COPING WITH COMMUNITY REINTEGRATION AFTER SEVERE BRAIN INJURY: A DESCRIPTION OF STRESSES AND COPING STRATEGIES

by

TRACEY ELIZABETH KARLOVITS

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ABSTRACT

One of the most fundamental challenges confronting persons with brain injury is community integration. The present study investigates the stresses associated with integration and the coping strategies used to deal with them. A basic qualitative approach was used to describe the stresses and coping strategies of 11 adults with severe brain injury during a critical period of reintegrating into a new community. Subjects identified nine problems as stressful. The stresses conform to a theoretical model of community integration, consisting of four factors: social support, independent living, occupation, and a general integration factor. These stresses may be used in the development of a new measure of stress for persons with brain injury. Eight coping strategies were developed to deal with these stresses. The coping strategies represent a sampling of three major types of coping: problem-focused, perception-focused, and emotion-focused. The findings show that subjects made more use of problem-focused coping strategies than any other type of coping, suggesting that persons with brain injury have awareness of the problems they face and the ability to assert some control over eliminating or managing these problems. The findings also demonstrate coping strategies that have worked for some individuals with brain injury. The stresses persons with brain injury face and the ways they cope with them are consistent with existing studies involving persons with brain injury. However, significant differences in some coping strategies reported in this study change how we think about some forms of coping. The findings delineate the need for professionals to assist persons with brain injury develop more positive, adaptive coping strategies. Professionals may also focus on finding ways to help minimize the stresses associated with reintegration for persons with brain injury.
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CHAPTER 1
INTRODUCTION

1.1. Statement of the Problem

In Canada, the incidence of traumatic brain injury has permanently altered the lives of an estimated 45,589 individuals (Ontario Brain Injury Association, 1996). Of these, 3,947 individuals have sustained severe brain injuries. Due to medical and technological advancements, individuals are more likely to survive severe brain injuries. Since survival is often associated with lifelong disability, investigations in the past several years have focused on the long-term impact of brain injury. Recently, writers have recognized that, due to the disabling effects of brain injury, survivors are exposed to additional stresses. Thus, an important area of research that has evolved from outcomes research is the study of stress and coping.

The severe physical, behavioral, and cognitive disabilities that result from brain injury create a major challenge for survivors in their efforts to re-enter the community (Morton & Wehman, 1995). Common problems cited to impede reintegration include using transportation, managing finances, and keeping appointments (Cervelli, 1990). Interviews with persons with brain injury have revealed broader issues of community integration such as loneliness, loss of independence, loss of family roles, and loss of control over one's life (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993).

Successful return to the community is influenced by how a person copes with the stresses associated with integration. Researchers have shown that a person's coping capacity affects their psychological, physical, and social well being (Moos, 1977; Cohen & Lazarus, 1979; Janis & Mann, 1977). Hence, the study of coping is an important aspect of stress research.
Coping refers to the efforts by which an individual manages personal or environmental demands that are perceived as stressful (Lazarus & Folkman, 1984). Pearlin and Schooler (1978) contend that coping can function to change the situation out of which stressful experiences arise (Problem-focused), change the meaning of such experiences before the emergence of stress (perception-focused), and control the emotional reaction to stress after it has emerged (emotion-focused).

Survivors of brain injury often develop their own coping strategies to deal with specific stressors. Frank et al (1990) report the use of information seeking as the most dominant coping strategy after brain injury. Common coping strategies reported by Willer, Allen, Liss, and Zicht (1991) include increased involvement in family decisions and activities outside the home, and greater awareness of limitations. Other studies have reported that individuals with brain injury use coping strategies in three characteristic ways: (1) relatively indiscriminant use of several strategies; (2) relatively rigid use of a few unchanging strategies; (3) relatively little use of any strategies (Moore, Stambrook, & Peters, 1989; Moore & Stambrook, 1992).

The investigation of coping with stresses associated with reintegration has received little attention from the research community. Among the very few studies is that by Willer, Allen, Durnan & Ferry (1990) who examined the coping strategies of young males with traumatic brain injury and their mothers and siblings. The most significant coping strategies identified by the young men with brain injury include developing and maintaining a good outlook, support from family and friends, and taking an active role in rehabilitation.

The few researchers who have studied stress and coping have provided an understanding of the problems faced by brain injury survivors and their families and how they deal with
them. What is not well understood is the types of stress persons with brain injury face during their re-entry to the community and how these specific stresses are dealt with. The very few studies that exist in this area have involved young men with brain injury who live with their original families.

Information about stress and coping in other settings is lacking. What types of stresses associated with integration are encountered by individuals residing in residential community programs? Do these stresses differ from the types of stresses encountered by individuals living with their families? What types of coping strategies do individuals residing in community residential programs develop to deal with stresses associated with integration?

1.2 Purpose and Objectives

The purpose of this study was to investigate, from the individual's perspective, (1) the types of stresses persons with brain injury face during reintegration and (2) how they are dealt with. This topic arose during my experience working with survivors of severe brain injury living in the community. As a Rehabilitation Home Support Worker, I witnessed first hand the challenge of community re-entry for individuals with brain injury. Through this study, I sought to increase our understanding of stresses associated with community reintegration of persons with brain injury and discover how they deal with them.

The present study uses a descriptive qualitative approach. An insider’s perspective generates a level of understanding that is best illuminated through the application of qualitative methodologies. Qualitative research produces findings not arrived at by statistical procedures. The focus is on understanding phenomena achieved by describing, explaining, and interpreting aspects of those phenomena (Bork, 1993).
The target population for this study consists of 11 adults with severe brain injury living in a community residential program. The interview questions and subsequent data derive from a larger study (McColl, Carlson, Johnston, Minnes, Shue, Davies, & Karlovits, 1998). The findings are based on information collected in months 4, 5, and 6 during the first year of reintegrating into a new community after rehabilitation.

Specific objectives of this study are to identify and describe the types of stresses persons with brain injury face during reintegration and to name and describe the coping strategies that persons with brain injury develop and utilize to cope with these stresses.

1.3 Rationale

This study has potential implications for clinicians, researchers, rehabilitation programs, and for persons with brain injury. From a practical perspective, knowledge arising from this study can be incorporated into existing programs designed to promote community integration for persons with brain injury. This information may allow clinicians to intervene on the potential stresses persons with brain injury face during reintegration and enable them to offer suggestions about how to cope with them.

In terms of research contributions, this study advances our knowledge about stress and coping and provides insight about the process of community reintegration for persons with brain injury. This study also provides the foundation for future research in the area of stress and coping for persons with brain injury and other disabilities.

This study has potential implications for community rehabilitation programs. Knowledge arising from this study will allow individuals involved with the care of persons with brain injury, such as home support workers, rehabilitation professionals, and counsellors, to
more effectively recognize specific situations as potentially stressful, enabling them to help minimize stress for their clients.

Finally, this study has potential benefits for individuals with brain injury and other disabilities. Because the findings are based on an insider’s perspective, this study provides credible insight into the experience of reintegration for persons with brain injury. Individuals who will also undergo reintegration may benefit from the experience of others. Prior knowledge may help individuals recognize a problem as potentially stressful and equip them with suggestions of how to deal effectively with them.
1.4 Overview of Thesis

Chapter 2 provides background information on the concepts of stress and coping, including common uses of the terms. In the first section, the concept of stress is augmented by a discussion of a common measure of stress. Community integration is introduced as the context for stress. In the second section, a review of Coping functions and strategies are presented. A discussion of coping with stresses associated with community integration is also provided. A review of the current literature on stress and coping of persons with brain injury illustrates the need for study in this area.

Chapter 3 introduces the study's methodology. An overview of qualitative research, including characteristics of qualitative research is presented. This is followed by a description of the most common form of qualitative research: basic qualitative studies, and a discussion of trustworthiness of findings. A description of the sample, data collection procedure, and data analysis is provided.

The findings of the study are presented in chapter 4. In the first section of this chapter, the types of stresses associated with integration are presented. The coping strategies that were used by participants to deal with these stresses are presented in the second section. Participant’s comments taken directly from the interviews illustrate each type of stress and coping strategy.

In chapter 5, the findings of the study are discussed. Reasons why persons with brain injury are of interest to the study of stress and coping is discussed. Finally, the relevancy
of the findings to other studies, their implications, and recommendations for future work is discussed.
CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

This chapter presents an overview of the stress and coping literature, including both empirical studies and theoretical orientations. Definitions of stress and coping are provided. The theoretical frameworks used to guide the analysis of this study are discussed. This historical background of these concepts is intended to facilitate understanding and to help clarify how they were used in this study.

The concept of coping is enhanced by an overview of coping functions and strategies, as well as a brief introduction to current theoretical models of coping. A current measure of stress is presented and the context for stress, community integration, is discussed. Finally, the section on coping with stresses associated with community integration is a review of the current studies.

A significant outcome of this review suggests that the study of stress and coping of persons with brain injury is a relatively new area of inquiry. The types of stress persons with brain injury face during community integration and the ways in which they can be dealt with is not well understood. An understanding of stress and coping is best achieved by studying the individual's perspective. In brief, more research in the area of stress and coping for survivors of brain injury is required.
2.2. The Concept of Stress

2.2.1. Definitions of Stress

The term stress, of Latin origin, has been a part of the English language since the fourteenth century. Its earliest meanings included "hardships, straits, adversity, affliction", as well as the process of using force or pressure on another (Mazure, 1995). Over time, the use of the term stress has broadened to include definitions such as "strain upon endurance" and even more specifically, strain upon a bodily organ or a mental power (Oxford English dictionary, 1989, p.885).

Stress has been defined as both a stimulus and a response. Thomas Holmes (1979) defines stress as a stimulus event that presents difficult demands. Hans Seyle (1976) defines stress as a response of physiological arousal elicited by troublesome events. Some authors have viewed stress as both a stimulus and response. Richard Lazarus and colleagues (Holroyd & Lazarus, 1982; Lazarus & Folkman, 1984) define stress as a special stimulus-response transaction in which the individual feels threatened.

The definition of stress that has been adopted by psychologists has been stress as a stimulus. Stimulus definitions include conditions arising within the person, for instance drive stimuli, such as hunger or sex (White, 1959), and environmental events (Lazarus & Cohen, 1977; Pearlin & Lieberman, 1979). Lazarus and Cohen (1977) refer to two main types of environmental events that are commonly cited as stress stimuli: daily hassles and life changes.
Daily hassles arise from a person's role and include feeling lonely, arguing with a spouse, being stuck in a traffic jam, to name a few. Life changes or events are noticeable modifications in one's life circumstances that require readjustment (Holmes & Rahe, 1967; Rahe & Arthur, 1978). Life events, affecting a large number of people, are viewed as universally stressful, such as natural disasters and war (Lazarus and Cohen, 1977).

More common are the life changes or events that occur on an individual level, affecting only one or a few people. Events can be largely outside of one's control, such as the death of a loved one (Bowlby, 1961, cited in Lazarus & Folkman, 1984; Parkes, 1972), a life threatening or incapacitating illness (Hackett & Weisman, 1964, cited in Lazarus & Folkman, 1984), or being laid off from work (Kasl & Cobb, 1970). Or, events may be influenced by the person, such as divorce (Gove & Tudor, 1973) or taking an important exam (Mechanic, 1962).

2.2.2. Measures of Stress

Writers have recognized that life change can produce significant stress for some people. Previous studies (Rahe, Meyer, Smith, Kjaer, & Holmes, 1964; Graham & Stevenson, 1963) have shown that social events requiring change in ongoing life adjustment is significantly associated with the time of illness onset. The questionnaire used in these and similar studies yield the number and types of social events that produce stress. Holmes and Rahe (1967) have attempted to bring greater precision to this area of research through a method by which the magnitude of life events can be determined.
The Social Readjustment Rating Scale, based primarily on the theory of life change, is a method for measuring the intensity and length of time necessary to accommodate to a life event. The SRRS contains 43 items derived from clinical experience. Subjects are asked to rate a series of life events according to their estimated duration of readjustment.

The items may be classified according to the individual's life style and occurrences involving the individual. These events pertain to major areas in the social structure of the American way of life. These include family constellation, marriage, occupation, economics, residence, group and peer relationships, education, religion, recreation, and health. The events listed evolve mostly from ordinary social and personal transactions, but also include those which are extraordinary.

Based on a convenience sample of 394 subjects, Holmes & Rahe (1967) found that the occurrence of each life event usually evoked or was associated with some adaptive or coping behavior on the part of the individual. Thus, each item has been constructed to contain life events whose advent is either indicative of or requires a significant change in the ongoing life pattern of the individual.

The SRRS has been subjected to a great deal of criticism (Dohrenwend & Pearlin, 1981). The main criticism involves the interpretation of the findings (Perkins, 1982, cited in Goldberger & Breizinitz, 1982). For instance, the life changes listed on the SRRS are dominated by negative events, for example the death of a spouse or loss of a job. Since these negative events also generate great frustration, it is arguably unclear whether
frustration or change creates most of the stress assessed by the scale. Thus, it is unclear whether the SRRS is a measure of life change or is an assessment of a wide array of different kinds of stressful experiences.

To overcome the interpretive problems with the SRRS, researchers began to consider the quality of the events rather than the magnitude of the changes they entail in order to determine whether an event is stressful. For instance, researchers have distinguished life events according to the desirability and undesirability of the subjects' life changes (Perkins, 1982; Zeiss, 1980, cited in Goldberger & Breiznitz, 1982) or the voluntary and involuntary character of the event (Pearlin, 1982).

A third distinction that is most commonly used is between scheduled and unscheduled life events (Pearlin & Lieberman, 1979). Scheduled events are those that have, in advance, a high probability of occurrence. These events are an inherent part of the life cycle, such as marriage, having children, career transitions, death of a spouse, and retirement, and are typically expected. While some studies have shown that scheduled events produce stress (Holmes & Rahe, 1967), others have failed to find any notable association between experiencing these kind of life events and symptoms of stress (Pearlin & Lieberman, 1979).

Unscheduled life events, on the other hand, happen without prior warning and are not normally a part of our expectations, as in the case of scheduled events. Examples of unscheduled events include divorce, injury and illness, job disruption, premature death,
ruptured friendships, and traumatic disability. Studies have documented the association between unscheduled life events and stress (Pearlin & Lieberman, 1979).

A second criticism with the SRRS is that it is too general. The items listed on the SRRS pertain to everyday events in daily life and do not address the specific stresses persons with unique challenges face, such as persons with disabilities. Consequently, the SRRS cannot generate a thorough understanding of stress for a significant portion of the population.

2.3. The Context for Stress: Community Integration

The literature suggests that individuals with disability face the same types of stress as others who are not disabled. However, because of the effects of their disability, persons also face unique stresses, such as stresses which derive from impediments imposed by their disability (Oddy & Humphrey, 1980; Lezak & O’Brien, 1988; Dawson & Chipman, 1995) and the barriers found in their environment, such as social stigma (Cutler & Tatum, 1983).

The literature also cites the period of community reintegration as a significant stressful event requiring considerable adjustment (Cogswell, 1977; Morton & Wehman, 1995). Such an event can cause disruptions in finances (Dawson & Chipman, 1995), employment (Oddy, Humphrey, & Uttley, 1978; Oddy, Coughlan, Tyerman, & Jenkins, 1985; West, 1995), and personal relationships (Thomsen, 1984; Elsass & Kinsella, 1987;
Moore, Stambrook, & Peters, 1989) among others, producing considerable stress for the individual.

Kreutzer and Wehman (1990) categorize the existing literature on community integration as involving three main areas: family, vocational, and community. The term community is sometimes described as integration into a social network. Based on this classification, Willer and colleagues (1993) proposed a definition of community integration that took into account home/family, social, and vocational independence. They conceptualize community integration as the opposite of handicap (World Health Organization, 1980) with emphasis on the interaction between the individual and his or her environment.

Common to most definitions of "community integration" then, are three basic ideas: independence in one's living situation; relationships with others; and participation in productive and leisure activities (Ittenbach et al., 1993; Carling, 1990; Carlson et al., 1991; Rapp, 1988; Johnston & Lewis, 1991; Halpern, 1985). Using this conceptualization of community integration, McColl, Carlson, Johnston, Minnes, Shue, Davies, and Karlovits (1998) propose a definition of community integration that is specific to persons with brain injury. A purposeful sample consisting of 24 persons with severe brain injury were interviewed during the first year of integrating into a new community. A qualitative methodology was used to analyze the data collected in five intervals: once every week within the first month, and then once a month in months three, six, nine, and 12.
The findings reveal that consumers define community integration according to nine indicators. They are conformity, acceptance, orientation, close relationships, diffuse relationships, productivity, leisure, independence, and living situation. These nine indicators are classified according to four factors based on the conceptualization of community integration: a general factor, social support, occupation, and independent living. Figure 2-1 illustrates these four factors of community integration.

Community integration provides the context for stress for this study. The model of community integration proposed by McColl and colleagues (1998) serves as the theoretical framework for stress. A number of researchers have maintained the value of using situation-specific measures of coping over the use of a general approach (Folkman, 1984; Pearlin & Schooler, 1978).

2.3.1. Stresses Associated With Community Integration

A few studies have been conducted on the problems that impede community integration for persons with brain injury. As such, we have an adequate understanding of some of the stresses that are associated with community integration. Cervelli (1990) reported common problems such as transportation, managing money, keeping appointments, and dealing with an uninformed and impatient public. Interviews with brain injured adults have revealed broader issues of community reintegration such as loneliness, loss of control over one's life, and loss of family ideas as significant problems (Willer,
Figure 2-1
Theoretical model of community integration (McColl et al, 1998)
Rosenthal, Kreutzer, Gordon, and Rempel, 1993). Medical problems were found to be less of a concern than problems in living.

2.4. The Concept of Coping

2.4.1. Definitions of Coping

Coping has been a subject of interest for nearly half a century. Originating as an organizing theme in clinical description and evaluation in the 1940’s, coping has been the focus of various psychotherapies, educational programs, and research (Lazarus & Folkman, 1984).

Coping is a term that is widely used in a colloquial sense, relying on the context to explain what is meant (McHaffie, 1992). There are a variety of ways to look at coping. Traditionally, coping was seen as a trait or style; it was not distinguished from automatic adaptive behavior; it was confounded with outcome; and it was equated with mastery (Lazarus & Folkman, 1984). A number of limitations with the traditional view of coping prompted a reformulation of the term coping.

Most definitions of coping encapsulate the notion of attempting to restore equilibrium in response to stress (Weisman & Worden, 1976-7; Pearlin & Schooler, 1978; Monat & Lazarus, 1985). This definition equates coping with adaptation. However, coping and adaptation are distinct concepts. Murphy (1962) suggests that coping is “the process of coming to terms with a challenge and adaptation is the result” (p.6).
The preferred definition of coping is "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are perceived as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p.141). By emphasizing taxing or exceeding resources, coping is placed within the rubric of psychological stress and out of that of adaptation.

Coping is viewed as a process through which the individual manages the demands of the environment that are appraised as stressful and the emotions they generate. The view of coping as a process is widely accepted (McHaffie, 1992). It is not static, rather, it changes in quality and intensity as the individual "searches, sifts through and evaluates the cues within any situation (Lazarus, Averill, Opten, 1974). It does not necessitate a total triumph or total surrender but rather a striving toward acceptable compromise (White, 1985).

Based on the definition proposed by Lazarus and Folkman (1984), for the purposes of this study, coping is defined as purposeful cognitive or behavioral efforts aimed at managing internal or external demands that are appraised as taxing or exceeding the resources of the person.

2.4.2. Functions of Coping

A coping function refers to the purpose that a strategy serves. Coping functions have been identified by various writers. White (1974), who writes within an ego psychology framework, cites three coping functions:
(1) to keep securing adequate information about the environment, (2) maintain satisfactory internal conditions both for action and for processing information, and (3) maintain...autonomy or freedom of movement, freedom to use [one's] repertoire in a flexible fashion (p. 55).

Mechanic (1974), who works within a social psychological perspective, also cites three functions: dealing with social and environmental demands, creating the motivation to meet these demands, and maintaining a state of psychological equilibrium in order to direct energy and skill toward external demands.

A common distinction among the coping functions cited above is between coping that is directed at managing or changing the problem causing the distress and coping that is directed at controlling the emotional response to the problem. The former is referred to as problem-focused and the latter as emotion-focused (Lazarus & Folkman, 1984). These two major functions have been observed by other writers (George, 1974; Kahn et al., 1964; Mechanic, 1962; Murphy, 1974; and Murphy & Moriarty, 1976) and are accepted in the models proposed by Mechanic (1974), Pearlin & Schooler (1978), Pearlin, Leiberman, Menaghan, & Mullen (1981), and White (1974).

These two functions of coping are also used in response measures, such as the Ways of Coping (Folkman & Lazarus, 1980). The Ways of Coping is a checklist of 68 items listing a broad range of behavioral and cognitive coping strategies that may be used in specific stressful situations. The strategies were derived from the framework suggested by Lazarus and his colleagues (Lazarus, 1966; Lazarus and Launier, 1978) and suggestions offered from the coping literature (Mechanic, 1962; Sidle et al., 1969; Weisman and
Worden, 1976-77). The strategies include items from the areas of defensive coping (ie avoidance, intellectualization, isolation, suppression), information seeking, problem-solving, palliation, inhibition of action, direct action, and magical thinking. The checklist is binary, yes or no, and refers to specific stressful situations.

Other writers have proposed to subdivide the categories. Pearlin and Schooler (1978), for instance, make a separate distinction between strategies that control the meaning of the situation and those that control the emotional response itself. Perception-focused coping consists of cognitive attempts to control the meaning or interpretation of the distressful event after it occurs but before the emergence of stress.

According to the model proposed by Pearlin and Schooler (1978), coping serves three main functions. Coping can change the situation out of which stressful experiences arise; control the meaning of such experiences before they become stressful; and control the emotional reaction to the stress after it has emerged. Figure 2-2 shows the three major types of coping proposed by Pearlin and Schooler (1978).

Coping functions have been identified in specific contexts such as exam taking (Mechanic, 1962), political crises (George, 1974), parachute jumping (Epstein, 1962), and changes in institutional residence (Aldrich and Mendkoff, 1963). The current coping literature reveals coping functions within such contexts as health/illness (Ingledew, Hardy, Cooper, Jumel, 1996; Ryan-Wenger, 1996; Melding, 1995), disease (Smari, Valtysdottir, 1997; Compas, Worsham, Ey, Howell, 1996; Sharts-Hopko, 1997),
Figure 2-2
Theoretical model of coping
community crisis (Ben-Zur & Zeidner, 1995), and surgical transplants (Kuiper & Nyamathi, 1991).

The coping framework presented by Pearlin and Schooler (1978) will serve as an analytical guide for the present study. The coping functions that I will be concerned with in this study involve efforts that change the situation out of which stressful experiences arise (problem-focused); efforts that control the meaning of such experiences before they become stressful (perception-focused); and efforts that control the emotional reaction to the stress after it has emerged (emotion-focused).

2.4.3. Coping Strategies

A strategy is a scheme a person adopts in order to cope with some specific stressful event. Problem-focused strategies are more probable when it is perceived that the problem is amendable to change (Folkman & Lazarus, 1980). In contrast, perception-focused and emotion-focused strategies are more likely when it has been perceived that nothing can be done to modify a stressful situation that is perceived as harmful, threatening, or challenging (Folkman & Lazarus, 1980). Perception-focused and emotion-focused strategies are more likely when the situation is uncontrollable, such as in the case of permanent disability (Thoits, 1986) or when the individual lacks the power or resources necessary to escape or alter the situation (Pearlin and Schooler, 1978).

Specific coping strategies are not inherently good or bad in terms of coping. Strategies that are effective in one situation can be quite ineffective in another. Further, not all
types of coping strategies are good for the person. Alcohol and other drug use, for instance, may reduce stress but will also increase risk to the person's health in the long run.

Since the 1980's, a substantial body of research has emerged in the area of coping strategies. Most of this research has studied coping within certain contexts in specific populations. For instance, coping with disease, illness, and disability have been examined. Jean, Beatty, Paul and Mullins (1997) examined the relationship between coping styles and psychological distress in a non-institutionalised sample of individuals with multiple sclerosis. Using both standardised measures and self-reports, the authors found that individuals with MS showed greater levels of depression and other indices of psychological distress than demographically matched controls but the pattern of coping strategies endorsed and the ratings of coping effectiveness were similar for the two groups.

When coping with disease-related stressors, subjects used more emotion-focused strategies but were no less effective than were some participants who coped with general stressors. Within the MS group, high levels of psychological distress were positively correlated with the use of emotion-focused coping strategies, but were unrelated to the use of problem-focused strategies. Most individuals with MS appeared to be able to modify their coping strategies to adapt to varying sorts of stresses. This finding has been demonstrated in other studies involving persons with MS (Spirito, Stark, Gil, & Tyc, 1995)
2.4.4. Theoretical Models of Coping

There are two major models of coping that derive from two distinct theoretical orientations: the behavioral model and the cognitive model. The cognitive model views stress as a transaction between a person and the environment. The perception of threat and its accompanying emotions trigger the need for coping efforts. Coping efforts can be directed toward the self, the environment, or towards both (Kahn, Wolfe, Quinn, Snack & Rosenthal, 1964).

The mechanism by which this interplay between person and environment can be understood is the cognitive process of appraisal. Appraisal is a judgement about the meaning or significance of a situation (Lazarus, 1966). It is the process whereby the potential outcome of a situation and the coping efforts employed to deal with the event are evaluated. It is a function both of the situation and of belief systems, cognitive styles and personal disposition (Lazarus et al, 1974).

There are two types of appraisals: primary and secondary (Cohen and Lazarus, 1979). Primary appraisal is a judgement about the significance of the event as it relates to the person's well-being, for example, "How much danger am I in from this situation?" Secondary appraisal is an assessment of what can be done. It evaluates coping resources and options available, their applicability and efficiency. Thus, how people cope depends on their own interpretation of the event in light of available resources.
The behavioral model of coping is based on the principles of behaviorism (Skinner, 1953). Coping behavior can be explained through a modified version of behaviorism, social learning theory. Coping is learned through the interaction between the individual (internal mental events), the environment (external events), and overt behavior. This is referred to as reciprocal determinism. Stress is viewed as a stimulus event that presents difficult demands (Holmes & Rahe, 1967; Holmes, 1979). The way in which one copes with stress depends on previous learning.

Both classical and operant conditioning can take place vicariously when one person observes another's conditioning. Observational learning occurs when an individual's responding is influenced by the observation of others, called models. For instance, alcohol abuse (drinking to cope), is explained by this model as a response that has been learned through social interactions.

The main difference between these two models is the way coping is treated. The behavioral model focuses on overt, observable behavior whereas the cognitive model is concerned with unobservable mental process or cognition. Although behavior is not ignored, it is regarded as less important than cognition.

Cognitive models have yielded some significant interventions for remediating some life problems. For instance, depression has responded well to cognitive therapies (Eifert & Craill, 1989; Dobson, 1989). More recently, cognitive rehabilitation, which targets various information processing deficits, seem to improve some of the difficulties of
schizophrenia (Spaulding, 1994) and neuropsychological difficulties (Gouvier, Webster, & Blanton, 1986, cited in Corrigan, 1997).

Although the cognitive model is theoretically descriptive of human behavior and has been shown to be successfully applied, its clinical applicability is limited to those segments of the population who have the intellectual, educational, and cultural background to understand the introspective nature of this approach (Bernstein & Nietzel, 1980). That is, the cognitive model may not be applicable to some persons affected with brain injury, particularly those whose principal problem arising from the injury is cognitive impairment. For this reason, rehabilitation of brain injured adults normally rely more on behavioral interventions.

2.5. Coping With Disability

A review of the nursing literature concerning coping with disability revealed only three studies. Interestingly, all three reports focus on coping effectiveness. Virtually no studies have been conducted that describe coping strategies of persons with a disability and how coping varies according to different stressful situations.

McNett (1987) examined coping effectiveness, using the McNett Coping Effectiveness Questionnaire (MCEQ), of 50 wheelchair-bound individuals residing in the community. The findings indicate that emotion-focused coping was significantly and negatively related to coping effectiveness, and problem-focused coping was significantly and
positively related to coping effectiveness. Another interesting finding was that perceived
social support was significantly and positively related to coping effectiveness.

In another study, Ferrington (1986) examined the relationship between personal control
and coping effectiveness of 104 hospitalized spinal cord injured patients. The level of
coping effectiveness was determined by the level of depression as measured by the Beck
Depression Inventory (Beck, 1967). The findings indicate that the significance of
personal control in influencing depression depended on whether the person desired
control. However, it is argued by other writers whether the presence or absence of
depression is a valid indicator of coping effectiveness (Lyon, 1993).

Nieves, Charter, and Aspianal (1991) examined the relationship between effective coping
and quality of life in a correlational study involving 40 persons who had incurred a spinal
cord injury. The MCEQ was used to measure coping effectiveness. The theoretical
framework for the study was the transactional perspective developed by Lazarus (1966)
and Lazarus and Folkman (1984). The main finding of the study was that coping
effectiveness was significantly related to quality of life ($r = .60$).

Very few studies have related coping and brain injury. Among the very few include a
study by Frank, Haut, Smick, Haut, and Chaney (1990) who compared the coping
strategies and perceived family functioning of 40 patients with closed head injury with a
control group, consisting of 17 individuals who had sustained traumatic injury without
brain injury. The authors report the use of information seeking as the dominant coping strategy after brain injury.

Willer, Allen, Liss, and Zicht (1991) used a structured, small-group discussion process to examine problems and coping strategies of 20 married men and 11 married women with traumatic brain injury and their able-bodied spouses. They report that the coping strategies most commonly used by wives with brain injury include the support they receive from their spouse, support they receive from others, particularly support groups, and the use of memory and organizational aids. The top three coping strategies used by husbands with brain injury include involvement in family decisions, understanding concerns of family members, and involvement in activities outside the home.

Kreting (1989) used an ethnographic approach to examine how adults with brain injury cope with the loss of self-identity. Three fieldwork strategies were used to collect the data from 21 moderately head-injured individuals living in the community. They were semi-structured interviews, participant observation, and documentary review. Data analysis involved thematic and content analysis. The findings, described in terms of recasting strategies which are linked to the theoretical concept of self-identity and personhood, suggest that brain injured subjects cope with loss of self-identity through concealment, blind spots, and redefinition.

In a recent study, Malia, Powell and Torode (1995) used the “Ways of Coping Checklist” to evaluate coping in a sample of 74 brain injured survivors. The findings showed that
brain-injured patients used four coping strategies: problem-focused, emotion-focused, avoidance, and wishful thinking. Less use of emotion-focused, avoidance, and wishful thinking coping strategies predicted better psychosocial functioning in the brain-injured group. Results similar to these have been reported for a wide variety of other health problems (Moos & Billings, 1982; Holohan & Moos, 1985, 1986; Miller, Brody & Summerton, 1988; Foldman, Lazarus, & Gruen, 1986).

2.6. Coping with Stresses Associated with Community Integration

Very few studies have investigated coping with stresses associated with integration. One of the few studies that exist is that conducted by Willer, Allen, Durnan, and Ferry (1990). A participant observation design was used to examine integration problems and coping strategies of 13 young men with brain injury and their mothers and siblings.

Key problems identified by young men with brain injury were abilities not always recognized by others, controlling behavior, relationships with peers, family stress, autonomy, and school. Coping strategies used to deal with these stresses were developing and maintaining a good outlook (perseverance), support from family and friends, taking an active role in rehabilitation, taking an active role in the community, and educating the public.

In summary, the study of stress and coping of adults with brain injury is a relatively new area of research. In the past decade, researchers have attempted to provide an understanding of the integration problems and coping strategies of adults with brain
injury living with their families. Survivors describe the problems they and their families face as problems in living. Problem-focused strategies are used more frequently to deal with these problems.

Knowledge of stress and coping of persons with brain injury in other settings during community re-entry is lacking. A significant number of brain injury survivors, for instance, live in community residential programs. It is important that attention be focused on various living situations to ensure a thorough understanding of stresses associated with community re-entry for adults with brain injury. This will allow comparisons to be made about the types of stresses persons with brain injury face during reintegration and the coping strategies employed to deal with them.
CHAPTER 3
METHODOLOGY

3.1. Introduction

The aim of this chapter is to introduce the method that was used to conduct the study and provide information about how the study was carried out. This study utilized a basic qualitative approach. The chapter begins with an overview of qualitative research followed by a discussion of basic qualitative studies. The section on trustworthiness of findings provides information about the reliability and validity of the study.

The data utilized in this study derives from a larger study (McColl et al, 1998). Information regarding data collection for this original study, including interviewer selection and training, protocol, procedure, and pilot testing are provided. The section on the study sample includes a discussion on the sample size, sampling procedure, and inclusion and exclusion criteria.

The final section of this chapter deals with data analysis. A detailed discussion about how the data was analyzed is presented. This begins with a description of the computer software used for data storage and organization. A significant portion of this section is devoted to the actual procedures that were utilized to analyze the data. The theoretical frameworks used to guide the analysis of the study is also discussed.
3.2. Qualitative Research

Qualitative research produces findings not arrived at by statistical procedures or other means of quantification (Strauss & Corbin, 1990). It encompasses many forms of inquiry that help us to understand and explain the meaning of social phenomena with as little disruption of the natural setting as possible (Merriam, 1998). Many writers have traced the roots of qualitative research to phenomenology and symbolic interaction. Qualitative research is often referred to as naturalistic inquiry, interpretive research, field study, or participant observation.

Several characteristics distinguish qualitative research from quantitative research. The key philosophical assumption underlying all types of qualitative research is the view that reality is constructed by individuals interacting with their social environment. Field and Morse (1985) assert that the purpose of qualitative inquiry

"...is to identify the properties existing in the real world and to gain a fuller understanding of what constitutes reality for the informants in a particular real-life setting" (p.111).

Unlike quantitative research which takes apart a phenomenon to examine component parts, qualitative research examines the whole phenomenon to examine how all the components work together.

As Merriam (1998) explains "it is assumed that meaning is embedded in people’s experiences and that this meaning is mediated through the investigator’s own perceptions" (p.6). The primary concern for qualitative researchers is understanding the
phenomenon under study from the participant’s perspective. This is sometimes referred to as the emic, or insider’s perspective, in contrast to the etic, or outsider’s view.

A second characteristic is that the researcher is the primary instrument for data collection and analysis. Data are mediated through the researcher rather than through a questionnaire or computer, as are typical instruments used in quantitative research. The human researcher is differentiated from other data collection instruments by several characteristics. According to Guba and Lincoln (1981), the researcher is responsive to the context; techniques are adapted to the circumstances; the total context is considered; nonverbal cues expand what is known about the situation; the researcher can process data immediately, can clarify and summarize as the study evolves, and can explore anomalous responses.

A third characteristic of qualitative research is that it usually involves fieldwork. The researcher goes to the people or setting in order to observe behavior in the natural setting. Less common are qualitative studies which involve only documents, such as written material or photographs.

Fourth, qualitative research uses an inductive research strategy. Rather than testing existing theory, the research builds abstraction, concepts, and theories. Often, qualitative research is undertaken because there is a lack of theory or an existing theory does not adequately explain a phenomenon. For instance, despite a substantial amount of theory available in the area of stress and coping, we do not have an adequate understanding of
stress and coping with respect to persons with brain injury. Typically, qualitative research findings are in the form of themes, categories, typologies, concepts, or theory which inductively derive from the data.

Finally, the output of qualitative research is richly descriptive. Words or pictures, rather than numbers, convey the essence of what the researcher has learned about the phenomenon. Descriptions of the context provided by the researcher is usually supported by the participant’s own words.

In addition to these more common characteristics of qualitative research are several others which are more or less common to most forms of qualitative research. For instance, ideally, the design of the study is emergent and flexible. However, this is not always possible as thesis, dissertation committees, funding agencies, and so on often require the design to be specified in advance. Sample selection is often nonrandom, purposeful, and small, compared to the larger, more random sampling of quantitative research. Finally, the researcher spends a great deal of time in the natural setting of the study in close contact with the participants.

3.3 Basic Qualitative Study

The term basic or generic qualitative study refers to studies which exemplify the characteristics of qualitative research described above. Researchers who conduct this type of qualitative study are not interested in culture, building a grounded theory, or intensive case studies of a single unit. Rather, the purpose of basic qualitative studies is
to discover and understand a phenomenon, process, or perspectives of the people involved.

The basic qualitative study draws from concepts, models, and theories from such disciplines as educational psychology, developmental psychology, cognitive psychology, and sociology (Merriam, 1998). Data are collected through face-to-face interviews, observations, or document analysis. The findings of basic qualitative studies is a combination of description and analysis, an analysis that uses concepts derived from the theoretical framework of the study. The analysis usually results in the identification of recurrent patterns occurring in the data (in the form of categories or themes). In these studies, analysis does not extend to substantive theory as is the case of grounded theory studies. Neither are these case studies that focus on a single unit.

Basic qualitative studies are the most common type of qualitative research (Merriam, 1998). Examples of basic qualitative studies include a study of male nursing students (Blankenship, 1991), a study of censorship and public school teachers (Herzog, 1995), and a study of women’s development (Levinson & Levinson, 1996).

3.4. Trustworthiness

It is argued (Agar, 1986; Guba, 1981) that terms such as reliability and validity are relative to the quantitative view and do not necessarily fit the details of qualitative research. Since the nature and purpose of qualitative research differs from quantitative research, different criteria by which qualitative research is evaluated must be applied.
For instance, reliability typically involves replicability and consistency. In qualitative research, variation in experience, rather than exact replication is sought (Field & Morse, 1985). Thus, variability is expected in qualitative research and consistency is defined in terms of dependability (Krefting, 1991).

Dependability refers to the variability that can be ascribed to identified sources (Guba, 1981). Sources of variability include increasing insight of the researcher or changes in the informants situation. Another important source of variability stems from the fact that qualitative research looks at the range of experience rather than the average experience, so that atypical or non-normative situations are important and are included in the findings (Krefting, 1991). Therefore, although the individual under study may not represent a group, their experience is, nonetheless, significant.

Other researchers (Bork, 1993) suggest that a common test of reliability in qualitative research is the application of the findings to similar groups, events, and settings over time. If the findings can help to interpret, understand, or predict behavior, the findings are considered to have reliability.

Reliability of qualitative research can be assured through the use of specific strategies that are introduced throughout the research process (Polit & Hungler, 1995; Field & Morse, 1985). Some strategies can be addressed in the study's design or can be applied during data collection and during the interpretation of the data (Krefting, 1991). Several strategies were employed in this study to ensure reliability.
First, the study used multiple interviewing. Concurrent collection of data through interviewing and observation continued over an extended period of time. This allows for the internal consistency of the data from which concepts emerge. Second, during interviewing, the questions were stated in different ways by the interviewer to ensure understanding of the questions by participants.

Third, the study has theoretical reliability. The data were coded according to a theoretical framework which is accepted among researchers as empirically and theoretically sound (Mechanic, 1974; Pearlin, Menaghan, Leiberman, & Mullen, 1980; White, 1974).

Fourth, a form of member checking was used. The responses of each participant were checked with their own responses given in subsequent interviews for consistency. This is a type of member checking that does not violate the ethical standards of the study since the informant’s responses are compared with their own responses rather than the responses of other individuals unrelated to the study (Krefting, 1991).

Finally, the study has inter-rater reliability. The coding scheme was tested for reliability by comparing it with that of three other individuals who were knowlegable about stress and coping.

Validity is also addressed differently in qualitative research. In quantitative research, external validity refers to the ability to generalize from the research sample to the general
population (Payton, 1979). In qualitative research, validity generally refers to whether the findings of the study represent reality.

Several internal procedures were employed in the research design to ensure that the findings represent reality from the perspective of the participants. First, data were collected directly from the persons being studied over an extended period of time in a setting that the participants normally live and function. During interviewing, responses were repeatedly restated to ensure accuracy in interpretation.

Second, data was collected from multiple persons and subjected to constant comparative analysis to determine consistency and accuracy across persons. Third, all data were treated as legitimate. If an initial theme did not fit additional data, the theme was either eliminated or modified until it did represent the data.

3.5. Sample
3.5.1. Sample Size
The study uses a purposive sample of 11 adults from a larger study (McColl et al, 1998). Subjects have experienced a moderate to severe brain injury. According to Morse (1994), a minimum of six participants is an adequate sample size for qualitative studies. Sample size in qualitative research not only refers to number of participants but also to number of interviews (Sandelowski, 1995). A total of 33 interviews (3 per subject) were used in this study.
3.5.2. Sampling Procedure

The sample consists of 11 individuals who have experienced a severe brain injury. Severity is indicated by post-traumatic amnesia of 24 hours or greater, or a Glasgow Coma Scale rating of 8 or less. Subjects were recruited from eight transitional living or community re-entry programs for brain injured adults in Ontario. At the time of data collection, all members of the sample lived in the transitional living or community re-entry programs. The names of the programs and their location are summarized in Table 3-1.

Table 3-1
Transitional living or community re-entry programs from which subjects were recruited and their location

<table>
<thead>
<tr>
<th>LOCATION</th>
<th>SITE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Etobicoke</td>
<td>Community Head Injury Resource Services</td>
</tr>
<tr>
<td>Hamilton</td>
<td>Anagram</td>
</tr>
<tr>
<td>Kingston</td>
<td>Regional Community Brain Injury Services</td>
</tr>
<tr>
<td>London</td>
<td>Dale Head Injury Services</td>
</tr>
<tr>
<td>New Market</td>
<td>York Simcoe Traumatic Brain Injury Services</td>
</tr>
<tr>
<td>Mississauga</td>
<td>Peel and Halton Community Access Services</td>
</tr>
<tr>
<td>St. Catharines</td>
<td>Brain Injury Community Re-entry</td>
</tr>
<tr>
<td>Thunder Bay</td>
<td>Organization for the Multi-Disabled</td>
</tr>
</tbody>
</table>

Eight of the 11 subjects were repatriated clients who had received rehabilitation services in the United States (for more than six months) between 1986 and 1990. The remaining subjects were non-repatriated clients who otherwise conformed to the study’s criteria. All members of the sample had been in in-patient rehabilitation immediately prior to entering the study and had been away from the community they entered for at least one year. Table 3-2 shows the characteristics of the participants for the present study.
Table 3-2
Participant Profile

<table>
<thead>
<tr>
<th>SUBJECT</th>
<th>GENDER</th>
<th>AGE</th>
<th>TIME POST INJURY (Years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>002</td>
<td>M</td>
<td>31</td>
<td>23</td>
</tr>
<tr>
<td>004</td>
<td>M</td>
<td>21</td>
<td>2</td>
</tr>
<tr>
<td>006</td>
<td>M</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>013</td>
<td>F</td>
<td>24</td>
<td>15</td>
</tr>
<tr>
<td>014</td>
<td>M</td>
<td>39</td>
<td>21</td>
</tr>
<tr>
<td>015</td>
<td>M</td>
<td>36</td>
<td>3</td>
</tr>
<tr>
<td>016</td>
<td>M</td>
<td>24</td>
<td>5</td>
</tr>
<tr>
<td>021</td>
<td>M</td>
<td>34</td>
<td>14</td>
</tr>
<tr>
<td>022</td>
<td>M</td>
<td>22</td>
<td>2</td>
</tr>
<tr>
<td>026</td>
<td>M</td>
<td>24</td>
<td>5</td>
</tr>
<tr>
<td>029</td>
<td>M</td>
<td>19</td>
<td>3</td>
</tr>
<tr>
<td>AVERAGE</td>
<td>88.8% (Male)</td>
<td>26.6 (Age)</td>
<td>8.5 Years</td>
</tr>
</tbody>
</table>

The subjects ranged in age from 19 to 58 years, the average age being 26.6 years.

According to brain injury statistics, the majority of individuals who have sustained a traumatic brain injury are young males between the ages of 19 and 25. The fact that the majority of the subjects in this study fell between the ages of 19 to 25 (10 of which are male) may assist transferability of the study findings.

Eighty-eight percent (88.8%) of the sample was male (10 males, 1 female). The over representation of male subjects is consistent with the gender distribution in the incidence of brain injury. Men with traumatic brain injury far out number women with traumatic
brain injury. The time since injury ranged from 1 to 23 years with the average time post injury being 8.5 years.

3.5.3. Inclusion and Exclusion Criteria
For the original study, subjects were included if they spoke English, had adequate verbal skills, were over the age of 18, the time post injury was more than one year; their ultimate destination will be the community, rather than a long-term care institution, and they had not lived in the community for at least one year. Subjects were excluded from the study if they consistently could not be reached for interviews or were unable to conduct the interview for reasons of memory, distractibility, illness, or other concurrent diagnosis.

From the sample of 19 subjects in the original study, subjects were included in the present study if they had completed an interview during the 4, 5, and 6 month within the first year of integrating into a new community. Subjects were excluded from the study if they did not mention any coping behavior or the stress for which coping was applied in at least one of the three interviews.

3.6. Data collection
3.6.1. Procedure
Data collection for the original study began in June 1994 and was completed in December 1996. The data were generated through semi-structured interviews composed of open-ended questions (Appendix B). Open-ended questions such as these provide
guidance to the interviewer, yet, are designed to allow flexibility to capture unanticipated aspects of community integration.

The questions pertained to the experience of community integration. The literature supports the use of an indirect approach to the study of coping. Assessing coping is problematic in that it is difficult to obtain information from people about how they cope. Some authors (Folkman & Lazarus, 1980) suggest that asking people directly about how they cope is not fruitful since we cannot assume that people will know what we mean by coping.

Further, an indirect approach provides the opportunity for individuals to openly express their ways of coping with stress. This allows their true experience to be presented. This also shows insight and awareness regarding the types of problems they face and their recognition of their ability to deal with these problems in a variety of ways.

The interviews were conducted in person in the privacy of the participants' home, a quiet room in the residential program site, or other environments chosen by the participants. Three interviews were conducted in the presence of a third party, which was usually a staff member. The interviewers' observations during each interview were recorded in written form.

In the original study, subjects were interviewed eight times throughout the first year in the new community at the following intervals: one month, two months, three months, four months, five months, six months, nine months, and one year. Only information
collected during months 4, 5, and 6 were used for the present study. This particular time
frame was chosen for two reasons.

First, it was believed that this time frame would capture the critical period of adjustment
to the new community in terms of stress and coping. Within the first three months,
participants are more involved in settling into the new surroundings of the rehabilitation
facility rather than the larger community. Thus, the essence of stress and coping would
not be captured during this time period. Likewise, as participants become integrated into
the community, the stresses they normally would encounter may be dealt with
successfully by the last few months of the first year. Therefore, important stresses and
coping strategies developed to deal with them would be missed.

Second, it was important that three consecutive interviews for each participant be used
for data analysis. Additionally, the maximum number of participants was sought. It was
during this particular time frame (months 4, 5, and 6) that the greatest number of
participants had completed three consecutive interviews. Therefore, months 4, 5, and 6
was selected as the time frame for data analysis.

The duration of the interviews ranged from 10 minutes to 1 hour. All interviews were
audio-taped by the interviewers and transcribed by clerical staff. The written text of the
interview was sent back to the specific interviewer who conducted the interview session
for verification and correction, when necessary.
3.6.2. Protocol

Four forms were used for the purpose of providing information to and collecting information from participants for the original study (Appendix A). They include the following:

(1) Study Information Sheet
(2) Consent Form
(3) Interview Cover Sheet
(4) Demographic and Injury-Related Information Sheet

An information sheet describing the study and explaining its purpose was provided for each participant. Written consent was obtained from each participant prior to the commencement of the study. Two types of information were gathered on each participant by the interviewer at the time of the first interview, demographic information and injury-related information.

3.6.3. Interviewer Selection and Training

Twelve individuals were hired to conduct the interviews with participants for the original study. Interviewers were recruited at each of the nine sites involved in the study. Interviewers were selected based upon their knowledge of the population under study and their previous experience and training with interviewing. Individuals were trained specifically for the study in a one-day workshop to ensure consistent application of the interviewing process and were supervised throughout the duration of the study.
3.7. DATA ANALYSIS

The computer software QSR Nud.ist (Non-numeric Unstructured Data—Indexing, Searching and Theorizing; Aladdin Systems Inc., 1994) was used to organize and store the transcribed data. Two types of procedures were used to analyze the data for both coping and stress: a priori coding and open coding. A priori coding involves coding data according to a particular theoretical framework. Open coding involves conceptualizing and categorizing phenomena through close examination of data (Strauss & Corbin, 1990). The use of these two coding procedures are illustrated in Figure 3-1.

The theoretical framework used to guide the analysis of coping was Pearlin and Schooler’s (1978) classification of coping. According to their model, coping can be categorized as efforts to change the situation out of which stressful experiences arise (problem-focused); efforts to change the meaning of stressful experiences before they become stressful (perception-focused); and efforts to control the emotional reaction to the stress after it has emerged (emotion-focused).

The data was organized according to one of three types of coping: problem-focused, perception-focused, and emotion-focused. This was done by coding each interview line by line for any comment that revealed an effort to change a situation that was perceived as stressful; change the meaning of the experience before the emergence of stress; and controlling the emotional reaction to the stress after it has emerged.
Figure 3-1
Two types of coding applied to the data for coping and stress
Second, using the three data sets that emerged from the data based on the theoretical framework of Pearlin and Schooler's (1978) model of coping, the data were coded again, this time using an open coding technique. The purpose of open coding is to give structure to unstructured data (Brink & Wood, 1988). This process is referred to as content analysis.

Content analysis is the most common type of analysis used in qualitative studies (Field & Morse, 1985). The aim of this procedure is to develop categories of responses and describe those categories. Each passage or paragraph in the interview is reviewed in order to identify and code the major intent of the section and the significant meanings within the passage (Brink & Wood, 1988). Content analysis provides information about the power of the various themes, therefore, giving the researcher confidence in the results.

Each incident of coping behavior was continuously compared with other incidents so similar incidents of coping were given the same name. This is known as the constant comparative method of analysis (Glaser & Strauss, 1967). To aid in this process, questions were asked of the data, such as “What is this?” What does this represent?” “How does this comment relate with other comments?” This resulted in a list of concepts that represented the coping behavior of the participants. As much as possible, the informant’s own words were used.
Finally, the concepts were listed and then grouped with similar concepts. The categories of similar concepts were given a name to represent the concepts within that particular category. For instance, the concepts “keep mouth shut”; “monitor self”; “keep on everyone’s good side”; and “stay out of people’s way”; are all instances of avoiding problems with others. Therefore, the category for these concepts was named “avoidance”.

The resulting categories represent coping strategies used by the participants to manage or deal with stress. These strategies are named and defined in Appendix C. The categories were then classified according to the three types of coping: problem-focused, perception-focused, and emotion-focused.

The theoretical framework used to guide the analysis for stress was the model of community integration proposed by McColl and colleagues (1998). Since coping was analyzed in the context of community integration, this model was most appropriate. According to this model, community integration is comprised of four factors: a general integration factor, independent living, social support, and occupation.

To code the data for stress, the three data sets (problem-focused, perception-focused, and emotion-focused) that emerged from coding the data for coping were used. For each instance of coping that was found, the text (i.e. paragraph) was reviewed for the stress for which coping was applied. This flow of data analysis is illustrated in Figure 3-2.
Figure 3-2
The flow of data analysis: Using the three coping data sets to code the data for stress
Stresses were coded according to McColl and colleagues (1998) theory of community integration. The data were coded according to stresses associated with overall integration (general integration), one's living situation (independent living), relationships (social support), and productive activities (occupation).

After the data was subjected to the first level of coding, a priori coding, the data were then coded according to an open coding technique. Content analysis was used to develop categories of responses and describe those categories. Thus, for each incident of coping that was found in the data, the passage or paragraph was analyzed to reveal the stress for which coping was applied.

The constant comparative method of analysis was also used during this process. The problems found to be stressful stated by each respondent were given names. These concepts were compared with other concepts so that similar concepts were given the same name. For instance, statements pertaining to dealing with limits or restrictions on one's independence or freedom were termed "loss of independence".

These concepts, which represent problems that were found to be stressful to participants, were then listed and then categorized according to general integration, social support, independent living, and occupation. Again, as much as possible, the own words of the informants were used to describe the problems they found to be stressful. The stresses to which coping was applied in this study are named and defined in Appendix D.
In summary, two coding techniques were used to analyze the data for both coping and stress: a priori coding and open-coding. The resulting categories of coping and stress consist of both an emic and etic perspective. Emic refers to the participant's perspective derived from data. Etic categories represent the researcher's perspective and were drawn from the theoretical frameworks of the study.
4.1 Introduction

The purpose of this chapter is to present the findings of the study. As two analyses were performed, the chapter is divided into two sections. The stresses associated with integration are presented in the first section. Definitions for each type of stress are provided. Comments taken directly from participant interviews illustrate each type of stress. The stresses are categorized and presented according to the four factors of integration: social support, independent living, occupation, and general integration.

The second section deals with coping with stresses associated with integration. It names and describes the coping strategies employed by participants to deal with the stresses identified in the first section. Definitions for each coping strategy are provided. As with stress, participants’ comments are provided to illustrate each coping strategy. The strategies are presented according to the function they serve, i.e., problem-focused, perception-focused, and emotion-focused, and the frequency with which they were mentioned by participants.
4.2. Stresses Associated With Community Integration

Participants identified nine types of stress. They are problems with orientation to the community, transportation, lack of a daily routine, one's living situation, loss of independence, difficulties with others in relationships, loneliness, problems with school and work. These problems represent stresses associated with overall integration, relationships, independent living, and productive activities. These stresses can be categorized according to four factors of community integration (McColl et al, 1998). They are general integration, independent living, social support, and occupation. This categorization of stress is illustrated in Table 4-1.

Table 4-1
Categorization of stresses into four factors of community integration

<table>
<thead>
<tr>
<th>GENERAL INTEGRATION</th>
<th>INDEPENDENT LIVING</th>
<th>SOCIAL SUPPORT</th>
<th>OCCUPATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orientation</td>
<td>Living situation</td>
<td>Relationships (close and diffuse)</td>
<td>School</td>
</tr>
<tr>
<td>Routine</td>
<td>Loss of Independence</td>
<td>Loneliness</td>
<td>Work</td>
</tr>
<tr>
<td>Transportation</td>
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</tbody>
</table>
General Integration: General integration refers to integration into the community on a general level. It involves knowing one's way around the community, having the means to get around, and having a daily routine. Stresses characterized as general integration include lack of orientation to the community, problems with transportation, and lacking a daily routine. General integration may be described as an individual’s direct connection to the community in which they live. Studies (McColl et al., 1998) have shown that general integration factors are significant in determining one’s sense of belonging to the community.

For many people with brain injury, problems with using transportation can be quite difficult. For some respondents in this study, not having a drivers license prevented them from easily getting around the community. These respondents mentioned problems with transportation as a significant stressor:

"One thing my brain injury has done to me is that I can't do certain things anymore. I can't drive anymore - my drivers license was revoked. I have to rely on public transportation or other people giving me rides, unfortunately, because I'm so far out in Scarborough."

"The only difficulty I've run into is transportation. Because of the medication I'm on, a drivers license is unavailable."
The community in which participants lived was new to them. One respondent found that not being oriented to the new community and not knowing his way around was stressful. This tends to be especially important in light of the potential to become lost:

"There was a bit of fright when it came to me making it out on my own in the community which I was not too familiar with. I was afraid of being lost, afraid of being embarrassed to ask someone where I was and where to go to get to a certain place."

This respondent found it stressful not having a daily routine due to his involvement in intensive rehabilitation:

"I’ve been taken out of the system for a long time. I’m trying to get back into the community."

**Independent Living:** Independent living refers to integration into the home environment. It involves one's actual living arrangement and the extent to which an individual can be independent or self-determining in this setting. Stresses categorized as independent living include those which arise from problems with one's living arrangement and experiencing a loss of independence due to one's living situation.

Independent living was a major theme found in discussions of community integration. All but one member of the sample lived in a community rehabilitation facility. Some participants found their actual living arrangement quite stressful. They recognized that
living with people that are not of one’s choosing, in addition to the complications of brain injury, can be difficult:

"It's hard living with people you don't trust or like. Just stuffing 3 head-injured people together doesn't mean it's going to work. It's tough from the word go. I run into problems every now and then but this is the biggest problem so far. They've got to be aware that living with Brian and Mike is difficult. I'm neither willing or able to put up with much more."

This respondent talked about a lack of privacy due to his living arrangement:

"I don't really feel like myself because I have people following me around."

Most participants found the loss of independence arising from their living situation stressful. Loss of independence resulted from the rules of the organization. A few participants maintained that the rules limited their freedom to come and go as they please:

"I don't have much independence. I can't leave the townhouse without supervision and that really gets to me. It feels like I'm in open custody or something."

This respondent mentioned that organizational rules prevented him from feeling integrated into the community:

"Because of the rules to follow, I'll never feel part of the community living here. I hate living here. I have to find a job, find my own apartment."

This respondent talked about not being able to spend time with friends:
"Because I'm in this service, I don't have any independence. My friend called me Wednesday to ask if we could get together and go out and do something. I asked if I could go downtown to meet her or pick her up and come back here and they [staff] said, 'No, you don't have any independence', and I got really mad."

For others, it was the inability to be self-determining that was stressful. One respondent talked about not being able to make her own decisions:

"My mom used to speak up for me. Being in HRC, people made decisions for me - it's like I had no say here. I would try something and I'd get 'No, no, this is not the way things are going to go'."

Social Support: Social support refers to integration into a social network. This involves one's relationship with others, close and diffuse. Close relationships involve ties between an individual and family members and friends. Diffuse relationships are those relationships that are not necessarily characterized by closeness or intimacy. Types of stresses that can be categorized as social support include difficulties arising within one's relationships with others or feelings of loneliness due to the lack of meaningful relationships.

Several participants mentioned finding it stressful to deal with people with whom they were close to, such as family members and friends, and people they were acquainted with, such as co-workers, employers, and people in the community. For this participant, dealing with family members was particularly stressful:
"There are some things that I don't understand and I get frustrated. Like if my sister is talking to my dad about something, I won't understand because they talk up here saying words I've never heard of."

This respondent talked about experiencing stress in friendships:

"At times I tend to monopolize the conversation. I'm trying to keep an eye on that. I'd be roughly corrected in the past and I realize it doesn't win too many friends...When he explodes at me, I'm always asking myself, 'Did I do something wrong for him to do that?' There's always a fear in me that I did something to provoke the attack."

A major barrier for this population is the prejudices of people toward persons with brain injury (Willer, 1991). During attempts to become part of the community, a few participants were confronted with people who had prejudicial attitudes and mentioned finding this experience stressful. Participants were confronted with prejudices of others within diffuse relationships.

Some respondents talked about the reaction of others about brain injury in the general community:

"When I first tell people that I have a head injury, they go "yuck!" and they back off. I think they don't know enough about the issue of brain injury and the problems associated with it."
"There's always that, 'Well, she has a brain injury so you'd better stay away from her.' People in the normal community will either slow things down or slow things down and talk real loud."

A few respondents talked about their experience of facing prejudicial attitudes from employers:

"A lot of people won't hire because I have a head injury".

"My brain injury has only affected one job since my accident and that was more or less because, I feel in any case, that it was the wrong job for me to participate in because a lot of the people working in this job are a lot younger than me. Even after they sat down with me and I told them what all the different problems with brain injury are, they still couldn't grasp it and they had a lot of trouble with it."

For some participants, dealing with co-workers was stressful:

"There was a guy at work constantly bothering me."

For others, the lack of meaningful relationships was particularly stressful. This respondent found it stressful living alone in the new community:

"When I was at the TLC, I was with a group of people all the time. When I was back home before I came here, I had staff with me all the time. And when I was in the States before I went to Timmins for therapy, I was with people all the time."
What I found difficult when I first came here to my apartment was dealing with a lot of restlessness.

This respondent felt alone due to feeling unconnected to others in the new community:

"I'm still in a dilemma because my community right now is pretty disjointed because I don't really know anybody around here in my community, like socially speaking. I know a lot of people through work but they are not the kind of people I would call up and say 'Hey, would you like to go for a cup of coffee?"

**Occupation:** Occupation refers to integration into productive activities. This involves work, paid or unpaid, and educational activities. The types of stresses that can be categorized as occupation include problems experienced in the workplace and getting established in school.

A significant aspect of integration for persons with brain injury was to become involved in productive activities. One respondent found his work environment stressful:

"Yesterday was a bad day at work. I wasn't pleased with too much of anything and then I had to listen to that radio station. Sometimes I can only handle some things for so long and then I have to evacuate myself."

One respondent found it stressful to get established in school:

"I've been struggling very hard at getting myself settled into school work. I've been going back and forth to different institutions. I've been finding it very hard."
4.3. Coping With Stresses Associated With Integration

The second objective of the study was to investigate how the participants coped with the stresses they faced during integration. Eight coping strategies emerged from the data. They are avoidance, do things differently, community involvement, reaching out, ignoring, self-reliance, perseverance, and substance use. These strategies can be categorized as problem-focused, perception-focused, and emotion-focused. Table 4-2 shows this categorization of coping strategies.

Table 4-2
Categorization of coping strategies into three major types of coping

<table>
<thead>
<tr>
<th>PROBLEM-FOCUSED</th>
<th>PERCEPTION-FOCUSED</th>
<th>EMOTION-FOCUSED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidance</td>
<td>Ignoring</td>
<td>Substance use</td>
</tr>
<tr>
<td>Do things differently</td>
<td>Self-reliance</td>
<td></td>
</tr>
<tr>
<td>Community involvement</td>
<td>Perseverance</td>
<td></td>
</tr>
<tr>
<td>Reaching out</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The coping strategies are presented according to the prevalence with which they were mentioned by participants. They are named and discussed in relation to the context within which they occurred. Definitions for each strategy are provided. The participant’s comments, taken directly from the data, are included to illustrate each coping strategy.

Problem-focused Coping Strategies

Problem-focused coping involves behavioral efforts to change the situation out of which stressful experiences arise (Pearlin & Schooler, 1978). This category of coping was the
most common type of coping used by the sample participants in response to stress. Problem-focused coping strategies were used to deal with problems in relationships and the work environment. Four of the eight strategies can be categorized as problem-focused forms of coping. They include avoidance, do things differently, involvement in community, and reaching out.

**Avoidance:** Avoidance is defined as changing a situation by evading it. In its most simplistic form, avoidance involves leaving the situation. Moreover, avoidance also involves making an effort to prevent further problems that have the potential to arise. In this way, avoidance involves recognizing the problem and then making an effort to deal with it in such a way that will not make the problem worse.

Avoidance was the most common problem-focused coping strategy. Types of behavior that characterized avoidance include keeping quiet, staying out of people's way, leaving a situation, and controlling one's behavior. Avoidance was used to deal with difficulties with others in close and diffuse relationships.

Some participants removed themselves from a stressful situation. One participant talked about leaving a stressful situation in the workplace:

"Yesterday was a bad day at work. I can only handle some things for so long and them I have to leave. I go out and drive around just to balance myself out."
Several participants attempted to prevent further problems from arising. This respondent avoided problems with family members:

"I just basically stay out of people's way, that way you don't get into any problems."

Some participants talked about avoiding arguments with others they lived with in order to preserve their independence:

"Around here, I can't think of anyone that I really get along with. Sometimes I get into arguments with the people I live with. If we are arguing, we get our independence taken away. So I keep my mouth shut; try to keep on everybody's good side so problems don’t happen."

This respondent avoided a stressful situation by controlling his behavior in social situations:

"I try to get along with people as much as I can. I go to the YMCA and if there’s an argument, I don’t sit there and argue, I keep my mouth shut and walk away because I don’t want any arguments."

**Do things differently:** Do things differently is defined as finding an alternative way to do something that can no longer be easily done the usual way. The practice of doing things differently was attributed to the larger community rather than in one's home environment. Stressful problems experienced in the community were dealt with by finding alternative methods.
The only type of stress experienced in the community that was dealt with by doing things differently was transportation. A few participants sought alternative ways to get around the community because they did not have a drivers license. This participant did not have a drivers license because of the deficits associated with his brain injury:

"I can't drive anymore. That just means doing things a little bit differently. Like in order to get back into the community means now I have to rely upon public transport or other people giving me rides."

For some, it was the daily use of medication that prevented them from obtaining a drivers license:

"I have a problem getting there and back. Because of my brain injury, I can't get a license because of the medication I have to take. So now I have to take the bus."

**Community involvement:** Community involvement is defined as becoming connected to one's community through involvement in community activities or getting to know one's way around the community (orientation). Types of activities include taking courses to prepare for employment, looking for employment, and going to school.

For a few respondents, becoming involved in productive activities would eventually lead to living independently in the community. For this respondent, taking courses that would prepare him for employment helped to deal with the stress arising from his living situation:
I'll never feel like part of the community living here. I hate living here. I have to find a job, find my own apartment. Jobs are not as available as they used to be. That's why I'm taking the employment prep workshop."

Participants became involved in activities in an effort to establish a routine for themselves. For this respondent, an important aspect of developing a routine was to gain independence:

"Being out there working, whether it be paid or unpaid, is providing some sense of routine, some sense of regularity. I haven’t had an income other than government disability, so I’m exploring ways to make my own living, like going to school at night. I’m [also] getting out there looking for jobs. Everything I’m doing is leading me to my final goal of independence."

Some participants recognized that some activities needed to be carried out autonomously:

"I’m increasing my time alone. I’m attending meetings by myself and I’m attending classes by myself."

"I’ve been taking the bus on my own and going to places on my own more often than ever. [Becoming part of the community] is something I had to discover on my own. There was a bit of fright when it came to making it out on my own in the community, which I wasn’t too familiar with. Afraid of getting lost, afraid of being embarrassed to ask someone where I was or how to get to certain places. I find the more I go out and experience this, the easier it gets."
Reaching out: Reaching out is defined as opening up to others. This involves disclosing information about oneself and talking to someone about a problem. Self-disclosure pertains to telling people in the general public about having a brain injury in order to present oneself in a different way or make a good impression. Talking to someone allows the problem to be presented in a different way. Participants talked to staff members about difficulties arising within relationships.

Several respondents reached out to others through self-disclosure. This participant disclosed the fact that he had a brain injury to correct false perceptions of others:

“Some people will look at me and they will know that something is wrong. A lot of people that I have met can’t tell if something is wrong. A little bit of memory loss, but they might think that it is from drugs. So I tell them and they are surprised that I have a brain injury.”

One participant found that disclosing information about his brain injury often helped when making friends:

“I usually become my own best advocate and explain to them what has happened and what my problems are. I haven’t found that too many people have shied away. I found that more often people have been willing to stick around. So making friends isn’t usually a problem.”
A few respondents shared information about their brain injury with co-workers and employers in an effort to deal with prejudicial attitudes:

"I tell them about what medication I take, when I take it, and what the dosage is. I think it is responsible to do that".

Other participants reached out to others by talking to someone about a problem. Participants talked to a staff member to deal with problems they had with other co-residents:

“There are a few things during the day that I don't particularly like but I have to deal with them. I talk to the staff about them instead of getting angry.”

“Here in the residence we’ve had a rather turbulent week and my toleration level, even though it’s been fairly good until now, is weakening. I’m meeting with [staff name] to talk about a few things. Even though yesterday helped out a little bit, there are still a lot of things on my mind.”
Perception-focused Coping Strategies

Cognitive attempts to change or control the meaning of experiences before they become stressful are known as perception-focused forms of coping. As with problem-focused strategies, perceptual strategies were used to deal with problems in relationships, school, transportation, and loss of independence. Three of the eight strategies may be grouped as perception-focused forms of coping. They include ignoring, self-reliance, and perseverance.

Ignoring: Ignoring is defined as not taking notice of something or someone. This involves a conscious effort to not think about the problem or situation or keeping oneself occupied with other thoughts or activities. Since ignoring changes the meaning of the problem (by choosing not to perceive it as a problem), it is categorized as a perceptual coping strategy.

The most common perception-focused coping strategy was ignoring. Participants used this strategy when dealing with difficulties in one’s relationships. One participant used this strategy when difficulties arose between himself and those he lived with:

“It’s hard living with other people, especially people you don’t trust or like. I run into problems every now and then but this is the biggest problem so far. He says things that are hard to take back. I just try to ignore it.”

This respondent would ignore co-workers by occupying himself with other tasks:
"There was a guy at work constantly bothering me. Basically, I was ignoring him. I just did my work and did what I had to do."

One respondent talked about ignoring prejudicial attitudes of potential employers:

"I don't really care about my head injury. I know I'll do better in my life. I just leave that all behind and I forget about it, that's how I do it."

**Self-reliance:** Self-reliance is defined as choosing to rely on oneself to manage a stressful situation. This involves making a conscious decision to handle the problem in such a way that is suitable to oneself rather than taking the advice of others or leaving it up to others to handle the problem. In this way, the individual feels more in control of the situation. Self-reliance is a perceptual strategy because it involves changing the meaning of the problem.

The second most commonly mentioned perceptual strategy was self-reliance. A few participants talked about deciding to rely on themselves to help them cope with stresses associated with school and a loss of independence. One participant decided to rely on his own judgement after becoming unsatisfied with the advice he had received from others about school:

"I've been struggling very hard at getting myself settled into schoolwork. I have been going back and forth to different institutions and taking people's advice but now I've finally said 'Never mind everyone else, I'm going to do what I want, what I feel is best'. I'm not going back and forth anymore."
This respondent attempted to handle a loss of independence arising from her living situation by deciding to depend only on herself:

"My mom used to speak for me and people made decisions for me; it was like I had no say. Being here in HRC, I would try something and get 'No, no, this is not the way things are going to go.' I thought, I'm going to do this myself; thank you for your time but I don't need you.' It was like I had this attitude that I don't need anybody and that's basically how I got by. If I depend on other people, I'm never going to get anywhere."

**Perseverance:** Perseverance is defined as not giving up or being persistent when dealing with a stressful situation. It involves taking a conscious stand as to how one will deal with a particular situation. Being persistent gives the individual several chances to solve the problem, postponing the chance of failure. In this way, the meaning of the problem is changed because the individual is continuously making an effort to solve it.

Only one respondent made use of perseverance as a coping strategy. This respondent talked about being persistent when dealing with problems with transportation:

"I've never been the kind of person that when I'm not allowed to do something, I say I'm never going to do this again. I'm fairly stubborn that way. I'll attack it from every different angle until I figure out a way to do it that will work and not only work but a way that is feasible for me to do it."
Emotion-focused Coping Strategies

Efforts directed at controlling the emotional response to the stress after it has emerged are known as emotion-focused forms of coping. This type of coping was the least prevalent among the participants. Emotion-focused coping was used only to deal with loneliness. Substance use was the only strategy that can be categorized as emotion-focused.

Substance Use: Substance use is defined as a coping strategy that involves taking alcohol or drugs in an effort to cope with stress. The purpose of using alcohol and other drugs is to control the emotional reaction to stress. It does not involve the use substances for recreation/leisure purposes.

Only one participant mentioned using alcohol and other drugs as a coping strategy. This participant used alcohol and other drugs as a way to cope with feelings of loneliness:

“When I was at the TLC, I was with a group of people all the time. When I was back home before coming here, I had staff with me all the time. And when I was in the States doing therapy, I was with people all the time. What I found very difficult when I first came here to my apartment was dealing with a lot of restlessness. I have drank a few times and used drugs a couple of times to escape my true inner feelings.”
CHAPTER 5
DISCUSSION

5.1. Overview

Stresses associated with community integration and the coping strategies used to deal with them were investigated. Persons with brain injury are of interest to the study of stress and coping for several reasons. First, because of their disability, persons with brain injury are exposed to various stressful situations. Knowledge about the types of stress persons with brain injury face could allow clinicians to be proactive in minimizing stress. Second, an individual’s coping capacity is crucial in determining successful readjustment to community living. Persons with brain injury can provide insight into the coping strategies that are useful in promoting community integration.

The findings show that participants identified nine stresses associated with integration. They are orientation, transportation, routine, living situation, loss of independence, relationships, loneliness, problems with school, and work. Eight coping strategies were developed by participants to deal with these stresses. They are avoidance, do things differently, reaching out, community involvement, ignoring, self-reliance, perseverance, and substance use.

Several observations may be made about the findings. First, the types of stresses reported in the present study are similar to those that have been reported by other researchers. For instance, problems with transportation was reported by Cervelli (1990) and Willer and colleagues (1991). For participants in the present study, it was the inability to easily get around the community due to not having a drivers license that was stressful. Broader
issues associated with community integration, such as loneliness and loss of independence, were also reported by Willer et al (1991).

Stresses reported in other studies but not reported by participants in the present study include loss of role of husband, father, and provider. The differences in types of stress can be attributed to the different contexts within which stress was examined. For instance, the participants were married men and women with brain injury who lived with their spouses. The participants in the present study were mostly single men (with the exception of one female) who lived in community residential facilities with other people with brain injury. A few of the stresses identified here are directly related to service, such as loss of independence and living situation.

A second observation that may be made is that persons with brain injury develop similar coping strategies to deal with stress. Willer and colleagues (1990) reported involvement in community activities. The authors also report that "never give up" was a theme repeatedly heard among the participants. This is similar to the coping strategy perseverance identified by participants in the present study.

Other similar coping strategies include ‘seeking social support’ (Willer et al, 1990). This coping strategy is similar to ‘reaching out’ reported in the present study. Participants reported talking to someone to deal with a problem however, rather than turning to family and friends for support, participants turned to staff for support in coping with problems.
This may be because staff members were more accessible to participants than family members.

Educate the public (Willer et al, 1990) is also similar to self-disclosure reported in this study in that both involves telling others about brain injury. A significant difference between the two coping strategies is that educate the public pertains to increasing awareness of brain injury in the community and informing people of the consequences of drinking and driving. Self-disclosure involves presenting oneself in a better way to people in order to make a good impression.

Another similar coping strategy previously reported is avoidance. In a study by Malia and colleagues (1987), avoidance involves running away from or repressing the problem. Avoidance as reported in the present study involves preventing further problems or not fanning the flames. As such, avoidance can also be viewed as an active/positive coping strategy.

Further, because of its meaning, avoidance is not generally considered a problem-focused strategy. Problem-focused coping strategies are considered positive in that they recognize the problem and try to deal with it. This study demonstrates that avoidance can also be categorized as a problem-focused strategy.

A third observation that may be made is that problem-focused coping strategies were reported more frequently than perception-focused or emotion-focused strategies. A
possible explanation for this may be that this form of coping is the easiest to employ. In the course of rehabilitation, persons with brain injury are taught how to directly deal with a problem. Therefore, it seems more likely that problem-solving techniques would be used more often.

However, problem-focused coping involves recognizing the problem which may not be so easy, especially for people who are cognitively impaired. The use of problem-focused coping strategies indicate that persons with brain injury have the capacity to perceive problems clearly and develop a positive problem-solving approach to coping, at least with respect to those situations which are amendable to change.

To summarize, the findings show that persons with brain injury tend to face similar stresses and develop similar coping strategies to deal with them. The differences in the types of stress and coping strategies that were previously reported and those identified in the present study can be attributed to the different contexts within which stress and coping were assessed. Overall, although the coping strategies reported here lend support to those found in previous studies, there are also some significant differences.

5.2. Limitations of the Study

As with any study, the findings must be viewed in light of a number of limitations that require discussion. First, the patient population was predominantly male and all white, which may affect generalizability of the findings. However, the predominant use of male subjects is consistent with the statistics on brain injury. Males with brain injury tend to
outnumber females with brain injury. Additionally, in qualitative studies, the experiences of a group of individuals in a given population is considered more significant than whether the individuals are representative of that population.

Second, the sample was recruited through residential community agencies and thus, only contains those individuals who re-entered the community through transitional programs to independent living or life-long supported living. Therefore, the coping strategies and stresses reported are unique to those who share similar living arrangements with others with brain injuries.

Third, stress and coping was assessed in the context of community integration during a specific time frame. The stresses and coping strategies were reported within months four, five and six of the first year of integration. The findings are limited to the types of stress and coping strategies reported during this time frame. This study does not provide any information about changes in stress and coping over time.

Finally, the findings are limited to the questions that were asked. The stresses and the ways in which they were dealt with were offered within the context of the experience of reintegration after brain injury. The questions were formulated according to the three major areas of integration: home integration, social integration, and vocational integration, as well as the experience of brain injury. Although all aspects of integration experience were addressed, including the experience of brain injury, the questions asked cannot be considered exhaustive.
5.3. Theoretical Implications

This study has implications for the current stress and coping literature. First, this study has contributed knowledge about stress and coping of persons with brain injury. We have a better understanding of the types of stresses persons with brain injury are likely to face during their re-entry to the community. Similarly, this study has revealed coping strategies that have not been reported in previous studies. Thus, as a result of this study, we now know more about how persons with brain injury cope with stress.

Second, this study challenges the way we view some forms of coping and their efficacy. For instance, the coping strategy avoidance, as reported in previous studies, involves running away from or repressing the problem. As such, avoidance has been endorsed in the coping literature as a passive/negative coping strategy and was viewed as not generally effective. This study has demonstrated that avoidance can also involve preventing further problems from arising. In this way, avoidance may be viewed as an active/positive coping strategy and therefore be effective in dealing with stress. Further, as avoidance involves dealing directly with a problem to change it, it may also be viewed as a problem-focused coping strategy.

Third, this provides a unique theoretical formulation that changes how we think about stress and coping. The stresses reported here may help to form the basis for a new measure for stress. Current measures of stress are often too vague to generate a thorough understanding of the types of stresses people are likely to face in specific stressful situations. Stresses measured in specific contexts may be more useful than general
measures. Similarly, measures of coping that derive from a specific context offers strategies that are more likely to be useful.

Existing measures of stress are too general for people facing unique challenges, such as persons with brain injury. The SRRS, for example, is designed for the general population and contains all possible changes a person may be confronted with in daily life. Although the SRRS touches upon all major domains in life, such as family, marriage, occupation, economics, residence, relationships, education, religion, recreation, and health, some important stresses are lacking.

To elucidate, change in residence is listed in the SRRS as a stressful event. For persons with disabilities, a change in residence usually involves much more than what is implied on the SRRS. A change in residence often involves moving in order to access rehabilitation services. The choice of where to move is limited to where rehabilitation facilities exist. Just a few years ago, several hundred people were relocated to the United States due to a lack of such facilities in Canada.

Additionally, individuals are usually housed with other people with brain injury, often not at their choosing. Thus, stresses such as living arrangement or loss of independence are not addressed by general measures of stress, such as the SRRS. As a result, these stresses go undetected.
The issue of relationships for persons with disability is also nonspecific in the SRRS. Persons with brain injury often need to re-establish ties with family members and develop new friendships as established friends go their own way. These new friendships often involve others who have a disability. When dealing with the general public, they often are confronted with social stigma, a major barrier for persons with disabilities.

Although persons with disability are likely to face the same sorts of stresses as the general population, the largest difference, as shown in this study, is the impediments imposed by their disability found in their environment, such as issues of mobility, social stigma, independence, and disruptions in routine.

Conversely, the stresses described here specifically relate to community integration and do not address the more general, day to day stresses that people generally face, such as marriage, holidays, vacation, death of a loved one, major purchases, etc, as in the SRRS. Rather, it addresses stresses associated with integration that are specific to persons with disability.

As with stress, measures of coping are also general in nature. The Ways of Coping checklist, for example, is a measure of how people cope with the stresses of daily life. It contains 68 items that describe possible ways a person may cope with a particular stressful situation. The 68 strategies are categorized as two functions: problem-focused and emotion-focused (Folkman & Lazarus, 1980).
The coping strategies described in this study represent how persons with brain injury cope with the stresses associated with integration. The coping strategies derive from self-reports from individuals who have experienced integration after brain injury. Some of the coping strategies reported in the present study represent many of the same domains as the WOC checklist, such as defensive coping, problem-solving, direct action, and inhibition of action. However, using Pearlin and Schooler's (1978) classification of coping, the coping strategies have three functions: problem-focused, emotion-focused, and perception-focused.

The use of three coping functions as opposed to two (problem-focused and emotion-focused) may be useful in that it allows the researcher to be more specific when assessing coping. For instance, perceptual coping strategies, such as perseverance, tells us that despite cognitive impairment, persons with brain injury can successfully change the meaning of a potentially stressful situation. Thus, by using perception-focused coping as a third category, we have learned even more about how persons with brain injury cope with stress and their capacity to cognitively change the potential impact of stress.

In summary, the nine stresses identified by participants may form the basis for a new measure of stress that is specific for persons with brain injury. This new measure could be useful in assessing stresses associated with community integration. The eight coping strategies reported by participants to deal with these stresses may also contribute to a new measure of coping or be incorporated into an existing coping checklist that may be used in assessing coping for persons with brain injury. As such, this study offers clinicians a
practical way of thinking about the stresses persons with brain injury face during integration and the coping strategies they might use to deal with them.

5.4. Clinical Applicability

This study provides clinicians and practitioners with a way to intervene on the stresses persons with brain injury face during integration and offers suggestions for ways to cope with them. Knowledge of potential stresses enables clinicians to help minimize stresses for persons with brain injury during their re-entry to the community. This will help to make the transition into the community less stressful for individuals.

For instance, this study has shown that loss of independence is a significant stressor for individuals with brain injury. This tends to be particularly true for individuals living in community rehabilitation programs where independence is restricted by the enforcement of rules. Clinicians may develop new ways of extending more freedom to individuals to help alleviate this type of stress. However, this is a dilemma for clinicians who must balance increasing opportunities for independence while at the same time assuring the individual’s safety.

Knowledge of useful coping strategies can also allow clinicians to offer possible ways to deal with stress. Since problem-focused coping strategies predict better psychosocial functioning in persons with brain injury (Malia et al, 1987), clinicians may encourage the use of problem-solving skills to alleviate stress. This study offers various problem-solving strategies to cope with stresses associated with integration. With the increase in
knowledge about stress and coping, professionals may play a bigger role in assisting persons with brain injury reintegrate into the community.

5.5. Implications for Future Research

This study opens up a number of opportunities for future research. The first opportunity involves the validation of the stresses and coping strategies reported by participants of this study. To my knowledge, this study is the first to examine stresses associated with integration of persons with brain injury living in community residential programs. This study provides the opportunity for researchers to make comparisons in the types of stresses associated with integration of individuals with brain injury living in a similar setting. Comparisons in the types of coping strategies developed to deal with these stresses may also be made.

The second opportunity for future research involves the development of new measures of stress and coping. The validation of the stresses and coping strategies reported here can lead to the possible development of a new measure of stress and a new measure of coping specifically for persons with brain injury. The new measures of stress and coping may also be used with other disabled populations undergoing integration, such as individuals with mental illness.

Third, a natural extension of this study is to investigate stresses associated with integration and coping strategies at different stages of integration. This study examined stress and coping during months four, five, and six during the first year of integration.
Data collected during the end of the first year can reveal differences (or similarities) in the types of stresses persons with brain injury face and the coping strategies used to deal with them. Such investigations can also show the types of coping strategies that are effective in alleviating certain types of stress associated with integration.

Future research may also consider investigating why persons with brain injury use various types of coping strategies. This study showed that persons with brain injury develop many ways to deal with stresses associated with integration. However, this study does not ascertain why these various coping strategies were developed.

Finally, investigating the relationship between stress and coping during integration may also be worthwhile. Knowledge of those adults with brain injury who experience more stress and their preferred coping strategies can be useful in designing clinic-based or inpatient counselling programs.

CONCLUSION

In conclusion, this study highlights the importance of the study of stress and coping of persons with brain injury. An indirect approach was utilized to investigate the stresses associated with integration and the ways in which they were dealt with by persons with brain injury. Participants were asked about their experience of brain injury during a critical period of adjustment to a new community. The concepts of stress and coping were applied to their statements. The findings are, therefore, based on self-reports.
Despite the shortcomings of this study, the findings have shed some light on the stresses adults with brain injury are likely to face during their re-entry to the community and suggests ways to cope with them. The nine stresses reported in this study conform to a model of community integration proposed by McColl and colleagues (1998). The eight coping strategies captured by the analysis of this study can be viewed as a sampling of three major types of coping distinguished from one another by their functions. Although the findings do not show the full range of coping strategies persons with brain injury develop to deal with stresses, they do, nonetheless, represent the types of coping strategies that are employed to deal with stresses associated with integration.

The findings lend support to existing studies involving persons with brain injury. This consistency suggests that the stresses experienced by persons with brain injury are universal to this population. Differences in stresses may be attributed to the different context within which persons with brain injury are examined.

The coping strategies reported in this study are very similar to those reported by other writers. However, there are some significant differences in some coping strategies. Consistent with other disabled populations, persons with brain injury tend to rely more on problem-focused coping strategies to adapt to different stressful situations.

The findings have both theoretical and practical implications. This study changes how we think about stress and coping. Knowledge arising from this study may allow clinicians and practitioners to intervene on the stresses persons with brain injury face...
during integration and offers suggestions for ways to cope with them. The stresses and coping strategies reported here provides researchers with the foundation upon which a new measure for stress and coping can be developed. This new measure would be useful for persons facing unique challenges, particularly persons with brain injury.
References


APPENDIX
STUDY INFORMATION SHEET

STUDY TITLE: Community reintegration after acquired brain injury
INVESTIGATORS: Dr. Mary’Ann McColl  Dr. Peter Carlson
Queen’s University  Regional Community Brain Injury Services
(613) 545-6110  (613) 547-6969

BACKGROUND INFORMATION:
Between 1986 and the present, close to 500 individuals from Ontario received rehabilitation services in the United States, due to shortages of rehabilitation facilities in Ontario. As of 1991, individuals began to be repatriated to Ontario communities, and over the next 2 years, a total of approximately 100 are expected to return. Considerable effort has been invested in the host communities to ensure the availability of appropriate services and resources to support these individuals. Transitional living centres in the host communities have geared up to increase their enrollment. Home Care Programs have developed special expertise and services for brain injury. However, in spite of these formal supports, it is clear to all that a large measure of the success or failure of these repatriation initiatives will be attributable to the informal support systems that individuals are able to rally around themselves.

The proposed research aims to discover the impact and importance of a variety of personal and social factors on successful community reintegration among brain injured adults in Ontario.

DETAILS OF THE STUDY:
Your participation in this study would be much appreciated. If you agree, an interviewer would meet with you five times at your convenience to conduct approximately a 40 minute interview, asking you about how your friend/family member with a brain injury is managing in the community.

RISK AND BENEFITS:
There are no apparent risks to participating in the study. You will not be asked to do anything that you do not wish to do, and you may refuse to answer any questions about which you are uncomfortable. There will be no direct benefits to you from participating in the study, although we hope that the information learned will benefit future survivors of acquired brain injury.

CONFIDENTIALITY:
All information used in the study is considered strictly confidential, and your anonymity will be protected at all times. The information given to the investigator will be stored in a secure place, and will be identified by a number only. Your name will not be associated with the study. The information you provide will be used in combination with that of approximately thirty other people, and your identity will be protected at all times.
CONSENT FORM

I have read and understood the attached study information and I have had the study explained to my satisfaction. I have been given sufficient time to consider the information and seek advice if desired.

I am voluntarily agreeing to participate in this study on the understanding that I may withdraw my consent to participate at any time, without future consequences. If any questions during the study, I understand that I can contact the above-named investigators or the Director of the School of Rehabilitation Therapy at Queen's University, Dr. Malcolm Peat (613-545-6103).

_____________________________  _______________________
signature of participant        date

_____________________________  _______________________
witness                        date

_____________________________  _______________________
signature of investigator      date

PLEASE NOTE THAT COPIES OF THE FORM WILL BE LEFT WITH YOU SHOULD YOU HAVE QUESTIONS AT A LATER DATE.
### DATA COLLECTION PROTOCOL
### DEMOGRAPHIC AND INJURY-RELATED INFORMATION
### FROM RECORDS OF COMMUNITY PROGRAM:

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| | __ separated __ divorced  
| | __ common-law __ widowed  
| | __ other; specify: |
| **LIVING SITUATION** | __ alone __ with family  
| | __ with friends __ supported living  
| | __ other; specify: |
| **EDUCATION** | __ less than high school  
| | __ completed high school  
| | __ completed vocational training  
| | __ completed university |
| **USUAL OCCUPATION PRIOR TO INJURY** |  |
| **USUAL OCCUPATION AT PRESENT** |  |
| **COMBINED HOUSEHOLD INCOME** | __ < $10,000 __ $45 - 75,000  
| | __ $10 - 25,000 __ > $75,000  
| | __ $25 - 45,000 __ not stated |
| **PERSONAL INCOME** | __ < $10,000 __ $40 - 60,000  
| | __ $10 - 20,000 __ > $60,000  
| | __ $20 - 40,000 __ as above |
| **SIGNIFICANT OTHER** |  
| Name |  
| Address |  
| Phone no. |  
| Relationship |  |
| **PERMISSION TO INTERVIEW SIGNIFICANT OTHER** | Signature  
| Date |  |
APPENDIX B

COMMUNITY INTEGRATION INTERVIEW

1. Do you feel like you are part of your community, like you belong in your community?

IF YES

IF NO

2. What kinds of things make you feel this way? 2. What would need to happen for you to feel a part of the community?

3. What does it mean to you to be a part of the community?

4. What stands in your way of feeling comfortable and integrated in this community?

5. How do you feel problems associated with your disability interfere with:
   (a) Your participation in the community?
   (b) Your ability to get or keep a job?
   (c) Your ability to live on your own in the community?
   (d) Your ability to get along with other people?
   (e) Having a close relationship?

6. What steps have you taken in the past week/month/three months toward finding a place for yourself in this community?

7. Has anyone helped you in your efforts to become part of this community?

8. Have you met with any problems/difficulties/barriers in your attempts to find a place in this community?

9. Do you have any plans in terms of becoming more comfortable with this community or becoming more a part of the community over the next week/month/few months?
APPENDIX C

COPING DEFINITIONS

Problem-focused strategies — Strategies which attempt to change a stressful situation when it arises.

Avoidance: Changing a situation by evading it. Avoidance involves leaving the situation but also involves making an effort to prevent further problems that have the potential to arise.

Do things differently: Finding an alternative way to do something that can no longer be easily done the usual way. The practice of doing things differently was attributed to the larger community rather than in one's home environment.

Community involvement: Becoming connected to one's community through involvement in community activities or getting to know one's way around the community (orientation).

Reaching out: Opening up to others. This involves disclosing information about oneself and talking to someone about a problem. Self-disclosure pertains to telling people in the general public about having a brain injury in order to present oneself in a different way or make a good impression.

Perception-focused strategies — Strategies that attempt to change the meaning of the situation before it becomes stressful.

Ignoring: Not taking notice of something or someone. This involves a conscious effort to not think about the problem or situation or keeping oneself occupied with other thoughts or activities.

Self-reliance: Choosing to rely on oneself to manage a stressful situation. This involves making a conscious decision to handle the problem in such a way that is suitable to oneself rather than taking the advice of others or leaving it up to others to handle the problem.

Perseverance: Not giving up or being persistent when dealing with a potentially stressful situation. It involves cognitively changing the meaning of a potentially stressful problem by deciding not to give up.

Emotion-focused strategies — Strategies which attempt to control the emotional reaction to the stress after it has emerged.

Substance Use: Taking alcohol or drugs in an effort to cope with stress. The purpose of using alcohol and other drugs is to control the emotional reaction to stress. It does not involve the use substances for recreation/leisure purposes.
APPENDIX D

STRESS DEFINITIONS

Social Support: Social support refers to integration into a social network. This involves one's relationship with others, close and diffuse. Close relationships involve ties between an individual and family members and friends. Diffuse relationships are those relationships that are not necessarily characterized by closeness or intimacy.

General Integration: General integration refers to integration into the community on a general level. It involves knowing one's way around the community, having the means to get around, and having a daily routine. Stresses characterized as general integration include lack of orientation to the community, problems with transportation, and lacking a daily routine. General integration may be described as an individual's direct connection to the community in which they live.

Independent Living: Independent living refers to integration into the home environment. It involves one's actual living arrangement and the extent to which an individual can be independent or self-determining in this setting. Stresses categorized as independent living include those which arise from problems with one's living arrangement and experiencing a loss of independence due to one's living situation.

Occupation: Occupation refers to integration into productive activities. This involves work, paid or unpaid, and educational activities. Stresses characterized as occupation include problems in getting established in school and the work environment.