action (Kome, 1998). The introduction of ergonomics to some workplaces indicates that some employers are taking responsibility for occupational illnesses. The field of ergonomics deals with the modification of work stations and job designs in order to ensure that physical stresses on the job will not lead to injury (Melhourn, 1998). Those employers willing to introduce safety measures to prevent occupational injuries and illnesses may suffer financially initially, but will profit in the long run (Martin and Bammer, 1997).

A number of employers have established workplace guidelines and regulations in the name of prevention. The Japanese Ministry of Labour created policies in 1964 requiring that keyboard operators perform less than 40,000 keystrokes per day, and work for no longer than five hours at a time (Nakaseko et al., 1982 as cited in McDermott, 1986). The U.S. Occupational Safety and Health Administration is attempting to develop

legislation with regards to “tolerable” repetitive action and force (Ranney, 1997:289). In Canada, British Columbia is the only province to have added a section on ergonomics to the Occupational Health and Safety Act in an effort to prevent musculoskeletal injuries in the workplace (Kome, 1998). However, a “legislative vacuum” exists elsewhere in Canada; while some employers have implemented RSI prevention plans, others are resisting ergonomic regulation (Kome, 1998:175).

Not all employers will choose to reorganize and restructure the work environment in order to make it a safe place. When it comes to occupational health, there are employers/managers who hold the assumption that a work injury is a “chance” happening (Ranney, 1997:287). Thus, rather than putting effort into preventing the appearance of cases, each worker presenting a RSI will be treated as they come along. Cases are treated as being due to mishaps or accidents on the part of the worker, on the assumption that they would normally not have occurred had the worker been more careful. Leaving safety up to the worker is not an uncommon mentality among employers. Eakin (1992) studied occupational health and safety within the context of small workplaces. Upon interviewing small business owners on the issue, she found that many shared the perspective that safety was the responsibility of the worker. She found a tendency to normalize or discount health hazards. By placing a focus on the individual worker, the onus of responsibility for occupational injury is removed from the employer and the environment in which individuals work. The logic is as follows: if the employer is not responsible for injury, then s/he is also not liable for injury.

Medicine and the Diagnosis of ‘RSI’

Diagnosis is “central to the work of all medical professionals” (Brown, 1995:39). Physicians are taught the different structures of the body, and learn to locate and identify the source of injury or disease in order to initiate treatment and restore health. However, the manner by which physicians judge the legitimacy of claims and arrive at diagnoses will vary. In his examination of the medical judgements of physicians, Dodier (1994) found that frames guide the interpretations of an individual’s complaints. These frames differ chiefly in terms of the extent to which the physician places priority on subjective and objective symptoms.

As Dodier’s study focused on physicians practicing occupational medicine, the findings have implications for the diagnoses of occupational injuries, and RSIs in particular. The frames discussed by Dodier (1994) will be used in this section to organize the debate about RSIs within and between medical circles, the core of which is whether or not a diagnosis of ‘RSI’ can be made when there is little consensus concerning its cause, clinical features and prognosis (McDermott, 1986).

Clinical, Solicitude, and Psychological Frames of Diagnosis

Physicians operating from a strictly clinical frame do not consider the claims of the patient to be ‘real’ until there is “proof” of their existence (Dodier, 1994:492). This frame reflects the medical model which has long dominated Western medicine. Within this context, “an individual grievance cannot be satisfied on its own merits...it must also correspond to objective criteria” (Dodier, 1994:492). For example, a physician will not

issue a diagnosis because a patient believes the burning sensation in her/his wrist is inflammation; swelling in the affected area should be present. In accordance with the doctrine of specific etiology, physicians believe that there is a specific cause for every ailment, which can be located using their tools and expertise.

As there is no current assessment tool for RSI, it is difficult to determine the exact nature of causation (Blanc et al., 1996). With no way of measuring symptoms and determining the diagnostic criteria for RSIs, the question, “is it or is it not a specific medical condition?” remains unanswered (Boyling, 1998:107). There are some medical practitioners and scientists operating within the clinical frame who believe there are no tools to measure RSIs because there is in fact nothing to measure, i.e., there is no underlying pathology (Ranney, 1997). Others argue that there is no physical evidence of RSIs because “medical science has not yet developed the methods or insight to explain what is happening” (Ranney, 1997:106).

Within the clinical frame, the absence of abnormal values or ‘proof’ of injury can lead physicians to dismiss the complaints of their patients as unsubstantiated. They consider symptoms as not being due to an underlying medical condition. As traditional medical thinking locates the source of illness inside the human body, physicians will perform numerous in-depth physical examinations, and request X-rays and blood work to rule out the presence of any systemic diseases that may have manifested themselves in symptoms similar to RSI (Braker, 1993). Disorders with symptoms related to RSIs include gynecological surgery, arthritis, diabetes, and previous acute trauma (de Krome et al., 1990 as cited in Sprout, 1997). When the patient is female, the physician may also

give attention to hormones since RSIs are associated with pregnancy, breast-feeding, the use of oral contraceptives, and menopause (Kome, 1998; Sprout, 1997). Due to the high prevalence of RSIs among women, some employers support the notion that the biological make-up of women predisposes them to the occupational condition (Kome, 1998:95). In their examination of women with RSIs, Reid et al. (1991:610) found that the women were provided with explanations of RSIs relating to their reproductive function by health care professionals. It is unlikely that men with RSIs will face such explanations as there does not appear to be a similar attribution of RSIs in the literature to male hormones. Consequently, arguments relating RSIs to female hormones are weak and offensive to women.

A portion of the physician's examination may also include taking a patient history to determine the duration of symptoms, as well as any behaviors that may have precipitated the pain and discomfort (e.g., alcohol, tobacco, and caffeine consumption have been related to the development of CTS) (Nathan et al., 1996; Sprout, 1997). Physicians operating within the clinical frame will go through a process of elimination during a diagnosis to rule out the various potential causes of illness. Without a positive test result from any of the procedures that are performed, the physician cannot issue an accurate diagnosis, nor proper treatment.

In comparison to physicians operating within the clinical frame, where the objective signs of illness must be present before making a diagnosis, there are physicians who consider the presence of such signs as irrelevant and label individuals as sick in their absence (Mishler, 1981). Within the context of "solicitude" frames of diagnosis,

physicians acknowledge that pain is a subjective experience (Dodier, 1994:498) and not necessarily a sign of physical injury or damage (Eccleston et al., 1997). Thus, the physician will believe a patient when s/he says “it hurts,” even if there is little evidence suggesting a reason for the pain; “we [physicians] can’t find any objective proof, but we have to take account of a complaint” (Dodier, 1994:498). Although these doctors do not completely abandon the search for ‘proof’ of illness, they will concern themselves with subjective symptoms when forming a diagnosis. Consequently, a diagnosis of RSI can be given when a person reports symptoms such as burning, tingling, and stiffness, but does not show objective evidence of them.

Rheumatology is a medical field that has been especially helpful in diagnosing RSIs. In fact, people with RSIs are often referred to a rheumatologist or an orthopaedic surgeon by a general practitioner (Kome, 1998). Rheumatologists are considered to work within solicitude frames of diagnosis, for they recognize the relationship between localized pain and tenderness at different sites throughout the musculoskeletal system (Arksey, 1994). With the adoption of a “holistic approach” to care, body parts are not isolated from one another, and the effect of damaged parts on one another is not overlooked (Arksey, 1994:458). For example, rheumatologists will treat an individual for back pain, even though injury has been sustained to the neck. In understanding that there are numerous factors related to joint pain, they may be more likely to support the existence of RSI than those medical professionals making medical judgements within a strictly clinical frame.

There are some medical scientists and clinical practitioners, including orthopaedic

surgeons who believe that RSIs have a psychological basis, and not an organic one (Hopkins, 1989:244). The attribution of illness to psychological factors is due to the medical reasoning, “if there are no observable signs, the illness cannot be real” (Arksey, 1994:459). Currently, however, there is no direct way to distinguish between ‘real’ and ‘unreal’ pain (Jackson, 1992). Yet physicians operating within the clinical frame may attempt to do so; they will question the legitimacy of complaints that are not observable and try to address the source of the “hidden suffering” (Dodier, 1994:504). In this manner, the psychological frame of medical judgement is a combination of the clinical and solicitude frames.

There are a number of research studies examining the relationship between a RSI and occupational or emotional grievance. In his review of mass psychogenic illness among Malay cultures, Hocking (1987) suggests that the occurrence of illness among women working in particular occupations may be a reflection of the powerlessness over their work situation. He points out that the Malay women may react this way in fear of disapproval of expressions of their unhappiness, i.e., “illness is seen as a safety valve” (Hocking, 1987:528). Others have used the term “mass hysteria” to describe the similar occurrence of a widespread group reaction to work (Ferguson, 1987:213). In the early part of the twentieth century, the condition described as “writer’s cramp” was considered likely to attack “people of nervous temperament” (Quintner, 1989:1006). By 1910, writer’s cramp became known as a form of neurosis, and was removed from the list of injuries covered by the British Workman’s Compensation Act (Melhourn, 1998). Few studies have been able to identify the various components of psychological reaction to the

workplace (McDermott, 1986). Despite the ambiguous relationship between psychological factors and the development of RSIs, the perspective that occupational injuries are a form of neurosis remains popular today.

Occupational neurosis occurs when workers “unconsciously develop symptoms in order to obtain compensation, either monetary or psychological” (Martin and Bammer, 1997:103). The concept of malingering is similar to occupational neurosis in that the individuals are viewed as using their illness for personal gain. However, a difference between the two is that with malingering, workers deliberately develop symptoms or fake pain and disability as a means to have access to privileges they may not receive otherwise (Martin and Bammer, 1997). The gains of illness will vary according to the needs and wants of the individual. Incentives may include financial rewards in the form of compensation, litigation rewards, and disability income, or less tangible payoffs including the “manipulation of others and avoidance of work, domestic, or social responsibilities” (Craig et al., 1999:41). While the rewards that may be gained are quite large, in reality the actual incidence of malingering is quite low (Jensen, 1997). Regardless of the small number of cases, clinicians still consider malingering when medico-legal issues arise, and when there is a discrepancy between disability and clinical findings (Craig et al., 1999).

Who's in Charge Anyway? The Treatment of RSIs

The lack of medical consensus on the cause of RSIs makes decisions regarding treatment difficult. Just as there is a range of disorders that fall under the acronym “RSI,” there is also a range of treatment options that may be prescribed to an individual.

Treatments can include everything from rest, immobilization, stretches, splints, and chiropractic, to non-steroidal anti-inflammatory drugs, steroid injections, and surgery (Kome, 1998). Overall, treatment of RSI does not tend to be successful, and in many cases prolonged disability and chronic pain occur (Guidotti, 1992 as cited in Yassi et al., 1996; Quinter, 1989). Surgery will not be performed for all RSIs, but is done to treat nerve entrapments. Endoscopic flexor retinaculum release is a common surgical procedure done to correct CTS (Palmer, 1995). However, the growing awareness of the debilitating conditions (such as reflex sympathetic dystrophy) that can result from surgically treating CTS has led organizations, including the American Society for Surgery of the Hand to promote more conservative methods of treatment (Kome, 1998). Surgery is also inconvenient. Pain experienced after surgery can interfere with the return to daily activities and, in the long run, the benefits may be minimal since the condition is likely to reappear when the individual returns to the same working environment that caused the problem in the first place (Kome, 1998).

It can be argued that the transition to, and recommendation for, less interventionist methods may have contributed to surgeons (particularly orthopaedic surgeons) disputing the existence of RSIs. Orthopaedic surgeons have been accused of having vested interests in RSIs. Arksey (1994:458) believes that these surgeons are denying the existence of RSIs because these disorders leave them “surgically thwarted,” or in other words, without the proper tools to treat the condition effectively and foster rehabilitation. Consequently, orthopaedic surgeons find themselves in competition with rheumatologists, the other field of specialists involved in the diagnosis and treatment of RSIs.

Rheumatologists involved with the treatment of RSIs have had to deal with the opposition of orthopaedic surgeons. The source of tension between the two fields of medicine may be related to the notion that those responsible for treating particular forms of illness are active in its definition. Thus, “RSI is a modern bone of contention so far as professional empire building” is concerned (Meekosha and Jakubowicz, 1986:399). Clinicians argue that rheumatologists and physiotherapists are interested in defining RSIs to influence medical thought, and accuse them of having an economic interest in the condition as well, i.e., at the same time these medical bodies display support for the existence of RSI, they are able to publicize their own treatment models for the rehabilitation of RSI (Arksey, 1994:458). For example, Boyling (1998:108) points out that physiotherapy is leading research in the treatment of RSIs, and thus calls for “substantial funding” to address the shortage of physiotherapists in the British National Health Service.

Medical professionals operating within clinical frames may also express a reluctance to accept the input of alternative health care professionals such as massage therapists or chiropractors. These groups are viewed as practicing methods that lie outside traditional medicine. Alternative health care professionals do not adhere to the premise of the biomedical model, and criticize the reductionist focus on the germ theory, and the mechanical treatment of the body using surgery, medication, etc. (Clarke, 1996:345). One group of individuals willing to draw on the support of alternative health care professionals are the women and men living with RSIs. Dissatisfaction with their encounters with physicians has led some to seek the services of those health care

providers who take their complaints seriously.

In their examination of lay belief and health behaviour, Telles and Pollack (1981:250) found that individuals who find it difficult to specify their health problem in a way that “suits medicine,” or who have had their health complaints dismissed by a physician, are likely to avoid medical help altogether, go to alternative healers, or devise their own treatment plan. Ewan et al. (1991:177) found that in addition to cortisone injections and pain medications, methods of pain management for a sample of women with RSIs included “hot baths, creams and lotions, physiotherapy and chiropractic treatment.” Self-care activities of RSIs may also include icing the affected areas, taking ibuprofen, daily exercise, changes to diet, yoga or tai-chi (gentle stretching), herbal remedies, water therapy, and adequate sleep time (Kome, 1998). Thus, persons living with RSIs do not dismiss the knowledge of alternative health care professionals as readily as those physicians operating from a clinical frame. Instead, they are willing to use the knowledge to become active in the treatment and management of RSIs in the form of self-care.

B. The Social Control of RSI

In reviewing selected medical debates regarding RSIs, it may be concluded that the tensions between various medical perspectives exist because “RSI offers either a threat or a promise” (Arksey, 1994:492). For some medical professionals, the power to diagnose and administer treatment will result in economic gain and the establishment of the importance of that particular field. For others, the legitimation of RSI as a medical

category represents the prioritization of subjective complaints and the expectation that a diagnosis can be made without physical evidence. The RSI debate sheds light on the role of “professional empire building” (Meekosha and Jakubowicz, 1986:399), and the predominance of the medical model in this process.

The tools of medicine permit physicians to see into the human body. The view is believed to be objective, and shows the body as it ‘really’ is (Arksey and Sloper, 1999:1193). However, since RSIs do not produce physical signs of illness (symptoms are subjective), medical professionals adhering to the biomedical model are hesitant to legitimate them as specific medical conditions. With no formal agreement on definition and etiology, RSIs are contested (Brown, 1995). Aside from the political struggles, the delay in legitimating this occupational illness can also be attributed to the relation of RSIs to morality, i.e., “is [RSI] an excuse for malingering?” (Turner, 1987:15).

In his essay on the changing concepts of disease, Cohen refers to disease as “deviations from the normal” (Mishler, 1981:3). In the deviance perspective, illness produces a shift away from what is normal and proper (Clarke, 1996:242). It also emphasizes the social control function of medicine, where medicine is a “moral enterprise” like law and religion, and controls the presence of that which is undesirable in society (Friedson, 1975 as cited in Clarke, 1996:242). Hocking (1987:526) suggests that Western society sees sickness as deviant behaviour because it fosters a dependence on others, when it is independence that is valued. As our culture also values ambition and productivity, and offers rewards for those who choose to expend their labor power in the form of a wage or salary, it follows that there is a lack of tolerance for that which is in

opposition to these ideals. Thus, in the area of occupational health, medicine should handle work-related injuries in a manner that encourages the return to work.

Melhourn (1998:112) suggests that the high rate of RSIs in Australia is in part due to the greater social acceptance of the inability to work because of a physical ailment. Scheper-Hughes and Lock (1986) describe Australian medical professionals as acting as “custodians” of illness by encouraging entry into the sick role when it was not warranted (as cited in Reid and Reynolds, 1990:185). With the social and medical recognition of RSIs, both individuals who are suffering from the condition and those who are not could come forward, and report their condition for compensation purposes (Hopkins, 1990). As diagnoses have been given without the presence of physical evidence, it has been argued by some researchers that physicians have not exercised disciplinary control of RSIs (Hopkins, 1990).

Dembe (1998:235) believes the recent drive of physicians to distinguish clearly between fraudulent and genuine work injuries, and to reach “definitive” judgements despite medical uncertainty, derives from the economic and political concerns over the excessive costs of compensation. Semple (1991:537) warns physicians, and in particular orthopaedic surgeons, to consider the consequences of a diagnosis of RSI as it has implications for both the patient and society as a whole. Barton (1989) believes that people want a diagnosis of RSI for musculoskeletal aches because of the compensation settlements available. Physicians are encouraged to not be free with the diagnosis of conditions as work-related. This concern is apparent in Canada and the United States, where RSI is still a source of confusion and friction among physicians and researchers

(Kome,1998).

While RSIs are taking place in a context of medical and political debate, the impact of the condition on the individual (beyond compensation opportunities) is less clear. The illness experience of persons with RSIs needs further investigation as only a few studies on the subject have been undertaken. One can look to the research done on chronic illness and chronic pain to fill in the gaps, so to speak, of the illness experience for the women and men living with RSI.

C. The Illness Experience of RSI

Bury (1982:168) describes the onset of chronic illness as a “biographical disruption.” The individual who has developed an illness will not only have to make adjustments in the manner by which s/he conducts activities of everyday life; s/he will have to renegotiate goals and future plans in light of the condition. A loss of physical capacity and changes to roles and responsibilities can cause former images of self to crumble away. Identity must be re-shaped with the inclusion of the new restrictions in order for feelings of self-worth to be restored (Charmaz, 1983). The process by which this occurs will be different for each person, and for women and men in general, since the significance of losses that are sustained because of a chronic illness differ by gender (Sidell, 1997).

Chronic conditions confound commonsense notions of illness because they do not disappear completely with medicine and treatment; symptoms are only controlled and minimized (Hilbert, 1984). As RSIs can develop into chronic pain (Yassi et al., 1996),

persons living with these conditions may find that neither they, nor those around them can understand how the pain and discomfort in joints can last for two years, even after having surgery on the affected area. It is important for both the person living with a RSI and those around her/him to understand the chronic nature of the condition, for the RSI does not only have long-term consequences for the person afflicted, but also for those with whom s/he interact and have relationships. As Bury (1991) believes that the meaning of a chronic illness lies in the consequences it has for the individual, a brief overview of the physical and social consequences of RSI will provide insight into the illness experience for the women and men living with the condition.

Physical and Social Consequences

Uncertainty is a defining quality of chronic illness (Nancarrow Clarke, 1996). It exists on several levels and is experienced in varying degrees by an individual over the course of illness. In the initial stages of illness, individuals will try to make sense of the changes that are occurring to their bodies. Reid et al. (1991) report that the women with RSIs in their study did not associate early symptoms with their jobs. Common interpretations of the discomfort felt included “writer’s cramp,” and “it’s a part of growing old” (Reid et al., 1991:606). Similarly, among a sample of individuals living with rheumatoid arthritis, Bury (1982:170) found that swollen fingers and early morning stiffness did not cause alarm, but rather was considered a “nuisance,” or a sign of overexertion.

However, there comes a point in time when bodily changes can no longer be

dismissed as ‘nothing.’ These events are turning points, as there is no other option for the individual, but to seek a professional opinion. Upon the diagnosis of a chronic illness, uncertainty regarding the cause of symptoms will be minimized, and heightened for the occurrence of symptoms. Living with chronic illness means adjusting to a loss of confidence in body and health (Kleinman, 1988). Consequently, the uncertainty of illness does not just surround why symptoms occur, but also when and how often they appear. Wiener (1975) found that persons with arthritis dread the next time a flare-up will occur. Typical of other chronic conditions, RSIs have no rhyme or reason to aches and pains, fatigue, and weakness of limbs. According to a sample of women living with RSI, “uncertainty about what might precipitate an exacerbation of pain is one of the most problematic aspects of the condition” (Ewan et al., 1991:176). Ewan et al. (1991) discovered that at times no activity could trigger a flare-up once a RSI had developed.

The unpredictability of symptoms can make a person feel vulnerable (Frank, 1995). Charmaz (1991) uses the terms “good days” and “bad days” to describe how symptoms of illness become central to daily living, and can determine the range of activities that may be undertaken, as well as the duration of participation. On a good day, symptoms interfere minimally with activity, giving individuals greater control over their bodies and actions, whereas on a bad day, illness cannot be easily ignored (Charmaz, 1991). Thus, each morning, persons living with chronic illness will have to face the possibility that they might not be able to meet the physical or social demands of the day.

Persons with RSIs may also experience social consequences with the development of RSIs. As members of society, each of us sits at the centre of a web of connections and

obligations to others. Thus, illness will not be experienced in isolation. All relationships and responsibilities affiliated with one's roles will be affected. Roles refer to the cluster of duties and responsibilities associated with a particular social position (Hewitt, 1994). Since the inability to maintain social roles will have consequences for those reliant on their performance, it is useful to study illness in the social setting where it is an ongoing concern (Hilbert, 1984).

Due to the physical limitations of RSIs, persons living with these conditions may experience difficulty when engaging in daily activities that commonly occur in the home, including vacuuming (usually the worst offender), ironing, washing clothes, dressing, hanging clothes on the line, cooking (including peeling vegetables, lifting pots), washing and drying dishes, etc. (Bammer and Blignault, 1988; Stone, 1983). However, because women continue to be responsible for child care and fulfilling household duties, whether working inside or outside of the home, it may be that they will experience more difficulty in adjusting to RSIs than men.

Gove (1984) believes that women's role obligations within the home prevent them from engaging in the proper rest and relaxation necessary for recovery from illness. For women living with RSIs, rest and immobilization of the affected area are important for rehabilitation (Kome, 1998). However, many women report that these often prescribed treatments are ill-suited to their reality of daily living (Ewan et al., 1991). Among a sample of women with RSI, total rest of the upper limbs was considered "impractical," especially when caring for family members, or children (Ewan et al., 1991:177). Similarly, Thorne (1990) found that mothers living with chronic illness described the

illness management advice of health care professionals to be at odds with everyday mothering. In this same study, Thorne (1990) reports that the chronically ill women held certain assumptions of what a mother should be. These beliefs made the illness experience more difficult, especially when their condition prevented them from meeting the standards of a 'good' mother. Some even worried about the loss of custody of their children and not being a good role model for them (Thorne, 1990). In their examination of persons living with rheumatoid arthritis, Reisine et al. (1987) found that women were concerned about their ability to arrange holiday gatherings, care for others, and keep the family together, and they were less satisfied with themselves when physical limitations prevented their planning and involvement in activities of this nature.

Paid employment is a central feature in the life of many women and men. Occupational status signifies independence and personal achievement. An aggressive work ethic is a dominant discourse in our society, making it difficult for those not part of the workforce to feel as though they are contributing (Thorne et al., 1997:3). Thus, for those unable to continue working because of illness, the loss of employment can be devastating both financially and emotionally.

Traditionally, men have been encouraged to seek paid employment in order to provide families with financial security and stability; they are cast into the breadwinner role (Lindsey, 1994). As the onset of illness can create changes in the ability to work and occupational status, men may experience a threatened identity. Tarasuk and Eakin (1995) found that men living with chronic low back pain were adamant about remaining in the workforce. They felt that they could not jeopardize their position by exhibiting symptoms

of their disability, as doing so could cause them to lose their jobs. Without a job or access to compensation, the men were concerned about becoming financially vulnerable, and possibly having to turn to welfare for support (Tarasuk and Eakin, 1995).

However, as men are no longer the sole source of income for some families, women can also experience the financial and emotional hardships that accompany a chronic illness. The decrease and/or elimination of income, combined with medical and daily living expenses, will not only result in limited monetary resources, but in psychological strain. While a number of studies have documented the financial losses that frequently follow the development of a RSI (Brown et al., 1986), there are only a few that pay particular attention to the emotional impact of RSIs. Reid et al. (1991) found that women unable to return to work due to a RSI, reported a sense of failure for no longer contributing financially to, or for lowering the social status of, the family. Ewan et al. (1991:183) also found a theme of guilt among a sample of women living with RSIs.

To summarize the findings of Shadbolt (1988), the greater the degree of disability among women with RSIs, the greater the level of psychological strain. The non-performance of usual work activities because of a RSI has been found to contribute to anxiety and depression (Bammer and Blignault, 1988). It is not uncommon for individuals living with illness to experience a number of emotions in response to role negotiations and adjustments. Kleinman (1988) believes that life becomes characterized by confusion, shock, anger, and even despair when chronic illness develops. While these stages are similar to those present when grieving over the loss of a loved one, the difference when struggling over the loss of control over one's body is that the process

does not end. With chronic illness, an individual will experience periods free of illness, then relapse, and then recover again (Taylor and Epstein, 1999:28). Thus, just when an individual is learning to accept her/his condition, new symptoms can appear, placing her/him back into states of discouragement and hopelessness (Taylor and Epstein, 1999).

While a physician will provide treatment and medication to help alleviate and manage symptoms, it is the person living with a RSI who must learn to cope with her/his condition (Lubkin, 1986). 'Getting on with life' is a difficult process as it involves regaining control of a life and body that have become characterized by uncertainty. As indicated earlier, the meaning of a chronic illness lies in the consequences it has for the person afflicted (Bury, 1991). Thus, the way in which an individual understands her/his condition will be either positive or negative, depending on the degree to which s/he feels the RSI has interfered with her/his life. In addition, the significance of a chronic illness can influence the meaning an individual attaches to her/his condition (Bury, 1991). Images of illness will reflect reality and stereotypes (fact and fiction), and can change over time with the introduction of new information and/or contrary evidence.

An awareness of the stereotypes of RSIs that are present in society will not allow persons living with the condition to predict the acceptance of RSIs by those within their own social environment. Persons with RSIs learn that there is a range of reactions with regards to the way symptoms of their condition are received by others. Whereas the complaints of some will be met with concern and offers of support, those of others are met with mixed acceptance. The reactions of others can play an important role in the illness experience of the person with a RSI since personal identity is constructed on the

basis of social relations (Brodwin, 1992). Since the illness experience of RSIs is influenced by the context in which it occurs, persons with RSIs will affect and be affected by those around them. Thus, how others react and respond to chronic illness can affect how a person comes to understand her/his RSI and the meanings attached to the condition.

The significance of RSIs among one's social network will not only have implications for the illness experience, but legitimation. Impressions and evaluations of RSIs by health care personnel, employers, peers, and family will influence whether or not a RSI is considered a 'real' condition.

D. The Legitimation Experience of RSI

The medical reliance on signs of illness is a reflection of physical reductionism, a principle upon which medicine is based (Clarke, 1996). Primacy is given to substance, not emotion, and reality is equated with that which is physically observable (Ware, 1992). Thus, when some physicians are confronted with a patient whose complaints are neither visible nor measurable (Schlesinger, 1993), logic would suggest that the problem is not real, but imaginary. Consequently, conditions and symptoms that are medically invisible may be seen as psychogenic in origin (Ware, 1992). "If pain is not 'in' the body, where can it be but in the mind?" (Rhodes et al., 1999:1196).

The mind/body dualism is rooted in medical thinking. The physician can examine and treat the human body without regard for emotions and the subjective experience of the patient (Clarke, 1996). According to Western metaphysics, the body is symbolic of

emotion, blamelessness, and accident, while the mind represents reason, accountability, and control (Ware, 1992). In the case of physical illness, an individual is relinquished of personal responsibility for her/his condition as illness exists in the body (Ware, 1992). Since discipline, self-control, and accountability are qualities related to one's morality, individuals who are ill will not only have symptoms assessed and judged by others, but their character as well.

Ewan et al. (1991:188) found that women living with RSIs felt as though the modifications to home and work life because of their conditions were considered a "moral flaw" by family, co-workers and the community at large. The reference to morality is a reflection of the continuing moral dimension of beliefs and practices surrounding health and illness (Bury, 1991). Persons living with a RSI may be subject to moral evaluation and stigma because of the nature of the condition. Jackson (1992) explains the stigmatized status of pain as the result of the challenge it poses to assumptions about biological and mental processes. Pain is more likely to carry stigma than acute illness due to its mysterious origin, its association with psychological disorders, and its invisibility (Jackson, 1992).

Without objective signs of illness and a clearly understood cause, RSI does not meet the cultural standards for biological illness (Jackson, 1992), making the legitimization process problematic. Consequently, persons living with RSIs may have to face accusations of being morally responsible for their conditions, and of faking illness for personal gain. RSI has become a metaphor for strain in the workplace, and a manifestation of the threat to economic and social life by individuals who are neglecting

their duties and responsibilities for reasons that are not clearly legitimate (Reid and Reynolds, 1990). The application of this metaphor to all persons living with RSIs suggests a homogeneous population, when in fact there is diversity in the RSI experience. However, an aspect of RSI that will be shared among those with the condition is that of living with a hidden disability. The next section examines the extent to which invisibility can be a challenge for persons living with RSIs, and how it can be an obstacle to legitimation.

‘Looks Can Be Deceiving’ : The Invisibility of RSI

The illness experience of an individual can be influenced by whether or not her/his condition and symptoms are visible to others. Among a sample of women and men with back injuries, Tarasuk and Eakin (1995:209) found that many felt the absence of physical signs of injury was detrimental to their relationship with others at work. Rather than feeling that co-workers accepted their injury at face value, these individuals expressed concern about the way their injury and absenteeism was being perceived; “everyone’s so cynical...especially with the back injuries...it’s like, ““have a nice time at the cottage.”” Bury (1991:456) points out that definitions of illness between persons living with a chronic condition and those around them may not shared when symptoms are invisible. Recall the person with back injury mentioned earlier. To her/him, back injury is a reason for not performing regular duties at work, while for others it is a convenient excuse for not doing so. Feelings of confusion and frustration may result for those living with these hidden conditions, as they are unable to understand how others do

not see their pain, especially when it is quite apparent to themselves.

However, when an individual is afflicted with a hidden illness like RSI, chronic fatigue syndrome, or chronic pain, s/he can delay, or avoid altogether, conflicting definitions and inaccurate perceptions of illness. Conditions that are not immediately recognizable to others give persons living with them the choice of whether or not they will reveal their illness to others, as well as the freedom to decide when, and to whom (Schlesinger, 1993). Thus, invisibility can serve to protect persons from unwanted questions and negative reactions (Schlesinger, 1993). Cameron and Bernardes (1998) found that men living with prostate cancer did not disclose their problem to family and friends initially. Similarly, in her comparison of male and female perceptions of pain, Bendelow (1993) reports that several male respondents felt that expressions of pain left them vulnerable to being branded a 'sissy,' or homosexual. Thus, the concealment of symptoms of illness can work to repel or postpone the attachment of stigmatizing labels. In their study of women with RSIs, Ewan et al. (1991:175) found that the prevailing negative attitudes about RSIs prevented workers from reporting their symptoms to employers.

Eventually, there comes a time when one's illness will no longer be easy to hide. Splints, medication, and modifications within the home and workplace become necessary, drawing the attention of others who will notice and/or be affected by these changes. Once this occurs, an individual will be subject to both the comments and judgements of others in her/his social environment (Grunert, 1997). In the case of RSIs, only some aspects of the condition will become apparent and for the most part symptoms will remain invisible.

Consequently individuals may find themselves having to prove the existence and severity of their illness to physicians, workmates, friends, and family. While it is not uncommon for doubt, suspicion, and skepticism to surround contested conditions (Brown, 1995), the added characteristic of invisibility seems to heighten the problem of legitimation for these people.

Rhodes et al. (1999) found a solid link between visibility and legitimation for women and men with low back pain; study findings indicate that 33% of respondents felt that the invisibility of back pain led employers, co-workers, and family to question the legitimacy of their complaints. Furthermore, persons with multiple chemical sensitivities repeatedly have to prove to others that they are ill and disabled because of the non-specific nature of symptoms (fatigue, nausea, weakness), which makes requests for treatment and emotional support problematic (Lax, 1998). Thus, chronically ill persons may learn that without visible symptoms, they are not eligible for legitimation.

Ware (1992:351) found that respondents with chronic fatigue syndrome would react with great frustration to being told they “look great” by others. Due to the dissonance between how these respondents felt and how they looked to others, it is not surprising that there was a preference for a more visible condition among the sample (Ware, 1992). In their examination of women with RSIs, Reid et al. (1991:605) report that the lack of overt signs of the condition is viewed to be a great obstacle to establishing credibility by respondents. The women pointed out that a disfiguring condition would make the process less difficult because then the problem would be on the outside of their bodies, not the inside. For one woman with a RSI, having to “two broken arms” would

mean greater understanding from others (Ewan et al.,1991:175). Among a sample of chronic pain patients, Hilbert (1984) found that many of them talked about the benefit of having a neon sign that read 'pain' on their body, to remove any speculation of its presence.

When being faced with the task of having to prove the presence and severity of one's illness, a desire for a condition that is apparent to others can grow in individuals, particularly those living with an invisible condition. Unable to change the nature of their illness, they are forced to work with what they have, namely the symptoms they are experiencing. According to Telles and Pollack (1981), there are socially acceptable vocabularies and presentations of illness that we learn throughout our lives. While this knowledge can inform both the management and interpretation of most symptoms, invisibility complicates the process. As symptoms are not readily available to others, individuals must pay particular attention to the manner by which they will make invisible symptoms visible to others. There are particular signs (and behaviours) indicative of illness that can be utilized by these persons in an attempt to have their conditions deemed as being real by those in their social network. The challenge of the transformation, however, does not lie in the ability to describe and indicate symptoms to others, but to do so adequately in order to have experiences validated (Schlesinger, 1993).

The Presentation of Symptoms

Brodwin (1992) relates the presentation of self to the notion of performance. The way people present themselves to others will be determined by the situation, audience,

and desired impression they are trying to create. In the context of illness, one way persons can guide the impressions others form of them is by engaging in concealment or disclosure. With disclosure, proclamations of illness may have to be supported with evidence. As the human body is regarded as both an instrument and an ornament, the expectation for some may be that illness produces change in function *and* appearance. Consequently, when the signs of illness are lacking, individuals who are ill may have to actively say and do things to have their hidden suffering revealed to others (Brodwin, 1992).

Schlesinger (1993) outlines the different ways of making pain, an invisible problem, visible to others. She explains that these signs of pain work to verify the presence of pain in the body, and the extent and degree to which it is being experienced. Body movements (limping), mood changes, facial expressions (wincing), the use of devices that accompany an injury (using a cane, splint, bandage, etc.), and exposing prescriptions and/or medication can all be used to signify pain (Schlesinger, 1993; Telles and Pollack, 1981). Although the pain itself cannot be observed, these displays of sorts can warrant the status of being ill. In an effort to understand perceptions of health and illness among a sample of lay persons, Telles and Pollack (1981:247) found that when respondents were confronted with claims of being ill, the 'normal' procedure was to look for external signs; there was a "set of assumed correspondences between certain appearances and feeling sick." Pain in the form of acute, readily observable symptoms has also been found to elicit more sympathy, respect, and legitimation (Bendelow, 1993). Thus, the advantage of visual symptoms is that they can speak for themselves, instead of

having the person living with them justify and explain their presence.

Jackson (1992:161) explains that when the “visual emblems” of illness are missing, the only signs of its presence will be the words and expressions used to reveal what is being experienced. For women living with pain, indirect and direct statements of pain were used to used to make pain visible to others; while the former includes tone of voice and such things as whimpering and moaning, the latter refers to descriptions of pain and pain-related activities (Schlesinger, 1993). Descriptions of pain may become quite elaborate when persons are relying on them to prove illness, or convince others of their suffering. Health care professionals, employers, and family can promote dramatic descriptions and displays of illness by not recognizing or believing complaints of illness; individuals are left having to convince others of their illness, or make its presence better known (Craig et al., 1999). The over-reporting of symptoms and behaviours of these individuals are an attempt to not be defined as malingerers. However, recall that malingering is defined as “the intentional production of false or grossly exaggerated physical or psychological symptoms, motivated by external incentive” (DSM-IV, 1994 as cited in Craig et al., 1999:42). Thus, by trying to make their symptoms more visible to others they become vulnerable to stigmatizing labels, as actions and comments can be perceived as embellished, exaggerated, and even false.

Schlesinger (1993:248) points out that there are risks involved when demonstrating and speaking to others about one’s illness in the absence of concrete, physical evidence. The inability to do so effectively can result in misinterpretation, skepticism, and even rejection. Thus, these individuals must give careful consideration to

how they will present their illness to others, as all communications (verbal and non-verbal) are subject to evaluation. These evaluations will either confirm or dispel any existing suspicions of illness, which in turn will affect whether or not the RSI is legitimated.

The Evaluation of Illness

Social context plays an important role in the experience of illness for an individual. It consists of the structure and people in one's life (i.e., roles, positions, relationships, etc.), and can influence identity, experience, and interaction. When illness enters or disrupts this domain, it will affect all that surrounds the afflicted person. Thus, illness can be considered a social experience, for it not only involves the person living with the condition, but those with whom s/he is in contact. While illness touches the lives of many, it may not do so in the same way for each person involved. Whereas a woman with chronic pain will grieve over the loss of control over her life, her family and friends may feel frustrated over its continual presence and demands on their own lives (McCaffery & Beebe, 1989 as cited in Howell, 1994).

The value of understanding evaluations of illness, or the way it is perceived by those in one's social network, is the insight it can provide into why illness is or is not legitimated. Bury (1991) believes that it is not only the nature of an illness and its symptoms that can make legitimation problematic, but the perception of them by self and others. Thus, for persons with RSIs, legitimation can be problematic due to the invisible nature of symptoms, and because "any claims which allow people social exemptions are

likely to be scrutinized by others” (Robinson, 1988:113). This scrutiny, if experienced, will not only come from physicians and other health care professionals, but employers, co-workers, and family, who also carry out a “sanctioning” function when it comes to illness (Telles and Pollock, 1981:248).

Physicians and Other Health Care Professionals

The physician has the authority to diagnose disease. A diagnosis represents an “official” form of validation (Bury, 1981:456). Since legitimation by a physician can take responsibility for the condition away from the individual (Ware, 1992), persons who are ill want, and may seek, a diagnosis. According to Hilbert (1984:368), motivations behind the search for a diagnosis can also include the advantage of having a “disease category” when describing one’s condition to others, and the promise of an “escape” from the stigma of mental illness (Rhodes et al., 1999:1201).

Quintner (1995) argues that the social commentaries written during the ‘RSI debate’ of the 1980s in Australia, have contributed to and reinforced the medical and social stigmatization of RSIs. He feels these commentaries, which were written by physicians, contain a number of stereotypes of women workers that can have an affect on the relationship between physicians and their female RSI patients (Quintner, 1995). In these commentaries, the pain and discomfort of women with RSIs has been associated with a lack of fulfillment in work, the manifestation of personal conflict, and the communication of powerlessness in the workplace. Since none of the explanations are based on the knowledge and expertise of science, Quinter (1995) argues that these

physicians are merely offering a personal opinion of the problem, and not a medical opinion. There can be no positive outcome for women with RSIs when viewed in such a negative light. The only outcome under such circumstances is the presence of suspicion and blame in the medical encounter.

Reid et al. (1991:607) found that in general, women with RSIs had “unsatisfactory” encounters with medical specialists. Professionals often discounted or trivialized their complaints, and related the pain and discomfort felt to “psycho-social” factors having to do with family, gender, body shape, and emotional distress. Arksey and Sloper (1999:488) made similar observations. Women were told symptoms were due to menopause, and for one in particular, due to “her large breasts with the resultant pull down on her shoulders.” Arksey and Sloper (1999) also report that in comparison to 17% of the male respondents with RSIs, 26% of women had encounters with doctors who viewed their RSIs as being psychological in origin. The women with RSIs who were told by a physician that the pain is in their heads, interpreted the statement as meaning that injuries do not exist, and that they are malingering or neurotic (Reid et al., 1991).

Dissatisfaction with a medical encounter will not only surround the interpretation of symptoms that are given, but also the manner by which these diagnoses are presented. Specialists rated as “hostile” by respondents with RSIs, were likely to have questioned their state of mind or trivialized symptoms in a manner described as “insulting” and “arrogant” (Arksey and Sloper, 1999:487). Physicians may react this way to patients when they are skeptical about the authenticity of presenting complaints. According to Kleinman (1992), it is virtually impossible for a doctor to provide empathetic care to a

patient when trust and support are replaced by suspicion and mistrust. Not having the support of a health care professional will be a source of disappointment and frustration for an individual who is hoping to have her/his subjective experience validated (Bank and Kerns, 1996). In the event that medical validation does not occur, or when there is a conflict between the messages of the physician and the reality of the patient, the patient may develop a distrust of health providers and choose to avoid future medical encounters altogether (Bank and Kerns, 1996). Meekosha and Jakubowicz (1986) report that some women with RSIs, tired of facing the disbelief of specialist after specialist, express the desire for amputation. This would not only get rid of the pain, it would also free them of the need to question the legitimacy of impairment.

Employers/Co-workers

Physicians are not the only group of individuals to question the legitimacy of illness. In addition to a physician's office, illness can present itself in the workplace and the home. When illness enters the workplace, the worker who is ill or injured will be subject to the questions and judgements of others. These judgements can be either supportive or destructive (Grunert, 1997). However, the process by which illness is evaluated in the workplace by employers and co-workers need not be the same as it is in other settings. According to Dodier (1985), the criteria of diagnoses of workers can be different from that of a physician. Moral evaluations that are formed may be based on the behavior and character of the ill person (social characteristics), and not necessarily the presence of physical signs. Consequently, one's reputation as a worker, as well as past

behaviours (e.g., absenteeism) can influence whether or not fellow workers and superiors believe their claims of poor health (Dodier, 1985).

In their examination of women with RSIs, Reid et al. (1991:610) discovered how important it was for the respondents to be identified as a “hard worker,” when wanting their condition legitimated by workmates and employers. Women with RSIs were able to avoid stigmatizing labels when they had the reputation of being a “diligent” worker, and/or had co-workers agree that the job being performed was difficult and physically strenuous (Reid et al., 1991:610). These women with RSIs were able to have their conditions legitimated by co-workers because they had been rendered morally acceptable by others. Ewan et al. (1991) found that the hard manual labor of chicken processing gave a legitimacy to women workers in that industry that was not available to those women performing keyboard work.

Seniority and social status at work has also been found to give persons with low back pain “immunity” from accusations of malingering (Tarasuk and Eakin, 1995:213). Higher positions in the workplace can limit the amount of additional responsibilities placed on fellow co-workers; the greater flexibility in work hours and duties allows injured workers to keep regular job demands, and not displace them on others (Tarasuk and Eakin, 1995). Dodier (1985) points out that the less a worker must justify changes in work speed and absenteeism with a medical certificate, the less likely s/he will be subject to the moral evaluation of those in the workplace.

There are certain criteria that can form the basis of moral evaluations of illness in the workplace. Individuals who do not meet these criteria, or who fall outside of these

categories, are left open to suspicion, disbelief, and even rejection by others. Whether the evaluations of illness are positive or negative will be apparent in the way ill persons are treated by others in the workplace, or by how relationships with a boss or co-workers have changed.

Family Members and Friends

According to Kleinman (1988), there comes a time when family members will question the authenticity of a person's pain. This questioning can have a profound impact on the experience of illness, since the opinions of these people are significant, or emotionally important to the person who is ill (Hewitt, 1994). Family and friends make up an individual's support network. In times of sadness and happiness, these are the people who can be turned to for comfort and support. In times of illness, their validation and support will depend on their perception of the individual and the illness itself.

As mentioned earlier, illness will disrupt the life of the individual with a condition, as well as the lives of those with whom they are in contact. In some instances, family and friends will accept the physical and social changes that accompany illness, while in others it may be more difficult to do so, especially when they are not prepared for the impact on their own life. Meekosha and Jakubowicz (1986) believe that disability is often denied by family in two ways. There are those who deny that anything is wrong, and those who can accept the injury, but not the implications of injury. With regards to the latter, a woman or man may accept the fact that their spouse has back pain, but not be ready to accept the loss of income that results from the inability to continue working.

Ewan et al. (1991:184) found that women with RSIs experienced tension in their marriages due to the redistribution of their duties to their spouses.

Reactions can become hostile when the denial surrounds the existence of illness. Crook (1982:71) reports that family and friends can contribute to a person feeling morally responsible for their pain or illness. When friends question the illness, some may choose to limit their interactions with the person who is ill, or stop them altogether. Women and men with chronic non-malignant pain report that friends cannot understand why they are always in pain, and do not call and visit as much as in the past (Seers and Friedli, 1996).

Struggles for legitimacy will be difficult for an individual when those around her/him respond in a manner that does not meet expectations (Ewan et al., 1991). The anticipation that illness be met with sympathy and support will be lost when suspicion and doubt are found in their place. The experience of legitimation will not be the same for everyone. Whereas some will find it problematic, others will not. People participate in different relationships with different people. It follows that the reactions of each to illness will differ. Thus, a man with a RSI may have a wife who is supportive of the physical changes, and a boss who is not. Whether or not this man finds it necessary to have his boss legitimate his RSI may depend on how much their opinion and support matters to him. The next section will look at what it is about legitimation that keeps some individuals on a continual search in its absence, and how its presence can impact the illness experience.

E. The Importance of Legitimation

In her study of women living with chronic non-malignant pain, Howell (1994) found that legitimation from self and others determined whether or not the women experienced a “healthy” or “unhealthy” progression through illness. When a woman’s progression through the experience of living with chronic pain was healthy, she was able to come to a point where pain was no longer the centre of her life (Howell, 1994). By caring for oneself and having others care for them, the women were able to move beyond the losses incurred by pain, and they learned to accept the limitations of their bodies.

Legitimation is defined as the process of accepting illness states and symptoms that are presented by another as real or genuine (Howell, 1994). In this study, the legitimation of a RSI occurs when the experience of pain is viewed as originating in the body regardless of objective findings, and not a consequence of psychological need or secondary gain (Howell, 1994). To have an RSI legitimated is to have others believe it exists. According to Schlesinger (1993), having experiences validated by oneself and others is key to the receipt of support and help. Thus, when illness is legitimated by those in one’s social network, persons living with illness have access to, and will experience the benefits of, social support. However, in order to cope successfully with illness one must avoid total dependence on others. A degree of independence must be attained as there is no guarantee that legitimation and the support will endure. Legitimation is not constant, but rather a dynamic process (Howell, 1994). Given that the interactions people have with others are not static, the legitimation experience may change as well (Howell, 1994).

Bury (1991) indicates that there may be a time when ill individuals risk losing the

support of others. Support may be lost with the continual reporting of problems since audiences are continually exposed to the same symptoms over time, without much variation in performance (Brodwin, 1992). Friends and family may grow tired of the same groans, winces, requests for help, and they become impatient when waiting for the condition to go away.

Losing the validation of others can have a profound impact on the identity of the person living with illness. According to Howell (1994), the negative definitions of self that are received in interaction will begin an individual's unhealthy progression through illness. In her examination of women living with chronic pain, she discovered that the women progressed towards illness when others doubted the reality of pain and minimized their need for help. Isolation, despair, and feelings of being trapped by pain characterized the illness experience of these women (Howell, 1994).

Ware (1992:355) reports that the "psychic suffering" of people living with chronic fatigue syndrome can be related to the shame they feel when told by others that their illness is not real. The experience of continually being told by others that 'nothing is wrong' led some of these individuals to accept the possibility that the problem was in their head, or that they were hypochondriacs. Feelings of being undermined (Rhodes et al., 1999), and humiliated (Ware, 1992), have also been associated with the disbelief and trivialization of symptoms by others. Ill individuals may choose to withdrawal from social life due to experiences of being embarrassed, discredited, ignored and/or rejected by others (Charmaz, 1983).

Howell (1994) reports that isolation from others can lead to despair. She found

that the women with chronic pain who felt isolated from others were unable to gain a sense of control over their life. The perception of being trapped in an intolerable life situation puts these women at risk of intentional suicide. Depression and several cases of suicide have been reported for persons living with RSIs (Meekosha and Jakubowicz, 1986; Salzberg, 1985 and Wall, 1985 as cited in Bammer and Blignault, 1988).

Information of this nature suggests that there are persons that would rather die than live with chronic pain.

The review of the literature reveals the complexity of legitimation of RSIs. Theoretical perspectives can be used to identify and clarify the process of legitimation for persons living with these conditions. The theories and concepts that are used to form the conceptual framework of this study are addressed in the next section.

II. Conceptual Framework

The Concept Map

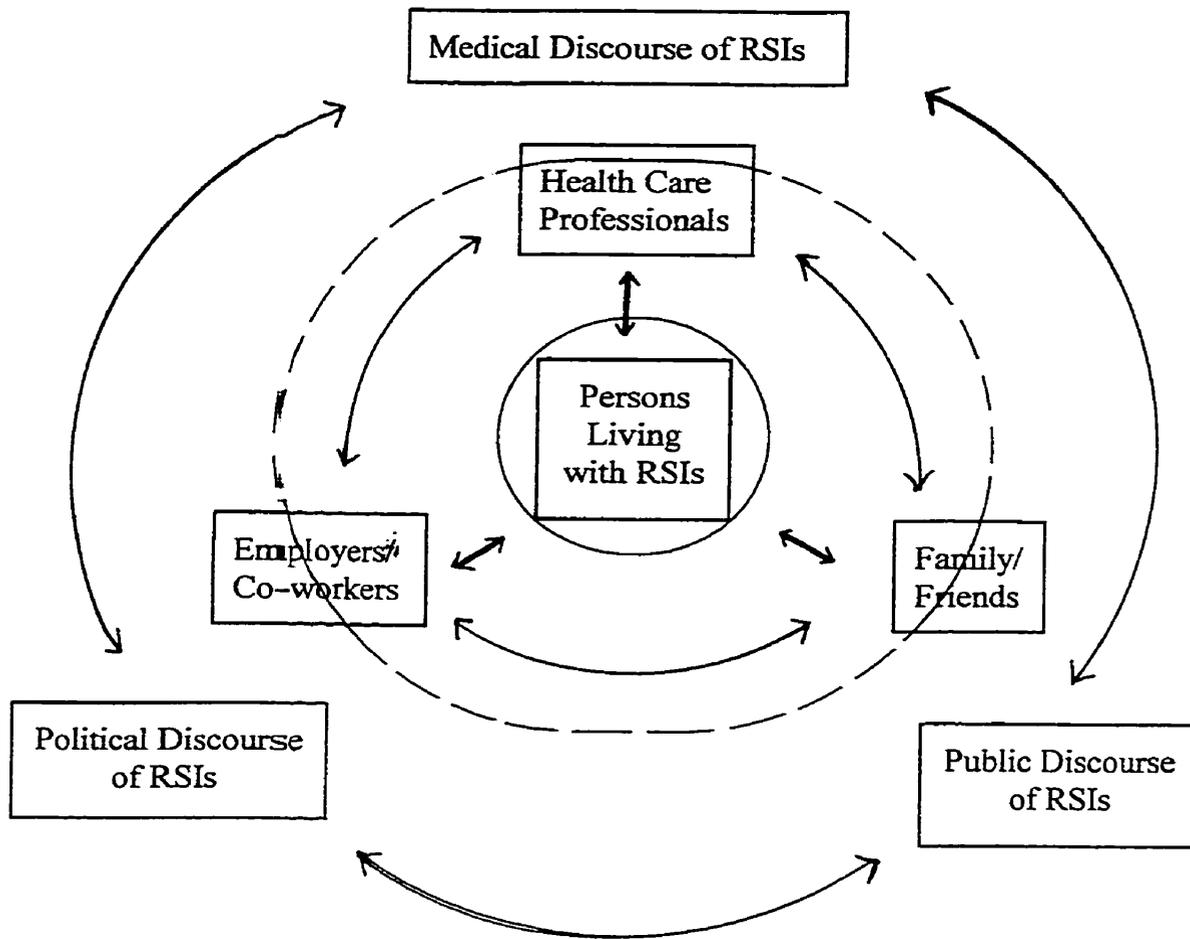
A concept map is the representation of what the researcher believes is ‘going on’ with the phenomena under investigation (Maxwell, 1996). While specific theories can be drawn upon to inform the study, the concept map reflects the reasoning behind the research in light of the issues examined in the literature review. Figure 1 is a concept map that illustrates the legitimation process of RSI.

The model depicting the process of legitimation for persons with RSIs signifies the distinctiveness, yet co-existence of macro and micro worlds. The outer area represents the macro world and the inner area the micro world. Within each area are ‘sources of

legitimation' that can affect the illness experience of RSI directly and indirectly. Arrows are placed between the sources to indicate the influence they can have on one another regarding whether or not RSI is legitimated. The legitimation or delegitimation of RSI by each source will impact the others to some degree, as the beliefs and arguments that are put forth by one will be either supported or criticized by the different perspectives of the others. The boundary separating the macro and micro contexts of illness is not solid, but fluid. Perceptions and interpretations of the RSIs can move between the spheres as well. Thus, as members of society, individuals can affect and be affected by their environment. Persons living with RSIs have been placed in the centre of both circles to illustrate that the illness experience of a RSI is influenced by the contexts in which it occurs.

At the macro level, the legitimation of RSI is influenced by medical and political factors, both of which are involved in determining the definition and cause of the condition as outlined in Part I of the literature review. With the interplay between professional and lay perspectives, and with the help of the media, the various arguments and explanations of RSIs are circulated in society and can enter public discourse to either promote or impede social recognition, awareness, and acceptance. The macro world 'sets the stage,' so to speak, for the micro world. As members of society, we are exposed to messages and information that can be incorporated into our own knowledge and understanding of phenomena. Thus, the explanations and understandings of RSIs generated by health care providers, researchers, and ergonomists (medical discourse), and management, compensation personnel, insurance companies, etc. (political discourse), interested in occupational health issues like RSIs, will enter the micro world to influence

Figure 1. The Process of Legitimation for Persons Living with RSIs



perceptions of RSIs in general, and in particular for the persons living with RSI and those with whom they are in contact. The way a RSI is perceived by oneself and others can have consequences for the illness experience as well. At the micro level, women and men living with illness interact and form relationships with health care professionals, employers, co-workers, friends, and family all of which can legitimate the existence of RSI for them. The presence or absence of legitimation from others will in turn affect whether or not the individual living with a RSI is able to find a meaningful place for illness in their own life, and develop a new identity.

Due to a lack of research and literature on the process and significance of legitimation for women and men living with RSIs, the area of interest of this study lies at the centre of the model. The focus of investigation is the relationship between the person living with a RSI and the sources of legitimation that exist within the micro context. Although not clearly indicated in the diagram, the individual with a RSI is also a source of legitimation, and thus will be examined in the course of the study as a means to understand how the individual comes to terms with her/his illness and legitimates RSI for herself/himself. It appears that individuals can become involved in the legitimation process by accepting or rejecting RSIs as part of one's self, and by actively seeking legitimation and/or influencing the evaluations and perceptions of their condition that are held by others. Note that the arrows connecting family members, co-workers, health care professionals, etc., to the center are not uni-directional. The bi-directional arrows are used to signify that when responses to RSIs are negative (i.e., symptoms are met with doubt and suspicion), the individual living with the condition may work to make them positive,

in an effort to legitimate her/his condition in the eyes of others.

It is not assumed that legitimation will be problematic for everyone. Thus, not all persons with RSIs will go to similar lengths to have their illness legitimated by others. For those who do, the importance of its presence lies in having one's definition of self and illness shared and confirmed by others.

In outlining some of the events that may be occurring in the process of legitimation, it becomes apparent that the process itself is a combination or series of meanings and interpretations of illness, actions and interactions, all of which are influenced by the context in which they occur. Consequently, an interactionist approach is taken to understand the basis of the process, and to clarify what events are taking place and why. A variety of concepts emanating from theoretical and empirical studies also inform this research, and are discussed in the next section of this chapter.

Symbolic Interactionism

A basic tenet of symbolic interactionism is that the self is social in nature. The self is the collection of attributes and qualities of a person, which will influence her/his thoughts, choices, and actions (Hewitt, 1994). It is created and maintained through interactions with others (Charmaz, 1983). Interaction gives us access to the appraisals of others, as well as the opportunity to identify with different people, both of which contribute to the way we define our selves (Karp and Yoels, 1979). Thus, it is in our interaction with others that we affirm our identity. The people with whom we interact can confirm and disconfirm conceptions of self as well, i.e, identities are “established and

validated (or invalidated) through the responses which others make to us” (Karp and Yoels, 1979:36). This notion has important implications for the onset of illness, when definitions of self are threatened in light of physical and social challenges, and stigma.

The occurrence of illness calls for the development of a new identity, for it is difficult to maintain former images of self in the face of illness (Charmaz, 1983). As interaction is considered key to this process, the way persons living with illness are perceived and treated by others can impact how the ill individual comes to define their condition, and whether or not they are able to accept it as part of self. Positive self-images are the outcome of interactions with others who confirm definitions of self, whereas negative self-images can result when complaints are met with accusations of malingering or paranoia (Charmaz, 1983). With interactionist approaches to illness, the way a person reacts towards her/his condition, or the types of meanings s/he attaches to it, will be the result of interactions with self and others (Howell, 1994).

Impression Management

In the context of illness, an individual may work to create a certain impression of self and illness in order to be viewed in a positive light, or to protect herself/himself against discrediting and stigmatizing identities (Hewitt, 1994). It is understandable that persons living with illness become concerned with how they are perceived by others, especially since the impressions of others are formed on the basis of images and information, which do not necessarily reflect the reality of the situation (Karp and Yoels, 1979). As the disability of RSI is not evident to others, women and men may focus on the

presentation of self and symptoms in order to shape interpretations of their condition.

Erving Goffman describes human beings as “persons of appearance” (as cited in Karp and Yoels, 1979: 75). Our appearance, or who we appear to be, can take precedence over who we really are (Karp and Yoels, 1979). In the case of RSIs, the invisible nature acts as an obstacle to the formation of an accurate ‘picture’ of the situation. How can one be certain of the numbness in the hands of a friend, when her/his hands look the same as one’s own? Consequently, the dissonance between the complaints and signs of illness can complicate the process of defining illness, and thus legitimation. In the event that those in one’s environment respond to the RSI with suspicion, the individual with RSI may realize the importance of *looking* as if s/he is ill, and may react by wanting to prove the existence of her/his condition to others. As there are limitations to the extent to which a hidden disability can be made apparent to others, individuals may have to rely more on verbal communications.

Public and Private Accounts of Illness

Just as we deliberately dress or act in a certain way to influence the impressions that are formed about us, we also provide selective information about ourselves to others (Karp and Yoels, 1979). The concealment or disclosure of illness will vary between individuals, and includes decisions regarding who one will confront and how much information about the condition will be shared. However, while a person living with illness may want to confide in another for comfort and support, s/he may find that the listener is interested in receiving an explanation of what happened. Scott and Lyman

(1968) argue that when interaction is disrupted by unexpected or inconvenient events, the individual considered responsible will have to account for them, or explain their occurrence. Accounts of illness are not simply the description of one's pain or symptoms, but also the articulation of one's situation in the world, where s/he continually re-affirms illness in different circumstances, and constructs it as part of her/his ongoing identity (Radley and Billig, 1996).

In their exploration of people's accounts of health and illness, Radley and Billig (1996) found that there is a greater or lesser need for the speaker to legitimate her/his position in light of what is being said. The entitlements of illness are earned, and will be given when illness occurs naturally or is not self-motivated (Radley and Billig, 1996). Consequently, ill individuals may use "legitimizing talk" when speaking to others, in an effort to appear as though they are not accepting the sick role too readily, and are still capable of participating in the social world (Radley and Billig, 1996). This form of talk is especially important when illness is chronic, as individuals may have to account for their condition against potential criticism (Bury, 1982).

Cornwell (1984) expands the notion of "legitimizing talk" in her distinction between 'public' and 'private' accounts. She reports that the need to legitimate one's position when talking about illness can also be related to *who* is listening. Public accounts of illness are given when an individual wants to create a positive impression on others. While sharing information about their condition, individuals are sure to mention and/or discuss medical histories, a diagnosis, the advice and expertise of a doctor (perhaps in the form of quotations), as well as anything else that can prove they are not personally

responsible for illness (Cornwell, 1984:131). In comparison to public accounts, private accounts of illness can be related to the disclosure of illness to significant others, or anyone else the speaker considers 'safe,' who will not judge or reject them on the basis of what is said. With private accounts, the lack of attention on having one's position legitimated is not because it is no longer a concern, but rather it is not as pressing an issue. Within this kind of account, descriptions of illness are blended into other descriptions of the individual's biography. While these personal stories can have arguments and even justifications, the story itself does not center around the need for legitimation (Cornwell, 1984).

In light of the lack of social and medical legitimation for illness of a contested nature like RSIs, it may be the case that for persons living with this chronic condition, public accounts are offered initially, until the speaker has some idea as to whether the listener is disregarding claims, or accepting them. It may follow that those who do not find the legitimation problematic will not be reluctant to give private accounts of illness.

Williams (1984:177) describes accounts as an individual's attempt to reconstruct a sense of order in the disruption of illness, and to understand its presence in relation to past experiences. Thus, how one comes to terms with illness and the meanings s/he attaches to the condition, will have an impact on the ability to develop a new identity and reaffirm that life has a course and that self has a purpose (Williams, 1984). When the self has a purpose, individuals who are ill express a desire to change their situation, and want to regain a sense of control over their lives (Kelly and Dickinson, 1997). Focus is not so much on recovery or remission, as it is on the mere ability to see oneself in the future.

The process of reaching a state of acceptance and well-being will be longer for some than others, as each person will define his/her illness and situation differently.

Phenomenology

According to phenomenological perspectives, humans act on the basis of meanings, i.e., actions are based on how a situation is perceived or interpreted. Consequently, phenomenologists aim to determine what an experience means for the person who has had the experience, in order to understand why s/he acted in a particular way (Ryan, 1996). In the context of illness, insight into the illness experience of persons with RSIs can occur by gaining the subjective perspective of persons living with the condition. Most experts agree that pain is a subjective experience, involving physical, mental, emotional, and social interactive processes (Howell, 1994). Consequently, the definition of illness by the person who is afflicted can differ from the perception of the condition by others. Sidell (1997) reports that in general, there are three definitions of chronic illness: clinical, social, and personal. Clinical definitions are based on physiological manifestations, social definitions are developed by family, friends, co-workers, and society in general, and personal definitions are formulated by the individual.

Personal definitions of illness can change over time, as meaning emerges from the interaction with others and the situation (Hewitt, 1994). Phenomenological perspectives do not support the existence of a single objective reality, rather reality is constructed by the individual (Hewitt, 1994). Consequently, how an individual *thinks* s/he is viewed by others will not necessarily correspond to how these others *actually* view the

individual. In their examination of epilepsy, Scambler and Hopkins (1983) distinguish between felt and enacted stigma. With enacted stigma, an individual experiences some form of discrimination, and with felt stigma a discriminatory act does not have to occur for adjustments in her/his behavior to be made. Reid et al. (1991) found that women living with RSIs experience anxiety about being believed by doctors, workmates and family. The anxiety may be the result of specific incidents in the past where the women had their complaints dismissed by others, or may arise from the possibility that these events can occur in the future. Thus, understanding the legitimation of RSIs from the standpoint of the women and men living with the condition is important, as how these persons make sense of the reactions of others will in turn impact her/his own understanding and experience of a RSI.

The context within which chronic pain is experienced is important as it will also impact the experience and meaning of chronic pain for an individual (Seers and Friedli, 1996) . For this reason, phenomenologists examine the context of illness when conducting research on chronic conditions; it is viewed as a source of meaning and understanding, and not contamination (Ryan, 1996). The context of RSIs is important as it has implications for the legitimation of the condition.

Due to the subjectivity of illness, women and men living with RSI will experience the condition differently. Although some aspects of RSI will be shared, such as a loss of function and control of one's body, women and men will experience illness under unique circumstances (Anderson et al., 1991). Schlesinger (1996) points out that gender has only recently been included explicitly as a variable in research on pain. The result has been a

lack of information on the gendered experience of pain, disability, and subsequently RSI. In the absence of such research, it is difficult to determine whether or not the experience of RSI differs between women and men living with the condition. Thus, the importance of this study lies in its exploration into the illness and legitimization experiences of RSIs, and its investigation of the impact of gender on these processes.

III. Research Questions

The purpose of this study is to explore the process that women and men living with RSIs use to seek legitimization, and to determine if and how this process differs by gender. As illness is influenced by the context in which it occurs, the impact of the social network on the illness experience of RSIs is examined. The significance of the presence or absence of legitimization on the rehabilitation of RSIs is also investigated.

The following research questions guide the study:

1. What is the process by which individuals with RSIs seek and receive legitimization?
2. Do persons living with RSIs find the legitimization of illness by others problematic?
3. Does the legitimization experience of women living with RSIs differ from that of men?
4. How does legitimization (or lack thereof) contribute to recovery and rehabilitation?

There are few studies that systematically investigate RSIs and the gendered experience of living with these conditions. This research sheds light on a group of individuals whose experiences and stories we generally know little about.

Chapter 3. Research Methods

This chapter addresses the research design of the study. It outlines the criteria used to determine the eligibility of women and men living with RSIs for inclusion in the study and the qualitative methods used to collect data from the female and male participants. Strategies utilized during the process of data analysis are also discussed.

Research Process

i. Sample Selection

A sample of 12 individuals (six women and six men) participated in the study. All participants were identified from the patient population of the Manitoba Federation of Labour Occupational Health Centre. The facility provides a number of services to injured workers including the diagnosis and treatment of occupational conditions such as RSI. The Annual Report of the Centre indicates that of the 166 new patients seen in 1999, diagnoses of the musculoskeletal system were the most common. Of these diagnoses, 86 (32.1%) were related to soft tissue disorders of the limbs and 44 (21.9%) were due to repetitive motion exposure (Manitoba Federation of Labour Occupational Health Centre Annual Report, 1999). Since there were individuals with RSIs attending the centre at the time of the study, the patient population was considered an appropriate potential sample.

Access to the clientele of the Occupational Health Centre was established through contact with the Executive Director. The support and involvement of the Executive Director proved crucial to the identification of the study sample. For reasons of confidentiality I was not permitted access to the personal information of RSI patients, nor

did I view medical records. The Executive Director offered the assistance of a physician who had been responsible for all diagnoses of RSI at the Centre in the last three years. It was fitting that he be responsible for the examination of medical charts for not only was he able to interpret all medical information written on the medical charts, but he was familiar with patient histories and the nature of their injuries.

I met with the physician prior to his examination of medical charts, as potential participants were to meet specific criteria. While participants brought their own characteristics to the study, all received a medical diagnosis of RSI in the upper-extremity and each had experienced the symptoms of RSI for at least one year post-diagnosis. Symptoms were moderate and ongoing, and disrupted activity and the routines of everyday life. All participants had a history of labour force participation even if they were unemployed and/or on compensation at the time of the interviews. The fulfilling of these four criteria created a degree of consistency in the experience of RSI among the sample.

The physician and I made a simple coding checklist which was used to monitor his coding of medical charts and clarified all selection criteria. For example, the checklist for the 'moderate severity of symptoms' criterion included a category for sleep disturbance and activity-related limitations. Whereas the presence of sleep disturbance was simply coded as 'yes' or 'no,' a scale was used to signify the extent to which RSI interfered with activity levels. The scale consisted of only four options where '1' represented no interference and '4' represented constant interference. Those patients who experienced difficulty sleeping and when performing activities because of RSI (coded as '3' or '4') met the study criterion regarding symptom severity and were placed on a list

for future recruitment. The physician reviewed the medical chart of the most recent RSI patient he had seen, and then moved backwards in time to the next most recent patient. He continued to apply the same criteria to each medical chart until a list of 24 potential study participants was formed.

I prepared a recruitment letter which was mailed by the Executive Director of the Manitoba Federation of Labour Occupational Health Centre to the individuals with RSI on the list (see Appendix A). Thus, my contact with the individuals on the sample list took place only when they indicated their interest in participating in the study. Follow-up techniques were needed as the response to the initial mail out of letters did not result in the anticipated 12 participants. Only seven (three women and four men) of the 24 individuals on the list were willing to participate. I was surprised to be contacted by more men than women initially, as there was concern that I would only acquire a small number of male participants due to a lack of interest and the reluctance to share one's experience of RSI in an interview. A second letter was mailed to the same 24 people and an additional two female participants came forward. At this point I decided to approach a 'new' group of individuals as it appeared that an additional mail out to the original list of 24 candidates would be unsuccessful in recruitment. I contacted the physician involved in the review of medical charts once again and requested a new list of only six individuals. Subsequent to this final mail out, two men and one woman volunteered to participate. Consequently, the sample size of 12 participants (six women and six men) with RSI was achieved.

ii. The Interviews

I conducted an in person, semi-structured, audio-taped interview with each participant. My initial contact with each participant was in the form of a telephone conversation. It was during this conversation that I informed the participant about the nature of this study, the use of a tape recorder, and the need of future contact for validity purposes. Even though the information was outlined in the recruitment letter, I felt it was important to have each individual understand what becoming a participant in the study involved. I also used our conversation to address any of their questions and concerns. Some of the individuals were curious about my interest in the topic of RSIs. Only a few expressed suspicion about my motives for doing this research. Some female participants wondered whether or not I was working for or collecting information for the Workers Compensation Board of Manitoba (WCB). Each was in the process of filing a claim and wanted to be assured that all information disclosed would be kept confidential. They were apprehensive about participating in the study as they feared comments made could harm their future involvement with the WCB. To alleviate these concerns, I explained the different measures that would be taken to protect confidentiality. These measures included the absence of a participant's name on transcripts and in the final report, destruction of all interview cassette tapes upon completion of the study, storage of data in locked cabinets, and the removal of potential identifiers when discussing specific aspects of a participant's experience of RSI.

I collected some demographic information from participants over the phone as a means to document the general characteristics of the sample population (see Appendix B

for the demographics form). Upon completion of the demographics form, a time and location for the interview was negotiated. All interviews were scheduled at the convenience of the participants. My first four interviews took place in the home of each participant. However, I quickly learned that there were distractions present in the home that easily interfered with the interview process (pets, children, telephone, etc.). Consequently, all interviews that followed took place in a meeting room at the Manitoba Federation of Labor Occupational Health Centre. The meeting room permitted a fair degree of privacy and none of the participants expressed being uncomfortable with the interview location. All interviews were one-on-one with the exception of a male participant who brought his daughter to the interview. I was concerned that her presence would cause him to hold back personal information, but he indicated that he had no secrets from his family and would not answer any differently if she were not there. The participant's daughter was a witness and did not participate in the interview.

Before the interview began, each participant was asked to sign a consent form (see Appendix C). All participants were provided with a copy of the consent form and an information sheet about the study. I briefly explained to each participant that all information gathered in the interview session would be kept confidential, and s/he was free to stop the interview at any point in time and/or refuse to answer any questions without consequence. Each participant understood that the Executive Director of the Manitoba Federation of Labour Occupational Health Centre would receive a copy of the final report and that a modified version of the final report would be submitted to academic journals. I obtained written consent from all of the women and men who

participated in study. Each participant also requested their own copy of the final report upon the completion of the study.

Participants were also asked to fill out a disability questionnaire before the interview, *The Disabilities of the Arm, Shoulder, and Hand*, also known as the DASH (see Appendix D). Studies using the DASH reveal that it is a valid and reliable tool (McConnell et al., 1999). The questionnaire can be used to gain information on the nature of an individual's symptoms, and the extent to which RSIs interfere with the performance of various activities inside and outside the home (McConnell et al., 1999). An abbreviated version of the DASH was used in the study in order to minimize the length of time needed to complete the questionnaire. Descriptive statistics are used to summarize the data from the questionnaire.

An interview guide was developed and consisted of a variety of questions to be asked during the interview (Appendix E). The questions covered a range of issues in order to capture the illness and legitimation experience of RSI. Areas explored during the interview included how RSIs have disrupted life in terms of physical limitations as well as role changes. Perceptions of RSI by physicians, employers, co-workers, friends, and family from the perspective of the participant were also examined. As this section was central to the focus of the study, the participant's legitimation experiences were divided into stages, pre- and post-diagnosis. I probed into instances of disbelief and negative reactions to determine if and how they affected the individual's own understanding of his/her condition and whether or not actions were taken to change the opinions of others. The presentation and invisibility of RSI symptoms was also addressed. The interview

concluded with questions dealing with the personal understanding of RSI and the advice these women and men had for others living with the same condition. Before the interview ended, all participants were given the opportunity to offer any insights of their own and/or share any additional information that was not already considered and should be included in their story.

As the interview itself was partially structured, I was able to explore various issues as needed and develop new questions over the course of the data collection (Patton, 1987:111). During my first few interviews, I was hesitant to deviate from the questions on the interview guide. However, as I grew more comfortable with the interview process, I became aware of the value of letting the participant take the lead in the interview. By allowing the participant to lead the discussion, the interview became more of a conversation, and I was more of a listener than an interviewer. I found it useful to let the participant set the pace of the interview and decide what type of information s/he was ready to disclose and when. Furthermore, as the illness experience is unique to the individual, there were areas of the interview guide that were relevant to some participants and not others. For example, exploration of the reactions of others was not necessary during the interview with a man who described himself as indifferent to the opinions of others. In comparison, I addressed the same issue more thoroughly with another male participant who expressed hostility towards his manager at a former workplace for not taking his RSI seriously.

Due to the informal nature of the interview, its length was dependent on the detail of the account. Interviews lasted one to two hours. Interviews with the female participants

were generally longer than with male participants; the former lasted close to two hours while the latter averaged about an hour. However, the length of the interview did not determine the quality of the information that was collected. The men did comment on the emotional and personal struggles they had been faced with since the development of RSI even though it was not to the same extent as for the female participants in the study. I probed into areas as needed, particularly when the discussion was considered valuable to study findings and conclusions.

The personal interview proved to be a useful technique for both the interviewer and the interviewee. Not only did the face-to-face interview allow the participant to have someone to talk to about their experience of RSI in a non-judgmental setting, but they were able to do so to their satisfaction. Showing one's injury became an important part of the interview. Participants displayed scars, bandages, and pointed to the specific areas of the upper limbs affected by RSI and in pain. The women and men demonstrated the types of movements from which they are either partially or completely limited such as clenching a fist, grasping objects (holding a pen or a jug of water), and lifting, to name a few. Other actions that would have otherwise gone unnoticed (if I did not interview participants) were those related to non-verbal communication. Since I was interested in how the women and men in the sample felt their RSI was perceived by those in their environment, the manner in which specific instances of negativity were shared was noted. Participants mimicked the comments, gestures, faces and attitudes of others during such recollections. Tone of voice and emotional states altered as well. One woman became very quiet and teary-eyed when describing the difficulty of living with constant pain in

her wrists. A few participants became frustrated and raised their voices when describing the way they had been treated by the WCB in relation to their compensation claims. During such moments of the interview, I felt it was crucial to appear neutral and not debate with the participants.

It is interesting to note that it was the women and not men of the study who found the interview physically strenuous. Four of the six women indicated that it was difficult for them to share their story of RSI as it brought up a number of unresolved feelings, one of which was disappointment. Physical and emotional states soon complemented each other. The more these women discussed difficult issues related to their role as a spouse or worker, the more physically exhausted they became. As the interviews progressed, the women became restless and tired (sighs increased, they rubbed their limbs, stretched and/or put their face in their hands). The changes in demeanor and behavior I witnessed allowed me to understand why these women sometimes chose to conceal their RSI from people they do not know.

iii. Data Analysis

Data analysis consisted of two processes, the analysis of data and the interpretation of data (Patton, 1987). While the former involved the organization of data, the latter involved making sense of the meaning of the data (Patton, 1987). The analysis of data in this study was inductive and was guided by the principles of grounded theory as outlined by Strauss and Corbin (1990). Grounded theory is based on the description, classification, and interrelationship of concepts that have emerged from the data (Dey,

1993).

I began data analysis immediately after the first interview and continued to do so until all interviews were complete. I transcribed each interview verbatim and created transcripts for all participants in this study. As data analysis was an on-going process (Maxwell, 1996), key concepts were identified when the transcripts of the initial participants were examined. These broad concepts were used to guide the examination of subsequent transcripts.

Conceptualization of the data occurred when I finished interviewing all participants in this study. Strauss and Corbin (1990) describe this process as taking apart the sentences and paragraphs of the data, and giving each event or incident a name that represents a phenomenon. For example, I used the term ‘complaining’ to represent that portion of the interview where participants addressed fears of being perceived as a “whiner” and they distinguished between the disclosure of symptoms and complaining. If a particular comment of a participant was important, it was underlined and marked for inclusion in the chapter on study findings. These quotations were included in the text to capture the originality and detail of participants’ responses.

Once concepts were attached to the data, they were organized into broad categories. These broad categories were then coded. As recommended by Strauss and Corbin (1990), I chose codes that were reflective of the data they represented. I did not spend a great deal of time coding categories, but rather focused on the patterns and themes apparent in the data. Major themes in the data included the presentation of symptoms, sources of legitimation and rehabilitation. The properties of these broad

categories were developed with subcategories of data (Strauss and Corbin, 1990). For example, within the category of 'presentation of symptoms' were subcategories relating to patterns of communication and the invisibility of RSIs.

As it was my intention to explore the gendered nature of RSIs, I spent a great deal of time sorting through the transcripts of female and male participants. I created a journal for each group of participants to document and compare their experiences of RSIs. The constant comparative method is a technique used in grounded theory (Strauss and Corbin, 1990). The value of the comparative method is that variation in the data of the women and men with RSIs is viewed as originating from "different modes of knowing," and thus are included, not excluded, from the analysis (Glaser and Strauss, 1967 as cited in Howell, 1994:101). To aid in the comparison of male and female participants with RSIs, I constructed charts on the different themes in the data. I used coloured markers to highlight the areas of similarity and dissimilarity in the experiences of female and male participants with RSIs. In doing so, I was able to readily identify the extent to which female and male participants differed in their illness and legitimation experiences of RSIs. Data from female and male participants were continually contrasted in order to develop typologies and elaborate explanations generated in the analysis (Tarasuk and Eakin, 1994).

A summary of the data analysis was distributed to the women and men in the study for feedback (Appendix F). Maxwell (1996) points out that the solicitation of feedback from others (member checks) is a useful strategy to identify threats to validity including bias, and flaws in logic or method. I also enclosed with the discussion summary

the profile of each participant used to put her/his story into context. The participant was instructed to review the profile and indicate if there were any identifiers that s/he felt jeopardized confidentiality. All participants in the study were contacted and were given the option of receiving the outline via mail, email, or fax. The women and men in this study were given one week to look over the outline and supply feedback in an additional meeting and/or phone conversation. I felt member checks were an important addition to this study as it gave participants the opportunity to comment on the analysis, and to point out any elements of their story that might have been overlooked.

All feedback from the participants who received a copy of the discussion summary was taken into consideration before drawing final conclusions. Overall, the feedback received from the women and men was positive. They were not concerned with the information in their individual profiles, and did not request to have any aspects of their story removed.

Chapter 4. Participants in the Study

Summary of Participants

Overall, participants in this study shared similar characteristics. At the time of the study, participants ranged from 30 to 60 years of age (mean age = 41.6). Half of the participants belonged to the 30 to 39 age group (n=6), while the remaining participants were in the 40 to 49 (n=3) and 50 to 59 (n=3) age groups. The majority of the sample was married (N=9). Of the three men not married, one was in a common law relationship and another was engaged to be married. As the latter did not share a household with his partner, he was classified as 'single.' Only three women and two men were parents to children living within the home (mean age of children = 14.7). The entire sample population was Caucasian and resided in the Winnipeg area. Three of the 12 participants (two men, one woman) identified themselves as members of an ethnic group (European descent). The sample characteristics are summarized in Table 1a and b.

Table 1a. Age of Participants

Age	Women	Men	Total
30 to 39 years	3	3	6
40 to 49 years	2	1	3
50 to 59 years	1	2	3

Table 1b. Marital Status of Participants

Marital Status	Women	Men	Total
Married	6	3	9
Single	0	3	3

Of the 12 participants, three had post-secondary education, three received a high school diploma, and four had some high school training. See Table 1c.

Table 1c. Education History of Participants

Education	Women	Men	Total
Post-secondary	2	1	3
High school diploma	1	2	3
Some high school	2	2	4
Vocational training	1	0	1
Finished elementary	1	0	1

At the time of the study, half of the participants were unemployed. See Table 1d for the employment status of the women and men. In terms of occupational status, three female participants did clerical work, whereas the men occupied factory/ production work positions (Table 1e). Those women in the study who did have experience in non-traditional sectors such electronics assembly and factory work (N=2) migrated into

Table 1d. Current Employment Status of Participants

Employment status	Women	Men	Total
Employed	3	3	6
Unemployed	3	3	6

Table 1e. Employment At Time of the Injury

Occupation	Women	Men	Total
Clerical	3	0	3
Cashier	1	0	1
Factory/production	2	6	8

female-traditionally occupations once injured with RSIs (clerical and beauty consultant).

All participants had RSIs of the upper extremity. Of the 12 participants, three were diagnosed with carpal tunnel syndrome, three had tendonitis, and the remaining participants were living with a non-specific form of RSI in the hand, elbow and/or shoulder. See Table 1f.

Table 1f. Form of RSIs of Upper Extremities

Form of RSI	Women	Men	Total
Carpal Tunnel Syndrome	2	1	3
Tendonitis	2	1	3
RSI of neck-shoulder-elbow	0	4	4
RSI of neck-shoulder-hand	2	0	2

The women and men reported living with RSI symptoms for an average of 4.6 years (range=4-5 years), despite having only been diagnosed with RSI around three years ago (mean=3.8 years). It is common for individuals with chronic conditions like RSIs to live with symptoms for a period of time before receiving a diagnosis. This can be due to delays in the recognition and reporting of symptoms, and the difficulties surrounding the diagnosis of RSIs (Kome, 1998). Over the years, symptoms of RSIs for participants varied in severity, and would disappear and reappear depending on the individuals' activities. It was interesting to find that while the women and men had all been diagnosed and treated for RSIs, some were still involved in the diagnostic process at the time of the study. This was because of contradictory diagnoses between physicians regarding the

specific form of RSI and its location, ineffective treatments and/or compensation claims.

Even though participants were self-selected into this study, the occupational and employment status of participants in this study reflect the characteristics of individuals with RSIs in the literature. Female and male participants held positions in industries where individuals are at high risk for RSIs. Kome (1998) points out that RSIs are common among women in data entry, cashiering and electronics assembly. Likewise, the men held positions in manufacturing and production work, two Manitoba industrial sectors where RSIs are prevalent (Yassi et al., 1996). Furthermore, half of the participants in this study experienced a change in employment status because of RSIs while the other half of the sample was unemployed. These findings are similar to that of Keough et al. (2000), who found that job loss was a frequent event for the women and men living with upper-extremity cumulative trauma disorders in their study.

Profile of Female Participants

A brief profile of female and male participants will be used to put their stories and experiences into context. Participants have been given a pseudonym to protect their anonymity.

Anna

Anna is 42 years old. She is married and is the mother of two children. She has been living with carpal tunnel syndrome for about 13 years and feels it is the result of the data entry position she has occupied for 21 years. Anna underwent surgery on her right hand in 1987. Her hand was fine until she became pregnant in 1991 with her second

daughter. She underwent a second surgery, but this time on her left hand. The surgery was effective. In 1998, Anna began experiencing pain again. Massage therapy has since kept her symptoms under control. In retrospect, Anna wishes she would have known about the benefits of massage therapy earlier. She feels that because she was diagnosed with CTS in the early '80s, her treatment was limited to either anti-inflammatories or surgery. She presently has minimal discomfort, but suspects her CTS will be aggravated by computer work.

Anna has not received compensation for CTS. While intent on filing for compensation at one point, her supervisor was “not verbally supportive” of her condition. Consequently she felt the supervisor would not be supportive of a compensation claim. Anna relates the difficulties she encountered in her workplace to having been the first person in her department diagnosed with a RSI. She remains in the same workplace and over the years has seen a rise in RSIs among co-workers.

Overall, Anna has come to terms with her condition and feels that “life is good.” She has learned to live with her limitations by pacing and sometimes avoiding activities. Anna feels that being informed is an important component to living with the condition successfully, and she has spent many hours searching for information on RSIs. She is currently contemplating joining an arthritis support group as another means to be “in more control” of her condition.

Beth

Beth is married and is 32 years old. She has tendonitis. At the time of injury, she held a temporary data entry position within a large company. She considered this job her

“foot in the door” to launching a career in the department. However, an ergonomically incorrect desk and repetitive keyboarding led to her condition. Beth often experienced pain and discomfort after a day of work, but only decided to go to the doctor when it became difficult to open a jar and brush her teeth. Beth was initially diagnosed with CTS, but subsequent tests revealed tendonitis. She did not think it was a “big deal” because “people get that and it goes away.” It has been two years since the diagnosis and Beth has not seen any progress with treatment. She describes her treatment history as “improper and aggressive.” She feels that physicians have neither listened to her nor understood her condition, which has caused her once positive views of the medical system to change.

Beth has not been able to return to work since being injured and is currently receiving wage loss benefits from WCB. Although eager to work again, she is concerned about her ability to obtain employment. Once confident in her potential to succeed in the field related to her degree, she is now unsure of how she will be perceived by potential employers. She worries, “I don’t know how employers are going to look at me.” Beth feels the condition has affected all aspects of her life. She is in constant pain and can no longer participate in those activities she once enjoyed. She had originally planned to start a family in her early 30s, but now considers this “not an option” because she is “just managing” doing some daily activities. Beth feels the condition has changed her life “in every single way you can imagine” and is struggling to accept the condition as a permanent part of her life.

Cathy

Cathy is 51 years old. She is married and has one child at home. She has a RSI in

her neck and right shoulder, the pain of which extends down into her hand. Cathy was living with weakness in her arm for two years before going to the doctor. She was referred to a physiotherapist by her regular physician, who tried to counter depleting muscle strength with ultrasound and exercises. Treatments were unsuccessful and she was later referred to a specialist in the area of occupational health who diagnosed her with a RSI. Cathy is currently on a waiting list for therapy, and uses her left arm to compensate for her right arm which “doesn’t do what it used to.”

Cathy feels that a lack of understanding of her work situation by physicians complicated the diagnostic process. Due to the nature of her position, she works for a period of four months and then is off work for about three months. While time away from work activities alleviates the pain, the return to work intensifies the severity of symptoms because of the high pressure demands, overtime, and deadlines of the job. Since her work on the computer is “not physical labour,” Cathy feels that physicians have been unable to grasp the physical stress of work responsibilities and tasks on her body.

At the time of the interview, Cathy was on sick leave, and she recently filed for compensation. She is concerned about the outcome of her claim and future financial situation. Unable to spend extended periods of time on the computer, she is unsure of how to utilize her computer skills. Consequently Cathy feels vulnerable and is “thinking like crazy” about the type of work she can perform if she is released from her job. Cathy is frustrated with having to organize her day around her arm and is disappointed that she is unable to do those activities she once enjoyed.

Debbie

Debbie is 41 years old. She is married and is the mother of two children. At the time of her injury, she had been working as a supermarket cashier for eight years. Although her position was only part-time, she explains that a busy summer schedule of long hours and minimal breaks contributed to the development of her condition. Constant aches and swelling in her right and left forearms brought Debbie to her physician who diagnosed the discomfort as tendonitis. She has since been through physiotherapy, ultrasound and acupuncture to alleviate symptoms. Her physician referred her to a psychiatrist because she was “crying all the time” when describing her injury to anyone. Although she was prescribed anti-depressants, Debbie chose not to take them as she “didn’t want to depend on pills to get through life.” On her own initiative, she found a chiropractor who has been a “savior” in the management of her condition.

Debbie received compensation for a period of two months and then was “cut off.” She contacted her union representative who was reluctant to put in an appeal on her behalf. She is currently appealing her own claim with the WCB, which does not deny her injury but presumes she can work with her limitations. Debbie has tried to do so, but with minimal success. After leaving her cashier position, she received a training allowance through Employment Insurance and took a 21 week administrative assistant course. Her work placement in an office was physically strenuous and she was unable to keep the position. She then had a “short stint” with bookkeeping, but again found the work difficult to perform because of her injury.

Although unemployed, Debbie is hoping to find an administrative assistant job

which does not require a lot of data entry. She is concerned about her financial situation and describes herself as “broke.” She had hoped to send her son to university but does not see this as a possibility now. She has lost confidence in herself and is “emotionally drained.”

Emma

Emma is 30 years old and is married. She was working as an electronics assembler for seven years when she developed a RSI. Her first episode of RSI occurred four years ago when wrist pain in her right hand forced her to take six weeks off of work. She was granted compensation during this time and was treated with anti-inflammatories and a brace. She returned to work in a position in a different department where she no longer used power tools and machinery. Symptoms subsided for a year until Emma was moved back to the shop floor where she had worked previously. Four months later her symptoms reappeared, but this time in her neck, shoulder, and hand.

Despite having had a history of RSI in the same arm, the process of diagnosing her symptoms was lengthy. Emma saw various physicians who offered treatments that were ineffective. She underwent physiotherapy, cortisone injections, and a “diet” of anti-inflammatories. She was frustrated because she felt that her complaints were not being taken seriously. She said, “it seemed like a little game to everybody.” As the most recent case of RSI was more serious than the first, she was off work for a year and a half. Emma received compensation for eight months and then was “cut off.” Unable to afford the costs of physiotherapy, she quit treatment. Emma felt she was in a “downward spiral” until finding her chiropractor. The chiropractor diagnosed her condition as RSI and has

helped her regain movement in her arm.

Emma has some difficulty with certain tasks but overall describes her condition as “better” than it was a year ago. Although she must pace her activities, she is able to do most of the things she enjoyed before developing RSI such as bike riding and walking. She had hopes of being a photographer one day, but does not have the money to buy, nor the strength to carry, the equipment. Once released from her assembly position, she started her own business.

Faye

Faye is 38 years old. She is married and has been living with a RSI for ten years. At the time of her injury she was working in a factory doing silk screening and cutting plastics. Numbness and tingling in her hands led her to a physician who recommended surgery for carpal tunnel syndrome. She had surgery on her left hand and it was successful. Four weeks later she underwent surgery on her right hand. Unfortunately, this surgery was not successful as the surgeon had severed one of the nerves in the web space between her thumb and index finger. She was left without feeling in that area of the hand. She has subsequently undergone six operations on her right hand to correct the problem (the last of which took place only a few months before the interview). The physical consequences of the surgeries are apparent. In her words, “it is quite the scar.”

Due to the numerous surgeries over the past 10 years, Faye was unable to return to work and has been off since. She did return to the factory and worked for only six months in order to get her benefits re-instated before her next surgery. She received compensation for approximately six years, but was denied any future coverage a year and a half ago. She

has since faced economic losses and found a lawyer to manage all matters with the WCB. Faye entered a job program with the WCB and took some computer courses. She was given a receptionist position for a short period of time, but was soon replaced when surgery and recuperation kept her away from the office.

Faye is tired of surgery, but wants the condition “fixed” to get rid of the constant pain. She said, “you wake up in pain and go to bed in pain.” She is currently trying a technique where needles are inserted at various trigger points along the arm, and she is beginning to see progress. Until recently Faye has used her left hand to compensate for the damage in her right. However, this adjustment is no longer effective as symptoms are reappearing in her left hand.

Profile of Male Participants

Andy

Andy is 30 years old and was diagnosed with a RSI of the shoulder and elbow over a year ago. For three years he has been working as a skilled labourer doing production work and using machinery and heavy materials. Andy knew something was wrong when his arm became weak and would go numb from time to time at work. He went to a physician and three months later his symptoms were diagnosed. Andy was “surprised” to be diagnosed so quickly and was “happy” to have a physician who was able to recognize his symptoms as RSI. However, the physician “did not have the time, inclination, or ability” to follow-up the problem. He was referred to numerous physicians for treatment and was “put-off a little” by them because he was not receiving the attention he felt he deserved. At one point he was “extremely upset” with a couple of the

physicians for not sending in compensation forms on time.

Andy describes his workplace as unstructured and flexible. Without a specific set of assigned duties, Andy can change his work tasks according to “personal preference.” Thus, when his arm is “acting-up” he can choose duties that are “less intense” which makes working with his injured arm easier. Andy was given “restricted duties” for a period of time after reporting his RSI to the occupational health nurse at work. The health and safety department of his workplace could not find him lighter duties so he was sent home and went on compensation for a few months.

Andy will soon be married and is leaving the province to pursue a career in computer programming. Although he has undergone a variety of treatments, massage therapy “keeps the symptoms down.” Andy hopes the condition is “temporary” even though he is aware that it may be a permanent part of his life. He is trying to “make the best” of the situation and intends to find a specialist in his new province to combat the problem.

Brad

Brad is 35 years old and has been involved in production work for four years. He describes his job as involving “repetitive work” and the use of “light, awkward” tools. Brad has not held steady employment for about three years. The first year he was away from work was not due to a work-related injury. Shortly after he returned, Brad hit the lower portion of his right arm with a hammer accidentally and had to wear a cast. He returned to the same position a year later. Then one day when he was carrying a piece of material, he felt a “sharp pain” that traveled through his arm and up into the shoulder. The

pain has yet to leave his arm. Brad is living with constant pain and is willing to “throw away a million dollars” to have his arm back.

Brad was diagnosed with a RSI a year ago, but there is some discrepancy with regards to the location of the injury. The physicians and specialists he has seen feel that Brad has RSI of the shoulder, but he believes the problem is in his wrist and wants a CT scan to know for sure. He has tried a variety of treatments including cortisone injections, anti-inflammatories, an anti-depressant, acupuncture and massage therapy, but “nothing has helped.”

Brad received compensation for eight months and then was “cut off” after seeing a physician at the WCB. He then collected Unemployment Insurance for a period of time. When these payments stopped he considered applying for welfare. Reluctant to face bankruptcy, Brad contacted the “sick department” at work for a position with light duties. As there was a long waiting list, Brad decided to return to his original position. He knew he could only do so if his arm was fine, so he “lied to everyone to go back to work.” Brad will begin work in a few months. Although he risks making his arm worse, he feels that his job skills are limited and does not want to lose the wages he has secured with the company.

Carl

Carl is 57 years old. He is married and was diagnosed with tendonitis a year ago. When the “burning” started in his knuckles and the “uncomfortable feeling” in his right hand first appeared, Carl thought that he might have arthritis because of his age. He went to his physician who did not detect arthritis and told him to “carry on” with work. A few

months later his hand “locked up” when he was driving and he had to pry it off of the steering wheel. He returned to the physician and this time was diagnosed “right away.” Carl thought that he did not have a condition that was going to “cripple” him for life, and was “fixable.” However, after trying numerous treatments, he has learned otherwise. The tendonitis soon appeared in both of his hands. Cortisone injections, anti-inflammatories, and braces provided minimal relief. He was referred to a surgeon and had surgery in his right hand. The surgery was successful and symptoms have yet to return. He is currently waiting to have surgery on his left hand.

Carl was not offered any job modifications at his workplace and he continued to work between the surgeries. He wore gloves to ease the “pressure” of heavy lifting and refused to put in any overtime because of his injury. At one point while off work and waiting for an operation, he applied for compensation, but was denied as his company “never had anyone with this injury before.” Carl retired a few months ago after being a printer for 39 years. He had had “enough” with the company. A week before retiring he received a compensation cheque from WCB.

Carl feels that his condition is “small potatoes” because it is temporary. He believes he will not have to deal with pain once he has had the last operation. He looks forward to the operation and getting on with his life. He does not feel any of his future plans have changed and intends to spend his retirement traveling with his wife.

Doug

Doug is 49 years old. He is married and has been living with pain and swelling in his right arm for about three years now. He has been to almost a dozen different

physicians and specialists and has had bone scans, x-rays, and a MRI performed. Overall, he describes the process of getting a diagnosis as “one thing after another.” His diagnoses have included a pinched nerve, carpal tunnel syndrome, a blockage, and finally a RSI of the shoulder and elbow area.

Doug worked in a factory setting for 23 years where he ran a hand packaging machine. For eight to nine hours each day he would lift heavy objects and place them on a conveyer belt. When the pain first began in his elbow, he reported the problem to the foreman but he did not fill out the “green card” for injuries. As the pain subsided for a couple of months, he did not follow up with the paperwork. When a lump later appeared on his elbow he was sent home by the occupational health nurse at his workplace. He went to his physician who gave him some pills which caused his hand to swell up. That was two years ago and Doug has not worked since. He applied for compensation but was denied because he had not filled out the proper documentation when he was injured. He received Unemployment Insurance sick pay for 15 weeks and has gone on welfare because of his hand. He has spent a lot of time appealing his claim with the WCB and feels that he has been “very unjustly treated.” He did not receive support from his union representative who explained that the union does not make “deals” with the WCB.

Doug describes the experience of his RSI so far as a “long haul,” and he is unsure of what is next for him. His financial situation is “frustrating” and “grim.” He knows he has to work, but does not know who will hire him; he does not feel that he can offer much to an employer because when using his arm, his hand swells and it is difficult to grasp objects.

Edward

Edward is 38 years old and has been a skilled labourer for 16 years. When the pain in his shoulder and elbow began, he did not have a regular physician. He went to a walk-in clinic and found the physician was unwilling to become involved in the management and treatment of a workplace injury. He was referred to a few other physicians who were not able to find any “evidence to back-up” his story. Consequently, Edward was left without a cause for the “mild tingling” and “really bizarre pains” in his arm. He has recently been diagnosed with a RSI of the shoulder and elbow by a specialist in the area of occupational health. Edwards visits a chiropractor twice each week to alleviate the pain of his “sore and strained” muscles.

Edwards feels that the maneuvering of large trucks and usage of heavy equipment caused his condition. He describes his workplace as “pathetic” and feels it is “unsafe.” He has written to the Labour Board asking them to come down to the work site and view the conditions company workers must endure. As Edward has been employed with the company for many years, he is very knowledgeable of its policies and regulations. He has offered his diagnosis and medical documentation as a “courtesy” to management. Although he has yet to be offered a different position, he has take it upon himself to modify his own duties. Edward does not feel vulnerable for he knows that he will “never get laid off” because of his seniority and union membership. He acknowledges that he would be more concerned if his job was in the private sector. Edward has filed for compensation to cover his chiropractic fees.

Edward hopes that his condition will be temporary, but he is expecting to deal

with the progressive “deterioration” of his arm. He is learning about his limitations daily and is trying to adjust accordingly. He had planned to renovate his home this year, but is unsure of his ability to complete the project.

Fred

Fred is 52 years old and is married. He has been living with the symptoms of RSI for ten years. Fred was diagnosed with CTS three and a half years ago. He had carpal tunnel release surgery on his right hand, the results of which were “not very good.” He underwent a second operation to repair the nerve damage sustained, but again saw limited success. He has not undergone surgery for CTS in his left hand. He was sent by WCB to a pain clinic in another province for three weeks. During his stay, he was involved in a therapy program which required that he meet with a psychologist, a condition he found “somewhat degrading.”

Fred saw about six different physicians at the WCB. He had to wait eight months before receiving any compensation, a situation that produced some “financial hardship” for his family. As he was president of a local union and chairperson of a health and safety committee at one point in time, he knows “how to deal with people” and how to “keep cool,” despite being “frustrated and irritated.” Once his claim was supported by the WCB, the management of his workplace realized that he did not file a “fraudulent claim” and he was given a new position without a decrease in pay. At time of his injury he assembled transformers and operated a crane, but now he spends time on a computer in the shipping department.

For Fred, “everything is A-1.” Although he has frequent headaches, weakness in

his hands and diminished motor skills, he is “carrying on with life.” Pace has become the “magic word” for all activities in the home and at work. He wears braces for support and to minimize the impact of stress on his hands.

Chapter 5. Findings of the Study

I. Introduction

This chapter consists of the findings of the interviews with the six women and six men who participated in this study on the legitimization experience of RSIs. The equal number of female and male participants allowed for the examination of the gendered experience of RSIs, an aspect of the condition that has not been well-studied in the past.

Several issues emerged over the course of the interviews and they have been organized into four major themes: The Illness Experience of RSIs, The Presentation of Symptoms, Sources of Legitimation, and The Recovery Process. The first theme highlights the characteristics of RSIs that are shared with other chronic illnesses and those that are unique to the condition. It also reveals the physical, social and economic consequences of RSIs for participants. Participants in this study used a number of terms when referring to RSIs and describing their experiences. Illness, condition, injury, and disease were concepts used interchangeably by the women and men when discussing RSIs. The second theme addresses the means participants take to present a RSI to those around them. The third theme explores the sources of legitimation available to participants. These sources were both internal and external to the individual. The fourth theme highlights the impact of the presence or absence of legitimation on the recovery process. Similarities and differences in the experience of RSIs between the women and men in the study are noted and discussed in each section.

II. The Illness Experience of RSIs

The onset of RSI disrupted the lives of all participants in the study. The women and men were faced with the task of adjusting to the physical, social and economic consequences of the condition.

Physical Consequences

Uncertainty is a defining quality of chronic illness (Nancarrow Clarke, 1996). Participants in this study experienced uncertainty with the onset of symptoms of RSIs. As all the women and men interviewed had been diagnosed with RSIs of the upper extremity, the focus of uncertainty was not so much on the cause of symptoms, but rather on their appearance and disappearance over time. Participants were easily able to identify those activities which aggravated symptoms during the initial stages of RSIs because symptoms were intermittent. Consequently, any sudden appearance of symptoms which coincided with activity was obvious. However, once symptoms became constant, the women and men found it difficult to distinguish between those activities that irritated RSIs and those that did not. They felt as though any activity produced pain. Carl described his RSI as “mind boggling” and “sneaky.” He was puzzled by his symptoms which would reappear with activity: “I wish [the RSI] could be different, that it would just come up and clobber you and be done, instead of playing around for a year or two.” Similarly, Doug was confused by his ability to work with his arm one day only to “pay the price” the next day. Edward felt the RSI in his arm had gotten progressively worse over time and he anticipates permanent disability is just a matter of time. He explained, “It’s like having ten hours on the phone left and when the battery runs out, you can’t get a new battery.”

The majority of the participants in the study were living with the symptoms of RSI on a daily basis.

At the time of the interview, each participant was asked to fill out the Disabilities of the Arm, Shoulder and Hand (DASH) questionnaire as a way to document RSI symptoms and her/his ability to perform different activities. The questionnaire consists of 28 questions addressing the physical and social interference of RSI symptoms. All participants in the study filled out the DASH regardless of whether or not symptoms of RSI were present at the time of the study. In order to highlight the physical limitations of the women and men in the study, tables on their ratings of symptom severity are listed. Table 2a and 2b represent the self-reported symptoms of RSI present in arm, shoulder or hand of the women and men within the week before the interview:

Table 2a. Rating of RSI Symptoms by Male Participants

	None	Mild	Moderate	Severe	Extreme
Pain	0	1	3	2	0
Pain with specific activity	0	0	4	2	0
Tingling	0	1	4	1	0
Weakness	0	0	3	3	0
Stiffness	0	0	2	4	0
*TOTAL	0	2	16	12	0

*Totals may exceed 6 because some respondents reported multiple symptoms.

Although not listed in Tables 2a and 2b, headaches and difficulty sleeping were reported by the women and men.

A few participants commented on bodily changes caused by RSIs. Andy felt his

Table 2b. Rating of RSI Symptoms by Female Participants

	None	Mild	Moderate	Severe	Extreme
Pain	1	1	0	3	1
Pain with specific activity	0	2	0	2	2
Tingling	3	1	1	1	0
Weakness	2	0	0	2	2
Stiffness	1	1	2	2	0
*TOTAL	7	5	3	10	5

*Totals exceed 6 because some respondents reported multiple symptoms.

arms had gotten “smaller” because of his inability to participate in regular physical activity. Beth became aware of the decreased size of her wrist when her watch became “too big to wear.” She felt there was “nothing left” of her wrist and reported she had “no muscle mass left in her forearms.” Debbie also found that the contour of her upper limbs had dissipated over time and she missed her “nice shaped arms.” To combat the muscle depletion of RSI, Emma was lifting weights at the time of the study.

Participant responses to the disability questionnaire reveal that the women and men in the study have experienced difficulty when performing and engaging in a variety of activities. Activities frequently identified as troublesome included carrying a heavy object (over 10 lbs.), opening a tight or new jar, gardening or yard work, as well as any activities that force the arms to be lifted above the head, such as changing a lightbulb or placing an object on a shelf. Edward, like a number of participants, pointed out that “the smaller the task, the harder it is to do.” Thus, many participants found it “awkward” to brush their teeth, comb their hair, hold a pen, and cut a piece of food with a knife.

Participants also indicated that leisure activities were affected by RSIs (e.g., mowing the lawn, baking, walking/petting a pet, playing sports, bike riding, sewing, and drawing).

Bury (1991) points out that persons facing chronic illness create strategies to manage the interference of the condition in their lives. Female and male participants in the study shared their own strategies of living with RSIs. The majority of participants reported the use of the limb unaffected by RSI to compensate for the injured limb. However, there were a few men who were reluctant to do so as they feared over usage of the “good arm” would encourage the development of a RSI and thus leave them with the condition in both arms. Pacing activities was also mentioned by participants. The women and men monitored the types, and limited the duration of their activities. Emma and Beth spread housework over a couple of days rather than doing chores all at once, while Fred learned to “take it easy” when at work and not carry as many materials at one time.

A number of participants reported being conscious of RSIs when entering situations. Prior to the development of the condition, the women and men did not have to consider the potential negative impact of activities on arms and hands. Decisions were based on interest and a willingness to participate, and not on whether upper limbs could physically withstand the activity. For Edward, “it’s a conscious decision of trying not to use the arm” because he knows there are painful consequences of doing so.

Beth was the only participant in the study who had become “creative” in the management of her RSI. She described herself as an “engineer” and purchased an assortment of devices to alleviate the pain of the condition including a head set for her telephone and large kitchen utensils (spoons and can openers) to reduce grasping motions.

Social Consequences

Participants in the study experienced role changes with the development of RSI, and they discussed how duties and responsibilities once held in the home and workplace were altered in response to the condition. With regard to the private sphere, women and men with children living in the home did not feel their role as a parent had been affected by RSI. These individuals had school age children who were independent and willing to help out with household tasks. Fred was the only participant who experienced a temporary adjustment in his role as a parent. During the three years he was away from work, Fred stayed at home with his children. While he appreciated the opportunity to spend more time with them, it was “hard” for him to accept that he was no longer working. He said, “I didn’t want to be at home. I wanted to work.”

Williams (1984) writes that the breakdown of social roles due to illness is felt most in the domestic setting. For a few participants in this study, the breakdown of roles within the home was not felt in terms of a being a parent, but rather as a spouse or partner. Whereas the majority of women and men who were married or in a common-law union welcomed the assistance of a spouse or partner, some were uncomfortable with the role changes that accompanied the onset of RSI. These individuals had clear conceptions of what their roles were in the marriage partnership and were upset when they were unable to contribute in the same capacity. In comparison to the other women in the study, Beth did not like the greater involvement of her husband in typical household duties such as cooking, cleaning and laundry. She did not want him responsible for those tasks she once performed. “My husband has taken over 75% of the tasks that I used to do.” She

expressed frustration over her role loss and yearned for things to return to the way they were before she had RSI:

It's frustrating because these are things that I like to do, these are things that I want to do, and these are things that I am tired of him having to do. I want things to go back to normal.

Similarly, Carl was troubled when his wife performed what he considered was his “job.”

He shared a story illustrative of his concern:

[My wife] was very understanding. She knew I had a sore hand and whatever she could do - like we went grocery shopping for some dog food, it's a 10 lb. bag or something, and she was carrying it and not me because I couldn't! (Laughs) That's when you start to feel like a useless tit because there's your wife picking up the bag and everyone's looking at you and you're thinking, 'Holy cripes!'

Carl was frustrated by the weakness in his arms which kept him away from those physically demanding tasks he felt he should be responsible for, and he was worried about how he appeared to others when his wife performed them instead.

A number of participants in the study felt their contribution to family finances was affected by RSIs. Emma was uneasy with her decreased contribution to the household income and felt “not quite equal anymore” with her husband. Emma was working at the time of the study, but the job did not provide the same wage as that which she had received from her former workplace. She was “angry” about not having a large pay cheque and “hated” when she had to ask her husband for some extra money. For Doug, unemployment was a source of stress as he was no longer supporting his family financially like he “should.” He explained, “I am the one that should be bringing the most money in and I am not bringing any in. I feel it's unfair to the wife, really.” Doug struggled with his role loss as the breadwinner and did not feel it was “right” to no longer

be the major income earner for his family.

Role changes of participants were not limited to the private sphere and entered the public sphere, to affect their roles as workers. The women and men reported alterations in occupational status with the onset of RSIs because of the inability to perform tasks as effectively and intensively, or for an extended period of time in the workplace.

Symptoms of RSIs also precipitated sick days, sick leaves, and unemployment. At the time of the interviews, six participants were unemployed. While the other half of the sample was employed, these participants encountered modified duties, different positions or the transfer into a new workplace.

Participants with RSIs who were able to continue working with the condition reported a shift in their attitudes toward work. These individuals believed they could not approach work in the same way as they had before the development of the condition, and they acknowledged the physical limitations of RSIs. Andy admitted, "I can't work as long and as hard as I used to." Fred explained how his RSI forced him to become a "smarter" worker. "I use my brains more than my muscle which an old guy like me should be doing." Anna enjoyed working on the computer and paced the amount of time she spent on data entry in order to manage pain. Carl was retired at the time of the interview, but indicated that when working, he had to hold tools differently and "work around where the pain is." Emma was the only employed participant who discussed her work attitude in terms of motivation. She described herself as "really gung-ho" about work until the onset of RSI at which point she became "more slack." Emma confessed, "I don't have the same drive to get everything done. I have paper work stacked up on my desk and I look at it and

go, 'I'll get to you later.'”

A few of the women and men who were unemployed at the time of the study shared hopes of one day being employed in a position that would accommodate RSIs. Debbie revealed that she sought a data entry position that encompassed a variety of tasks she could organize around her tendonitis. Brad indicated his limited job skills restricted him to production work. He wanted a position which allowed for frequent breaks because of the inflammation of his elbow. It was during the discussion of future employment that insecurities surrounding employment potential arose. Doug worried that he would be seen as a liability by potential employers, “Who in their right mind is going to hire me?...if I come to you, you're not going to hire me if you know what's been going on for three years.” Similarly, Beth was unsure how to address her RSI with potential employers and questioned the amount of information she should disclose. She pondered, “How do you talk to an employer? How do you tell them about what happened and what your needs are? What do you have to say and what do you not have to say?” Beth had not faced the situation of seeking employment yet, but anticipated its occurrence in the near future.

Economic Consequences

A number of articles have documented the financial hardships that frequently accompany the development of a RSI (Brown et al., 1986). The majority of participants in this study faced the economic consequences of RSI. Only three of the 12 participants indicated that they did not experience a change in their financial situation following the onset of the condition. The remaining participants reported economic problems, most of which resulted from unemployment.

The presence of symptoms at work, the continual interference of doctors' appointments, and the need for slings, braces, and surgeries were viewed by female and male participants as obstacles to employment. Each felt his/her RSI was work-related. However, the women and men who applied to the WCB for compensation to replace lost income quickly learned that the compensation process was lengthy and time consuming. Participants reported being overwhelmed by the compensation claim procedure, and they commented on the responsibilities that needed to be fulfilled if a claim was to be successful. These responsibilities included the collection of letters from employers and physicians on the nature of the RSI and extent of injury, filling out accident and compensation forms, and visiting physicians working for the WCB, to name a few.

Edward reflected on this unique aspect of the illness experience of RSIs:

I told you about a couple of girls in the office that are having the same symptoms as me, the tingling and pains. Well I told them to start filling out the accident slips and that now. It's kind of sad, but you have to plan out your injury. An injury shouldn't be planned out.

Edward was an active agent in the legitimization of his condition. Not only was he responsible for documenting the symptoms of his condition, but providing all relevant information to external sources of legitimization. Edward did so without any guarantee his efforts would produce positive outcomes. Anna was the single participant in the study who did not file for compensation and thus was not exposed to such responsibilities in her illness experience of RSI.

The delays of the compensation process complicated the financial situation of participants. Fred indicated that there were "hardships" during the nine months he waited to be accepted for compensation. His family "did without some things" and "learned how

to handle money better” during this time. A number of participants were still waiting for the outcome of compensation claims at the time of the study. These individuals reflected on the economic losses they had sustained as a result of the development of RSIs. Brad explained, “I mean, what can I say, I am almost - if I don’t win the lottery or something like that I’m screwed, I’m really screwed.” Doug also shared his concerns:

I mean none of us are starving or anything like that, but that’s not the point. You are dwindling down on your savings that should have been for ten years from now. Now if I get better I may have to work until I am 70 years old before I can quit. That’s also frustrating.

Doug, like a number of participants in the study, was reliant on his compensation claim to remove him from his present financial insecurity. Faye hired a lawyer to handle the appeal of her compensation claim which was denied by the WCB. She had been granted compensation for a number of years but was cut off from payments a year and a half ago. Her financial situation has since deteriorated, “when you get cut down from \$1200/month to \$160/month, it’s a little hard to live on.”

For a few participants, financial hardship was not a current, but future, concern. Before developing RSI, Beth foresaw her “earning potential,” given her degree in management. She is now uncertain of a career in the computer field for which she was trained. While Beth was receiving WCB wage loss benefits at the time of the interview, she described her financial concerns as “strong” for she is not confident in her ability to gain and occupy a full-time position in the future. Edward was employed at the time of the study but believed it was just a matter of time before he could no longer work because of his arm. He expected financial losses if his compensation claim was not successful.

Gender Differences

Overall, there were few differences in the illness experience of RSIs for the women and men in the study. All dealt with the symptoms and physical limitations of the condition and encountered the economic difficulties that accompany unemployment. However, gender differences did emerge when role changes in the private sphere were examined.

The women and men in the study were affected differently by the changes that occurred to the role of a spouse or partner subsequent to the development of the condition. Whereas both female and male participants shared a concern with the impact of RSIs on the financial dimensions of a marriage or common-law union, it was the women and not the men who expressed feelings of vulnerability. Half of the women felt that RSIs negatively affected the marriage relationship, and they feared that the difficulties imposed by the condition would drive their husbands away. Emma felt her inability to participate in certain activities led to the exclusion from social functions with her husband. She believed her lost wage limited the quality time she and her husband spent together for they could no longer afford to travel and go out for dinner on a regular basis. Beth also felt that her relationship with her husband had changed since she developed a RSI. She described her RSI as “a roller coaster” for both her and her husband. She believed the condition cost her the “fun times” of the relationship, “We don’t laugh like we used to because [the RSI] has taken so much from us.” She explained:

It’s one day up and one day down and he has had to deal with that. And I thank God that he has been able to deal with it. He is supportive and he hasn’t just said, ‘Oh my God, this is enough’... I also wonder when is he going to get sick of this? When is he going to say, ‘I have had enough?’

I don't think that will happen because I think we have a very good marriage, but it is in the back of your mind. It is something that comes out once in a while.

Beth struggled with the possibility of her husband's resentment because of her lack of contribution to household maintenance and the finances. She did not like the greater financial responsibility imposed on her husband, and she considered his role gains a potential source of separation.

Cathy was concerned that her time away from work would disrupt the financial arrangement between her and her husband. Cathy and her husband took turns participating in the workforce which allowed each to pursue artistic interests for a period of time. She questioned her value as a spouse and wondered whether or not her husband would come to view her negatively with time if his artistic freedom was jeopardized by her RSI.

So yeah I need to work and I like to work. I really like the feeling of making money... It's not a high income but it allows us to stay afloat and pursue our non-working activities that make us happy. So for me, I feel enormous pressure if I am dropping out of that formula because then he has to pick up all the slack and he gets no time to be an artist or be the things he likes. And I think that could really impair our happy little home in that the pressure mounts on one person. What if he comes to see me as being home all of the time while he is doing his work? I mean I know in a marriage you roll along and do it, but it bothers me enormously.

Debbie was the only female participant in the study who felt the presence of RSI strengthened her marriage, and brought her and her husband closer together. She was "dependent" on him to carry out housework and fulfill other responsibilities of the home which made her realize how much she "needed" him.

In comparison to the sentiments of the female participants, the men in the study did not express fear of losing a spouse or partner because of RSIs. It is possible that

changes in the marriage relationship did occur, and the men chose not to comment on them. Doug was the only male participant who addressed the “stress” he felt the condition put on his wife. However, he did not pursue the issue.

III. The Presentation of Symptoms

This section addresses the presentation of RSIs, particularly how participants communicate about the symptoms of RSIs. A number of themes emerged regarding the manner by which participants let others know about the condition. The invisibility of RSIs was viewed as an obstacle to the presentation of symptoms. Participants communicated symptoms both verbally and non-verbally.

Invisibility of RSIs

All participants in the study dealt with the difficulty of adapting to the hidden nature of RSIs. Each shared how the absence of physical signs of injury was an obstacle to the accurate interpretation of her/his situation by others, and made the recognition of a RSI problematic.

Bury (1991:456) points out that a “disjunction” in the definition of the situation is likely to exist between persons living with a chronic condition and those around them when symptoms are invisible. This was apparent in the stories told by participants. They commented on how the outer appearance of upper limbs did not reflect what they were feeling. In comparison to a rash or a cut, the aching, stiffness, and burning sensation felt by persons with RSI were not obvious and often went unnoticed by others. For many participants this was a source of frustration, as others could not “see” that something was

wrong with them.

...if my arms would have been totally bruised up and down, well they would see and 'Oh, there must be something wrong with you.' But since they didn't see it, well if you look normal then you should be normal inside I guess.

(Debbie)

It makes it harder for other people to understand because they can't see it and even (laughs) - like for instance, you know the doors where you have the wheelchair buttons? I use those instead of pulling a door. And I think people look and think 'She's a young girl, why is she not opening the door?' (Beth)

...like there's no red light on the top of my head or anything that goes off when I am in pain or when I can't do something. So it might have made it easier if there was like a level indicator or something to say, okay, Andy's arm is starting to get really sore or tired, or whatever. Then they would understand.

(Andy)

I mean I am a healthy guy, I don't look hurt. They think I am either trying to get time off work or who knows? Who knows what they are thinking. And again, I can't blame them if they are seeing no physical - but again, it seems to me there are has to be something...It would be different if there was some sort of way like a machine they could hook up and find that your muscles are sore and you are not making up the story of pain.

(Edward)

Without any signs of injury, participants explained how they were susceptible to, and had faced, skepticism from others. The reaction can be related to the incongruence between what is seen by others and what is real to the person with a RSI. A number of participants indicated that the lack of visible signs of a RSI caused those around them to question the existence of the condition and suspect to malingering.

Yeah, it causes me concern and I don't know how we would get around the stereotype because I feel it is negative. You can't see the pain, so you think the person may or may not be telling the truth.

(Anna)

Now my disability is something we can't see which makes it even harder sometimes because people don't believe you when you are not sitting in a wheelchair or you don't have a cast. I mean you don't have something that looks abnormal.

(Beth)

She was saying that it didn't look like I was injured in spite of how I felt. It's like I told you, you can breathe air but you can't see it, but you can breathe it so it's there, right? (Brad)

Brad used the same line of reasoning when he encountered suspicion about his injury from a physician at the WCB. The physician was unable to locate any damage in his arm and Brad was denied further compensation. As a result, he considered the policy of the WCB to be: "If you can't see it, it never happened." Cathy had recently filed a compensation claim at the time of the study. Although she had not faced any difficulty yet, she was "warned" about the WCB and its reliance on physical evidence. While the warning did not prevent her from contacting the WCB, Cathy was apprehensive to visit her physician when the onset of symptoms occurred. She did not want to visit her physician because she did not have "anything measurable" like a sore throat or bruise, and consequently felt like a "hypochondriac."

Two of the 12 participants in the study had a visible form of RSI. They commented on the benefit of having swollen and discolored upper limbs. Doug found that having a "very visible problem" made it "easier" to have his RSI taken seriously, while Emma felt her bosses would not have believed her pain "if they didn't see the purple hand." While the rest of the participants could not show their injury to others, they were aware of the advantages that came with a visible condition. Statements like "I think other people would believe you right off the bat" and "there would be more understanding and less of a hassle with it," indicate that the women and men in the sample associated a visible injury with the recognition and acceptance of that injury. There were some participants in the study who displayed scars from surgery on wrists and hands. However,

as the scars were usually on the inside of the arm, they were not obvious unless directly shown to other people. Faye was the only participant in the study who displayed scars large enough to attract the attention of others. After eight surgeries she was left with numerous markings on her wrist. Faye, like the other participants with visible signs of injury, reported that the scars were a means to prove injury.

While having visible evidence of an injury was considered important by many in this sample, a few participants made reference to the value of having an invisible condition. Debbie and Fred appreciated the option of disclosure when symptoms first appeared. As neither wanted to be treated differently by co-workers, the lack of overt signs of injury provided each with an opportunity to conceal her/his condition from those at work. However, once symptoms increased in severity and accommodations were needed, they could not hide the RSIs and began to tell others about it.

Non-Verbal Communication

Due to the invisible nature of RSIs, participants in the study put effort into the presentation of symptoms. As symptoms were not readily apparent to those around them, participants made their presence known through non-verbal and verbal communications. Forms of non-verbal communication included the use of braces and slings, as well as showing scars, and changing behaviour. Cathy considered her sling “the best thing [she] could have done to communicate the problem.” In wearing a sling, a “lump” was created under her sweater which provoked curious co-workers to ask questions and gave her the opportunity to share information about her RSI. In comparison, Debbie and Doug felt that mood changes were an indication to others that they were in pain. Debbie described

herself as “emotional” when symptoms were acting up and Doug became “grumpy” when he was unable to move his arm freely. However, while braces, slings and scars worked to bring attention to the RSIs, they were not always available to participants. Most of these visible cues were a product of treatment and thus were not used pre-diagnosis or when symptoms first appeared. Consequently participants were often left to introduce symptoms verbally and explain their RSI to others.

Verbal Communication

The disclosure of symptoms by participants to those in their public and private lives occurred at different points in time over the course of the illness. There was variability among the sample with regards to who they shared information with and when they chose to do so. Most participants told others about symptoms when they initially appeared. As pains were interpreted differently by the participants, disclosure was a casual mention of discomfort for some and a concern that something might be wrong for others. Participants told a range of persons including physicians, employers, co-workers, family members, close friends and/or a spouse. Disclosure to significant others generally occurred because the women and men in the study *wanted* persons they cared about to know what was happening to them, and they sought comfort, opinion or advice. With increasing physical limitations, participants also felt there were individuals who *should* know about symptoms.

Many participants felt it was important to tell employers and co-workers about symptoms since it was at work that symptoms appeared. Brad and Fred felt co-workers

should know why they were unable to perform tasks as efficiently, while Emma wanted her supervisor to know why her behaviour might change over the course of the day. Days away from work and sick leaves also prompted participants like Andy and Doug to talk to co-workers and supervisors. Cathy was the only participant who did not talk to co-workers initially due to a lack of opportunity. Working the night shift limited her contact with those in the workplace and when she did interact with co-workers, she did not want to speak of her symptoms. It was not until Cathy was diagnosed with RSI that she began telling others about her symptoms. She felt the diagnosis gave her “permission” to do so.

For a few participants, developing an understanding of the symptoms and the condition was favored prior to disclosure. Beth waited until diagnosed to tell the management of her workplace that she was injured. The delay gave her a chance to learn about the seriousness of the problem. Edward brought a letter to work that he received from his physician. As the letter described his diagnosis, he used it to assist in his explanation of RSI when talking to co-workers and supervisors. In general, the diagnosis opened the door for participants to disclose symptoms to more people. As there was now a “name” for symptoms, aches and pains were transformed into a bona fide medical condition.

Once you have a name for something, you go ‘okay.’ It puts it into perspective and then I guess you feel that you have a right to tell people about what’s going on I suppose... until I found out what it was called, you know, people would just kind of look at you, kind of dumbfound because they think, ‘Well it’s a pain in her arm, she probably slept funny.’ (Anna)

None of the women and men interviewed discontinued disclosure upon receiving the diagnosis of RSI. Awareness of the condition itself did not prevent them from telling

others. In fact, many participants became more sensitive to the wincing and groans of others and offered the diagnosis in the attempt to have others take seriously any symptoms of her/his own. When Andy saw a co-worker grabbing at her/his shoulder, he shared what he had gone through with a RSI “just in case” the co-worker had a similar condition. He told his co-worker “you’re not imagining things” in order to let her/him know how serious the problem can become if ignored and not taken care of. Edward, Anna, and Doug also encouraged co-workers at their own workplace to seek the help of a physician when in pain.

A reluctance to disclose RSIs developed in participants with time, particularly with casual acquaintances or when meeting people for the first time. It was found that the women and men in the study did not talk openly about the condition with those they did not know. Whereas a few participants did not feel the need to tell others about their RSIs because symptoms were minimal or gone altogether, others chose to do so in order to avoid the explanation of RSIs that was likely to follow. There was a general feeling among participants that disclosure required a lot of work, especially when the listener was unfamiliar with the condition. Andy laughed, “It’s like, here we go again.” For some participants, disclosure was necessary if the RSIs had consequences for the other person.

Brad explained:

It's not that it's none of their business and in a way it isn't, depending on what the situation is at that time or moment. Then if there wasn't - if we were driving a car, boat fishing or in plane, you don't need to know and neither does anybody else. But if we were carrying luggage together (laughs), I think you would need to know.

He felt a situation could warrant disclosure to individuals unaware of his condition, but

mostly he preferred to not mention his RSI “out of the blue.”

The task of disclosure did not seem as arduous to participants when the listener asked for information on the condition. An invitation to talk about RSIs assured participants that the listener was interested in her/his condition and that they would not be perceived as “complaining.”

Complaining

The notion of complaining emerged from the interviews when the topic of disclosure was discussed. Participants were concerned about how they were perceived by others when talking about RSIs.

A number of participants revealed that they had learned from others’ perceptions of someone who frequently talked about their problems. These perceptions were internalized and directed the behavior of the women and men in the study.

You know when it comes to pain, I remember when I first started working for [company name], somebody was telling me about one of the men in the office bringing his wife to some social activity outside of work hours. They said, “Don’t ever get stuck in the corner with her because all she will do is whine about what is wrong with her.” So I get the idea that these people I work with can be very labeling. They warned me about this lady. They don’t want to hear about all your problems, especially physical things. So you go okay, I will put this in the back of my memory. (Anna)

I’ve always been - I was raised, ‘If you are in pain just tell somebody then keep your mouth shut and don’t say anything more about it,’ you know, don’t be complaining about it all the time.

(Andy)

Participants also observed the pain behaviors of those around them and adjusted their own behaviours accordingly. Cathy and Fred each worked with someone who

complained about a lot of different problems. Cathy found it difficult to be a friend to the co-worker who “always had something wrong with her.”

*There's a guy I work with that has a bad leg and he limps all the time.
Everyday he is crying and complaining about it. It's like, we know [name],
so what? What do you want us to do?* (Fred)

Fred, like Cathy, was annoyed by the co-worker, and did not want to be judged in the same way by others.

There was also a sense among a few participants that they could control how RSIs were perceived by others. In the attempt to avoid looking like a ‘whiner’ or ‘complainer,’ these participants gave consideration to how often RSIs would be discussed. The belief was that by not talking about the RSI constantly, the risk of being viewed negatively decreased. For Edward, the context within which his injury was discussed was important. He felt that if he talked about his injury while working, he was not complaining. However, when “sitting there and telling [co-workers] about how sore his back or arm is on a break,” then an accusation of complaining was appropriate. Beth simply decided not to tell others about her condition “unless asked” because she felt that “people don’t want to hear from people who are always negative.”

Anna felt that negative reactions from co-workers could be avoided by not talking about her RSI constantly. She explained, “you don’t want to sit there and bitch and complain about it constantly because then they will just give you a negative reaction.” The desire to have the RSI viewed positively was also expressed by Cathy. Cathy believed that the diagnosis of RSI gave her “something to stand on,” and transformed her “whining” into a “legitimate complaint.”

Gender Differences

There were gender differences among participants with regards to the presentation of RSI. Female and male participants in the study not only differed in the manner by which they let others know about RSI, but in the reasons they had for doing so.

It was the general preference of the women in this study to use physical displays of illness when communicating to those around them that they were in pain or having a ‘bad’ day. For the women, a bad day signified intense symptoms which made the performance of activities at home or at work difficult. They discussed how rubbing limbs, using heating pads, ice, a sling or brace and lying on the couch were signals to those around them that they were in pain. A few of the women also explained how others “just know” when they are in pain by the way they are acting. Faye “yells” and gets “aggravated.” Beth becomes “quiet or cranky.” Beth also pointed out that people can “look at her face” and recognize that she is in pain. Anna was the only female participant who preferred telling others when she is in pain in order to prevent the misinterpretation of her actions. She did not want her co-workers to “speculate” why she was rubbing or shaking her wrist and felt that “people won’t know what’s wrong unless you tell them.”

Half of the female participants reported that the behaviour of their husbands would change during a bad day. Beth, like Emma, found that her husband became “tense” and even “angry” because he did not know how to help and make the situation better for her. By contrast, Faye found that her husband avoided her and would “stay away” until symptoms subsided and her mood changed.

As stated earlier, participants of this study tended to conceal RSIs from

individuals they did not know or with whom they had minimal contact. For the women, reasons to conceal were related to the way in which the news of RSIs had been received by others in the past. As disbelief, disinterest, and ignorance were expected with disclosure, female participants did not see any “worth” in talking about the RSI with just anyone. Beth did not like to talk about her condition because of the negative reactions to RSI she received from close friends. She explained, “How do I expect more from people that don’t even know me?” Cathy did not want to mention her RSI to new people because of the assumption her symptoms will be met with a lack of “sympathy.” Emma was no longer concerned with how symptoms were perceived by others since they had pretty much disappeared. However, in earlier times she concealed the condition from potential employers in order to escape the stigma of being an “injured worker.” Emma elaborated: “I don’t write that as the reason why I was let go of my work because nobody else will hire me. If you say you have a RSI, everybody runs in the opposite direction. It’s like injured worker, uh oh!” Similar concerns regarding employment were expressed by other women in the study.

Another issue raised by the women was the complexity of the condition. A few of the women found it easy to overwhelm a listener with explanations of RSI and thus tried to simplify the condition in order to make it more understandable. Debbie commented, “Most of the time I just tell them that I have a strain and then I just leave it at that.” Beth described how it was difficult to explain to her new neighbors why she did not work and was at home all day:

They asked, “What do you do all day? Do you work?” And I am like, “No.” And you know, that’s when it gets hard because that’s when you

have to start explaining, "Well it takes me longer to do everything...". Then it gets to the point when it's too much for them to comprehend and it's too much for you to get into. So usually it's like (starts laughing), let's talk about something else.

Beth also revealed that it is "too much" for her to talk about her RSI with anyone. She initially did not want to participate in the study because it is "emotionally draining" for her to "rehash" events and experiences that are a result of the condition. Consequently, Beth will not talk about her condition unless asked to do so by others. The invitation to discuss a RSI was important to other participants in the study, a few of which were men.

While an invitation to disclose encouraged female participants to use verbal expressions of injury, the men in the study did not feel the need to let others know about the RSI, whether or not they were in pain. Once a male participant told someone about his RSI, whether it be a co-worker, friend or family member, subsequent disclosures were not viewed as necessary. Andy explained that he told co-workers why he had to stretch his arm only when symptoms first appeared. He did not continue to do so with time because he felt his co-workers could figure out for themselves why he was stretching. Edward described how he "whined and cried a lot" to co-workers and supervisors initially and then stopped:

...I am past complaining about my arm, back and neck. We all do the work and we know about our neck and back because the environment is so poorly maintained. There's no point in complaining. Everybody knows.

It did not bother Brad whether or not all of his co-workers knew why he was in pain because it was "none of their business" anyway. The only workmates he interacted with already knew about his RSI and thus he did not go out of his way to tell those who were not aware. Doug was the only male participant who reported a desire to discuss his RSI

openly with others. Doug had a visible form of RSI where swelling occurred with the use of his upper limb. The swelling itself attracted questions and he was willing to answer them.

A number of the men in the study did not see the value of letting others know when they were having a bad day. For example, Fred felt that no one needed to hear about his RSI because “everybody has problems.” Statements like “there’s no use crying about it...it’s not going to get any better” and “what difference does it make?” show that the men were stoic and more reluctant to disclose symptoms since doing so did not change the outcome of the situation. Telling others about the pain and discomfort in upper limbs did not make it go away and thus they did not see the point in sharing symptoms with others just for the sake of sharing. By not announcing symptoms at work, it was common for the men to continue working when in pain. When asked why they chose to conceal the pain from others, responses included:

If the hand bothers me, I just go over to the water trough and I soak it down. I guess that's more like freezing it maybe for like five minutes and then I just go back to my job. What's the point of telling anyone anymore? (Fred)

I am not the type to complain, I just sort of carried on and did the best I could with what I had. It was getting really bad at the end there..but it's not like you can't do something because you can still do things. (Carl)

IV. Sources of Legitimation

Both external and internal legitimation are important to those with a RSI. The women and men in this study differed in the priority each group placed on the legitimation of RSIs by these sources.

External Sources

External sources of legitimation for participants in the study included: health care professionals, co-workers and management, friends and family. As such, the medical and social legitimation of RSIs will be discussed. Of significance is the legitimation by physicians working for the WCB, because of the financial implications of the legitimation process.

Health Care Professionals - All participants in the study experienced some sense of “relief” when the diagnosis of RSI was received. Not only was the uncertainty surrounding the cause of symptoms removed, but RSIs were legitimated or deemed “real” by a medical professional. The legitimation of RSI by Emma’s physician was important to her and worked to alleviate insecurities and self-doubt. The diagnosis meant, “I do have a problem, it’s not in my head like everyone is trying to tell me.” Cathy was also “happy” to learn from her physician that she had a RSI, and was “not nuts.” For Andy, having his symptoms recognized “officially” was a source of comfort. He stated, “it’s nice to have somebody else’s word you can lean on.” Edward “flaunted to the maximum” the letter he received from an occupational therapist. He felt the legitimation of RSI by a medical professional gave him the legitimacy to refuse certain duties at work since “someone else was seeing his problems.” The medical legitimation of RSI was critical for all those participants in the study who wanted access to work accommodations, sick leaves and compensation. Debbie wanted her RSI legitimated by a physician because, “at least it would get me a [modified] job or some kind of training to get into a new job.”

However, participants in the study discovered that the diagnosis did not ensure the support of the entire medical community. The legitimization of RSI by one physician or health care professional did not include or guarantee the acceptance of it by others. The lack of support of RSIs by health care professionals (pre- and post-diagnosis) was evident to female and male participants through the lack of attention given to symptoms, the reluctance to become involved in the treatment of the condition, and the skepticism they experienced when dealing with some other health care providers.

A number of participants in the study interpreted the quick examination of upper limbs and numerous prescriptions to mean that the RSI was not being taken seriously by physicians. Andy described feeling “put off a little” by his physician who seemed to rush through his appointments. To him, these actions said, “I don’t have time to sit down and really think about this and figure it out for you, so just keep taking these pills and seeing your physiotherapist.” Fred, as well as many other participants, found that his symptoms were “downplayed a lot” by both his physician and the specialists to whom he was referred. Referrals were a reported source of frustration for participants in the study. The women and men in the study did not appreciate being passed along or shuffled between health care professionals for a diagnosis and treatment. To Emma, the process “seemed like a little game to everybody.” She felt as though the different physicians did not want to deal with her condition, and wanted to get rid of her as soon as possible. Emma explained how she was perceived: “We’ll just give her some pills and hopefully she will just go away.” Doug was also tired of the “run around” he had been given by health care professionals and made the comment to one physician in particular, “For all the good you

are doing, you might as well cut the hand off and put on a wooden one!”

A lack of effective treatment was an additional source of frustration for participants. Debbie described the referral process as “torture” and was upset by her physician who “didn’t want to put out any effort” when treating her RSI. Similarly, Brad and Fred grew weary of the treatments offered by every new physician seen. For Beth, dealing with physicians who were unwilling to listen to the needs of her body was a problem. She felt a “cookie cutter approach” to the treatment of her RSI was taken: “Everything was, ‘This is the way it is going to go and if you don’t like it or your body doesn’t like it, too bad. This is what our program is.’” Beth did not feel the treatment she was exposed to was appropriate, and she felt neglected when no alternative treatments were offered.

A few participants in the study encountered physicians who were unwilling to become involved in the treatment of a workplace injury. Andy and Carl revealed that they had dealt with physicians who did not want to participate in the letter-writing back and forth to the workplace and the WCB regarding the nature of injury. Edward recalled what happened during an initial visit with one physician:

... I am describing to him how these doctors want to get a hold of him and within a half an hour he says, “I don’t want to do anything with your company. Your company has nothing to do with me. There is conflict there if they are writing me.” I can understand his position. He says he’s got a busy clinic to run and I am not his only patient so he can’t spend hours on the phone talking about physiotherapy.

Edward suspected that the reluctance displayed by the physician was related to his¹

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Due to the inability to determine the sex of a physician during the interview, the pronoun ‘he’ will be used to refer to all physicians in order to avoid confusion and create

suspicion of his RSI: “there was no evidence to back up my story.” He reflected on how physicians had reacted to his condition, “They haven’t really listened to my story as more than what I perceive as whining from a young guy who maybe doesn’t like his job or is tired of having to work so hard.”

Participants in the study reported that RSIs were met with suspicion and disbelief by various health care professionals. Debbie was disappointed when her physiotherapist did not believe her pain. She recalled a particular incident when she “broke down” and cried in front of him, and was “ignored.” It was not until Debbie explained how “freaked out” she was because of the problems with her workplace and the WCB that her physiotherapist welcomed her to take some time and lie down in one of the examination rooms. In comparison, Emma was angered by the disbelief she encountered by physicians. She had hoped that there would be an understanding of the condition and its consequences because physicians have “actually studied the body,” and thus should know better. For Brad, it was difficult to interact with a specialist who was skeptical of his condition and did not want to listen to his account of his injury. Brad demanded a MRI and hoped the results would legitimate his pain. The test was denied by the specialist who did not feel it was necessary as he suspected the x-ray would not show any damage in the injured arm.

Whereas Brad wanted a medical test to counter disbelief, Beth decided to take her husband to appointments with her physician. She felt the need to do so in order for symptoms and complaints to be taken seriously:

consistency.

...I found that being a woman (laughs), like it was in my head. Like not just in my head, but they didn't take it - they didn't listen to me. I actually started bringing my husband to appointments with me because I found that they gave me more credibility when I had my husband, a male, sitting there with me. They listened to me, they listened to him. And that's what it has become. I take my husband in because I feel like they believe him over me.

Beth was the only participant in the study who felt a need to have someone present when interacting with her physician. She attributed the doubt she received to being a woman.

WCB Physicians - Most participants in the study had contact with physicians at the WCB. As RSIs are a compensable injury, these physicians were consulted in order to determine if an injury had indeed occurred and if so, whether or not it was caused by factors related to the workplace. The legitimization of RSIs by these physicians is crucial if access to compensation is to be granted. Out of the 12 participants in the study, seven had received compensation for some period of time (three women and four men) and one still collected wage loss benefits. Two participants entered the compensation process at the time of the study. Cathy had just filed for compensation and Edward was waiting to see a physician at the WCB. Doug was denied compensation on several occasions but remained determined to appeal judgements until his claim was successful. Only one participant in the study did not file for compensation with the WCB.

Women and men who had RSIs legitimated by physicians associated with the WCB report negative encounters before and after compensation claims were granted. These participants feel that they have been treated “poorly” and “unfairly.” Brad was “cut off” from compensation after a physician told him that “his injury never happened.” Faye was also told that there was nothing wrong with her and that the problem was “in her

head.” Doug was denied compensation for not providing the proper documentation to the WCB. At his appeal hearing he was questioned by a physician, “If you haven’t worked for two years, why isn’t your arm better?” Doug was angry because ~~has~~ wanted to work during this time, but cannot find a job that does not involve the use of his arm.

Beth wondered how WCB physicians “could go home and sleep at night,” knowing that they are so mean to people. She explained, “...they ~~make~~ you feel like you are lying, they make you feel like you are stupid. They treat you ~~like~~ you are not human and they are just rude.” Fred stated that he had been subject to the “mind games” and “harassment” of WCB physicians and shared the following story:

I went to see one of the doctors from the WCB, probably about the eighth one at that time and we sat in the office and quote me, as I am sitting there, you are the doctor and I am me, he says to me, “What do you think your wife, your co-workers, and your friends think of you sitting at home with your feet up having a beer or a coke?”

Some participants in the study provided explanations of why the legitimization of RSIs by the WCB physicians was difficult. One reason cited was not the poor judgement of the physician alone, but the system the physician represented, which Carl referred to as “crap.” Faye felt that the physicians at the WCB did not have her best interests in mind but that of the WCB. She explained, “It’s one of their doctors, you know. [WCB] tells them what they want to hear.” Beth indicated that it was the “mentality” of the WCB to doubt injury in order to detect fraudulent claims. She presumed that the physician she had seen called her a “liar” because it is “part of their job” to be tough on people filing for compensation.

A few participants made reference to the criteria which regulated compensation

claims but were hidden from the public. Fred indicated that a person's behavior can impact the outcome of a claim. He explained how people have to be "strong" and not "lose your cool" with the WCB physicians because it "takes a flick of the pen and you are off the list." He did not feel he could act the way he wanted to when belittled by a WCB physician because of the vulnerable position he was in.

Like most normal people would have smacked the doctor, used a lot of bad language, walked out, not kept appointments and the whole bit, and not be going through all the crap I had to go through.

When his RSI was met with disbelief, he chose to remain docile. He described how he set aside his dignity in order to have his RSI legitimated.

This is something you have to - I hate to use the word accept because no one should have to accept that but unfortunately in cases when you have no money coming in, you sort of have to swallow your pride a bit and play the game like when a cop stops you for a speeding ticket, 'Oh I am sorry officer, I will never do it again,' that type of thing.

For Edward, a successful claim was a matter of terminology. He was warned by a workmate to pay attention to the words used when describing injury in a letter to the WCB. Edward explained, "you have to watch your wording in [a letter to the WCB] because if you word something the wrong way they won't cover you, and if you word it the right way they will cover you."

Edward not only questioned the intention of physicians at the WCB, but those associated with his workplace.

So what I am not confident with is this Dr. _____ and the therapist. They are hired by [the company] and the managers. Now I am not saying that they are bad doctors and they are going to put me in harm's way, but the incentive there is to please the company, not to please me, I would think.

Co-workers - Participants in the study reported a division between co-workers with regards to the legitimization of RSI. It was found that while some co-workers were supportive of a participant's RSI, others were not. Co-workers who were supportive of the RSI expressed interest when initially told about the condition, and they expressed concern when symptoms were present at work. For a number of participants it was felt that while co-workers listened to complaints and tried to understand the RSI, they could not truly relate to the consequences of the condition. A number of participants found that friendships promoted the acceptance of RSIs. Cathy felt that a few of her co-workers gave her the "benefit of the doubt" regarding her RSI, even though "they don't really understand what it is." Carl described the "blank" look he received from some co-workers when he told them about his RSI. He reported that although his workmates had not heard of the term before and did not know what the condition involved, he did not confront any negative reactions. Andy's co-workers were aware of the condition, but not its limitations. He found that while they knew he was in pain, they did not understand how he was personally affected. Anna also worked with a group of individuals who were not personally familiar with the condition. She explained that they would smile and offer sympathy when she was in pain, but "deep down inside you knew they didn't have a clue."

In comparison, there were participants in the study with co-workers who could understand the problem. For these participants, the ease with which RSIs were legitimated by co-workers was due to shared positions and tasks, and thus a familiarity with the physical demands of the job. The reporting of co-workers with aches and pains

of their own was limited to the male participants of the study. While a few of the women were aware of injuries that occurred at their workplace, they did not have any contact with these individuals. Edward, Fred, Carl, Andy and Doug all worked with individuals who were living with some form of injury. Edward explained, “We have a lot of the same injuries so when I tell them that my arms are screwed, they believe me because I know their back is screwed from their job.” Brad indicated that he felt comfortable talking to a particular person at work about his pain because the man was injured himself and thus knew what he was going through. Edward admitted that he was “happy” to have a co-worker who was also injured for it “showed justification” for his own problems. However, Edward only had his RSI legitimated by those co-workers who were similar in age and had been working at the job for a long time. He explained that some of the “junior guys” who were new to the job did not want to work with him because he was “slowing them down.”

The lack of acceptance for RSIs was apparent to the women and men in the study by way of moments of “friction,” general comments meant to get “under the skin,” and “office gossip.” Time away from work was the most frequently reported source of tension between participants in the study and fellow workmates. Co-workers questioned the motives behind sick days, sick leaves, and compensation claims. Debbie described how some co-workers thought she was “sick of her job” and was trying to “get out of work” when she filed for compensation. When Beth was down to working four hours a day, she was frustrated by a few of the co-workers who remarked, “Oh it must be nice to get to go home now.” A few of Andy’s co-workers even found it “convenient” that he needed time

off for his RSI during the summer. His time away from work was viewed as a holiday and not a period of recuperation. Emma felt her co-workers were “jealous” of her when she was not working. In general she felt most of them believed her RSI, but those who did not would comment, “Oh lucky you, you don’t have to work.”

It was the case for a number of the participants in the study that the reactions of co-workers changed with the need for surgery. These participants found that RSIs were legitimated by non-supportive co-workers after they underwent an operation for the condition. They felt that the surgery was an indication to others that the condition was serious. Carl felt his operation showed co-workers that he “wasn’t pulling somebody’s leg,” and Faye felt the surgeries confirmed any suspicions that something was wrong with her hand. For Fred, the operation and cast sent a message to co-workers: “this guy has been telling the truth all along.” Cathy felt that her co-workers as well as her supervisor were forced to say “there must be something wrong here,” when her RSI had “driven” her to the point of not working.

Management - The lack of support of RSIs that came from management was much more explicit than that received from co-workers. Each participant reported incidents of mistreatment and outright rejection from employers and supervisors which were an indication that her/his RSI was not seen as legitimate. Changes in employer-employee relationships occurred over time or with particular events such as the diagnosis, compensation claims and sick leaves.

My boss actually walked right by me. After I went in and handed in this little green workman’s compensation thing I had to give her she said, “Fine,

thank-you,” and gave me this sort of on and off smile. She then got up and walked right by me as if I was invisible! It was the weirdest thing! And to me it just said you are no longer useful to me and therefore you don’t exist.
(Cathy)

Like I said, for the first two weeks [after telling my employer the diagnosis] the managers kept talking to me in personal conversations one-on-one when out having a cigarette, letting me know that maybe I should quit my job. My managers were telling me that my head boss is telling them that I am useless and that he wants to dump me and get rid of me, and to do whatever they can to pressure me to do the job.
(Edward)

As soon as I was taken off work, everything was totally different...like the whole while when I came back [my boss] wouldn’t acknowledge me. She wouldn’t say good morning to me, but she would say good morning to the people around me. She wouldn’t ask me how I was doing, it was always me going into her office and saying “Look it, um, I am not feeling so great, [my arm] is really sore. I am having a hard time doing this, is there something else I can do?”
(Beth)

According to Beth, she went from being considered a “star performer” and “greater than sliced bread” to “nothing.” Debbie experienced a similar “Jekyll and Hyde” with the management of her workplace. She described herself as “one of the favorites” until diagnosed with RSI, and then the supervisors became “downright mean.” She specified how they were no longer friendly: “they never included me with any kind of smiles, like they would never look at me, they would more or less avert their eyes from me.” Doug explained how his boss and the occupational nurse at his workplace were “very reasonable” regarding his injury until he announced that he would be filing for compensation and then he was “treated like dirt.” Carl did not appreciate being laughed at by his boss when he told him about his compensation claim for a RSI. He was embarrassed when his boss told him in the crowded canteen at work, “What the hell for? I know most of that stuff is hereditary!” Carl was not given any modifications to his job by

supervisors who, he felt, were influenced by his boss. When asked if he felt his boss' reaction affected that of his supervisors, his reply was, "Oh I know damn well it did! They don't wipe their behinds unless he tells them."

The lack of acceptance of RSIs was also conveyed with subtlety by management. The notion of 'actions speak louder than words' was supported by the women and men in the study. In the words of one participant in the study, "none of [management] have ever said, 'You're not hurt, you are faking it.' Their actions alone have stated that."

Participants felt offerings of accommodations were an indication of whether or not the RSI was seen as legitimate by those in charge. Half of the participants in the sample were issued modified duties by management. The remaining six participants either continued working under the same conditions or eventually left the workplace.

Participants who were not given any job modifications once injured were told by management of their workplace that there were "none available." A few of participants did not believe this and felt that management simply did not want to deal with the problem. Carl was insulted by the reluctance of his boss to give him a trainee when he was injured. A trainee would have alleviated the brunt of physical labour in his job for a period of time. Carl "had enough" with the lack of consideration to his needs by his boss and retired shortly thereafter. Faye also decided to leave her job when she was not given an alternate position. Andy and Edward decided to modify their own positions in response to the lack of action taken by management. Each was in the position to do so because of the flexibility of the work environment and the independent nature of the job they held.

For those participants who did receive job modifications, the length of time needed for implementation was significant. A few discussed how the delay between the initial reporting of symptoms and actions taken by management was interpreted. These participants felt ignored and concluded that the RSI was not properly acknowledged. Thus, while accommodations were ultimately granted, participants were not pleased by the lack of attention received. Cathy described the “head in sand” approach taken by management to her condition. She applied for a new job within the department and made it clear when she interviewed for the position that she was doing so because of her arm. She did not get the job and an ergonomist was brought in to assess and modify her job. While the gesture was appreciated, Cathy felt “disrespected” since the changes came “way too late.” She then decided to go on sick leave. The theme of ‘too little, too late’ was also addressed by Beth who felt “brushed underneath the carpet” by management. When Beth told her manager about her RSI, an occupational therapist was called to the workplace. However, her employer did not adhere to the recommendations, one of which was the installation of a \$40 keyboard tray. He said to her, “if you get one then everybody else in the company will want one.” While Beth felt that her condition was “overlooked” by management, she believed that her RSI was a learning experience for future cases. She noted that when some of the other women in the office started having similar problems, management was much more responsive. Tasks were looked at “carefully” and dealt with “quickly.” Emma pointed out that it was only after she was injured that an occupational health nurse was added to her workplace.

The manner in which jobs were modified was also important to participants. In the

words of Debbie, “[managers] have no concept of how to bring a person back after an injury.” Debbie, like a number of participants in the study, commented on the absence of a formal system in the workplace to designate duties to injured workers. It was felt that while the workplace alluded to the presence of “light duties” to physicians and the WCB, there was no policy in place which specified duties to be performed. Consequently, some women and men in study described how management modified duties as they felt appropriate when an injury occurred.

...so the lead hands didn't have enough work for themselves, so I sat at the desk all night and did nothing. The next day I went in and asked my manager, "Could you find something for me?" And he was like, "Well what did you do last night?" So I told him, "I sat at the desk and stared at the ceiling." He wasn't too happy about that and said, "Well, I don't have anything for you to do." (Andy)

And the one time I was talking to a foreman, he's not there anymore, and he says, "Why don't you come back and work for me on light duties?" And I said to him, "What are you going to get me to do?" They have a pole that's about 12 feet long with a mop on the end of it and you are supposed to wipe overhead pipes. But you can't do it with one hand so I said, "I don't think so." And I went to the doctor and told him, and he just laughed and said, "Not a chance." (Doug)

They actually told me at work, they said, "Why don't you carry a little chair with you and then you can run the crane and sit down." Like I am going to walk around with a little stool? Yeah sure. (Fred)

They put me on price-checking for light duties. You see this is why I hesitated to go on light duties in the first place. They put you on price-checking which is running all over the store taking items from baskets from underneath the cashiers, taking them out of the basket and putting them into bins, and then you would have to take the bins and put them into more bins. It was worse than cashiering because there was more lifting. I was really hurt after that. (Debbie)

Debbie went on to describe some of the other consequences of light duties. She lost her status as a cashier which meant “you don’t get the good shifts anymore and you don’t get

treated well by the supervisors anymore.” Edward lost his “overtime rights” when he told management about his injury. Edward tried to avoid being placed on “restricted duties” because the term meant “disabled” to the management of his workplace. He wanted to avoid the label for fear he would be “laid-off.” Although Edward belonged to a union, he could be moved to a different department and sent home if no work was available to suit to his needs. He explained: “If I get laid off, the company doesn’t have to recall me because I am not 100%, so that’s causing me to not go to a department that’s not going to hurt my arm because I could get laid-off there.”

Family Members and Friends - Participants in the study reported the legitimization of RSIs by family members and friends. Family members identified during interviews included parents, siblings, and children. It was the expectation of most participants that parents would be a source of support. Statements like “I mean your parents are your parents, you know, they are behind you pretty much,” and “they are supportive even though they don’t understand it,” were given by the women and men in the study when asked about the reactions of parents to RSIs. Faye also reported that her parents have tried to make her feel better when her symptoms were acting up.

Women and men in the study who were parents indicated that children living in the home were supportive of RSIs. Anna and Cathy found that it was difficult for their younger children to accept the condition initially due to an inability to make sense of the limitations caused by the RSI. However over time, both found that the children could identify when “mom was in pain” and helped out around the house without being told.

Carl received information on RSI from his son who had a hand injury of his own. Carl considered his son a useful resource for symptom management.

While the majority of participants had the support of family, there were a few women and men in the study without the support of particular family members. Debbie and Doug faced skepticism from siblings. Debbie was told by her sister, “Oh come on, [the pain] can’t be that bad,” while Doug had a brother who figured he was “half faking” his RSI. Cathy was accused of “malingering” by her mother who felt she was trying to “wiggle” her way out of work. Cathy explained that her mother had a “working class mentality,” where employers are considered one’s “superiors.” Cathy felt her mother did not accept her condition because the RSI was not legitimated by her supervisor at work. Whereas Emma found her mother supportive of her injury, it was her mother-in-law who was reluctant to accept the RSI. Emma was frustrated by the remarks made by her mother-in-law to her husband. She explained, “it was the constant talking of it, you know, always saying that I should be working and that someone my age shouldn’t be sitting at home.” Emma believed these remarks “influenced” her husband’s perception of her condition: “After a while my husband sort of felt like you know, ‘Yeah, get over it already and get on with what you used to do.’”

Spouses and partners were also a source of legitimation for participants. The majority of participants in the study felt that RSIs were accepted by their partners. Doug revealed that his wife had been “really good about the whole thing” and Cathy shared her husband’s attitude towards her RSI, “rest and do whatever you have to do.” Carl and Anna also received “understanding” and “sympathy” from their spouses. However, there

were a few participants who did receive negative reactions from their partners. Brad faced disbelief from his girlfriend who thought he was off work too long. He recalled, “[she] said I was never injured and that I should go back to work.” The relationship fell apart shortly after the comment was made. Faye reported that her husband was both supportive and unsupportive. She explained, “it’s like he’s brain dead and then he’s alert.” Faye felt there were times when her husband doubted her pain and questioned the limitations of a hand with CTS.

For Emma, the lack of acceptance of her condition by her husband affected the relationship between them. Emma said that since the development of the RSI, she was unable to participate in activities she and her husband once enjoyed together, like canoeing and backpacking. Symptoms have since disappeared, but Emma and her husband have not returned to the activities. She explained, “I couldn’t do a lot of things for two years, so it came to the point of him not even asking anymore and now he basically just does the things that we used to do together by himself or with his friends.” Beth had also become more isolated since developing the condition. The lack of contact with a group of friends was not her choice, but rather the decision of others. She explained:

Like there was a time when I couldn't even do up my pants, so going out, doing my hair and putting on make-up was, "No, I can't." They didn't understand, "Well what do you mean you can't?" And it was like, "I can't, it hurts too much." They didn't understand that and so of course it became less and less that they asked me. Even just talking on the phone became - they didn't want to disturb me.

Beth described herself as a “loyal, supportive friend,” and felt her exclusion from social activities was undeserved. While she admitted missing the presence of these individuals

in her life, she felt that they must not have been her friends in the first place because a true friend would have stood by her.

Gender Differences

Both the women and men in the study sought the legitimation of RSIs from external sources. Overall, there were no differences between the women and men in the study with regards to the medical legitimation of RSIs. Both groups of participants found the legitimation of RSIs by health care professionals in general, and by those working for the WCB in particular to be problematic. Gender differences were apparent in the social legitimation of RSIs, particularly when the reactions of co-workers and the management of their workplaces to RSIs were examined.

There were no women and men in the study who had problems with the management of their workplaces prior to the development of RSI. Conflicts and changes in the employee-employer relationship occurred with the onset of the condition. A few participants indicated that there were managers, supervisors and/or co-workers who they did not particularly like and only had contact with them on a casual basis. However, these participants did not have poor relationships with the individuals and thus any tensions between the two were viewed as a result of the RSI.

Both the women and men interviewed were surprised by the negative reactions to RSIs from those at work. They were upset, and they engaged in avoidance behaviors. Carl reported that he “stayed away” from his boss when his RSI was not accepted. Although participants in the sample chose to limit interaction with unsupportive persons,

the women and men did so for different reasons. Whereas the men in the study were angry and offended, the women were hurt and disappointed. The male participants felt their reputation as a worker warranted the legitimation of RSIs, while the female participants felt their reputation as a person was not considered in the process.

The men in the study expected that the reputation of being a “hard worker” would have served to buffer or prevent disbelief and rejection. Consequently, they found it difficult to accept the realization that all the time and effort expended at the job did not guarantee the legitimation of RSI by those in charge or those with whom they worked. Fred was puzzled by the skepticism he faced from some of his younger workmates. He did not understand why they did not believe his limitations, especially since he had always been willing to help them out with different aspects of the job in the past: “I have always been right there with both hands.” Other male participants expressed similar sentiments:

Everyone else seemed to realize it [except his boss], I had been there for thirty-nine years and never missed any time. I wasn't like a slacker! I was off six weeks with my gall bladder and that was the only time I ever missed it. It's not like I was trying to get out of work or something. It was just that you get to the point where you can't work anymore. (Carl)

Well, I think that I have worked as hard as I could for them and did the best job I could, and then to get treated like this? It's just not right. But when it's a big company like that, you are a number and they don't care. I can remember driving to work during snowstorms when you couldn't even see the end of the car hardly and I would come into work. And then there's guys that live in the city, and they can't come into work because of the snowstorm. But this is what you get after trying to do your best for them? (Doug)

...I am upset that I am not getting the respect that maybe I feel I should get... I am a 16 year employee and I have never had a problem at work and I don't miss time. I should be treated like an employee but they treat everybody like gas station attendants. (Edward)

Brad felt that his reputation as a “serious” person contributed to his co-workers’ acceptance of his RSI, i.e., “the guys know me.” When Brad told his boss about his RSI, he relied on his reputation to counter any suspicion around his injury. Brad explained, “He knows, my boss knows I don’t lie. I told him before right to his face, ‘[Boss], if I was going to lie to you, I would give you a good one.’ But he knows I don’t lie.”

It was not until Carl, Fred and Andy were granted a compensation claim that RSIs were legitimated by management. With injuries written in “black and white” by the WCB, these participants felt that employers had no choice but to acknowledge the RSI. Edward was the only male participant interviewed who was not surprised by the lack of support received from his manager and supervisor. He described the mentality of management at his workplace: “And the saying is, ‘It’s not what you did for me yesterday, it’s what you are going to do for me today.’” With this in mind, Edward revealed how he was “defensive” at work all of the time because he knew that while injured, management would not be on his side but against him.

In comparison to the men, there were a few women in the study who felt their reputation as a worker was a disadvantage. These women discussed how they were manipulated by employers who played on their passivity and compliance. Cathy felt her manager did not take her request for lighter duties seriously because her manager knew that she would not say or do anything otherwise: “Good old Cathy, she’ll come through so don’t worry about it.” Cathy was also told by a supervisor to be “a good sport” and not complain about the pain, which Cathy interpreted as “shut-up and don’t make a fuss.” Beth also felt she was an easy “target” because she was “very quiet, shy and reserved.”

It was common for the women in the study to not question the actions and reactions of employers and co-workers. Feelings were internalized and not vocalized. In comparison to the men, the women did not focus on their role as a worker, but what they had contributed to the workplace as a person. Statements like “how could you think this of me?” indicated that female participants were offended by the perception of them to others as persons capable of lying and faking pain.

My manager made the comment, “Well, you don't want to do this job anymore do you? You want to do something else, that's why you are doing this.” At first I didn't really understand what she meant. Then after a couple of minutes it clicked and I went, “That's what you think?!” I was shocked and hurt, and I was disappointed that somebody would think that - if it was that bad, I would have quit and got something else. I wouldn't have faked pain, you know.
(Beth)

I remember when I told [my manager] face-to-face that I was thinking about filing for compensation for this and she literally chuckled. We had a one-to-one meeting, like a private meeting in her office with the door closed and I just felt like a fool when she laughed. I thought to myself, but this just isn't a ploy to stay off work, this is actually happening! What is wrong with you? I still tell people to this day that I did not file for compensation because so and so laughed in my face.
(Anna)

Emma was “shocked” and “really upset” when she was told by the Human Resources officer that she no longer had a job to which she could return. Emma had intended to return to work shortly and did not expect the termination of her position. Even though she “had no idea what happened,” Emma did not question her termination and left the issue alone.

For half of the women in the study, the disbelief and rejection encountered at work contributed to a “loss of innocence” in the workplace:

It has changed, it has hardened me. I really lost my innocence in the workplace. I mean I came to realize that I wasn't a personality there. I was

just a number in a sense, even though you work so closely with some of these people. I don't know, I just feel like you know, it didn't matter that I was Cathy, it just mattered that I was a worker who could or couldn't do the job... I look and I see that there are no human relationships here based on friendship, caring or anything. They are strictly contractual. I don't know why it took me so long to see that. I worked there for 10 years before I realized that is the nature of the workplace. (Cathy)

I was so loyal to them and they just more or less booted me out of there with nothing except for this injury which I got for working for them. So I have no, I don't feel that I have any more loyalty to give any place that I work. (Debbie)

[The supervisors] don't care. They just want their work done and they don't give a shit about you. If you are not making money, they want to get rid of you. (Faye)

The anger that grew in response to the mistreatment from management was internalized by the women and fostered a bitterness which affected their own perceptions of employer-employee relations in the workplace.

Internal Sources: The Self

Internal sources of legitimation consisted of the participant's perception of her/his condition. Whether or not the women and men in the study legitimated RSIs for themselves was influenced by the importance each placed on the belief and acceptance of the condition by those around them.

The self-legitimation process began with the onset of symptoms. The appearance of tingling and stiffness in the upper limbs of the women and men signaled to them that something might be wrong. Due to the vague and subjective nature of RSI symptoms, participants engaged in self-diagnoses. Women and men attributed pain and discomfort to such things as age, overuse, arthritis, computer work and tasks they performed at work.

Explanations of symptoms led some participants to seek the help of a physician sooner than others. While some of the participants waited to see if pain “would go away,” others listened to the advice of those around them and went to see a physician. The internal legitimation of symptoms was important for participants at this stage for it encouraged help-seeking behaviours among participants.

Participants in the study who legitimated their own RSIs did not give priority to how the condition was perceived by others. This lack of concern closed the door to the internalization of negative reactions. Fred, like a number of participants in the study, simply “didn’t care” what others thought of him or his RSI. He knew his condition was real and refused to be bothered by those who felt otherwise, “I knew I had it and I didn’t care what they thought.” The self-legitimation of RSIs by the women and men in the study was evident in the following statements:

I don't care whether people believe me or not. All I know is that I am being honest with myself so I am happy. (Brad)

I can deal with myself and my injury and consider myself in the long run. Whether people believe me or not... I mean I have never been one to worry about what people think anyway, I don't care. (Edward)

And I really didn't care what people thought because I knew for myself the pain was valid. I am not a whiner. I don't sit there and complain about how much pain I am in every five minutes. (Anna)

...I know what's wrong, I know it's there and if you don't believe me, well that's your problem not mine. I don't care who it is. If you don't believe me like what am I supposed to do to change your mind? I am not going to going to sit there and try and persuade you, “No, this is how it is.” If you don't believe me then (pause) we'll leave the blank empty. (Faye)

A number of participants legitimated RSIs in response to the absence of legitimation from external sources. These individuals discussed how the acceptance of the

condition by others was important initially but not over time. A lack of energy to care about and change the perception of others led them to focus more on themselves. Thus, rather than legitimating the RSIs on their own merit, they chose to do so because of the limited options available. Beth explained:

...it used to matter probably more than now. It's like I don't care (laughs). This is what I have and if you don't believe me, it doesn't matter. It's not going to change the way I feel... personally I think that I am too exhausted now.

Doug and Debbie were resigned to the fact that “people will believe what they want to believe” and “what can you do about it?”

The remaining participants in the study sought external sources of legitimation largely because they did not want to be regarded poorly in the eyes of others. Carl, uncomfortable with people having a negative impression of him, explained, “if no one believes you, they will think you are a slacker!” Cathy did not want to “be seen as a liar.” She explained:

I don't want people to think of me as, um, like what if they feel that I am just trying to scam off compensation or something? Or that I am one of these nutcases that sits on a corner? I don't want that, I want to be believed!

Emma felt that her condition would be taken more seriously when accepted. She wanted to be listened to and not ignored by others.

Gender Differences

Female and male participants differed with respect to the importance of internal and external sources of legitimation. Whereas the majority of men had an internal focus and legitimated RSIs for themselves, most of the women in the study sought the

legitimation of RSIs from external sources. Anna, Faye and Beth were the only women who legitimated RSIs for themselves. However, whereas Faye “could care” less about what others thought of her RSI, Anna and Beth displayed inconsistency in their views on legitimation. Anna, who did not care what others thought of her RSI because she knew her pain was “valid,” also revealed the need to “fit in” and be accepted by others: “You want to have people understand you and sympathize to a certain point. You don’t want people thinking you are a hypochondriac.” Similarly, Beth who indicated that it “didn’t matter” whether or not others considered her RSI as real, also admitted that she wanted others to believe her as she is someone “who tries really hard to please other people.” The contradictory remarks suggest that the women were not as steadfast in their views on self-legitimation as the men. Overall the men in the study expressed consistent beliefs and statements regarding the self-legitimation of RSIs. Most of the men were not interested in how they appeared to others in general and did not question the existence of their condition, even when they were doubted by others.

A number of women in the study experienced self-doubt when confronted with skepticism and disbelief. These women not only questioned the reality of pain, but their own ability to cope. A few wondered whether the condition was due to their own weakness and immaturity.

Like when people start looking at you and it's like, “Well there's nothing wrong with you,” or “We can't find anything wrong with you,” you start thinking, is there nothing wrong with me? I mean they start wanting to give you anti-depressants and you are going, ‘Am I depressed?’ I can't be depressed. I am sure that I am in pain but I don't think that I am going through a depression and that I am not in this pain. Is it in my head? (Emma)

I think my managers thought that I was trying to pull the wool over their

eyes and that I was just making [the RSI] up... you know so when you see that and the doctor writing reports, you know, little inklings along that line as well, you start to question yourself. Am I being a baby here? Do I just buck up and...? (Beth)

...and I still even now sort of doubt, like I believe this is a workplace injury but I still think, 'Oh gee, I don't know what I might have done, maybe I'm just a baby.' (Cathy)

Cathy pointed out that she became “depressed” and “frustrated” when others did not believe her. Doubt and blame prevented the self-legitimation of RSIs, which in turn affected the women’s ability to find a meaningful place for the condition in their lives. The rehabilitation process for the women and men in the study will be discussed in greater detail in the next section.

V. The Recovery Process

The rehabilitation process of RSIs can be affected by the legitimation of the condition by self and others. Howell (1994) examined the impact of the presence or absence of legitimation on the rehabilitation process of women living with chronic non-malignant pain. She found that a healthy and unhealthy progression through illness was determined by patterns of validation by the women themselves and by those around them. Howell (1994) relates

The work of Howell (1994) has implications for the women and men living with RSIs in this study. Data collected from the interviews indicate that out of the 12 participants, four exhibited what is described by Howell (1994) as a “healthy” progression with RSI at the time of the interview and eight did not. The terms “healthy” and “unhealthy” are used in this study to capture how the reactions of self and others to

RSIs impact the recovery process of women and men living with these conditions. As the rehabilitation process is based on experience and interaction, all participants in the study have the capacity to change the direction of the progression and move towards or away from a positive self-image with RSIs. Consequently, the terms “healthy” and “unhealthy” are intended to describe general patterns of behaviour of participants in this study, and not constrain female and male participants to categories that are value-laden.

Howell (1994) relates a healthy progression through illness to being able to live a fulfilling life despite the presence of pain. Similar to the women living with chronic non-malignant pain in Howell’s study, there are women and men in this study who are leading a meaningful life with RSIs. These individuals monitor activities to manage the severity of symptoms, but do not let physical limitations prevent them from participating in that which they enjoy. These individuals adjusted to the RSI and tried to make the best of the situation. For Anna, education is an important component of rehabilitation. She has gathered information on the condition because “the more informed you become, I think you learn to deal with it on a different level.” She elaborated, “I accept [the RSI], I am okay with it. It happened and that’s the way it is and I am trying to do something about it.”

Anna, like a number of participants in the study, did not view herself differently because of the RSI. Each believed s/he was still the same person, except for the addition of physical limitations that were not present before. Andy explained:

I mean I don't actually have a concrete knowledge of all the limitations, so I have to be careful when I am doing certain things. But as far as changing my views of myself as a person, the overall view of me, I am still the same person.

Carl did not feel the RSI changed his life “at all.” As far as he was concerned, an upcoming surgery was going to make his arm “normal” again. He did not change future plans and intended to spend his retirement traveling with his wife.

One participant in the study who was at risk of an unhealthy progression through his experience of living with RSI was Edward. Although Edward had legitimated his own condition and was not overly concerned with the acceptance of his RSI by others, he did not expect the negative reactions from the management of his workplace. The lack of acceptance of his RSI caused him to become uncertain of his future with the company. He admitted that he has not realized the full impact of his condition. His RSI has disturbed sleeping patterns which in turn has made him “a little bit grumpier.” He was pessimistic about the treatments available and wanted the pain of the RSI, which he described as “a constant toothache,” to go away.

Howell (1994) characterizes a unhealthy progression through illness by low self and other validating patterns. Most participants in the study found the legitimation of RSIs by others problematic to some degree. However, some participants were able to move on with life in spite of the presence or absence of legitimation, and to accept the condition as part of self. Those women and men who did not legitimate RSI themselves found it difficult to reconstruct identities after the onset of the condition. According to Howell (1994), an unhealthy progression through illness is also defined by the reluctance of an ill individual to accept symptoms of illness. In this study, there were women and men who found it difficult to adjust to the limitations of RSIs. Pain represented a large portion of their identities. Cathy and Doug discussed how the impairments caused by RSI

made them feel:

It makes me feel useless, it does. It makes me feel like, well what the hell good are you? I know that's - I can intellectualize all these things away, but I know I respond that way. (Cathy)

I just wish it wasn't there because it's just terrible and part of what makes it hard to accept is that you're not sick, but you can't work! And my dad, he's going on 84 and he is doing more than I am doing! (Doug)

Howell (1994) points out that perceptions of being trapped in a life of pain are reflective of an unhealthy progression through illness. Despair and hopelessness were also felt by the women and men in this study who were consumed by the pain of RSIs:

I wish I could get rid of my pain so that I could go work. It's just the constant pain all the time. You can't do anything. You wake up in pain and go to bed in pain. It's never gone, it's always there. (Faye)

...[the RSI] affects everything you do. It becomes - like you become depressed because you can't do the things that you used to do, you don't know when you are going to be able to do them again and everyday there is pain. The pain can be a pain that is dull and you can live with, or it can be a pain that is extreme and you are taking the maximum amount of painkillers a day and that doesn't even take the edge off sometimes. (Beth)

You know my brain power just isn't the same because all I have is pain, pain, pain. It's thinking about my muscles and I am scared now, and I lack confidence because of this. (Debbie)

Brad described his pain as “100% constant” and was pessimistic of his own rehabilitation. “This is the way it's going to be, the same pain, like it's not going to change.” He considered himself “partially disabled” and received a disabled sticker for his car.

These women and men were worn-out by the persistence of pain in their lives, and they reported changes characteristic of depression, including a lack of energy and motivation, weight gain, irritation and a loss of confidence (Cockerham, 1996). Doug has found himself getting “lazier,” “grumpier,” and “not as easy to get along with.” He

laughed,

I was getting to know the Jenny Jones show pretty good already. But you know that's what happens. You just sit and you get in a rut and you just don't feel like doing anything.

Beth and Debbie described themselves as “emotionally drained” and “exhausted.” Each felt that aspects of their former selves had been lost as a result of the development of the condition:

I don't have the confidence to do a lot of things. I guess I am more scared of the physical pain on some things, but emotionally too I am just drained. My friend says, “Your spirit has been broken,” and it's true. That's what it feels like. (Debbie)

I don't see myself as the same productive, goal focused, oriented, motivated person anymore. Now I am a ‘I have to sit back and relax because I can't do this right now’ person because I hurt too much. I want to do this, but I can't do this and um, I am angry. I am angry that this is happening to me at such a young age. (Beth)

Howell (1994) noted that the women in her study exhibiting an unhealthy progression through illness were at high risk for intentional suicide. Two women with RSIs in this study said they were at risk as well. Whereas Debbie was direct in her thoughts, Faye was more subtle and hinted at committing suicide indirectly:

I gained 80lbs., I lost 60 already. Yeah sitting on compensation just makes you get depressed. You gain weight, you get lazy (pause), it brings you down and if you are not smart enough to pick yourself up and get going, you fall into a slump. If you are fighting compensation and you are not getting anywhere, what is the next thing you are going to do? That's not a good answer.

If it wasn't for my friend and my husband, you know, I um, I probably would have committed suicide. (Debbie)

There were unhealthy participants in the study who exhibited the potential to move towards a healthy progression through illness. These individuals accepted the losses

because of the RSI and had begun to legitimate RSIs for themselves. Fred reflected back to an earlier stage of RSI and commented on how he has grown since then:

If someone thinks you are not doing your job all of the time, how would you think about them? You wouldn't like them very much would you? You would try to ignore them to a certain extent, and maybe that explains a lot of the headaches and maybe some of the depression sometimes... then you start getting to a boiling point so to speak, but that's not the case anymore. I am much better.

Fred discussed how he had been angry and “pissed off” with the inability to do the things he used to do but he has learned to “use his head a little more.” He stressed, “You have just got to accept it and get on with your life. If you don't, you are going to be in the nutty bin.” Similarly, Emma expressed a readiness to accept her RSI as part of self. She abandoned the belief that her condition was temporary, and she refused to be defined by the RSI. She explained,

I don't want to be treated differently at all. Just because I have this doesn't mean that you know, I am an invalid. I can still do things, but now I do them at my own pace.

Gender Differences

Howell (1994) based her study on a sample of women. The findings of this study indicate that patterns of illness progression are present among women and men living with RSIs. Female and male participants displayed behaviours characteristic of a healthy and unhealthy progression through illness as defined by Howell (1994). Those participants who withdrew RSI as a central feature of their lives displayed a healthy progression through illness. They continued to manage and control the appearance and severity of RSI symptoms, but did not allow the condition to dictate their activities of

everyday life. While the legitimation of RSI by others was problematic to a degree for these women and men, each was able to focus inward to legitimate his/her own condition amidst the negative reactions, and to accept it as part of self. Gender differences were not apparent among the women and men who displayed a healthy progression through illness. There were gender differences for those whose progression could be characterized as unhealthy as defined by Howell (1994). Female and male participants were not equally represented in the latter illness category, and differed in the extent to which RSIs had an impact on their identities.

The term biographical disruption is used by Bury (1991) to refer to the adjustments made in the lives of persons with chronic illness. Participants of this study experienced biographical disruption with the onset of RSIs. Each limited her/his participation in various activities and renegotiated goals and plans for the future. In contrast to those participants who were able to move on with life in spite of RSIs, women and men who experienced an unhealthy progression through RSIs were not able to do so. Edward felt his RSI cast him into a state of “limbo” where uncertainty characterized his occupational status. Because of his condition, Edward no longer had the job security he once possessed. He was not confident in his ability to perform production work in an industry he had worked in for 16 years. Brad and Doug experienced difficulty adjusting to unemployment. Doubtful of their ability to gain future employment, they were anxious and expressed many financial concerns. In sum, the male participants with RSIs who were on an unhealthy progression experienced disruption in one aspect of life, namely their identities as workers.

In comparison to the men, the women who were on an unhealthy progression through RSIs did not limit the uncertainty and disruption of RSIs to one aspect of their lives, but called their whole identity into question. Threatened self-concepts complicated and delayed the recovery process. In the words of Beth, “[RSI] affects your life in every single way you can imagine.” Beth explained:

[RSI] changes your whole life; it changes the way you feel about yourself; it changes the way you feel about others; it changes what you do, not just work or your daily activities, but your social activities.

Beth felt the condition disrupted both her public and private life. She was upset over the loss of her job and potential career with the company, friends, and the relationship once shared with her husband. Beth wanted to have children but was unsure of the possibility because of the RSI which forced her to put most of her plans on hold. Beth was “angry” over not being able to do what she wanted because of pain, and she emphasized, “I can’t even stress the importance of how much [RSI] changes everything.” Debbie also felt that RSI changed her life and had “taken much out” of her. She shared feelings of low self-esteem and low self-confidence. Debbie was upset over the loss of her position as a cashier. Unemployment led to her being “broke” which in turn affected her plans to send her oldest son to university. Debbie felt the condition was “emotionally draining” and found it difficult to deal with the pain on a daily basis. Debbie, along with Faye, was so overwhelmed by the condition that she contemplated suicide at one point in time. Faye shared her own stories of being “depressed” because of a RSI. Faye felt the condition prevented her from living a “normal” life. She had planned to start her own business but knew that was not possible if her legal battle with WCB was not successful.

For Cathy, RSI compromised her and her husband's artistic pursuits. While Cathy held a position in the workplace, she defined herself as an artist and found it difficult to accept her inability to sew and write because of RSI. Cathy was not comfortable with her lack of contribution to the household income and worried the condition would negatively affect her marriage. At times she engaged in self-doubt and self-blame which discouraged rehabilitation. It is important to note that Cathy, like the other women on an unhealthy progression through RSI, also felt that the condition had a positive impact on her identity. Cathy believed that she had become "tougher" with a RSI and was no longer the "big marshmallow" and "wimp" she used to be. These women reported that RSI had forced them to become "stronger" individuals which they felt was a necessary component of coping with illness. However, the way in which women defined strength raises the question of whether or not the changes to identity are indeed positive as the women associated their new found strength with becoming "meaner," "less patient," and "caring less" about the opinions of others.

Chapter Six. Discussion and Conclusions

In this chapter, the process of legitimation for the women and men living with RSIs is discussed. Attention has been given to the strategies adopted by study participants to facilitate legitimation and the forms of retaliation taken by each when her/his RSI was not accepted by others. The impact of gender and context on the legitimation experience of RSIs is also examined. The section concludes with a discussion of the limitations of the study and some directions for future research.

The Process of Legitimation

Legitimation is an important component of the illness experience. A number of researchers have examined the legitimation experiences of persons living with chronic fatigue syndrome (Clarke, 2000; Cohn, 1999; Cooper, 1997; Ware, 1992), chronic low back pain (Tarasuk and Eakin, 1994; Rhodes et al., 1999), diabetes mellitus (Hernandez, 1996), and hypothyroidism (Milliken and Northcott, 1996), to name a few. While these studies provide insight into the struggles between those persons who have chronic, non-specific symptoms and health care professionals, the focus of legitimation has not generally extended beyond the diagnostic and treatment process. In the case of RSIs, there is a need to examine both the medical and social legitimation of the condition.

RSIs have political, legal and moral implications when legitimated as work-related. Tarasuk and Eakin (1995:205) state that “issues of legitimacy are particularly salient with respect to illness and injury in the context of work.” They assert that the lack of tolerance for compensation claims in the medical and political arena has magnified the problem of legitimation for injured workers. Tarasuk and Eakin (1995) examined the

illness experience of men living with work-related back injuries and found that the suspicion of injury (or non-injury) by employers and co-workers damaged working relations of male participants and fostered the belief that one's personal integrity was under attack. The need to be believed by others and to establish integrity was also present in a study of women with RSIs. Reid et al. (1991:608) used the term "pilgrimage" to describe the dominant theme of the women's accounts of illness. The pilgrimage was the search for "relief, belief and understanding" from physicians, co-workers, friends, and family.

The present research is an extension of the work of Tarasuk and Eakin (1995) and Reid et al. (1991). While these two studies recognize the importance of context in the legitimization of work-related illness or injury, the impact of gender on this process was not examined. What distinguishes the present study is its focus on both context and gender in the legitimization of RSIs.

The experiences of participants in this study highlight the complexity of legitimization in the context of illness. There was no single process by which the women and men had RSIs legitimated by others. While participants sought to have the condition accepted by those around them, the nature and duration of the search for legitimization was specific to the individual. Each participant negotiated and renegotiated definitions of RSI in interaction because legitimization was neither fixed nor stable.

The behavior of the participants in this study is not consistent with the findings of Milliken and Northcott (1996:219) in their study of the chronic condition hypothyroidism. They assert that "seeking validation is not a freely chosen activity but is

necessitated by the nature of illness.” In this study, female and male participants played an important role in the legitimation of a RSI. Each had the capacity to legitimate the RSI for herself/himself, to determine from whom external legitimation would be sought, and to resolve at which point the search would be initiated or terminated. While all participants sought the medical legitimation of RSIs, they varied in the extent to which RSIs were legitimated by employers, co-workers, friends and family. Unable to control how the news of their condition would be received by those around them, actions were taken by the women and men to influence and/or regulate definitions of RSI in the medical encounter, workplace and home (Hilbert, 1984). The patterns of behaviour of participants that emerged when legitimation was the goal of interaction are considered to be strategies of legitimation.

The strategies of legitimation used by the participants of this study can be understood in terms of illness behaviours. Mechanic (1961:52) describes illness behaviours as “the ways in which symptoms are perceived, evaluated and acted upon by a person who recognizes some pain, discomfort, or other signs of organic malfunction.” Illness behaviours can differ between persons depending on the nature and status of one’s condition. Stewart and Sullivan (1982) argue that illness behaviours vary between persons who are acutely ill and chronically ill. In their examination of multiple sclerosis (MS), Stewart and Sullivan (1982) found that the illness behaviour process of women and men living with the condition was complex. Whereas the adoption of the sick role status for acutely ill persons is straightforward, they found that the women and men with MS had difficulty obtaining an accurate diagnosis of symptoms. Stewart and Sullivan (1982)

report that the mild and vague symptoms of MS prolonged the diagnosis process, and affected doctor-patient and patient-significant other relationships for persons living with the condition.

The work of Stewart and Sullivan (1982) is relevant to the illness experiences of participants in this study who are living with a chronic condition. However, as RSIs are also contested in nature, women and men with RSIs are open to suspicion and face potential stigmatization from those in their social network and community. With this in mind, the legitimization behaviours of the women and men in this study do not only reflect their attempts to manage the condition in everyday life, but to secure identities in the eyes of others and themselves. Strategies used by participants to promote the confirmation of RSIs and identities include selective disclosure, determining the significance of legitimization from a source, dismissive and avoidance behaviours, and proving behaviours. These strategies were situation-specific, and often occurred in combination with one another.

One strategy used by participants to facilitate the legitimization of RSIs was selective disclosure. Due to the invisible nature of the condition, participants were given the opportunity to decide when and how much information about RSIs would be shared with others. Both verbal and non-verbal forms of communications were used by the women and men to introduce RSIs to those around them. However when legitimization was sought, disclosure was not simply a matter of symptom communication. The act itself was the result of careful deliberation whereby each participant determined with whom s/he would discuss the condition and the amount of information s/he would provide. The

amount of information the women and men with RSIs shared with others was illustrative private and public accounts of illness (Cornwell, 1984).

Schneider and Conrad (1980) examined disclosure behaviors of persons living with epilepsy and documented the strategies used by these women and men to manage discreditable information about themselves. They found that disclosure ensued in two forms, “telling as therapy” and “preventative telling.” The meaning of these concepts can be developed with reference to the disclosure behaviors of the participants in this study. The women and men with RSIs distinguished between the want and need to tell others about their condition. When symptoms of RSI first appeared, participants reported the desire to disclose them to significant others including family members, friends and/or a spouse or partner. The willingness of the women and men to discuss their RSIs openly with those they cared about was reflective of private accounts of RSIs. Female and male participants sought legitimation from these sources to gain support, advice and comfort. Furthermore, as RSIs had consequences for the participant and those with whom s/he had contact, legitimation from significant others was required for physical limitations to be taken seriously and roles in the home adjusted.

Schneider and Conrad (1980) point out that talking about illness with others can have a cathartic function because the burden of such information no longer rests entirely on the ill individual. While the women and men with in this study disclosed RSIs to those they cared about, they did not express the desire to discuss their condition openly with casual acquaintances or persons they had just met. In these instances, participants limited the amount of information they disclosed to others and offered public accounts of RSIs. A

few participants indicated that disclosure was only needed in these instances if the RSI would affect the other person.

Participants were unable to be selective in disclosure when telling others became necessary. Schneider and Conrad (1980) found that the women and men with epilepsy did not conceal illness when they felt those around them were likely to witness a seizure. Disclosure was viewed as a means to prevent fear in others and the mismanagement of such an event. Likewise, participants in this study felt they “should” disclose RSIs to supervisors and co-workers since symptoms were present, and often intensified at work. The women and men wanted persons at work to know the cause of any changes in their functioning and performance on the job. Thus, when RSIs increased in severity, the ability to be selective in disclosure decreased for participants as accommodations were needed and splints and/or surgical scars became objects of interest to others. Consequently, participants had no choice but to tell others, regardless of whether or not legitimation was sought from these persons and was considered important.

A second strategy used by participants to facilitate the legitimation of RSIs was determination of the value of legitimation from an external source. At the same time participants in the study were evaluated by others, the participants themselves evaluated the opinions of those around them. Charmaz (1983) argues that the impact of a positive or negative encounter on the ill individual is influenced by the perceived importance of *who* is reacting or responding to illness. For participants of this study, the significance of an external source was related to the value of legitimation, or more specifically, how they thought the presence or absence of legitimation from the source would affect them. In

other words, if legitimation from an external source mattered to a participant, s/he sought to have the RSI accepted by that person. The reverse occurred when the source was considered insignificant. The following comment by Cathy is illustrative of how participants in the study assessed the value of legitimation of RSIs by those around them.

I mean I can say, "Oh, I don't care if so-and-so doesn't believe me because I don't have to deal with them and they are not important to me." But for anybody that I feel is important in my life, like my family, my co-workers or my boss, it is essential that they believe me.

Thus, in accordance with phenomenological perspectives, each participant in this study acted on the basis of meanings s/he attached to situations and those around her/him.

Although evaluations of external sources were subjective, participants with RSIs used similar criteria to determine the significance of a source. The significance of an external source was determined by the potential consequences that could occur if RSIs were or were not legitimated, and by the extent to which the participant identified with the source.

All participants felt the legitimation of RSIs by a physician was essential. A diagnosis marked the "official support" of a medical professional and symptoms were indicative of a 'real' medical condition. Medical legitimation was sought by participants through visits and referrals to various health care professionals and compliance with prescribed treatments. When RSIs were diagnosed participants experienced relief. The diagnosis became a tool to counter disbelief and skepticism, and was used to make accommodations in the home and workplace. Those participants who wanted compensation for RSIs needed to have the additional legitimation of the condition as work-related. Consequently, the legitimation of RSIs by personnel and physicians

working for the WCB was pursued. Without legitimization from these sources, compensation for work absenteeism, wage loss and unemployment was not granted. A number of participants who were unemployed at the time of the study were reliant on a successful compensation claim for income. These women and men were uncertain of their employment eligibility and ability to occupy a full-time position.

Participants in the study also sought the legitimization of RSIs from the management of their workplaces. Managers and supervisors were deemed to be a significant source of legitimization because the acceptance of RSIs gave participants access to sick days, modified duties and/or a new position. For example, Anna wanted her RSI legitimated by her boss because she felt that “if an employer isn’t compassionate and isn’t on board with you, you are not going to get the support you need at work.” Debbie pointed out that supervisors at her workplace organized shift work and thus basically “control your life.” Debbie, like a number of participants in the study, did not want to be viewed as a “problem” to management. However, participants were not prepared for the extent to which RSIs affected employer-employee relations. They expressed feelings of shock and surprise when discussing the reactions of management to RSIs. They did not expect the disinterest, exclusion, rejection, and/or mistreatment that followed when RSIs were not legitimated in the workplace.

The legitimization of RSIs by family members and a spouse or partner was also sought by participants in this study. As RSIs disrupted the lives of the women and men with the condition and those they were in contact with, the acceptance of RSIs by family, spouses or partners and children meant access to social support and role adjustments in

the home. Female and male participants also wanted RSIs legitimated by these individuals because they valued their relationships with them. Participants in this study did not want those they cared about to have a negative opinion of RSIs. This issue relates to the second criterion participants used to determine the significance of a source, or the extent to which s/he identified with the source. For example, Andy explained why he wanted his RSI legitimated by his fiancé, “You don’t want the people closest to you having negative impressions or ideas about the things that are happening in your life.”

Charmaz (1983) points out that ill persons are likely to adopt discrediting information about themselves when they identify with the individual who has discredited them. A participant’s self-concept was affected when his/her definition of RSI was not adopted by significant others. This occurrence relates to the social nature of the self. A number of female participants in the study feared the possibility of not having RSIs legitimated by their husbands. These women were concerned that spouses would eventually become tired of RSIs and choose to leave. Feelings of vulnerability led each to question her value as a wife and financial contributor to the household income. Thus, the self-concepts of these women were affected even in the absence of such negative evaluations. The behaviours of these women are reflective of the concept ‘enacted stigma’ discussed earlier in the section on the conceptual framework of the study.

A third strategy used by participants in the legitimation of RSIs was dismissive and avoidance behaviours. This strategy presented itself to the women and men when negative encounters with others occurred. Dismissive behaviours included the participant leaving the issue alone and no longer seeking legitimation from the source. For example,

even though Anna knew she needed the signature of her boss to file for compensation, she did not try to change her boss' opinion of RSI when symptoms were met with disbelief. She explained, "I left it at that... we never got into any heated debates over it or talked about her feelings and my feelings." Similarly, Fred did not feel the need to prove his RSI when others reacted with skepticism because he had his condition legitimated by those who mattered the most to him. He reasoned:

I never tried to persuade anyone to think that I hurt myself. Like I don't care what they thought or not. I mean my wife, my family and my kids, they all supported me.

Avoidance behaviors consisted of limiting interaction with those who reacted negatively to RSIs. Carl refrained from conversing with a boss who did not believe his RSI was worked-related, "I figured if that's [his boss'] God damned attitude, then forget it!"

In the face of disbelief, participants also engaged in proving behaviours. This strategy was used by those women and men who did not tolerate the discounting of RSIs and felt compelled to ensure that the condition was legitimated by others. These women and men felt the need to counter skepticism and prove the existence of their RSIs. Proving behaviours are regarded as the individual's attempt to renegotiate the definition of RSIs with others. While two participants in the study had visible forms of RSI which served to weaken the burden of proof, those remaining found it difficult to "convince" others of pain. Cathy expressed feelings of frustration and helplessness:

How do you prove [RSI]? I mean I could convince you if you want to believe me or if you respect me, then you will be convinced that I am in pain. But really, whether or not you are going to believe me is entirely up to you.

Participants with invisible forms of RSIs used fixtures of injury to counter disbelief.

Some of the women and men displayed braces, slings and surgical scars to influence how their condition was evaluated, and others brought letters from physicians on the nature of RSIs to work for co-workers to examine. The actions taken by the women and men in the study to manage the way in which their RSIs were defined and perceived by others are illustrative of impression management.

Why some participants were driven to prove RSIs is difficult to ascertain from the current study. The study did not focus on this topic. This area of the legitimization experience deserves further attention in future research.

The Importance of Context

“The meaning and experience of illness is nested in a complex personal, socioeconomic and political nexus” (Anderson et al.,1991:101).

The basic tenet of this research is that the illness experience of RSI is influenced by the context in which it occurs. It is argued that the contested status of RSIs in and between medical circles and various interest groups has contributed to skepticism throughout society, and has affected people’s opinions and perceptions of the condition in general. Based on the stories of the participants in this study it is apparent the impact of the RSI debate is also felt on an individual level by the persons living with the condition. Female and male participants not only faced the challenges of the condition in everyday life; they were exposed to the larger controversy of RSIs through their contact and interaction with physicians, employers, co-workers, friends, and family. Participants became aware of the conflict surrounding RSIs when the legitimization of the condition by others was not readily available. While the confirmation of the RSI and self occurred for

some participants, most of the women and men found the process problematic. Each discovered that the search for legitimation left her/him vulnerable to discrediting, rejection, and accusations of malingering. Yet in spite of such encounters, the women and men continued their pursuit of legitimation, particularly when s/he felt the legitimation of RSI by an external source was important.

The significance participants attached to the legitimation of RSIs by an external source can be understood using the “hierarchy of credibility” developed by Howard Becker. According to Becker (1967), credibility is differentially distributed through a system that is ranked. In this system, “participants take it as given that members of the highest group have the right to define the way things really are” (Becker, 1967:127). Refusal of subordinate groups to accept these definitions reflects disrespect for the entire established order (Becker, 1967).

A definitive ranking system of external sources did not exist among the participants of this study. The women and the men varied with respect to the priority each placed on the external legitimation of RSI over time. For example, whereas Carl no longer cared about the disbelief of his boss since retiring from the workplace, Edward felt such views were crucial to his employment. While there was a subjective element to the determination of significant sources, all participants in this study recognized that there were individuals with the power to legitimate illness and grant access to services otherwise not obtainable when RSIs were self-legitimated.

All participants in this study felt the legitimation of RSIs by a physician was essential. Each acknowledged the high degree of credibility physicians hold in society and

made the medical legitimation of her/his condition a goal to be achieved. According to Turner (1987), the medical profession has first claim over the label of illness and disease regardless of its capacity to deal with it effectively. For the women and men in this study, a diagnosis marked the “official support” of a medical professional. They sensed relief when diagnosed with RSIs, and attributed pain and discomfort to a ‘real’ medical condition. As physicians are also the “gatekeepers” to various privileges and services (Nancarrow Clarke, 1996:239), male and female participants were aware that the medical legitimation of RSIs was necessary for access to treatment, compensation, modified work duties, sick leaves, and role changes in the home.

By seeking legitimation from physicians and other health care professionals, the women and men with RSIs gave these individuals the authority to evaluate their conditions using medical criteria. RSIs do not generally meet the criteria of illness as defined by medicine. The medical profession uses the biomedical concept of disease as its “yardstick” for the legitimation of illness (Hocking, 1987:526). Physicians are taught “if there are no observable signs, the illness cannot be real” (Arksey, 1994:458). Thus, the non-specific and invisible nature of RSI symptoms complicates interactions with health care professionals. The women and men in this study explained that without any signs of injury, they were prone to skepticism because they “don’t have anything that looks abnormal.” Complaints of pain were often dismissed and ignored by medical professionals. For example, one physician told Faye her RSI was “in her head” and another told Brad that his injury “never happened.” Nonetheless, as the female and male participants in this study recognized the worth of medical legitimation, they continued

their search for legitimation in the face of negative reactions. The search for medical legitimation led participants to a number different physicians and specialists. Some participants also sought the help of massage therapists, acupuncturists, and chiropractors.

Participants in this study also sought to have RSIs legitimated by co-workers and the management of their workplaces. The women and men felt the legitimation of RSIs by these sources was necessary for the maintenance of positive workplace relations, and for adjustments in their work tasks and roles. As participants did not have any prior problems with these groups, they did not anticipate that the legitimation process would be difficult. However, because information flowing from the top of a ranked system is the most credible (Becker, 1967), many of the women and men in this study found that the medical legitimation of RSIs was a prerequisite for the social legitimation of RSIs.

Dodier (1985:125) examined the evaluation of illness in the workplace and found that lay diagnoses are guided by “*a priori* interpretations” of behaviour such as the ill individual’s characteristics and past conduct at work. The women and men in this study considered themselves to be “good” workers with adequate performance and attendance levels. Many participants were also “friends” to co-workers and interacted with them outside of the workplace. However, while participants felt their reputation and work history made them eligible for legitimation, they learned that these factors alone did not guarantee the acceptance of the condition by those at work. Rather, employers and co-workers gave precedence to those factors which required the approval of a physician. Diagnoses, slings, surgeries and scars became important indicators of illness for participants. These items signaled to others that symptoms were serious enough to require

medical intervention, and removed any suspicions surrounding the authenticity of complaints.

The reliance of lay persons on physical signs of injury and illness occurs because “clinical and lay understandings of health and illness reflect and influence one another” (Schlesinger, 1993:235). In this study, participants did not only have RSIs evaluated according to the subjective criteria of a co-worker or friend, but also the medical criteria used by physicians and other health care professionals that were adopted by these persons. Thus, participants in this study discovered that lay persons, like physicians, rely on that which is physically observable when validating claims of RSIs. The invisibility of RSIs was not only an impediment to the medical legitimation of the condition, but affected the legitimation of RSIs by employers, co-workers, friends, and family.

Overall, participants did not find the legitimation of RSIs difficult among this latter group of individuals. A few participants did report instances of doubt and rejection, but most felt they had the support and acceptance of spouses and family members to allow for role changes in the home. All of the women and men agreed the legitimation of RSIs by those they cared about was important. However, since RSIs were accepted by these sources, the women and men did not have to prove RSIs to those in the home to the same degree as in the workplace and doctor’s office.

Participants in this study accommodated the demands of non-supportive others for physical signs of injury by providing evidence of RSIs. For example, Faye reported that her scars reduced the burden of proof, whereas Andy participated in “tests of ability” at work to show workmates how long he could hold an object before his arm grew numb.

Many participants chose to wear slings and braces to communicate symptoms to others, while a few utilized medical documentation. Edward frequently mentioned over the course of the interview that he “flaunted to the max” the letter from his physician on his RSI with workmates in order to have his symptoms justified. He commented on the value of the letter: “it’s the opinion that is holding my rope on the mountain and that is all that is holding me right now.”

The importance participants in this study allotted to the medical legitimization of RSIs exemplifies the power of the medicine in labeling and treating illness. While participants sought to have RSIs legitimated by the management of their workplace, co-workers, and friends and family, each considered physicians to be the key to community and social support. This finding mirrors the research of Telles and Pollack (1981:250) who argue that although lay persons carry out much of the social control of illness, it is likely the physician has “greater influence than anyone else on labeling people as sick.”

Physicians, and the medical field they represent, had a major role in the legitimization experiences of women and men in this study. The influence of medicine was apparent in the criteria used by the participant’s social network to evaluate RSIs, and in the behaviours of women and men living with the condition who aligned themselves with these criteria to present symptoms in a manner visible to others. Cohn (1999) points out that when symptoms of illness are largely subjective, individual claims of ill health are not sufficient for social recognition. For participants in this study, the social recognition of RSIs was aided by diagnoses, surgeries, the use of braces and slings, as well as sick leaves and compensation settlements. The legitimization process was problematic for those

participants who did not have access to these items. In their absence, the women and men developed strategies to promote the external legitimation of RSIs. These behaviours support the argument that women and men with RSIs affect and are affected by those around them.

Participants in this study created a 'hierarchy' of external sources when attaching value to the legitimation of RSIs by others. Physicians and other health care professionals occupied the top of the hierarchy, followed by the management of workplaces. It is difficult to determine the subsequent order of external sources. The women and men varied with respect to the significance they placed on the legitimation of RSIs by co-workers, spouses or partners, family members, and friends. Regardless of the structure of the hierarchy, it served a general purpose for participants in this study. The hierarchy identified effective avenues for the legitimation of RSIs by external sources. However, the hierarchy also presented the women and men in this study with factors which acted to their detriment. Not only did the women and men diminish and/or relinquish their own ability to legitimate RSIs for themselves, they gave the most authority to physicians, who are responsible for perpetuating the contested nature of RSIs in society. The irony of this is not lost on the participants.

Does Gender Matter in RSIs?

According to Lorber (1997), gender is built into every aspect of illness. Gender is related to the politics of the diagnosis, the delivery of health care, the risks for different diseases, and the behaviours of those who are ill (Lorber, 1997). Lorber (1997) is

supported by research in the area of gender and health which includes examinations of mortality and morbidity patterns (Verbrugge, 1987), the utilization of health services (Kandrack et al., 1991), and the unequal distribution of specific health conditions. In the context of occupational health, women are over-represented in studies of CTS (Rossignol et al., 1997), sick-building syndrome (Stenberg and Wall, 1995), and multiple chemical sensitivity (Wolf, 1994). However, the recognition of gender as a determinant of health does not offer a resolution to the differences that do exist between women and men. For this to begin to occur, “fine grained descriptive data” on the meaning and cause of gender differences in health and illness must take place (Ablon, 1996:99).

Crook (1982) insists that there is a need to recognize the different personal, social and cultural adjustments to illness made by women and men. The cultural features of illness have been explored in the context of race (Anderson et al., 1991), age (Arber and Ginn, 1991), and class (Wilkinson, 1990 as cited in Clarke, 1996). Zola (1966) discusses the influence of culture and ethnicity on the experience of illness. In his examination of patient complaints, Zola (1966) found that sociocultural background can produce different responses to similar disease entities. He studied how Italian and Irish Americans presented symptoms to a physician and reported that while there were no differences between the two groups with respect to symptom length, frequency and noticeability, each group described and reacted to their physical difficulties differently. Zola (1966:623) noted that whereas the Irish Americans understated their difficulties (“specific” reaction), the Italian Americans generalized theirs (“diffuse” reaction).

Although Zola’s understanding of illness and culture is based on the experiences

of women and men reporting complications of the ear, nose and throat, his work is useful for understanding the diversity of experience apparent among the participants living with upper limb RSIs in this study. Similar to Zola (1966), the findings of this study reveal that female and male participants do not perceive and respond to their conditions in the same way. However, whereas Zola (1966) attributes these differences to ethnicity, the critical factor in this study is gender.

The influence of gender on the illness experience of RSI is manifested in the behaviours of participants. Gender shaped the experience of RSI for each participant. Table 3 is a summary of the experience of RSI for the participants in this study. The behaviours of the women and men are grouped into two broad categories, which are best summarized by the statements “I want to be believed” and “I am not a whiner.” Each category is characterized by patterns of behaviour including the presentation of symptoms, reactions to the problem, key sources of legitimation, and the impact of discrediting encounters on identity. Together, these factors have implications for the rehabilitation of women and men with RSI in this study.

Table 3. The Experience of RSIs for Participants

	“I want to be believed”	“I am not a whiner”
Presentation of symptoms	Continuous	Infrequent
Reaction to the problem	Expressive	Stoic
Key source of legitimation	External	Internal
Reaction to discrediting of identity	Diffuse	Specific
Rehabilitation outcome	Unhealthy	Healthy

Participants’ fit in the categories is not fixed as legitimation is continually

negotiated in interaction. Positive and negative encounters with others will influence the actions of the women and men with RSIs, which will in turn affect their experience of illness. Whereas the “I want to be believed” category represents the experience of RSI for the women in the study, “I am not a whiner” illustrates the experience of the condition for the men. Explanations of the various categories follow.

Presentation of Symptoms (Continuous vs. Infrequent) - As RSIs are not readily apparent to others, the presentation of symptoms becomes an important component of the illness experience for women and men. Each participant in this study was responsible for introducing her/his condition to others and did so through a series of verbal and non-verbal communications. The initial disclosure of RSIs by participants occurred for a number of reasons. Some sought support and advice, while others felt it was important to account for mood changes, decreased productivity in the home or workplace, and work absenteeism.

Disclosure patterns of female and male participants differed over time. Whereas the women continually disclosed symptoms to others, the men reported symptoms infrequently. The women in the study wanted others to know at home and at work when symptoms of RSI were present. Pain was communicated with physical displays such as lying on the couch, putting on a brace, and rubbing the affected limb(s). For example, Cathy admitted that she “didn’t shy away from” putting her arm in a sling at work. She explained, “I am not exaggerating symptoms but demonstrating them” to co-workers. In comparison, male participants in this study did not feel the need to continually disclose

RSIs to those around them. Most of the men considered the disclosure of RSIs to be an isolated event. In the words of Carl, there was “no point” in telling his co-workers when he was in pain because doing so did not take the pain away. Other male participants felt that RSIs were not of significance or interest to others since “everybody has problems” or aches and pains of their own.

Reaction to the Problem (Expressive vs. Stoic) - This category is an extension of the previous. It deals with the manner by which participants reacted to RSIs, and the influence of these reactions on the communication of their symptoms to others.

Female participants in this study tended to be expressive about RSIs. They shared aspects of their condition with others and wanted those around them to know when they were in pain. Although the women were willing to discuss their RSIs with others, they did not want to be perceived negatively by others. The women were concerned that the continual disclosure of RSIs would prompt others to view them as complainers. However, female participants felt the invitation to talk about their condition dispelled such risks. The invitation to disclose RSIs was important to the women particularly when the listener was a casual acquaintance or someone she had just met for the first time. Due to prior instances of ignorance and skepticism, the women were hesitant to introduce RSIs to those with whom they were not familiar.

In comparison to the women, the men in the study displayed stoicism. They chose not to discuss RSIs openly with those around them. Similar to female participants, the male participants believed that the continual disclosure of symptoms left them vulnerable

to accusations of “complaining.” To avoid being perceived as “whiners,” the men only shared information about their condition if a situation called for them to do so. For example, Brad reported that he would tell another person of his RSI if the situation demanded the use of his injured arm, or if legitimation was desired. The men in the study were also reserved about the presence of symptoms. Male participants did not like to draw attention to themselves when symptoms were present, and dealt with aches and pains discretely. Andy and Fred preferred to take a break at work when in pain and simply return to the job without informing co-workers or employers of symptom occurrence.

Key Source of Legitimation (External vs. Internal) - The women and men in this study differed in the extent to which the external and internal legitimation of RSIs was valued. Whereas the male participants were more likely to legitimate RSIs for themselves, the female participants sought the external legitimation of RSIs.

The women in this study valued the opinions of others. Statements like “I want to be validated and have people understand me” indicate that the women felt it was important to have RSIs accepted by those around them. However, by placing priority on the external legitimation of RSIs, the extent to which the women legitimated RSIs for themselves was limited. Cathy felt that a “chain reaction” existed between the legitimation of her RSI by external sources and her emotional state. According to Cathy, the negative reactions of others contributed to her self-doubt and depression which in turn magnified her need to have others legitimate her condition. By continually directing the search for legitimation outside of herself, Cathy, like a number of women in the study,

reduced her own ability to self-legitimate her RSI. Of the three female participants who did share statements reflective of the internal legitimation of RSI, two admitted that they found disbelief bothersome. Without a firm belief in one's condition, the women in this study internalized the negative reactions of others. Disbelief by others introduced doubt in the minds of a few of the women and led them to question the reality of their pain. Psychological distress was common and two of the women revealed contemplating suicide at one point in time.

In contrast, the men in this study were not concerned with the reactions of others to RSIs. Male participants were indifferent to the opinions of others in general and "didn't care" what those around them thought of RSIs. The men "knew" their condition was real and did not question its existence when those around them thought otherwise. The external legitimation of RSI became an issue for the men once a diagnosis, social support, work modifications, and/or compensation were sought.

Reaction to Discrediting of Identity (Diffuse vs. Specific) - The absence of legitimation from external sources affected the women and men in the study differently. While both groups were hurt, frustrated and angry by the lack of interest and support received from others, the reactions of participants to discrediting encounters varied. Whereas the men felt that their credibility as workers was affected, the female participants felt their credibility as persons was discounted. These reactions can be characterized respectively as "specific" and "diffuse," terms used by Zola (1966:623) to capture the essence of differences in the cultural expressions of symptomatology.

Female participants' reactions to discounting were "diffuse." Tensions and conflicts experienced by the women at their workplace affected their identity as a worker and their identity as a person. The women did not feel their work presence was valued by the management of their workplace. This caused conceptions of employer-employee relationships to change. They were reluctant to give any future "loyalty" to a company upon learning they are "expendable" and that there are "no relationships based on friendship, caring, or anything" in the workplace. For example, Beth was hurt by the lack of support she received from her boss, and she was disturbed to learn that images of self she tried to project at her workplace were not realized and appreciated. Beth tried hard to please others "especially at work" by staying late and not taking regular breaks. She felt that these qualities were not recognized when RSIs were not legitimated by her boss. She explained, "I could not believe [my boss] would think negatively of me... and not see me for who I was." Cathy expressed similar sentiments, "I mean I try to be an honest and straightforward person in the world and the attitude I get [in return] is disbelieving and non-accepting. It's hurtful."

Discrediting encounters threatened the women's images of self. As a result, their self-concepts were weakened. Beth, Emma and Debbie no longer saw themselves as the "motivated" and "productive" persons they once were before the development of RSI. For Faye and Cathy, daily activities became organized around the pain of RSI and not by what they needed or wanted to accomplish. Female participants used statements like "[RSI] has just taken everything out of me" and "[RSI] has changed my life" to describe the impact of the condition and the reactions of others to the RSIs. The majority of the women

reported a loss of confidence and self-esteem.

In comparison, a “specific” reaction by male participants was found when RSIs were not legitimated by those around them. Discounting by employers and co-workers affected the men’s identities as workers. Male participants were hurt and angry when their RSIs were not legitimated by those in the workplace. Each man felt the legitimation of his RSIs was deserved due to his dedication and hard work on the job. However, the self-concepts on the men remained intact despite the lack of acceptance of RSIs by workmates and managers. Male participants explained that they had no prior problems at work and considered themselves to be “good workers.” As a result, any skepticism the men received from employers was not attributed to their own conduct or reputation, but to the unwillingness of the management of their workplaces to take responsibility for their injuries.

The internally focused legitimation of RSIs by male participants weakened the impact of discrediting encounters on other images of self. Overall, male participants in the study did not view themselves differently subsequent to the development of RSI. While the men were aware of the need to monitor and adjust their activities, they did not feel as though they had lost various aspects of their identities in the process. Andy’s statement “I am still the same person” suggests that his definition of self was unaffected by others’ questioning of his RSI complaint.

Brad and Doug were the two male participants who felt the condition diminished their status as being capable and independent persons. Brad considered himself “disabled,” and Doug felt he was financially failing his family. Doug was dealing with a

compensation claim appeal at the time of the study and was reliant on the external legitimization of RSIs by the WCB.

Rehabilitation Outcomes (Unhealthy vs. Healthy) - Participants with RSIs in this study were at various stages of rehabilitation at the time of the interviews. A number of the women and men had come to terms with the condition and were able to find a meaningful place for RSIs in their lives, while others were consumed by the pain of RSIs and expressed little hope for recovery.

Howell (1994) uncovers the complexities that exist between legitimization and rehabilitation. According to Howell (1994), the recovery process of illness is connected to patterns of validation by the ill individuals themselves and those around them. “Healthy” and “unhealthy” progressions through illness are the outcome of the presence and absence of legitimization from self and others (Howell, 1994:10•5). Application of these concepts to the participants in this study reveals that most of the women meet the criteria of an unhealthy progression through illness as defined by Howell (1994), whereas most of the men exhibit a healthy progression through illness.

Overall, the women in this study were unhealthy and progressed towards illness. A central factor contributing to their progression is the value each placed on the acceptance of RSIs by external sources. Although legitimization was problematic for both female and male participants, discrediting encounters had a profound impact on the identities of the women. Self-concepts were continually disconfirmed and threatened when RSIs were not legitimated by those in their public and private lives. Skepticism

received from others affected the women's relationships with spouses, tainted conceptions of work relations and altered plans they had made for themselves and/or their children. As most of women did not legitimate RSIs for themselves, the negative reactions of others to RSIs were internalized. Female participants spent more time trying to "convince" non-supportive others of the presence and severity of symptoms than finding a meaningful place for RSIs in their lives.

In comparison to the women, the men in this study were able to incorporate RSIs into their identities. Self-concepts of the men were maintained during the legitimation process of RSIs. Overall, they did not concern themselves with the opinions of others. Male participants "knew" their conditions were real, and did not alter images of self when others reacted negatively to RSIs. While rejection and accusations of malingering were a source of frustration, discrediting encounters did not lead the men to question the reality of their RSIs. Male participants concentrated their efforts on adjusting their lives to the condition, and not on changing the opinions of others who were reluctant to accept RSIs.

Due to the chronicity of RSIs, the women and men were at different stages of recovery over time. As a result, there is overlap between the categories on the rehabilitation of participants. For example, Anna and Emma indicated that while they struggled with the onset of RSIs, over time they were able to monitor those activities which exacerbated their symptoms. They were no longer overwhelmed with the physical consequences of the condition, and worked to minimize the interference of symptoms in their daily lives. These women moved from an unhealthy progression through illness to a healthy one. Likewise, there were a number of male participants who were healthy in the

study, but have the potential to progress towards illness. Edward, Doug and Brad reported difficulties adjusting to the physical and financial consequences of RSIs. Although they legitimated RSIs for themselves, each was concerned about his financial situation. Doug and Brad are reliant on compensation settlements to ease their concerns, and are troubled by the uncertainty of their claims with WCB.

The stories of the participants in this study reveal that gender does matter in RSIs. In this study, gender influenced the illness and legitimation experiences of female and male participants, specifically the process of legitimation, their reactions to RSIs and to others, and the presentation of symptoms. However, since these distinct patterns of behaviour were apparent among a small sample of women and men living with upper limb RSIs, further investigation into the gendered experience of RSIs is needed to determine the applicability of these findings to other persons living with these conditions. Future research studies addressing the impact of gender on the illness experience of RSIs should also give consideration to a variety of contextual factors that may influence the experiences of persons with these conditions including the severity of RSI, the stage of illness, the presence of support in the workplace, and the type of work performed by the injured person.

Limitations of the Study

This study has several limitations. One area of weakness is the generalization of findings. The stories of the women and men who participated in this study may not reflect the thoughts, behaviors and actions of all persons living with upper extremity RSIs. First

of all, the sample size is small. Despite the large number of people with upper extremity RSIs in Winnipeg (WCB Annual Report, 1997; Yassi et al., 1996), only 12 women and men participated in this study. As all participants were recruited from the Manitoba Federation of Labour Occupational Health Centre, members of the community not affiliated with the Centre were not given the opportunity to be a part of, and contribute to, this research. Furthermore, as the sample population of this study was women and men living with RSIs of the upper-extremities, the findings do not necessarily represent the experiences of persons with others forms of RSIs.

Due to a lack of diversity in sample characteristics, the experiences of women and men of various ethnic backgrounds have not been captured. As a result, it should not be assumed that the experiences of the women and men in the study reflect those of persons belonging to diverse ethnic groups. It is also noted that no participants in this study occupied upper management positions. While a number of industries were represented (i.e., clerical, cashier, and factory/production work), an examination of the impact of occupational status on the legitimization experience of RSIs could not be accomplished.

A second area of weakness of the study relates to the selection process. As indicated earlier, a physician from the Manitoba Federation of Labour Occupational Health Centre identified potential participants. The physician reviewed the medical charts of individuals with upper limb RSIs and created a list of women and men who met study criteria. Although a simple coding checklist was created to monitor the physician's coding of medical charts, the physician used his own judgement to determine whether or not an individual with RSI was eligible to participate in the study. It is not possible to

ascertain whether any systematic bias was introduced into the study because a physician at the Centre did an initial screen of the files. The alternative - using public notices to identify participants - might have introduced other kinds of biases. Using the approach I did at least assured me that the individuals had a common diagnosis, i.e., upper limb RSIs.

It should be noted that my contact with the individuals on the list of potential participants (created by the physician) only took place when they indicated their interest to participate in the study. Consequently, no information can be gathered on those persons who were eligible for inclusion in the study, but did not participate. It cannot be determined if the experiences of those individuals with RSIs who self-selected themselves into the study are similar to, or different from, those women and men who did not.

A third study limitation relates to one of the criteria used to determine eligibility. In order to examine the legitimization experiences of women and men in the pre- and post-diagnosis phase of RSI, all participants in the study received a medical diagnosis of RSI in the upper-extremity and each had experienced the symptoms of RSI for at least one year post-diagnosis. However, contradictory diagnoses between various physicians, specialists and/or WCB physicians blurred the boundary between these two phases of the illness experience. Although all participants had been diagnosed with RSI, the form and location of the condition was still questionable for many of the women and men at the time of the study. The lengthy compensation process complicated this issue further. There were a number of participants in the study who were either waiting to be examined by a

WCB physician or who had their diagnosis refuted by one of these health care professionals. Thus, it was possible for the medical legitimization of RSIs to be both present and absent at the same time. While this complicated the examination of transcripts, an important feature of the legitimization process was highlighted, its unstable and dynamic nature.

A final limitation of the study is the usage of retrospective data. Although participants in the study were eager to talk about their experiences of RSIs, many had been living with the condition for a number of years. Consequently, the quality of data has been compromised by time and the inability of the women and men to recall specific events accurately. It must be noted that all participants in this study shared thorough and detailed stories of their experiences of RSI. At no point in time did participants refuse to answer questions because they did not know the answer. A few participants chose not to talk about particular events. These men did not want to share the details of a negative reaction to RSIs because they felt “that is behind me now” and “it doesn’t matter anymore.” Such occurrences were minimal and emerged when the male participants were no longer in contact with the person and wanted to forget the experience. In order to respect the feelings of these participants, the issue was not probed further during the interview.

Implications and Directions for Future Research

The strengths of this study lie in its implications and directions for future research. This study contributes to the literature of RSIs which currently lacks a qualitative focus.

To date, the RSI literature concentrates on anatomy, epidemiology, ergonomics, and compensation policies, and not on the illness experiences of persons living with the condition. The personal accounts of RSI by the women and men in this study illustrate the physical, mental and social challenges posed by the condition. Exploration into the legitimization experiences of RSIs has also uncovered the impact of the presence (and absence) of legitimization from internal and external sources on the identity and recovery process of women and men living with, and in spite, of the condition.

The findings of this study also contribute to the literature on RSIs and gender. The scope of research on the gendered experience of RSIs is limited. Studies have documented the greater prevalence of RSIs among women (Ashbury, 1995; Doheny et al., 1995; Faucett, 1997; Kome, 1998), but have not specifically addressed in detail *how* gender matters in the everyday lives of the women and men with the condition. The stories of the female and male participants in this study reveal that gender influences the presentation of RSIs, the reactions to symptoms and sources of legitimization, and the recovery process. While the women and men shared the challenge of adjusting to the physical, social and emotional consequences of RSIs, they exhibited distinct patterns of behaviour characteristic of traditional gender socialization. These findings contribute to the arguments of Anderson et al. (1991) who assert that the experience of illness of women should not be subsumed under that of men. Further investigation into the unique experiences of women and men living with work-related injuries and illnesses is needed to enhance our understanding of gender differences in the context of occupational health.

There are practical implications of this study as well. The legitimization experiences

of participants can be utilized to fill the gaps existing between agents involved in the treatment and management of RSIs. Participants in this study were involved with numerous groups including physicians, specialists, employers/supervisors, WCB personnel and physicians, union representatives and lawyers, because of RSIs. Overall, the women and men were not satisfied with the services and accommodations received (or not received) by these groups. Most participants felt their complaints and concerns about RSIs were not taken seriously, or were ignored. A number of participants commented on the inability and/or reluctance of health care professionals to forward the proper documentation on their diagnoses to the management of their workplaces and the WCB. While these women and men recognized the hectic schedules of their physicians, they did not appreciate having to wait for letters and forms. Waiting was a common source of frustration and uncertainty among participants in this study. Regular and effective communication between interested parties would aid the decision-making process of compensation claims and diminish the circulation of inaccurate and misleading information on the condition. Any service providers who consider these types of communications to be “unwelcome intrusions” should not care for those with a work-related illness (Wyman and Baril, 1994 as cited in Gaines, 1998:337). Persons with RSIs should also be encouraged by service providers to join the communication process and become an active member in the team responsible for their rehabilitation.

Participants in this study discussed the difficulties they faced when interacting with different interest groups and offered their own strategies for change. The women and men felt the most important advice for others living with the condition was “be your own

advocate.” Participants did not always feel that the concerns they voiced were heard by those around them. At times, they felt that no one was acting in their best interest. While a number of the women and men in this study were members of a union, they were not impressed with actions taken by their union representative when dealing with management and/or the WCB. Thus, although the women and men felt it was important to stand up for themselves, they found advocacy difficult. Advocacy requires a sense of empowerment. However, one cannot be empowered when one does not have access to the appropriate resources, and lacks the skills to effectively communicate one’s needs to others. A number of participants reported that education was one means to be empowered.

The data collected from this study are useful for the creation of educational tools to increase the awareness of RSIs. As many of the participants were not familiar with the condition prior to its development, information on RSIs must be widely distributed. Educational fora need to occur in the community and not just the workplace. These fora would not only serve to provide information on the personal, social and emotional consequences of RSIs, but would bring together people who know others living with the condition. In her examination of how chronic fatigue syndrome is perceived by spouses, parents, and children of sufferers, Beaulieu (1995) found that the condition meant disruptions and strains to the lives of those close the sufferer. Currently there is no research on the impact of RSIs on the spouses, children, and family members of women and men with the condition. There is also a lack of research on lay perceptions of the condition. Studies on how RSIs are perceived in the community and by significant others

would not only enhance understanding of the legitimization experiences of women and men living with the condition, but assist in the formation of educational tools designed to unravel popular misconceptions and stereotypes surrounding the condition.

Today's workforce should also be more informed on RSIs. Information on the risks and consequences of RSIs ought to be made available in all workplaces through workshops and visual/print media. In order for this to occur, management has to take an active role in occupational health issues. Employers and supervisors set the precedent of how RSIs are responded to in the workplace (Gaines, 1998). As authority figures, they influence the acceptance and rejection of RSIs by workers. Employers and supervisors should work to protect the rights of injured workers, to prevent damaged work relations and to reduce conflict. In doing so, not only will they foster harmony in the workplace, they will encourage those with occupational illnesses and injuries to stay on the job. Keeping persons with RSIs in the workplace can occur with an appropriate support system where work accommodations and/or return to work programs are accessible.

There are no support groups in Winnipeg for women and men living with RSIs. A support for action group for women with RSIs was piloted for educational purposes by the Manitoba Federation of Labour Occupational Health Centre in 1995, and again this past year. The results have been positive, but a formal program has yet to be enacted. Based on the experiences of the women and men in this study, it can be argued that a supportive environment for those living with the condition is needed. Women and men with RSIs would benefit from being able to talk to others with the condition. A support group would not only be a place for women and men to have RSIs legitimated; they can

also learn from the experiences of others. If created, the support group should have an educational component. Many participants in this study commented on the lack of resources in the community for persons with RSIs. They were left to learn about living with the condition through ‘trial and error.’ Thus, a support group would also be a place where persons with RSIs could discuss issues such as how to disclose injuries to potential employers, how to handle disparagement from a co-worker or physician, and how to navigate the WCB system.

Further research into RSIs must occur in order for the different dimensions of the condition to be realized and understood. This study examined one aspect of RSIs, the legitimation experience. The characteristics of RSIs challenge the dominant discourses of health and illness in society, and complicate the process of legitimation in the everyday lives of women and men with the condition. Without physical signs of illness or injury, the female and male participants in this study faced skepticism, conflict, and even rejection by others. Their RSIs were evaluated by physicians, employers, co-workers, friends, and family members on the premise “if you can’t see it, it never happened.”

The experiences of the women and men with RSIs in this study demonstrate that illness is not only a time of crisis, but one of dispute (Cohn, 1999). Not only did they struggle to find a meaningful place for RSIs in their lives, they sought to maintain their credibility in the eyes of themselves and others.

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Appendices

**Appendix A
Recruitment Letter**

***Are you willing to share your experience
of Repetitive Strain Injury?***

My name is Jennifer Werhun and I am a graduate student at the University of Manitoba doing a research project on Repetitive Strain Injury (RSI). I am interested in the experience of RSI, that is, how people live with and in spite of this condition. While the term 'RSI' is used to describe a number of musculoskeletal disorders, it generally refers to a combination of symptoms including local tenderness, diffuse pain, inflammation, aches, loss of muscle strength, burning sensations, and/or periods of numbness. These symptoms can become progressively worse over time, and if not recognized and properly managed, may lead to permanent disability. If you are someone who experiences any of these symptoms, I welcome you to participate in this project.

The title of my project is called, "Does Gender Matter in the Legitimation of a RSI?" The study aims to find out if men and women experience RSI the same and if not, how it is different. If you are willing to participate in the study, your personal interview will focus on:

- how RSI has changed your life
- how friends, family and co-workers have reacted to your RSI
- how you let others know when you are having a 'bad' day
- whether you feel that others 'believe' you when you are in pain

The interview will last 1 ½ - 2 hours, on a date, time and in a location convenient for you. I want to assure you that all information you share with me will be kept confidential. If you choose to participate, your name will not be shown in any form in the project, and all tape-recorded interviews will be destroyed when the study is complete.

The project is not sponsored by the Manitoba Federation of Labour Occupational Health Center. The center is helping me find people to talk to about RSI, but has not been a part of the project design. A copy of study findings will be available to all participants wishing to learn about how other people experience RSI. A copy of findings will also be sent to the Manitoba Federation of Labour Occupational Health Center.

Your participation is much appreciated - not only will your story add to the quality of the project, but our time together will also be an opportunity for you to talk freely about your RSI in a relaxed, non-judgmental setting. Please note that after the interview, you will receive a summary of project findings for feedback.

I would be happy to answer any questions you might have. Please feel free to call me and remember, everything we talk about in our conversation will be kept confidential.

~Thank-you for your time and I hope to talk to you soon~

Jennifer Werhun
Graduate Student
Department of Sociology
University of Manitoba

Appendix B
Demographics Sheet

1. The participant is:

Female

Male

2. How old are you? _____ years

3. Are you now:

- _____ Married
- _____ Divorced
- _____ Separated
- _____ Single
- _____ Widowed

4. Do you have any children living with you?

Yes

No

If yes, how many children do you have? _____

How old are your children? _____

5. What is the highest level of school that you have completed?

- _____ Some elementary school (up to grade 8)
- _____ Finished elementary school (finished grade 8)
- _____ Technical/Vocational Training
- _____ Some high school
- _____ High school diploma
- _____ Post-Secondary Education (Community College, University)

6. Do you consider yourself to be a member of a particular ethnic group?

Yes

No

If yes, which ethnic group? _____

7. Are you currently employed?

Yes

No

If yes, what type of job do you have? _____

8. If not currently working, have you been employed in the past?

Yes

No

If yes, what is the most recent job you have had? _____

**Appendix C
Consent Form**

**University of Manitoba
Faculty of Arts
Department of Sociology**

Does Gender Matter in the Legitimation of a Repetitive Strain Injury?

The purpose of this study is to learn about the experience of RSI from a sample of men and women diagnosed with this condition. Under the supervision of Dr. Karen Grant of the University of Manitoba, and in cooperation with the Executive Director of the Manitoba Federation of Labor Occupational Health Centre Inc., Jennifer Werhun will conduct a research project as part of the requirements of her master's degree in Sociology.

As part of the study, the researcher would like to interview a number of women and men with RSI, to learn about how they live with, and in spite of, this condition. Interviews will take place one-on-one, and will last approximately an hour and a half to two hours long.

The sessions will be tape-recorded; all tapes will be stored in a locked cabinet in the researcher's office for security purposes, and tape-recordings of interviews will be erased when the study is complete. All information gathered in the interview will be kept confidential, and at no time will the name of participants be released, nor will any identifying information be used in the final report.

Participation in this study is completely voluntary. You are free to not answer any of the questions you are asked, and you are also free to withdraw from the study at any time. In no way will the services you receive at the Manitoba Federation of Labour Occupational Health Centre be affected by your decision to participate in this study.

The information collected in this project will be presented to the Department of Sociology for the completion of a master's degree. A final copy of the report will be given to the Executive Director of the Manitoba Federation of Labour Occupational Health Centre, and will be made available to any participants that are interested in the findings of the project. A modified version of the final report will be prepared for submission to academic journals.

The project has been approved by the Department of Sociology Research Ethics Review Committee at the University of Manitoba, and any questions or concerns you may have about the research process can be referred to the Head of the Department of Sociology (474-9260) for referral to the Research Ethics Review Committee.

In accordance with the Vulnerable Persons Act, the researcher is required to report any disclosure of abuse to the Public Trustee.

Consent Form (Copy 1)

**University of Manitoba
Faculty of Arts
Department of Sociology**

Does Gender Matter in the Legitimation of a Repetitive Strain Injury?

Consent Form

I, _____, agree to participate in the study, "Does Gender Matter in the Legitimation of a Repetitive Strain Injury?" I have read the information sheet about the project and understand that my participation is voluntary. I am aware that all information I share with the researcher will be kept confidential, and that at no time will my name be shown in the final report. I am free to refuse to answer any questions that I may be asked. I understand that I may choose to stop the interview or withdraw from the study at any time without negative consequences.

The interviews will last an hour and a half to two hours, and will be tape-recorded. Tapes will be stored in a locked cabinet for security purposes and all tape-recordings of interviews will be erased when the study is complete.

This project has been approved by the Department of Sociology Research Ethics Review Committee at the University of Manitoba. Any questions or concerns regarding the research process can be reported to the research supervisor on this project, Dr. Karen Grant (474-9912), the researcher conducting the interviews, Jennifer Werhun (474-9831), or the Chair of the Department of Sociology Research Ethics Review Committee.

At the end of the study, on my request, a copy of the findings of the research project will be provided. I understand that a modified version of the report will be submitted to academic journals.

Date

Signature of participant

Date
Participant Copy

Signature of researcher

Consent Form (Copy 2)

**University of Manitoba
Faculty of Arts
Department of Sociology**

Does Gender Matter in the Legitimation of a Repetitive Strain Injury?

Consent Form

I, _____, agree to participate in the study, "Does Gender Matter in the Legitimation of a Repetitive Strain Injury?" I have read the information sheet about the project and understand that my participation is voluntary. I am aware that all information I share with the researcher will be kept confidential, and that at no time will my name be shown in the final report. I am free to refuse to answer any questions that I may be asked. I understand that I may choose to stop the interview or withdraw from the study at any time without negative consequences.

The interviews will last an hour and a half to two hours, and will be tape-recorded. Tapes will be stored in a locked cabinet in the researcher's office for security purposes and all tape-recordings of interviews will be erased when the study is complete.

This project has been approved by the Department of Sociology Research Ethics Review Committee at the University of Manitoba. Any questions or concerns regarding the research process can be reported to the research supervisor on this project, Dr. Karen Grant (474-9912), the researcher conducting the interviews, Jennifer Werhun (474-9831), or the Chair of the Department of Sociology Research Ethics Review Committee.

At the end of the study, on my request, a copy of the findings of the research project will be provided. I understand that a modified version of the report will be submitted to academic journals.

Date

Signature of participant

Date

Signature of researcher

Research Copy

Appendix D
Disabilities of the Arm, Hand, and Shoulder Questionnaire

Appendix A. Final Version of the DASH

DISABILITIES OF THE ARM, SHOULDER AND HAND

THE **DASH**

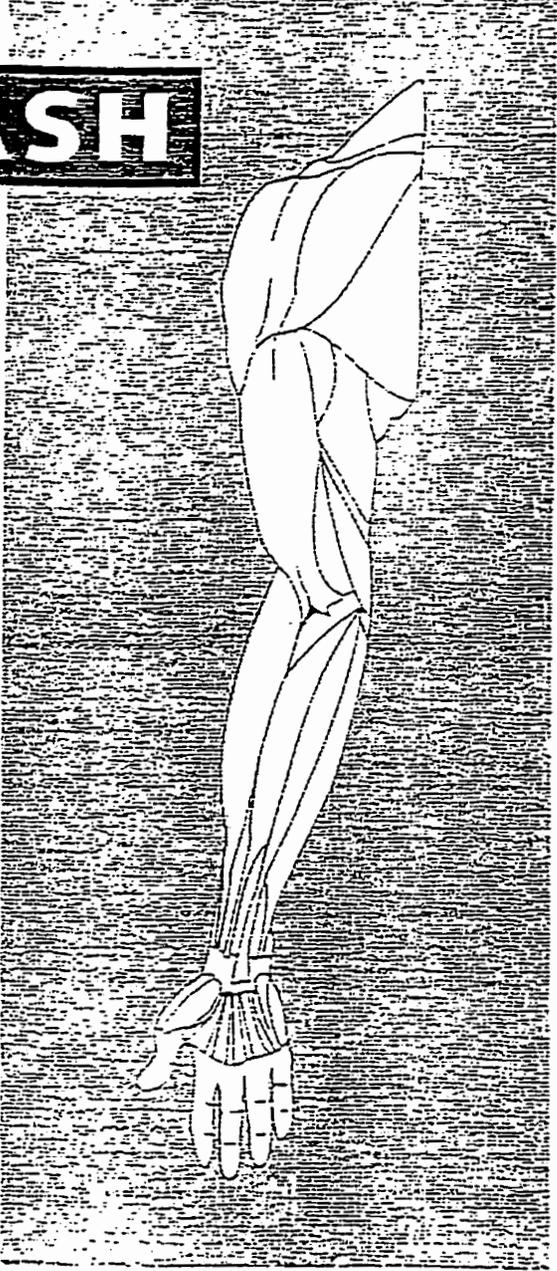
INSTRUCTIONS

This questionnaire asks about your symptoms as well as your ability to perform certain activities.

Please answer every question, based on your condition in the last week, by circling the appropriate number.

If you did not have the opportunity to perform an activity in the past week, please make your best estimate on which response would be the most accurate.

It doesn't matter which hand or arm you use to perform the activity; please answer based on your ability regardless of how you perform the task.



DISABILITIES OF THE ARM, SHOULDER AND HAND

Please rate your ability to do the following activities in the last week by circling the number below the appropriate response.

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
1. Open a tight or new jar.	1	2	3	4	5
2. Write.	1	2	3	4	5
3. Turn a key.	1	2	3	4	5
4. Prepare a meal.	1	2	3	4	5
5. Push open a heavy door.	1	2	3	4	5
6. Place an object on a shelf above your head.	1	2	3	4	5
7. Do heavy household chores (e.g., wash walls, wash floors).	1	2	3	4	5
8. Garden or do yard work.	1	2	3	4	5
9. Make a bed.	1	2	3	4	5
10. Carry a shopping bag or briefcase.	1	2	3	4	5
11. Carry a heavy object (over 10 lbs).	1	2	3	4	5
12. Change a lightbulb overhead.	1	2	3	4	5
13. Wash or blow dry your hair.	1	2	3	4	5
14. Wash your back.	1	2	3	4	5
15. Put on a pullover sweater.	1	2	3	4	5
16. Use a knife to cut food.	1	2	3	4	5
17. Recreational activities which require little effort (e.g., cardplaying, knitting, etc.).	1	2	3	4	5
18. Recreational activities in which you take some force or impact through your arm, shoulder or hand (e.g., golf, hammering, tennis, etc.).	1	2	3	4	5
19. Recreational activities in which you move your arm freely (e.g., playing frisbee, badminton, etc.).	1	2	3	4	5
20. Manage transportation needs (getting from one place to another).	1	2	3	4	5
21. Sexual activities.	1	2	3	4	5

DISABILITIES OF THE ARM, SHOULDER AND HAND

	NOT AT ALL	SLIGHTLY	MODERATELY	QUITE A BIT	EXTREMELY
22. During the past week, to what extent has your arm, shoulder or hand problem interfered with your normal social activities with family, friends, neighbours or groups? (circle number)	1	2	3	4	5

	NOT LIMITED AT ALL	SLIGHTLY LIMITED	MODERATELY LIMITED	VERY LIMITED	UNABLE
23. During the past week, were you limited in your work or other regular daily activities as a result of your arm, shoulder or hand problem? (circle number)	1	2	3	4	5

Please rate the severity of the following symptoms in the last week. (circle number)

	NONE	MILD	MODERATE	SEVERE	EXTREME
24. Arm, shoulder or hand pain.	1	2	3	4	5
25. Arm, shoulder or hand pain when you performed any specific activity.	1	2	3	4	5
26. Tingling (pins and needles) in your arm, shoulder or hand.	1	2	3	4	5
27. Weakness in your arm, shoulder or hand.	1	2	3	4	5
28. Stiffness in your arm, shoulder or hand.	1	2	3	4	5

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	SO MUCH DIFFICULTY THAT I CAN'T SLEEP
29. During the past week, how much difficulty have you had sleeping because of the pain in your arm, shoulder or hand? (circle number)	1	2	3	4	5

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
30. I feel less capable, less confident or less useful because of my arm, shoulder or hand problem. (circle number)	1	2	3	4	5

DISABILITIES OF THE ARM, SHOULDER AND HAND

SPORTS/PERFORMING ARTS MODULE (OPTIONAL)

The following questions relate to the impact of your arm, shoulder or hand problem on playing your musical instrument or sport or both. If you play more than one sport or instrument (or play both), please answer with respect to that activity which is most important to you.

Please indicate the sport or instrument which is most important to you: _____

I do not play a sport or an instrument. (You may skip this section.)

Please circle the number that best describes your physical ability in the past week. Did you have any difficulty:

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
1. using your usual technique for playing your instrument or sport?	1	2	3	4	5
2. playing your musical instrument or sport because of arm, shoulder or hand pain?	1	2	3	4	5
3. playing your musical instrument or sport as well as you would like?	1	2	3	4	5
4. spending your usual amount of time practising or playing your instrument or sport?	1	2	3	4	5

WORK MODULE (OPTIONAL)

The following questions ask about the impact of your arm, shoulder or hand problem on your ability to work (including homemaking if that is your main work role).

Please indicate what your job/work is: _____

I do not work. (You may skip this section.)

Please circle the number that best describes your physical ability in the past week. Did you have any difficulty:

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
1. using your usual technique for your work?	1	2	3	4	5
2. doing your usual work because of arm, shoulder or hand pain?	1	2	3	4	5
3. doing your work as well as you would like?	1	2	3	4	5
4. spending your usual amount of time doing your work?	1	2	3	4	5



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Appendix E

Interview Guide

Potential Interview Questions

Personal Introduction
Statement of Purpose
Assurance of Confidentiality

I. Background Information

1. Can you tell me a little bit about yourself?

2. When did you begin to notice the symptoms of RSI?
probe: > How did symptoms first appear? What did you think of them?
> When did you decide to go to the doctor?

3. How long have you had the symptoms of RSI?
How long ago were you diagnosed with RSI?
probe: > What did the doctor think caused the symptoms?
> Did diagnoses change over time?
> Have you seen more than one doctor? What types of doctors?
> What sorts of treatments have you been given for your symptoms?
> How did you feel during this time?

4. How did you feel when you were diagnosed as having a RSI?
probe: > Had you ever heard of the term before you were diagnosed?
> Did you know anything about RSI? If yes, from where? Do you know anyone that has a RSI? If no, what sort of explanation were you given of the condition by the doctor?

II. RSI and Disruption to Life

5. What sort of physical changes to your body has the RSI caused?
probe: > What things are you unable to do now that you could before?
> How do you feel that you are limited in the types of activities you can do? What work activities are affected by your RSI? What about activities within the home?

6. What adjustments have you had to make in the way you do certain things?
probe: > Do you give yourself more time?
> Do you find that you have to ask others for help? If yes, how does this make you feel? (at work and home)

7. Do you have any responsibilities in your home?

probe: > How has RSI affected your ability to fulfill your responsibilities?

How has RSI affected any of the roles you have?

probe: > How do you feel your role as a parent has changed because of RSI?

> How do you feel your role as a spouse has changed because of RSI?

If yes to any of the above, How do these changes make you feel?

> How has your family reacted to these changes?

> Do you feel that your role as a worker has changed because of RSI?

> Have you experienced any economic problems because of your symptoms?

III. The Reactions of Others

8. When you first began feeling pain and discomfort, did you tell anyone?

If yes, who? If no, when did you tell someone?

probe: > Why did you want to let others know?

> How did you tell them about it?

> Was there any time when you didn't feel like telling anyone? If yes, when?

> Did receiving the diagnosis make you want to tell anyone? If yes, why? If no, why not?

9. How did people react to your symptoms before you were diagnosed with RSI?

probe: > Did it appear to you that some people were more supportive than others?

> Did some people take your complaints more seriously than others?

If yes, who? *probe:* doctor, employers, co-workers, family, friends

> Did reactions changes over time? If yes, why do you think so?

> How do people react to your symptoms today?

10. How did people react to the diagnosis of RSI? (when first received)

probe: > Did they know what a RSI was? If no, did you tell them about it?

> Did these reactions affect your relationship with these people?

> Did these reaction affect your behaviour towards these people?

How do people react today when you tell them you have RSI?

> Do you feel that people have treated you differently since diagnosed?

If yes, why do you think this has happened?

> From your experience, do you feel you can 'guess' others reactions?

11. Have you ever experienced a negative reaction from others? If yes, how did that make you feel? Did you do anything?

probe: > What made the reaction negative? (verbal and non-verbal)
 > Did it matter who it was?
 > Why do you think they reacted this way?

12. Can you tell me about a time when you felt that someone did not 'believe' your pain?

probe: > How did that make you feel?
 > How important is it to you to have others 'believe' your symptoms?
 > How important is it to you to have others support you?

IV. Presentation of RSI

13. How do you let people know when you are having a 'bad' day?

probe: > What is a 'bad' day for you?
 > What sorts of things do you do to let them know?
 > Can some people tell you are having a 'bad' day, even without you telling them?
 > Does the behaviour of the people around you change during this time?

14. How do you let people know when you are having a 'good' day?

probe: > What is a 'good' day for you?
 > What sorts of things do you do to let them know?
 > Does the behavior of others change around you during this time?

15. Does it bother you that RSI cannot be 'seen' by others?

probe: > How do you feel this affects people's reactions to your symptoms?
 > Do you find yourself having to 'prove' to others that you have a RSI? If yes, how does this make you feel?
 > How do you think your experience of RSI would be different if it could be seen by others? (i.e., like a bruise or a rash)

V. Meaning of RSI

16. What do you think caused your RSI?

probe: > Do you feel your RSI is the cause of a particular event?
 > Has this understanding changed over time?

17. How do you think that RSI has changed who you are as a person?

probe: > How do you view yourself differently since you have developed a RSI?
 > Do you feel that RSI is a part of your life? If no, do you think that RSI is only temporary?

> Is there anything that you wish you could change about RSI?

18. What is next for you?

probe: > How have your plans for the future changed because of RSI?

> Are you trying to live your life as if you don't have RSI?

VI. Closing Comments

> Do you have any advice for other people who have RSI?

> Is there anything I missed that you would like to tell me?

Appendix F
Summary of Study Discussion

**“If You Can’t See It, It Never Happened:”
The Legitimation Experiences of Women and Men
Living with Repetitive Strain Injuries of the Upper Extremities”**

The following is a brief summary of the data analysis. The summary represents the major findings of the study. As it captures the experiences of all the women and men who participated in this study, the discussion is general in nature and serves to make sense of the meaning of your experiences of RSI.

You will also find enclosed a participant profile. The purpose of the profile is to put your story into context. A pseudonym has been assigned to each of you in order to protect your confidentiality. Please review the profile and highlight any identifiers that you would like removed.

I appreciate your cooperation with this project and I look forward to gaining any feedback. If you do not have anything to add to the summary, there is no need to contact me. However, if you have any questions, concerns, or comments, feel free to contact me. As I am looking forward to the completion of this study, please share your feedback within the week. Thank-you.

Sincerely,

Jennifer Werhun
Graduate Student
Department of Sociology
University of Manitoba

Summary of discussion:

1. The Process of Legitimation

- There was no single process by which the women and men had RSIs legitimated by others. While participants sought to have the condition accepted by those around them, the nature and duration of the search for legitimation² was specific to the individual. Each participant continually negotiated definitions of RSIs in interaction, for legitimation was not stable.

- Each participant had the capacity to legitimate the RSI for herself/himself, to determine from whom external legitimation would be sought, and to resolve at which point the search would be initiated or terminated.

- Actions were taken by the women and men to influence and/or regulate definitions of RSI in the medical encounter, workplace and home. The patterns of behavior of participants that emerged when legitimation was the goal of interaction are considered to be strategies of legitimation.

- Strategies used by participants include selective disclosure, determining the significance of legitimation from a source, avoidance and dismissive tactics, and proving behaviours. These strategies often occurred in combination with one another.

Selective disclosure = Due to the invisible nature of the condition, participants were given the opportunity to decide when and how information about RSIs would be shared with others. They distinguished between the want and need to tell others about their RSI. When RSIs increased in severity, the ability to be selective in disclosure decreased for participants as accommodations were needed and splints and/or surgical scars became objects of interest to others.

Determination of the value of an external source = At the same time participants in the study were evaluated by others, the participants themselves evaluated the opinions of those around them. If legitimation from an external source mattered to a participant, s/he sought to have the RSI accepted by the source. The reverse occurred when the source was considered insignificant. The significance of an external source was determined by the potential consequences that would be incurred if RSIs were or were not legitimated and by the extent to which the participant identified with them.

Dismissive or avoidance behaviours = This involved the participants leaving legitimation alone and no longer seeking it from a source once RSIs were rejected. Avoidance behaviors consisted of limiting interaction with those who reacted negatively to RSIs.

²

Legitimation refers to the process of accepting illness states and symptoms that are presented by another as 'real' or genuine (Howell, 1994). To have a RSI legitimated is to have others believe it exists.

Proving behaviours = There were participants in this study who did not tolerate the discounting of RSIs and felt compelled to ensure that the condition was legitimated by others. Some of the women and men displayed braces, slings and surgical scars to influence how their condition was evaluated, and others brought letters from physicians on the nature of RSIs to work for co-workers to examine.

2. Does Gender Matter in RSIs?

-While male and female participants shared the challenge of adjusting to the physical, social and emotional consequences of RSIs, they varied in the presentation of symptoms, the internal and external legitimation of RSIs, and the impact of RSIs on identity.

Presentation of symptoms

- As RSIs were not readily apparent to others, the presentation of symptoms became an important component of the illness experience for the women and men. Each was responsible for introducing her/his condition to others and did so through a series of verbal and non-verbal communications.

-Disclosure patterns of female and male participants differed over time. The women in the study wanted others to know at home and at work when symptoms of RSI were present. Pain was communicated with physical displays such as lying on the couch, putting on a brace, and rubbing the affected limb(s).

-Male participants in this study did not feel the need to continually disclose RSIs to those around them. For a few of the men, there was “no point” in telling his co-workers when in pain because doing so did not take the pain away. Other male participants felt that RSIs were not of significance or interest to others since “everybody has problems” or aches and pains of their own.

The internal and external legitimation of RSIs

-The women and men in this study differed in the extent to which the external and internal legitimation of RSIs was valued. Male participants were more likely to legitimate RSIs for themselves and the female participants sought the external legitimation of RSIs.

- Male participants were indifferent to the opinions of others in general and “didn’t care” what those around them thought of RSIs. The men “knew” their condition was real and did not question its existence when those around him thought otherwise. When RSIs were not accepted by others, the men expressed hurt and anger. However, the internal legitimation of RSIs weakened the impact of such discrediting encounters and self-concepts were not affected.

- In comparison, female participants valued the opinions of others. Statements like “I want to be validated and have people understand me” indicate that the women felt it was important to have RSIs accepted by those around them. By placing priority on the external legitimation of RSIs, the extent to which the women legitimated RSIs for themselves was limited. Of the three female participants who did share statements reflective of the internal legitimation of RSI, two admitted that they found disbelief bothersome. Disbelief received from others introduced doubt in the minds of a few of the women. A number of the women also reported a loss of confidence and self-esteem. Psychological distress was common and two of the women revealed contemplating

suicide at one point in time.

The impact of RSIs on identity:

- The absence of legitimation from external sources affected the women and men in the study differently. Whereas the identities of male participants as workers were affected, the female participants felt their identities as persons were discounted.
- A “specific” identity of male participants was discredited when RSIs were not legitimated by those around him. The skepticism received from others, particularly employers and co-workers, made the men feel as though all their dedication and hard work on the job had gone unnoticed.
- In contrast, the impact of negative reactions on the identity of female participants in the study was “diffuse.” Tensions and conflicts experienced by the women at their workplace did not only affect their identity as a worker, but their identity as a person.
- Participants with RSIs in this study were at various stages of rehabilitation at the time of the interviews. A number of the women and men had come to terms with the condition and were able to find a meaningful place for RSIs in their lives, while others were consumed by the pain of RSIs and expressed little hope for recovery.

3. The Importance of Context

- The basic tenet of this research is that the illness experience of RSI is influenced by the context in which it occurs.
- Participants became aware of the conflict surrounding RSIs when the legitimation of the condition by others was not readily available.
- While the confirmation of RSI and self occurred for some participants, most of the women and men found the process problematic. Each discovered that the search for legitimation left her/him vulnerable to discrediting, rejection, and accusations of malingering. Yet in spite of such encounters, the women and men continued their pursuit for legitimation, particularly when they felt the legitimation of RSI by an external source was important.
- The significance participants attached to the legitimation of RSIs by an external source can be understood using the “hierarchy of credibility” developed by Howard Becker. A definitive ranking system of external sources did not exist among the participants of this study. The women and the men varied with respect to the priority each placed on the external legitimation of RSI.
- All participants in this study felt the legitimation of RSIs by a physician was essential. Each acknowledged the great deal of credibility physicians hold in society and made the medical legitimation of her/his condition a goal to be achieved.
- Participants in this study also sought to have RSIs legitimated by co-workers and the management of their workplace. The women and men felt the legitimation of RSIs by these sources was necessary for the maintenance of positive workplace relations and for adjustments in their work tasks and roles.
- All of the women and men agreed the legitimation of RSIs by those they cared about was important.
- The importance participants in this study allotted to the medical legitimation of RSIs

exemplifies the power of the medicine in labeling and treating illness. While participants sought to have RSIs legitimated by the management of their workplace, co-workers, and friends and family, each considered physicians to be the key to community and social support.

- Thus physicians and other health care professionals occupied the top of the hierarchy, followed by the management of workplaces. It is difficult to determine the subsequent order of external sources. The women and men varied with respect to the significance they placed on the legitimation of RSIs by co-workers, spouses or partners, family members and friends.