

SHARED LEISURE AND RELATIONSHIP FUNCTIONING AMONG COUPLES  
EXPERIENCING A CHRONIC DISABLING CONDITION

by

NATHALIE GUERIN

(Under the Direction of John Dattilo)

ABSTRACT

Millions of Americans experience social, economic, and relationship losses and limitations associated with onset or exacerbation of a chronic disabling condition (CDC). Since many adults who have a CDC are likely to have heterosexual or same-sex partners, these losses and limitations may affect interpersonal interactions that influence perceptions of loss and relationship functioning. Although researchers have suggested that couples' shared leisure may be influenced in the context of a CDC, and that changes may affect relationship functioning, associations between shared leisure and relationship functioning required clarification. This exploratory study used a qualitative design to explore perspectives of shared leisure and relationship functioning among eight female adults with a CDC and their partners (N=16) residing in the Southeastern United States. This study provides clarification regarding the (a) nature of shared leisure, (b) factors that shape leisure patterns, and (c) influence of shared leisure on relationship functioning in the context of a CDC. Findings revealed that participants described changed leisure patterns that influenced their perceptions of shared leisure as a positive or negative experience. Factors that shape leisure patterns include differences in partners' perceptions of the CDC, as well as partners' use of activity-focused and relationship-focused strategies to participate in activities and interactions that satisfy expectations of preferred experience. Shared leisure both enhanced and diminished perceptions of interpersonal loss and relationship functioning depending on partners' ability to negotiate conflict and tension associated with CDC-related losses and limitations. Therapeutic Recreation specialists may benefit from findings to determine needs and provide interventions to couples experiencing a CDC who reside in their homes. In particular, leisure education interventions designed in collaboration with marriage counselors or support group facilitators may assist couples promote patterns of healthy relationship functioning through shared leisure. These interventions may facilitate opportunities for couples to acquire knowledge and skills helpful to their efforts to clarify values, problem-solve, negotiate conflict, and access resources and equipment helpful for participating in shared leisure in the context of a CDC.

INDEX WORDS: Chronic disabling condition, couples, interpersonal loss, relationship functioning, shared leisure, therapeutic recreation



SHARED LEISURE AND RELATIONSHIP FUNCTIONING AMONG COUPLES  
EXPERIENCING A CHRONIC DISABLING CONDITION

by

NATHALIE GUERIN

B.A., Concordia University, Canada, 1993

M.A., Dalhousie University, Canada, 1996

A Dissertation Submitted to the Graduate Faculty of The University of Georgia in Partial  
Fulfillment of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2004

© 2004

Nathalie Guerin

All Rights Reserved

SHARED LEISURE AND RELATIONSHIP FUNCTIONING AMONG COUPLES  
EXPERIENCING A CHRONIC DISABLING CONDITION

by

NATHALIE GUERIN

Major Professor: John Dattilo

Committee: Maureen Davey  
Douglas Kleiber  
Gwynn Powell

Electronic Version Approved:

Maureen Grasso  
Dean of the Graduate School  
The University of Georgia  
May 2004

## DEDICATION

For Mary and Bill who offered a reason and the support to start, and for Jim and Katie who offered a reason and the support to finish. I love you all.

## ACKNOWLEDGEMENTS

Several people are deserving of special recognition and particular thanks for assisting me throughout this long and challenging – but educational and empowering – journey.

Current members of the dissertation committee who deserve mention are Maureen Davey, Douglas Kleiber, and Gwynn Powell; past members are Patrick Horan and Sharan Merriam. Everyone generously contributed whatever knowledge, skills, and experiences they could to enhance the quality of this study, and some graciously withdrew from the process rather if they felt that my needs would be better served by so doing. You all deserve thanks for enhancing my appreciation of scholarship, and providing wonderful examples of a student-first philosophy.

Diane Samdahl and Patrick Horan deserve thanks for exposing me to Kuhn and encouraging me to think about assumptions – my own and those of others.

Susan Hutchinson, Lynne Cory, and Katie Bemisderfer deserve thanks for being my friends and constant supporters, even when time was short and the distance was long.

The sixteen remarkable participants who gave selflessly of their limited time and more limited energy deserve thanks for reminding me that the earning this degree isn't all that important, but what I try to accomplish with it afterwards is what really matters.

John Dattilo deserves special thanks for bearing with me and seeing me through this long, and often difficult, process with both high standards and great compassion. As a mentor and guide you have helped me to become a MUCH better scholar, educator, and more importantly, person. Plus you never spelled my name wrong, and that's saying a lot.

## TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS .....	v
LIST OF TABLES.....	ix
LIST OF FIGURES .....	x
CHAPTER	
1 INTRODUCTION .....	1
Relationship Perspective .....	2
Interpersonal Loss .....	3
Complexity of Leisure.....	5
Shared Leisure and Relationship Functioning .....	9
Implications for Leisure Services and Need for Research .....	12
Statement of the Problem .....	16
Purpose of the Study .....	18
Significance of the Study.....	18
Definition of Terms.....	20
2 REVIEW OF THE LITERATURE.....	21
Literature Review Strategy .....	21
Shared Leisure in the Context of a CDC .....	22
Complexity of Leisure.....	25
Relevance of Communal Relationships Theory to Interpersonal Loss .....	35

	Relevance of Shared Leisure to Relationship Functioning .....	39
	Implications for Therapeutic Recreation .....	46
3	RESEARCH METHODS .....	58
	Research Method.....	59
	Data Collection .....	60
	Data Analysis.....	64
	Rigor.....	68
	Researcher Assumptions .....	70
4	FINDINGS .....	73
	Participant Dyad Descriptions .....	74
	Research Objectives .....	80
	Nature of Shared Leisure.....	82
	Factors that Shape Leisure Patterns .....	110
	Influence of Shared Leisure on Relationship Functioning.....	143
	Summary of Figure One .....	162
5	DISCUSSION .....	167
	Sample Characteristics: Educated Women with a CDC .....	168
	Perceptions of the CDC.....	178
	Perceptions of Shared Leisure, Interpersonal Loss, and Relationship Functioning.....	184
	Influence of Leisure Patterns on Relationship Functioning .....	191
	Implications for Therapeutic Recreation .....	194
	Limitations.....	201

Areas for Future Research .....	204
REFERENCES .....	213
APPENDICES .....	227
A PARTICIPANT RECRUITMENT SITES .....	227
B NOTICE OF PARTICIPATION IN A RESEARCH STUDY .....	229
C INTERVIEW GUIDE FOR ADULTS WITH A CDC AND THEIR PARTNERS .....	231
D CONTACT SUMMARY FORM .....	234
E CONSENT FORM .....	236

## LIST OF TABLES

	Page
Table 1: Overview of Participant Dyads .....	73
Table 2: Nature of Shared Leisure .....	81
Table 3: Factors that Shape Leisure Patterns.....	109
Table 4: Influence of Shared Leisure on Relationship Functioning .....	143

LIST OF FIGURES

Figure 1: Shared Leisure and Relationship Functioning Among Couples

Experiencing a CDC..... 161

## CHAPTER 1

### INTRODUCTION

According to the National Center for Disease Control and Prevention (2003), over 150 million Americans experience cognitive, physical, financial, and social losses and limitations associated with illness or disability. The most commonly reported conditions include cardiovascular disease, arthritis and other rheumatoid conditions, diabetes, Alzheimer's disease, epilepsy, acquired brain injury, spinal cord injury, and multiple sclerosis and other neurological conditions (National Center for Disease Control and Prevention, 2003). Regardless of etiology, these illnesses and disabilities encompass a course that may be enduring, stable, unpredictable, and/or progressive; consequently, they may be referred to as chronic disabling conditions (CDCs) (Lyons, Sullivan, Ritvo, & Coyne, 1995).

Since illness or disability can occur at any age, many adults are likely to be involved in intimate relationships and have heterosexual or same sex partners (e.g., Shaw, 1997) during onset or exacerbation of a CDC. Consequently, relationship functioning and interpersonal interactions can be affected for both adults with a CDC and their partners. Relationship roles and lifestyles, as evidenced by allocation of household chores and responsibilities, shared recreational activities, or patterns of interpersonal interaction may be strongly established between partners (Cutrona, 1996). Consequently, CDCs are frequently associated with disruption of daily activities, stress, and anxiety for both individuals. Since onset or exacerbation of a CDC has potentially deleterious consequences for both individuals, it is helpful to utilize a relationship

perspective to examine issues related to shared leisure and relationship functioning (e.g., communication, role continuity, relationship stability) as they are perceived by each partner.

### Relationship Perspective

Although it is acknowledged that it is important to examine psycho-social issues associated with a CDC from the perspective of both adults with a CDC and their partners (e.g., Gulick, 1994; Knight, Devereux, & Godfrey, 1997; Pakenham, 1998) few studies have explored leisure-related issues using a relationship perspective (e.g., Lyons et al., 1995; Lyons, 1999). According to Lyons (1989), who explored effects of disability on friendships of adults with severe to moderate CDCs, a relationship perspective emphasizes interpersonal issues and quality of relationships as key factors in dealing with loss and change in the context of a CDC.

Lyons (1999) used a relationship perspective to investigate issues that most affected interactions of adults with a CDC and their families. Lyons' participants reported that relationship functioning was most affected by (a) learning how to deal with loss and change in the structure, quality, and function of existing relationships, (b) dealing with changes in personal identity and self-esteem, (c) learning how to communicate needs and expectations with significant others, and (d) learning how to establish equitable patterns of support and interaction with significant others, especially during companionate activities. Lyons suggested that it might be important to explore leisure not only as an experience in itself, but also as one context that may have implications for relationship functioning in the context of a CDC. These findings support the need to examine issues related to shared leisure and relationship functioning (e.g., communication, role continuity, and relationship stability) that are affected by losses and limitations associated with onset or exacerbation of a CDC.

Losses and limitations associated with onset or exacerbation of a CDC may result in numerous changes in lifestyle and interpersonal interactions for a couple. The person with a CDC needs to adjust and cope with changes and restrictions resulting from the direct and indirect consequences of the CDC. For example, chronic fatigue, pain, or cognitive impairments may reduce and/or eliminate ability to work, maintain one's house, and engage in social activities. This reduction in abilities can have negative consequences on both personal and financial resources as a result of job loss, reduction of social networks, and increased dependence on a partner (Knight, Devereaux, & Godfrey, 1997).

Partners of adults with a CDC must also manage considerable changes in the frequency, duration, and type of activities (e.g., work, chores, recreation) in which they participate. Partners may need to assume household chores and responsibilities that were formerly performed by the person with a CDC. Partners may also need to become informal caregivers (i.e., not formally trained or receiving financial compensation) and provide assistance when that person is unable to complete activities of daily living, such as maintaining personal hygiene or eating meals (Helgeson, 1993). They may also need to compensate for or manage financial losses associated with under/unemployment and increased medical expenses of the adult with a CDC (Perry, 1994).

### Interpersonal Loss

Onset or exacerbation of a CDC may affect relationship functioning by exacerbating perceptions of social and interpersonal losses associated with reduction in (a) discretionary time, (b) ability to engage in recreation activities, or (c) ability to receive affection and emotional support from a partners, friends, and family members (e.g., Kleiber, Brock, Lee, Dattilo, and Caldwell, 1995; Lyons et al., 1995)

Interpersonal loss stems from the negative evaluation of changes in the ability of one person to provide supports (e.g., emotional, financial, instrumental) that were characteristic of the relationship prior to onset or exacerbation of a CDC (Williamson & Shaffer, 1996; 1998). Interpersonal loss is particularly evident among people who describe their relationships as being high in mutually communal behaviors prior to onset or exacerbation of a CDC (Williamson, Shaffer, & Schulz, 1998; Williamson & Shaffer, 1998). Communal relationships (e.g., Clark & Mills, 1979; 1993) are those in which members interact with each other according to the norm of mutual responsiveness. That is, members offer assistance in response to needs of, or to demonstrate a general concern for, another without creating a specific obligation for that person to return comparable assistance. Clark and Mills (1993) noted that mutually communal relationships provide members with a sense of security and fulfillment. When a CDC changes established and desired patterns of interaction members experience interpersonal loss. The more negatively an individual evaluates changes associated with a CDC, the more negatively a person will react to the perception of interpersonal loss (Williamson & Shaffer, 1996; 1998).

However, Williamson and Shaffer (1996) suggested that perceptions of interpersonal loss might be ameliorated when opportunities are available to replace valued aspects of the relationship (e.g., social support, enjoyable shared activity). Shared leisure may be one context that facilitates communication, role continuity, and relationship stability by reducing perceptions of interpersonal loss associated with a CDC. Shared leisure may be a context that promotes social support and enhances individuals' ability to meet their social and emotional needs (Lyons et al., 1995). Consequently, partners may find that shared leisure minimizes the loss of valued aspects of the relationship (Williamson & Shaffer, 1996; 1998). Similarly, adults with a CDC may find that shared leisure facilitates continuity of daily activities with a desired companion

(Lyons, 1999). Shared leisure may also create opportunities to be seen as a partner, friend, or companion with important personal attributes to contribute to the relationship, rather than someone always associated with being dependent (Lyons et al., 1995; Lyons & Meade, 1995). Consequently, ability to participate in shared leisure in the context of a CDC may be helpful for minimizing interpersonal loss and facilitating interactions that promote relationship functioning.

### Complexity of Leisure

Kleiber (1999) suggested that one of the challenges encountered in the field of leisure studies is the lack of agreement concerning the definition of leisure. The failure to achieve consensus may be related to variations in ways that researchers (a) use guiding theoretical frameworks, (b) operationalize leisure, (c) rationalize participation in specific activities, and (d) describe outcomes such as enjoyment. Defining leisure is made more challenging by the fact that some researchers focus on the conditions that promote leisure experiences (e.g., Samdahl, 1988; Shaw, 1985; Mannell, Zuzanek, & Larson, 1988), while others emphasize psychosocial benefits derived from participation in leisure activities (e.g., Gordon, Gaitz, & Scott, 1976; Tinsley & Eldridge, 1995). Although these approaches are substantively different, both generate knowledge concerning the ways that leisure fosters positive affect (i.e., enjoyment). Furthermore, both approaches broadly examine the "combination of free time and expectation of preferred experience" (Kleiber, 1999, p. 3) that is generally agreed to be fundamental for leisure.

### Conditions that Promote Leisure Experiences

Researchers have described many conditions that are conducive to the experience of leisure and the relative influence of these conditions on positive affect and perceptions of enjoyment. For example, several studies have examined leisure-induced states of flow (e.g.,

Czikszenmihalyi, 1990; Czikszenmihalyi & Kleiber, 1991). Within this framework, flow occurs when there is (a) merging of action and awareness, (b) opportunity for mastery and control, (c) immediate feedback concerning clear goals, (d) complete absorption, (e) lack of self-consciousness, and (f) feelings of transcendence (i.e., self-actualization). According to flow theory, the conditions for leisure-related enjoyment are frequently associated with high intensity activities that foster peak performance and optimal arousal.

Alternatively, Samdahl (1988) used a symbolic interactionist approach and suggested that leisure-related enjoyment is most associated with the conditions of high self-expression and low role constraint. Samdahl found that positive affect was most prevalent during relaxing periods when individuals were able to engage in favorite pursuits, often with friends and family. This is consistent with Kleiber's (2000) argument that leisure is not inherently the result of active engagement, and that conditions of leisure may also include (a) disengaged and relaxed state of mind, (b) openness to possibility, (c) receptivity to the world, and (d) comfort with the conditions of life. Regardless of intensity of involvement and state of arousal, central assumptions concerning the conditions of leisure are that activities must (a) occur during discretionary time, (b) be freely chosen, and (c) be free of obligation to others in order to be perceived as enjoyable.

In summary, several investigations (e.g., Csikzentmihalyi & Kleiber, 1991; Samdahl, 1988) have emphasized conditions that promote leisure experiences. While there is conflicting evidence regarding the importance of involvement and arousal (e.g., flow, relaxation) to experience leisure, it is generally accepted that activities that are voluntarily undertaken during free time and promote positive affect are often described as leisure.

## Benefits of Leisure

Some researchers have emphasized psychosocial benefits of participation in specific activities (e.g., Gordon et al., 1976; Tinsley & Eldridge, 1995) and have detailed ways that leisure can provide psychosocial benefits. For example, Tinsley, Hinson, Tinsley, and Holt (1993) reported that non-leisure (e.g., work) activities most often satisfy needs for extrinsic rewards, accomplishment, learning, and altruism. In contrast, there is substantial evidence that leisure activities are often best able to provide psychosocial benefits such as enjoyment, companionship, relaxation, novelty, aesthetic appreciation, service, nurturance, affiliation, and intimacy (e.g., Gordon et al., 1976; Tinsley et al., 1985; Tinsley & Eldredge, 1995).

Gordon et al. (1976) suggested that, unlike work or other obligatory activities (e.g., chores), leisure activities provide symbolic and immediately pleasurable material interchanges with the environment. Although some obligatory activities such as work do provide positive experiences (e.g., feelings of accomplishment or mastery), rewards associated with these activities are often delayed and tangible (e.g., financial remuneration). Leisure activities also provide participants with opportunities to (a) seek diversion and pleasure, and (b) reveal their emotions, beliefs, and feelings (e.g., Chick, 1998). However, all activities exist along a continuum and are rarely considered purely obligatory or leisure (e.g., Shaw, 1985; Chick, 1998). Therefore, it may be possible to view some agreeable obligatory activities (e.g., playing with one's children, interacting with friends and family to maintain desired relationships) as leisure activities since they may fulfill needs for affiliation and nurturance. Stebbins (2000) argued some activities could be described as agreeable obligations since the individual has freely chosen to engage in the behavior, and therefore, positive affect and perceptions of enjoyment are likely to occur.

### Definition of Leisure

Kleiber (1999) suggested that it is generally agreed that the experience of leisure involves some degree of discretionary time and the expectation of preferred experience (e.g., enjoyment). There is also evidence that leisure experiences can provide numerous psychosocial benefits (e.g., Tinsley & Eldredge, 1995). In some contexts, leisure activities require conditions that promote peak performance and optimal arousal and provide benefits such as catharsis and independence (e.g., Czikszentmihalyi & Kleiber, 1991; Tinsley & Kass, 1978). In other circumstances leisure activities require disengagement and low role constraint and provide benefits such as relaxation, contemplation, or sensual pleasure (e.g., Samdahl, 1988; Tinsley et al., 1985). Occasionally leisure activities may involve agreeable obligation and provide benefits such as nurturing or affiliation (e.g., Stebbins, 2000; Tinsley & Eldredge, 1995). Although leisure can be experienced through participation in a variety of activities that provide a spectrum of psychosocial benefits, these activities most often occur during free time and are freely chosen to promote opportunities for preferred experience.

According to Samdahl (1988), although it is not necessary for all researchers to agree on a definition of leisure, it *is* important to specify “within each study the nature of that which is under investigation” (p. 27). Consequently, for the purposes of this study the defining qualities of leisure can be found in the perceived context of activities, behaviors, and experiences (e.g., Samdahl, 1988; Shaw, 1985) that (a) are freely chosen (e.g., Roadburg, 1983; Shaw, 1984), (b) occur during discretionary time (e.g., Kleiber, 1999; Shaw, 1986; Samdahl, 1988), (c) occur with the expectation of preferred experience, such as enjoyment (e.g., Shaw, 1985, Samdahl, 1991) and (d) provide one or more psychosocial benefits, such as relaxation, nurturance, creativity, catharsis, or independence (e.g., Tinsley & Eldredge, 1995). In this study, shared

leisure implies that the leisure experience occurs for both adults with a CDC and their partners as they engage in the same activity.

### Shared Leisure and Relationship Functioning

Several studies have examined associations between shared leisure and relationship functioning but have generated inconclusive findings. Holman and Epperson (1984) and Orthner and Mancini (1990; 1991) conducted reviews of the literature of shared leisure in families that did not include a member with a CDC, and reported that many studies described outcomes of shared leisure as including relationship satisfaction, stability, and cohesion. Although some investigators suggested that improvements in communication and problem solving were fostered through shared leisure, little evidence has been offered to explain the functional mechanisms by which shared leisure contributes to these outcomes. For example, Orthner's (1975) work on marital satisfaction suggested that (a) couples who spent time together in leisure reported greater relationship satisfaction, (b) an excess of independent leisure was associated with less relationship satisfaction, and (c) participation in parallel activities (e.g., watching television, reading in the same room) was only slightly correlated with relationship satisfaction. Although Orthner suggested that joint participation in leisure activity was positively associated with communication, role continuity, and relationship stability, it was not clear how shared leisure facilitated these outcomes or resulted from them.

Recent investigations have attempted to provide support for Orthner's (1975) contentions, and have suggested that shared leisure may also promote relationship functioning in the context of a CDC. Several studies have documented the therapeutic value of shared leisure for improving relationships among parents and siblings of children with CDCs. For example, Mactavish and Schleien (1998) surveyed 65 families and interviewed 16 members of families that included

children with developmental disabilities to examine benefits of shared leisure. The most commonly reported outcomes of shared leisure included fun, shared activity, improved family cohesion, and improved communication. Parents emphasized the importance of shared leisure in helping their children with disabilities connect better with other family members, develop skills, and improve self-perceptions to set foundations for future functioning. There is also evidence that outcomes of shared leisure in the context of a CDC may be equally beneficial in adult relationships. For example, Dupuis and Pedlar (1995) investigated associations between shared leisure and coping ability of family caregivers of older adults with dementia who had been institutionalized. Outcomes identified by participants included enhanced coping, improved communication, and enriched family relationships.

Evidence provided by these studies (Dupuis & Pedlar, 1995; Mactavish & Schleien, 1998) suggests that shared leisure may be an important context for engaging in activities and interactions that promote relationship functioning and reduce perceptions of interpersonal loss in the context of a CDC. However, it is unclear how shared leisure may also be relevant to the experience of interpersonal loss and relationship functioning for adults with a CDC and their partners. Studies examining outcomes of shared leisure in the context of a CDC have focused on (a) families that include a child with a developmental disability (e.g., Mactavish & Schleien, 1998; 2000), or (b) family caregivers (spouses or adult children) of seniors with dementia or other cognitive impairments (e.g., Dupuis & Pedlar, 1995; Dupuis & Smale, 2000; Voelkl, 1998). In contrast, studies examining outcomes of shared leisure among couples (e.g., Hill, 1988; Orthner, 1975; 1976; Holman & Jacquart, 1978) have not specifically included cases in which one partner has a CDC.

Based on the results of studies by Hill (1988), Holman and Jacquart (1988), Orthner (1975; 1976) and others, it is probable that shared leisure experiences can also contribute to relationship functioning for adults with a CDC and their partners. However, it may not be possible for all couples experiencing a CDC to promote relationship functioning and reduce interpersonal loss by participating in shared leisure. Research suggests that relationship dissolution (e.g., divorce) is more prevalent in couples experiencing a CDC than in the general population, and that “young couples” (i.e., young in age and longevity of relationship) are even more likely to terminate their relationship than their peers (e.g., Brown & Geisy, 1986; DeVivo & Fine, 1985; Simmons & Ball, 1984). Young couples who experience a CDC during the course of their relationship report greater difficulty adjusting to and accommodating changes in relational patterns than those whose relationships developed after onset of one partner's CDC (Crewe, Athelstan, & Krumberger, 1979).

One variable that contributes to relationship dissolution in the context of a CDC is dissatisfaction regarding leisure and recreation activities. For example, Urey and Hengeller (1987) reported that couples experiencing the greatest relationship distress post-onset of one partner's CDC reported participating in fewer leisure activities alone or with each other than either non-distressed couples or couples not experiencing a CDC. Similarly, Rodgers and Calder (1990) found that couples experiencing a CDC described time spent together and demonstrations of affection as a valued resource. However, these couples also reported difficulties and disagreements regarding shared leisure as a source of marital distress that was considered in decisions regarding whether to continue or terminate the relationship.

Despite ample evidence that onset or exacerbation of a CDC negatively affects relationship quality and longevity, particularly among young couples, little is known about how

relationship functioning is affected (a) as a whole, (b) for each partner, and (c) by type and severity of CDC (Lyons et al., 1995). Lyons and colleagues suggested that research exploring associations between exchange and equity processes, CDC-related role changes, and relationship functioning in may be particularly helpful to "clarify relational satisfactions and salient needs in relationships where at least one partner has disabling health problems" (p. 60).

Information about ways in which onset or exacerbation of a CDC changes relationship functioning is still limited Cutrona (1996). However, Cutrona (1996) and Lyons et al. (1995) suggested that couples' ability to sustain experiences that contribute to satisfaction with interpersonal communication, social support, and companionate activity may be extremely important. Additionally, Randall (1994a; 1994b) and Gordon and Feldman and (1998) have also suggested that it may be useful to further understanding of the unique life cycle and relationship challenges that are experienced by adults who acquire a CDC. Consequently, an exploratory study that provides adults with a CDC and their partners an opportunity to describe the relevance of shared leisure to interpersonal loss and relationship functioning may have merit. Therefore, this study is intended to enhance understanding of (a) associations between shared leisure, interpersonal loss, and relationship functioning in the context of a CDC, and (b) ways in which these associations may be perceived differently among partners.

#### Implications for Leisure Services and Need for Research

Recently it has been suggested that shared leisure in the context of a CDC may reduce interpersonal loss and promote relationship functioning (Guerin & Dattilo, 2001). Although Kleiber et al. (1995) described relationship loss between a father with an acquired spinal cord injury and his son, the relevance of shared leisure in the context of a CDC has been most extensively studied in the context of families that include a child or a senior with a CDC.

Consequently, it may be useful to explore these issues from the perspective of adults with a CDC and their partners. In particular it may be useful to explore whether shared leisure is relevant in the context of a CDC, and whether it is considered important by both partners. Additionally, it may be useful to explore the need for, awareness of, and utilization of adaptive strategies and resources that may facilitate participation in shared leisure in the context of a CDC. Therefore, there is merit in exploratory research that attempts to clarify the ambiguity associated with (a) shared leisure experiences, and (b) leisure-related needs among adults with a CDC and their partners.

### Ambiguity of Shared Leisure

Evidence suggests that there are numerous constraints that may impede participation in independent and shared leisure in the context of a CDC. Samdahl and Jekubovich (1997) suggested that typical models of leisure constraints include structural factors (e.g., time, money, health), interpersonal factors (e.g., family responsibilities, absence of a leisure partner, mismatched leisure partner) and intrapersonal factors (e.g., personality, self-esteem). Constraints to leisure may be exacerbated in the context of a CDC; Henderson, Bedini, Schuyler, and Hecht (1995) found that adults with a CDC identified additional (a) structural constraints such as energy deficiency and time shrinkage (i.e., additional time required to perform self-care and health maintenance activities), (b) interpersonal constraints such as perceived lack of leisure opportunities and choices and increased dependency on others for mobility and assistance during leisure, and (c) intrapersonal constraints such as self-limiting behaviors (e.g., ceasing participation, vicarious enjoyment) as factors that further restricted participation in leisure activities. Partners of adults with a CDC experience similar structural, interpersonal, and intrapersonal constraints to leisure and also frequently forego opportunities for personal rest,

relaxation, and exercise in order to meet work, household, and caregiving responsibilities (Sato, Ricks, & Watson, 1996).

Leisure service professionals recognize there are numerous constraints to leisure associated with a CDC, and have developed several therapeutic and wellness programs to address specific challenges encountered by adults with CDCs (e.g., Bullock & Howe, 1991) or their family caregivers (e.g., Bedini & Phoenix, 1999). However, Guerin and Dattilo (2001) suggested that these programs frequently emphasize strategies and techniques helpful in sustaining independent leisure functioning and may assume that people are not interested in sharing leisure. For example, Bedini and Guinan (1996a) investigated family caregivers' ability and desire to participate in leisure activities independent of their recipient of care. Caregivers described as "rechargers" (p. 234) created opportunities for exercise, socializing, and relaxation to maintain their physical and psychological energy. In contrast, those who participated in shared leisure were described as "consolidators" (p.233), and the authors suggested that caregivers did not really want to engage in leisure activities with their family member but perceived it as necessary to accommodate barriers related to time, money, and lack of outside assistance. However, since the purpose of the study was not to investigate caregivers' desire for or ability to participate in shared leisure, it remains unclear whether participants' leisure behavior was exclusively an attempt to overcome leisure constraints.

In the context of communal relationships, however, participating in shared leisure with a partner with a CDC may be a continuation of a desired pattern of interaction that has benefits for both individuals. Shared time during leisure activities may increase opportunities to offer and receive support, reduce perceptions of interpersonal loss, and promote relationship functioning in the context of enjoyable and positive meaningful events (Folkman, Moskowitz, & Ozer, 1997).

Given the lack of agreement on this issue, it is worthwhile to investigate perceptions of shared leisure among couples experiencing a CDC. Therefore, this study explored whether adults with a CDC and their partners perceive similar associations between shared leisure, interpersonal loss, and relationship functioning (e.g., communication, role continuity, stability).

### Ambiguity of Leisure-Related Needs

Although there is ambiguity regarding associations between shared leisure and relationship functioning in the context of a CDC, it has been suggested that attempts are frequently made to participate in shared leisure (Lyons et al., 1995). For example, Lyons and colleagues (1995) reported that families used strategies such as (a) reconceptualizing definitions of leisure that were less activity oriented, (b) reconfiguring participatory behaviors such as learning to become a spectator or coach instead of player, and (c) prioritizing and/or redistributing allocation of household tasks to maximize the potential of the person with a CDC participate in leisure activities – especially with children. However, Lyons et al. (1995) did not probe issues related to leisure in great depth, nor did they investigate constraints to and opportunities for shared leisure that were specific to adults with a CDC and their partners.

Although couples experiencing a CDC may attempt to participate in shared leisure, they may have difficulty sustaining activities, behaviors, and experiences conducive to preferred experience. Gignac, Cott, and Bradley (2000) suggested that lack of awareness of adaptive strategies and resources might impede efforts to participate in valued activities. Gignac and colleagues found that adults with a CDC rarely inquired about or used adaptive strategies helpful for minimizing limitations to their participation in valued activities (e.g., hobbies, socializing, travelling, outdoor activities). However, participants frequently utilized adaptive strategies to maximize their contributions in personal care, in-home mobility, community mobility, and

household activities. Participants frequently engaged in the process of selection (i.e., restricting or avoiding participation) or optimization (i.e., protecting physical and emotional reserves) in association with valued activities to maximize functioning in other activities of daily living. Consequently, it may be that adults with a CDC are more aware of, willing, and able to use adaptive strategies and resources that facilitate continued participation in activities of daily living than leisure activities.

Guerin and Dattilo (2001) proposed that when assistance is needed to participate in shared leisure in the context of a CDC, provision of therapeutic recreation (TR) services using a systemic approach might be viable. This approach could incorporate strategies to include partners during programs designed for treatment, leisure education, and recreation participation. However, little is known about (a) types of inclusive or adaptive strategies and resources currently used, (b) functional intervention, leisure education, and recreation participation needs, or (c) functional intervention, leisure education, and recreation participation services available to, known by, and utilized by couples experiencing a CDC. Consequently, this study examined perceptions of needs, challenges, and opportunities associated with shared leisure that may contribute to the research, design, and delivery of leisure services for adults with a CDC and their partners.

#### Statement of the Problem

Changes in relationship roles and responsibilities, patterns of interpersonal interaction, and socio-economic resources may affect perceptions of interpersonal loss in the context of a CDC (Williamson & Shaffer, 1996). Orthner (1975; 1976), Hill (1988), and other researchers suggested that shared leisure may be important for promoting aspects of relationship functioning such as communication, role continuity, and stability. While evidence provided by Dupuis and

Pedlar (1995), Mactavish and Schleien (1998), Voelkl (1998) and others suggests that shared leisure may promote relationship functioning in the context of a CDC, much of this evidence is based on investigations of families that include a child with a developmental disability or a senior with dementia or other cognitive impairment.

Crewe et al. (1979), DeVivo and Fine (1985), Simmons and Ball (1984) and others have demonstrated that onset or exacerbation of a CDC can be particularly detrimental for relationship functioning because it can decrease opportunities for and satisfaction with interpersonal communication, social support, and companionate activity (Lyons et al., 1995). Relationship functioning may be especially compromised for adults and their partners because CDC-related losses and limitations negatively affect their life cycle roles, expectations, and opportunities and increase the likelihood of relationship dissolution (e.g., Brown & Geisy, 1986; Randall, 1994b).

Although it appears that adults with a CDC and their partners continue to seek and create opportunities for shared leisure (e.g., Lyons et al., 1995; Rodgers & Calder, 1990), it is not clear that shared leisure is desired by, or similarly affects perceptions of interpersonal loss and relationship functioning for both partners (e.g., Bedini & Guinan, 1996a; 1996b; Larson & Richards, 1994; Rogers, 1997; Weinblatt & Navon, 1993). Although couples are able to utilize some adaptive strategies to include the adult with a CDC in leisure activities (e.g., Lyons et al., 1995), they may lack knowledge of strategies and resources that could facilitate continued participation in shared leisure (e.g., Gignac et al., 2000). Since there is ambiguity concerning these associations, this study explored the experiences of adults with a CDC and their partners regarding these issues.

### Purpose of the Study

The purpose of this study was to explore and describe associations between shared leisure, interpersonal loss, and relationship functioning from the perspective of adults with a CDC and their partners. In particular, this study was conducted to address the following questions: How do couples participate in shared leisure? What CDC-related changes do couples experience to their shared leisure? What resources (i.e., services and equipment) do couples use to participate in shared leisure? How is shared leisure associated with interpersonal loss and relationship functioning? What recommendations might be offered by adults with a CDC and their partner for leisure service providers? These questions prompted the following research objectives:

**Research Objective One:** What is the nature of shared leisure for adults with a CDC and their partners?

**Research Objective Two:** What factors shape the leisure patterns of adults with a CDC and their partners?

**Research Objective Three:** What is the influence of shared leisure on relationship functioning among couples experiencing a CDC?

### Significance of the Study

By examining issues related to shared leisure, relationship functioning, and leisure services using a relationship perspective that explores the experiences and perceptions of both adults with a CDC and their partners, this study makes theoretical and practical contributions for leisure service providers.

Theoretically, this investigation extends the relevance of communal relationships theory (e.g., Clark & Mills, 1979; 1993) to leisure-related issues in the context of a CDC. To date,

studies using communal relationships theory have focused on the mental health (e.g., anxiety, depression, resentment) of spousal caregivers (e.g., Williamson, Shaffer, & Schulz, 1998) and have suggested that interpersonal loss may be reduced through participation in valued activities such as leisure (e.g., Williamson & Shaffer, 1996; 1998). This study corroborates and provides insight into associations between shared leisure, relationship functioning, and interpersonal loss in the context of a CDC. The relevance of using communal relationships theory to explore associations between leisure experiences, interpersonal loss, and relationship functioning in the context of a CDC is demonstrated in this study. In addition, this study also adds to the literature advocating use of a relationship perspective by exploring perceptions of shared leisure from the viewpoint of both adults with a CDC and their partners.

There are also several practical implications of this study. This study provides additional insight regarding therapeutic aspects of leisure experiences in the context of a CDC, especially for interpersonal loss and relationship functioning. This study also documents adaptive strategies and resources used to participate in shared leisure in the context of a CDC, and identifies ways that couples learned about these strategies and services. This study also provides additional evidence regarding couples' perceptions of their leisure-related needs and offers recommendations for leisure service delivery. This information may assist therapeutic recreation (TR) specialists to improve delivery of services designed to have couples acquire knowledge, skills, and resources helpful for participating in shared leisure in the context of a CDC.

Information and recommendations generated from this study may assist TR specialists to develop, improve, and promote services that afford couples opportunities to become more skillful in facilitating shared leisure. Consequently, couples may derive potential benefits from shared leisure that promote healthy relationship functioning in the context of a CDC.

### Definition of Terms

Chronic disabling conditions (CDCs): non-congenital illnesses and disabilities that encompass a course that may be stable, unpredictable, and/or progressive (Lyons et al., 1995).

Communal relationships: associations in which members mutually provide benefits in response to needs, or demonstrate a general concern for another, without creating a specific debt or obligation for the recipient to respond in kind (Clark & Mills, 1993).

Relationship functioning: patterns of interpersonal interaction that promote communication, role continuity, and stability desired by adults with a CDC and their partners (e.g., Orthner, 1975; Mactavish & Schleien, 1998).

Interpersonal loss: negative evaluations of changes in the ability of one person to provide supports (e.g., emotional, financial, instrumental) that were characteristic of a relationship prior to onset or exacerbation of a CDC (Williamson & Shaffer, 1996).

Leisure: activities, behaviors, and experiences (e.g., Samdahl, 1988; Shaw, 1985) that (a) are freely chosen (e.g., Roadburg, 1983; Shaw, 1984), (b) occur during discretionary time (e.g., Kleiber, 1999; Shaw, 1986; Samdahl, 1988), (c) occur with the expectation of preferred experience, such as enjoyment (e.g., Kleiber, 1999; Shaw, 1985, Samdahl, 1991) and (d) provide one or more psychosocial benefits, such as relaxation, nurturance, creativity, catharsis, or independence (e.g., Tinsley & Eldredge, 1995) for both the adult with a CDC and their partner.

Shared leisure: infers that the leisure experience occurs for both adults with a CDC and their partners as they engage in the same activity.

## CHAPTER 2

### REVIEW OF THE LITERATURE

The purpose of this chapter is to provide an integrated review of the literature describing communal relationships and interpersonal loss, shared leisure and relationship functioning, and implications for therapeutic recreation for adults with a CDC and their partners. The chapter consists of the following sections: (a) description of the literature review strategy, (b) shared leisure in the context of a CDC, (c) complexity of leisure, (d) relevance of communal relationships to interpersonal loss, (e) relevance of shared leisure to family functioning, and (f) implications for therapeutic recreation.

#### Literature Review Strategy

The purpose of this study is to explore and describe associations between shared leisure, interpersonal loss, and relationship functioning from the perspective of adults with a CDC and their partners. In particular, this study addressed the following research objectives: What is the nature of shared leisure among couples experiencing a CDC? What factors shape leisure patterns among couples experiencing a CDC? What is the influence of shared leisure on relationship functioning among couples experiencing a CDC?

Creswell (1994; 1998) suggested that the purpose of a literature review in research using qualitative methods is not to detail technical or methodological flaws in existing research with the intent of replication or extension. Rather, the purpose of the literature review is to provide a framework for the question(s) under investigation. Accordingly, several strategies were used to identify, review, and synthesize literature relevant to this investigation.

Studies relating to interpersonal loss (e.g., Williamson & Shaffer, 1996; 1998) were initially read for this review of the literature. Reference sections of these articles helped to identify literature relevant to communal relationships theory (e.g., Clark & Mills, 1979; 1993). In addition to these articles, databases available through GALILEO (e.g., ERIC, Family Studies, Medline, PsycInfo, SocioAbs) and Web of Science were utilized to conduct a search for articles relevant to this study published between 1980 and 2004.

Phrases used in independent and combination keyword searches included:

(a) caregivers/family caregivers, (b) care-recipient/caregiver dyads, (c) communal relationships, (d) family communication, (e) family functioning, (f) family leisure, (g) stability, (h) illness/disability, (i) interpersonal loss, (j) leisure, (k) recipients of care, (l) recreation, (m) relationship functioning, (n) role continuity, (o) shared leisure, (p) spouse/partners, and (q) therapeutic recreation. A hand search of (a) *Journal of Leisure Research*, (b) *Leisure Science*, (c) *Leisure Studies*, and (d) *Therapeutic Recreation Journal* was also conducted using these keywords to guide reviews of titles and abstracts from 1975 to 2004.

#### Shared Leisure in the Context of a CDC

Numerous studies (e.g., Brown & Guisy, 1986; Crewe et al., 1979; DeVivo & Fine, 1985; Simmons & Ball, 1984) have demonstrated that onset of a CDC has detrimental effects on relationship functioning and can contribute to relationship dissolution. Furthermore, Randall (1994a; 1994b) argued that onset or exacerbation of a CDC may be especially devastating for young couples (i.e., young in age and longevity of relationship) because their relationships are usually at early stages of development. Onset or exacerbation of a CDC among young couples may create a life cycle skew where partners may be faced with making untimely decisions regarding family, children, living arrangements, and career opportunities. Additionally, couples

of any age and at any stage of their relationship may need to contend with changes in interpersonal expectations, perceptions of dependency and obligation, and willingness to forego personal aspirations to maintain the relationship. Consequently, many couples are at risk of terminating their relationships in response to negative changes in relationship functioning associated with onset or exacerbation of a CDC.

Onset of a CDC can have deleterious consequences on relationship functioning for all couples irrespective of partners' age or longevity of the relationship because of economic, social, and interpersonal losses. Evidence suggests that young couples are more likely to dissolve their relationship post-onset of a CDC than middle-aged or older adults (e.g., Crewe et al., 1979; DeVivo & Fine, 1985). However, it is also clear that relationship dissolution is higher among couples of any age whose relationship began pre-onset of a CDC than among couples in the general population (Crewe et al., 1979) or among couples who began their relationship post-onset of a CDC (Brown & Geisy, 1986; DeVivo & Fine, 1985).

Researchers (e.g., Brown & Geisy, 1985; Crewe et al., 1979; DeVivo & Fine, 1985) have suggested that couples who begin their relationship post-onset of a CDC may experience fewer relationship challenges because they are aware of associated losses and limitations prior to making a commitment to that partner. Furthermore, Gordon and Feldman (1998) suggested that middle-aged and older adults who acquire a CDC typically have stable relationships of longer duration and may be more skilled at protecting their relationship. According to Gordon and Feldman, couples in the early stages of their relationship may be less able to (a) view a CDC in the larger context of life events, (b) derive comfort in the knowledge that they have survived other challenges, and (c) devise strategies to engage in activities that promote relationship functioning.

One activity that is associated with relationship functioning is shared leisure. Studies by Orthner, (1975; 1976), Hill (1988), and Smith, Snyder, Trull, and Monsma (1988) have demonstrated that time spent together in shared leisure activities is positively associated with measures of relationship satisfaction and functioning (e.g., communication, problem-solving), especially during the first five to seven years of the union. Orthner (1975) suggested that shared leisure enhances the frequency and quality of interactions helpful for making initial adjustments that contribute to relationship stability. Hill (1988) concurred; stating that while effects of shared leisure may vary over the course of a relationship the greatest benefits accrue during the early years when the stock of shared experiences is lowest.

Unfortunately, evidence suggests that many couples have difficulty participating in shared leisure post-onset of a CDC and these difficulties are negatively associated with measures of relationship satisfaction and functioning. For example, Urey and Henggeler (1987) found that partners who reported greater marital distress post-onset of a CDC engaged in fewer leisure activities individually or as a couple than either (a) non-distressed couples experiencing a CDC, or (b) couples not experiencing a CDC. Similarly, Rodgers and Calder (1990) reported that while couples experiencing a CDC described time spent together and demonstrations of affection as "precious resources" (p. 31) but designated these areas of their relationship as problematic. Couples reported that disagreement regarding recreation and leisure time activities reduced their satisfaction with their relationship. If shared leisure is a valuable resource for couples, adults with a CDC and their partners may also find that difficulty participating in shared leisure may have particularly detrimental effects for relationship functioning.

In summary, research has demonstrated that shared leisure is viewed by couples as a valuable resource that can promote relationship functioning (Hill, 1988; Orthner, 1975; Smith et

al., 1988). Shared leisure may be especially important in the context of a CDC since relationship functioning can be protected with the exchange of affective behaviors that contribute to positive communication, role continuity, and stability (Urey & Henggeler, 1987). However, couples experiencing a CDC often find it challenging to participate in leisure activities and derive associated psychosocial benefits (Rodgers & Calder, 1990; Urey & Henggeler, 1987). These challenges may be especially difficult for adults who are less prepared for life cycle changes associated with onset or exacerbation of a CDC and less practiced at responding to threats to their relationship (Gordon & Feldman, 1998; Randall, 1994a; 1994b). Consequently, it may be important to explore how adults with a CDC and their partners participate in shared leisure and ways that shared leisure affects relationship functioning. In so doing, it may be possible to "identify characteristics of both success stories and sad tales and the way that leisure is reflected in them" (Lee, Brock, Dattilo, & Kleiber, 1993, p. 205) so that leisure service providers may be assisted in their attempts to address couples' needs.

### Complexity of Leisure

Defining leisure can be challenging since there are a variety of theoretical and methodological approaches for investigating the phenomenon (Kleiber, 1999). Research by Roadburg (1993) and lines of research by Shaw (1984; 1985; 1986) as well as by Samdahl (1988; 1991; 1992) are especially informative, since they demonstrate that when individuals provide details of their everyday lives they frequently distinguish between leisure and non-leisure activities. Additionally, a line of research by Tinsley and colleagues (e.g., Tinsley & Kass, 1978; 1979; Tinsley & Eldredge, 1995) is informative for illustrating that participation in leisure activities provides numerous psychosocial benefits that may be important for relationship functioning.

### Characteristics of Leisure Activities

Several studies (e.g., Roadburg, 1983; Shaw, 1985; Samdahl, 1988) have demonstrated that when individuals provide information concerning their participation in activities and associated experiences, they frequently distinguish between leisure and non-leisure activities and elaborate on characteristics of each. The most commonly cited characteristics of leisure activities identified in the research by these investigators included (a) discretionary (i.e., not necessary for employment, self-care, care of others, household maintenance) time, (b) free choice (i.e., perceived freedom to select activities and autonomy during participation), and (c) perception of positive emotional states (i.e., enjoyment).

For example, Roadburg (1983) investigated the association between freedom and enjoyment in relation to the classification of activities as leisure or non-leisure. Data were obtained from open-ended interviews with professional soccer players and gardeners in Great Britain, and with retired seniors residing in Canada. Among active professionals, reasons for defining activities as work included financial remuneration, dislike for the task, and perceived lack of freedom and autonomy. The most frequent reason mentioned for defining activities as work related to the fact that participants were paid. There was a strong association between payment and the definition of work, since participants indicated that payment involved obligation and need to tolerate both positive and negative role experiences. Participants also indicated that non-leisure activities were frequently less enjoyable because they involved responsibility, obligation, sacrifice, and lack of freedom and autonomy. Among retired seniors, the most frequently cited characteristics of leisure activities were also free time, lack of obligation, and enjoyment. These findings suggest that the combination of discretionary time, free choice, and enjoyment are important characteristics of leisure activities.

Shaw (1984) investigated the meaning and measurement of leisure in everyday life using data collected from a random sample (N=60) of couples from two areas of metropolitan Nova Scotia. Participants completed a 2-day time budget diary including one Sunday and one weekday. Participants later answered hour-long, structured interviews that assisted in the classification of, and distinctions among, their daily activities. Results demonstrated that while 80% of free time activities were described as leisure, some obligatory activities (e.g., eating, gardening) also received fairly high leisure ratings. Examination of perceptual dimensions of experience revealed that when activities were characterized as being both freely chosen and enjoyable they were more likely to be classified as leisure. Time spent with others performing obligatory and less freely chosen tasks (e.g., work, household chores, child care) was less frequently classified as leisure, while time spent with spouses, friends, or friends and family was most often classified as leisure. These findings provide additional support that characteristics of leisure activities include discretionary time, free choice, and enjoyment.

Shaw (1985) extended her use of the time-diary data by investigating the classification of leisure in everyday life. Results demonstrated that participants commonly classified activities as work (e.g., job, household chores, laundry) or leisure (e.g., sports, reading, social activities). Leisure activities were most often characterized as (a) occurring during discretionary time and being freely chosen, (b) enjoyable, and (c) associated with psychosocial benefits such as relaxation or independence. Shaw concluded that leisure is a meaningful concept that people use to define and classify their daily activities, and that leisure activities are usually associated with discretionary time, free choice, and enjoyment.

Shaw (1986) expanded her investigation of the ways that daily activities are classified using her time-diary data. Participants were asked to classify activities as work, leisure, or

neither work nor leisure and provide additional information about those activities classified as leisure. Of the average 7.26 hours per day reported as leisure, activities described as free time (i.e., not related to work, self-care, care of others, household maintenance) comprised 5.28 hours while those described as recreation activities comprised 3.22 hours. Free time activities included rest and relaxation, conversation, and social events. Recreation activities included cultural activities and entertainment, reading, watching television, and hobbies and crafts. Shaw noted that several activities not classified as recreation or free time were also described as leisure, and that these were typically breaks at work, gardening at home, and other activities that were characterized by greater freedom of choice and enjoyment. These data provide additional evidence that while leisure can be experienced during a variety of activities in numerous contexts, leisure activities are most often characterized as those that (a) occur during discretionary time, (b) are freely chosen, and (c) are perceived as enjoyable.

Samdahl (1988) also used time diary data to examine characteristics of leisure activities. Using the experience sampling method, data were obtained from 18 participants who completed questionnaires when randomly paged over the course of one week. Confirmatory factor analysis was used to derive the latent factor of leisure from a set of multiple indicators. Samdahl found that participants most often described activities as leisure when they reported low role constraint (i.e., little obligation), high self expression (i.e., freedom of choice), and positive affect (i.e., good humored, relaxed, comfortable). Evaluating differences between theoretical and connotative definitions of leisure, Samdahl found that role constraint and self-expression accounted for 43% of the variance in the connotative measure. Although the sample size was small and the range of activities described by participants not exhaustive, Samdahl suggested that

the connotative definition described by these participants is supportive of theoretical definitions that emphasize free choice and enjoyment as important characteristics of leisure activities.

Samdahl (1991) expanded her comparison of theoretical and connotative definitions of leisure using data from the same time diary study. Using Lisrel, Samdahl examined the extent to which a series of variables were potential causal determinants of leisure among her participants. Structural equation models were generated to evaluate the best associations between the latent concept of leisure and its potential indicators. Results demonstrated that leisure experiences were most associated with the conditions of (a) free time ( $r = .78$ ), (b) freedom of choice ( $r = .50$ ), and (c) enjoyment ( $r = .60$ ). Despite the small sample size and non-exhaustive representation of daily activities, these findings provide further evidence that free time, free choice, and enjoyment are frequently identified characteristics of leisure activities.

Samdahl (1992) used the time diary data to further examine characteristics of leisure activities. Samdahl found that activities sampled from the weekends and evening hours were more likely to be described as leisure than activities during the workweek. This was consistent with previous findings (e.g., Shaw, 1984) that activities that occur during non-work (i.e., discretionary time) were more likely to be classified as leisure. Informal social interactions, particularly at a friend's home, were also more likely to be perceived as leisure than were either formal or informal social interactions at work, inside a vehicle or store, at home, or at a park or recreation site. Recreation activities and general interactions were also more likely to be perceived as leisure than employment tasks, non-employment tasks, or personal care activities. Results also demonstrated that participants were more likely to report feeling relaxed, comfortable, and self-expressive during informal social interactions than when alone, engaged in a task, or during formal social interactions. This evidence is consistent with previous findings

that leisure is most often experienced during free time - particularly during recreation and other social activities that are freely chosen - when individuals are most able to experience enjoyment in association with their positive emotional states.

In summary, the study performed by Roadburg (1983) and the lines of research conducted by Shaw (1984; 1985; 1986) and by Samdahl (1988; 1991; 1992) support the relevance of distinguishing between leisure and non-leisure activities. The findings of these and other studies that examine individuals' participation in and perceptions of daily activities demonstrate that leisure activities are characterized as having greater choice, freedom, and potential for enjoyment. These studies also suggest that opportunities for informal interpersonal interactions with family and friends are especially valued as experiences conducive to enjoyment.

#### Psychosocial Benefits of Leisure Activities

Evidence provided by Roadburg (1983), Shaw (1984; 1985; 1986) and Samdahl (1988; 1991; 1992) suggest that characteristics of leisure activities include free choice, discretionary time, and enjoyment. Participants in these and other studies often described benefits of their involvement in leisure activities and suggested that a variety of psychosocial needs were successfully met through their participation in leisure activities. For example, Roadburg (1983) found that participants described greater independence and creativity when involved in leisure activities than work activities. In addition, Shaw (1985) found that participants described leisure activities as providing greater relaxation, comfort, and independence than non-leisure activities. Although these findings were limited, there is substantial evidence that leisure activities are uniquely suited to provide a broad variety of psychosocial benefits. A line of research conducted

by Tinsley and colleagues (e.g., Tinsley & Kass, 1977; 1978; Tinsley & Eldredge, 1995) provides considerable insight regarding the psychosocial benefits of leisure activities.

Several studies have examined the effects of participation in leisure activities and have demonstrated that there are distinctions among the psychosocial benefits achieved by participation in different leisure activities. For example, Tinsley, Barrett, and Kass (1977) examined whether different psychological needs can be met by participation in specific activities. College students ( $N = 352$ ) completed questionnaires that asked them to estimate the ability of five typical leisure activities (e.g., watching television, bicycling) to meet a taxonomy of 45 psychological needs (e.g., achievement, creativity, service). One-way ANOVAs were performed for each need dimension across the five activity groups. The authors found that six needs met or exceeded critical values ( $p < .05$ ), and were specific to the five leisure activities. Drinking and socializing provided greater satisfaction for the need for sex, while bicycling satisfied the need for catharsis. Reading and bicycling satisfied the need for independence more than other activities, while understanding was perceived to come from reading and attending plays, concerts, and lectures. The need for getting along with others and for affiliation was most satisfied by drinking and socializing. These data demonstrate that leisure activities satisfy a broad range of psychosocial needs, and that specific activities may provide unique psychosocial benefits.

Tinsley and Kass (1978) replicated and extended their original findings by using a larger repertoire of activities to evaluate the extent to which the ability of leisure activities to satisfy specific psychosocial needs was different for men ( $N = 263$ ) and women ( $N = 164$ ). Participants provided information on the extent to which their participation in 10 activities satisfied 45 psychosocial needs. A two way gender by activity ANOVA was performed for each need

dimension with the mean scale scores as the dependent variables. Results showed that no significant differences were observed among males and females ( $p < .01$ ) in the sex by activity interaction. The two-way ANOVAs yielded significant main effects of activity ( $p < .01$ ) on 33 need dimensions. Cluster analysis demonstrated that physically active (e.g., jogging, playing tennis) and intellectually oriented (e.g., playing cards, drinking and socializing) activities tended to be highly correlated. Reading books or magazines and watching television did not cluster with other activities. Physical activities satisfied needs for catharsis, independence, advancement, rewards, and ability utilization. Intellectual activities, as well as watching television and reading, satisfied needs for independence and relaxation. While there was substantial similarity between clusters to satisfy similar needs, results suggested that not all clustered activities were interchangeable in their ability to meet specific needs. Therefore, it may be that when participation in specific leisure activities is restricted, the ability to profit from associated psychosocial benefits may be reduced.

Tinsley and Kass (1979) used data from their 1978 study to further examine the ability of specific leisure activities to satisfy a variety of psychosocial needs. The need-satisfying characteristics of 10 leisure activities were examined using two independent factor analyses. The total domain of 45 psychosocial need-satisfiers was subjected to Rao's canonical factor analysis, resulting in 10 replicable common factors. The total domain of need-satisfiers was reduced to a subset of 27 needs characterized by differential satisfaction dependent on the specific activity involved. A principal components factor analysis of the 27 specific need-satisfier domains resulted in the following 8 replicable factors: self-actualization, companionship, power, compensation, security, social service, intellectual aestheticism, and autonomy. Tinsley and Kass suggested that these findings helped to understand the association between participation in

specific leisure activities and satisfaction of psychosocial needs. In particular, these data supported previous findings that while some leisure activities are able to satisfy several psychosocial needs, there are some benefits of participation that appear to be activity specific. Nonetheless, they acknowledged that future investigations would be improved by including activities such as volunteer work and other forms of public service to broaden the scope of activities clustering on the dimension of social service. Additionally, they recognized that future studies should include non-college populations and their leisure activities to investigate the association between factors such as age and social class on the need-satisfying dimensions of leisure activities.

Tinsley and Johnson (1984) also found evidence that many activities are able to provide similar psychosocial benefits, and proposed a preliminary taxonomy of leisure activities. Tinsley and Johnson surveyed college student volunteers ( $N = 923$ ) and non-college adults ( $N = 443$ ) concerning the extent to which 44 psychosocial needs were satisfied by 34 leisure activities. Ward's hierarchical grouping analysis was used, and resulted in development of nine activity clusters and eight benefit clusters. Activity clusters included intellectual stimulation, catharsis, expressive compensation, hedonistic companionship, supportive companionship, secure solitude, temporary indulgence, moderate security, and expressive aestheticism. Benefit clusters included self-expression, companionship, power, compensation, security, service, intellectual aestheticism, and solitude. The authors suggested that the validity of their taxonomy was confirmed by its consistency with previous findings. They cautioned that the number of leisure activities for which data were available was small when compared to the number of activities actually available to people. Consequently, they suggested that this taxonomy should be considered tentative and temporary. Nonetheless, these findings provide additional evidence that

people engage in leisure activities to satisfy a broad spectrum of psychosocial needs. However, it is important to note that while clustered activities may provide similar benefits, they are not interchangeable in their ability to satisfy specific needs and provide desired psychosocial benefits.

Tinsley and Eldredge (1995) expanded the original taxonomy to include 11 need-satisfying properties of leisure activities. College student (N = 2720) and non-student (N = 1049) volunteers provided data on the extent to which 11 psychosocial needs of exertion, affiliation, enhancement, expression, nurturance, compensation, sensibility, conscientiousness, status, challenge, and hedonism needs were met by participation in 82 leisure activities. Ward's hierarchical clustering analysis was used to identify subgroups of needs satisfied by specific activities. Twelve clusters of agency (e.g., bicycling), novelty (e.g., nature walks), belongingness (e.g., attending club meetings), service (e.g., visiting friends), sensual enjoyment (e.g., dining out), cognitive stimulation (e.g., reading), self-expression (e.g., crafts/hobbies), creativity (painting), competition (e.g., cards), vicarious competition (e.g., watching televised sports), relaxation (e.g., radio listening), and residual (e.g., bowling) were obtained. The authors noted that several clusters of activities assumed to be similar provided related but distinct benefits, and that specific activities such as visiting friends or vegetable gardening satisfied both hypothesized needs (e.g., affiliation, relaxation) as well as unanticipated needs (e.g., nurturance, novelty). While the list of activities and benefits included in the survey were not exhaustive, the authors suggested that these findings provided additional evidence that leisure activities can be important for providing a variety of psychosocial benefits.

In summary, studies by Tinsley and colleagues demonstrate that individuals derive a variety of psychosocial benefits (e.g., affiliation, creativity, independence, relaxation) from their

participation in leisure activities. Since many activities (e.g., sports, hobbies/crafts) are comparable in nature and provide similar psychosocial benefits, it is possible to describe them as clustered. However, there is sufficient distinction both within and between clusters of activities to suggest that activities are not completely interchangeable, and that psychosocial benefits may be most easily obtained from a varied repertoire of leisure activities.

### Definition of Leisure

Synthesizing results of studies described in the previous sections, for the purposes of this study the defining qualities of leisure can be found in the perceived context of activities, behaviors, and experiences (e.g., Samdahl, 1988; Shaw, 1985) that (a) are freely chosen (e.g., Roadburg, 1983; Shaw, 1984), (b) occur during discretionary time (e.g., Kleiber, 1999; Shaw, 1986; Samdahl, 1988), (c) occur with the expectation of preferred experience, such as enjoyment (e.g., Kleiber, 1999; Shaw, 1985, Samdahl, 1991) and (d) provide one or more psychosocial benefits, such as relaxation, nurturance, creativity, catharsis, or independence (e.g., Tinsley & Eldredge, 1995). In this study, shared leisure implies that the leisure experience occurs for both adults with a CDC and their partners as they engage in the same activity.

### Relevance of Communal Relationships to Interpersonal Loss

The definition of shared leisure proposed for this study may have implications for understanding relationship functioning and perceptions of interpersonal loss in the context of a CDC. Onset or exacerbation of a CDC may affect relationship functioning by exacerbating perceptions of social and interpersonal losses resulting from reduction in (a) discretionary time, (b) ability to engage in recreation, or (c) ability to receive affection and emotional support from friends, family, and partners (Lyons et al., 1995). Interpersonal loss stems from the negative evaluation of changes in the ability of one person to provide supports (e.g., emotional, financial,

instrumental) that were characteristic of the relationship prior to onset or exacerbation of a CDC (Williamson & Shaffer, 1996; 1998). This is particularly evident among individuals who described their relationships as being high in mutually communal behaviors prior to onset or exacerbation of a CDC (Williamson & Shaffer, 1998). Communal relationships (e.g., Clark & Mills, 1979; 1993) are those in which members interact with each other according to the norm of mutual responsiveness. That is, members offer assistance in response to needs of, or to demonstrate a general concern for another without creating a specific obligation for that person to return comparable assistance. Clark and Mills (1993) noted that mutually communal relationships provide members with a sense of security and fulfillment. When a CDC changes established and desired patterns of interaction members experience interpersonal loss. The more negatively an individual evaluates changes associated with a CDC, the more negatively a person will react to the perception of interpersonal loss (Williamson & Shaffer, 1996; 1998).

However, Williamson and Shaffer (1996) suggested that perceptions of interpersonal loss might be ameliorated when opportunities are available to replace valued aspects of the relationship (e.g., social support, enjoyable shared activity). Participation in shared leisure - one component of a history of mutually communal behaviors - may be a condition that reduces perceptions of interpersonal loss associated with a CDC. Partners may find that shared leisure lessens perceptions of interpersonal loss by reducing restriction of desired activities with the person with a CDC (Williamson & Shaffer, 1996; 1998; Williamson et al., 1998). Shared leisure may also facilitate opportunities to have affective, emotional, and esteem needs met by a desired source of social support (Lyons et al., 1995).

For the person with a CDC, ability to share leisure with a partner may also reduce perceptions of interpersonal loss by promoting continuity of normal daily activities with a

desired companion (Lyons, 1999). Parker (1993) argued that given normative emphasis on traditional role performance, and popular assumptions that disability and dependence are linked, people with a CDC may view themselves as debtors who have little opportunity to change that situation. However, shared leisure may also create opportunities for people with a CDC to be seen as a partner, friend, or companion with important personal attributes to contribute to a relationship, rather than someone always associated with being dependent (Lyons et al., 1995; Lyons & Meade, 1995).

### Shared Leisure in the Context of Communal Relationships

Partners of adults with a CDC frequently assume some or all of the responsibility of providing informal caregiving assistance to that person when he or she is unable to complete activities of daily living and/or domestic tasks (Kennedy & Wall, 1997). Partners whose prior relationships were low in communal behaviors may not have regularly or willingly interacted with that person during leisure activities. For them, ability to engage in leisure activities *separate from* the adult with a CDC and associated caregiving responsibilities may be highly restorative and reduce feelings of anxiety, depression, and resentment (e.g., Bedini & Guinan, 1996a; 1996b; Rogers, 1997). However, among people who did enjoy communal relationships, ability to participate in shared leisure with their partners to obtain valued forms of support may diminish their perceptions of interpersonal loss associated with reductions in intimacy and affection associated with their relationship (e.g., Williamson & Shaffer, 1996; 1998). Aronson (1997) found that spousal caregivers reported being most dissatisfied by interference of partners' CDCs on social/recreational activities and interpersonal relations. Aronson suggested that these losses compromised quality of life by reducing availability of positive life experiences and feelings of personal control over disruptions in relationships and role functioning.

Furthermore, the value of leisure is often attributed to opportunities for growth, personal development, and perception of mastery and control. Leisure is also valued for its ability to relax, sustain, and restore people physically, psychologically, and emotionally (Kleiber, 1999). In this sense shared leisure can be one context for experiencing "positive meaningful events" (Folkman, Moskowitz, Ozer, & Park, 1997) that encompass valued beliefs and goals appraised to be beneficial. Folkman et al. (1997) found that caregivers most frequently experienced positive meaningful events when they were engaged in conversation, social activities, or entertainment activities with others - including their partners with a CDC. Caregivers indicated that primary meanings of these interactions included connection, achievement, hope, affirmation, and respite from caregiving roles and responsibilities (Folkman et al., 1997). Additionally, Folkman (1997) found that positive meaningful events were associated with lower perceptions of distress and higher evaluations of quality of life among caregivers.

In the context of communal relationships, restriction of opportunities to offer and receive valued forms of support may be just as detrimental to the quality of life of the person with a CDC as it is to their partner (e.g., Lyons et al., 1995; Lyons & Meade, 1995). Consequently, opportunities for adults with a CDC to participate in shared leisure with partners as part of a history of communal behaviors may increase frequency of positive meaningful events that are associated with quality of life. Participation in shared leisure may also reduce perceptions of interpersonal loss by increasing frequency and quality of activities, behaviors, and experiences conducive to preferred experiences. These preferred experiences could help to improve their relationship functioning.

### Relevance of Shared Leisure to Relationship Functioning

Ability of shared leisure activities to promote relationship functioning in the context of a CDC is influenced by the structure and process of these activities. Adams (1993) suggested that participation in shared activities provides a structure (e.g., game, hobby) and/or an environment (e.g., home, park) in which people can interact. Shared leisure also provides a context in which people can engage in the behavioral, cognitive, and affective processes that influence their relationship. Behavioral processes are those actions that people do with and for others during the shared activity, such as self-disclosure, resource exchange, displays of affection, or conflict resolution. Cognitive processes are the internal thoughts that members have about themselves, other members, and relationships, such as evaluations of attractiveness, character, or similarity to self. Affective processes are the emotional reactions to members, including empathy, indifference, joy, anger, jealousy, or loyalty (Adams, 1993). Regardless of activity, shared leisure can be one context in which the "combination of free time and the expectation of preferred experience" (Kleiber, 1999, p.3) allows people to disengage from daily commitments and engage in the relational processes described by Adams (1993) in a more relaxed and responsive manner. The positive aspects related to this type of leisure-based interaction may also facilitate greater communication thereby reducing perceptions of interpersonal loss associated with CDC-related relationship changes.

#### Shared Leisure and Communication

Perceptions of interpersonal loss can stem from negative evaluations of changes in interaction associated with a CDC (Williamson & Shaffer, 1996; 1998). Among changes that occur, there is frequently a need to re-negotiate patterns of discretionary activity to accommodate losses and limitations of the person with a CDC. It may also be necessary to accommodate the

needs of partners whose roles and responsibilities have changed in response to these losses and limitations (Lyons, 1999). Consequently, onset or exacerbation of a CDC requires that couples experiment and communicate to re-establish familiar patterns of activity or develop new ones (Kleiber, 1999). Couples who regularly engage in parallel or joint leisure activities (e.g., attending a museum, playing a game) report greater levels of, and satisfaction with, interpersonal communication (e.g., Orthner, 1975; 1976; Holman & Jacquart, 1988) comprised of empathy, reflective listening, and supportive comments (Olson et al., 1989). Couples who regularly share leisure experiences also report arguing more over content, process, and timing of leisure (Hill, 1988), and discussions can become a battleground to ensure self-interests (Kleiber, 1999). However, when partners are focused on developing relationships and reconstructing patterns of leisure interaction that are communal, the need to negotiate mutually enjoyable activities requires extensive periods of positive communication.

The desire to participate in shared leisure in the context of a CDC may facilitate interactions during which partners express their expectations and engage in problem-solving initiatives regarding the process and content of those activities (Lyons et al., 1995). For example, couples may change their definitions of leisure or the types of activities in which they engage to reflect current interests, needs, and abilities. Lyons et al. (1995) found that families including a member with a CDC often described leisure in ways that were not activity-oriented but reflective of attitudes associated with a pleasurable definition of the situation and some element of discretionary time. Lyons et al. (1995) also found that changes to companionate activities were frequently made. These changes often occurred as a result of consensual strategies for adaptation, substitution, and changes in location, timing, and intensity of activities. In some instances, family members created new patterns of mutually enjoyable leisure experiences by

learning to participate in different roles, such as spectator or coach instead of player.

Successfully negotiating new definitions of leisure or new activity-based roles necessitates that partners communicate effectively to ensure that their changing needs, abilities, and preferences are recognized and accommodated.

There may also be an association between effective communication during shared leisure and non-leisure experiences. Gulick (1995) found that couples who spent less time with each other during recreation and socializing activities reported using emotion-focused coping (e.g., distancing, anger) more frequently than problem-focused coping (e.g., communication, goal setting) and also reported poorer adjustment. Gulick suggested that this might be reflective of partners' difficulty identifying and meeting their own and a partners' CDC-related needs.

Interestingly, Dupuis and Pedlar (1995) found that in the context of a CDC, shared leisure improved interpersonal understanding through enhanced communication. Participants in their study indicated they enjoyed more frequent dialogues, were more relaxed and responsive, and gained greater understanding of CDC-related losses and limitations.

Partners who report spending higher proportions of their time in shared leisure activities also report greater involvement in non-leisure activities (Orthner, 1976). It may be that communicating needs, preferences, and expectations in a leisure context establishes a precedent that affects willingness and ability to express expectations regarding non-leisure roles and responsibilities. The ability to communicate needs, preferences, and expectations regarding both leisure and non-leisure activities may enable couples to maintain patterns of mutually communal behaviors in the context of a CDC, thereby reducing perceptions of interpersonal loss.

### Shared Leisure and Role Continuity

Ability to communicate and reestablish patterns of shared leisure may have implications for role continuity in couples experiencing a CDC. Helgeson (1993) found that changes in relationship roles and responsibilities, and negative evaluations of changes in actual and perceived support were correlated with perceptions of loss and distress among partners. Kleiber et al. (1995) found that (a) loss of ability, (b) disruption of relationships, and (c) dependence on others also has implications for perceptions of interpersonal loss. Among adults with a CDC, disruption of leisure-related relationships is often more important than the loss of primary leisure skills or specific activities.

Kleiber (1999) suggested that in the face of negative life events leisure can be used as one context to reconnect with significant others in familiar and/or mutually agreed activities. Shared leisure can facilitate a sense of continuity even if it is necessary to modify activities or select alternative activities in response to CDC-related losses and limitations (Kleiber, 1999). In couples with a history of mutual demonstrations of concern for and responsiveness to each other's needs, there may be increased willingness to adjust standards used to judge contributions of a partner with a CDC (Cutrona, 1996). Consequently, leisure may be one context in which someone with a CDC can continue an established pattern of mutual communal behaviors by attending primarily to the emotional and esteem needs of a partner in spite of losses and limitations (Lyons et al., 1995).

Orthner's (1975; 1976) investigation of the importance of shared leisure for marital satisfaction supports the association between shared leisure, role continuity, and interpersonal loss. Orthner found a strong, positive relationship between engagement in joint leisure activities (i.e., activities that were high in communication and interpersonal interaction) and marital

satisfaction. He noted that it is incorrect to suggest that participation in leisure activities is the most influential variable affecting marital interaction. However, when changes in a relationship occur leisure may be one context where partners can enjoy both a sense of continuity and freedom in adopting alternate forms of behavior while remaining socially accepted in both new and old roles. Consequently, when these experiences are shared by partners, they affect the degree of understanding each has for the other (Orthner, 1975). When partners reestablish patterns of shared leisure they may create opportunities to sustain roles important to their self-identity (Samdahl, 1992). For example, the ability to be seen as a valuable, interesting, and desirable person who has important attributes to contribute to the relationship may be valued by a person with a CDC. Similarly, a partner may value opportunities to be being appraised as a person who is willing to offer and/or accept differential forms of support (Cutrona, 1996; Lyons, 1999; Lyons et al., 1995). Therefore, shared leisure might be one context where couples are able to sustain some roles characteristic of their relationships that were present prior to the onset or exacerbation of a CDC, thereby reducing perceptions of interpersonal loss.

#### Shared Leisure and Relationship Stability

The ability to participate in mutually enjoyable leisure activities that promote role continuity may also have implications for relationship stability. Olson and colleagues (1989) suggested that relationship stability is a product of relationship adaptability. That is, the short and long-term endurance and stability of a relationship is determined by the ability of members to change the relationship's power and structure base, roles, and rules in response to situational and developmental stress (Olson et al., 1989). Kleiber (1999) suggested that relationship stability might depend on members finding compatible patterns of enjoyment and mutual self-expression. However, shared leisure experiences also provide opportunities to engage in emotional bonding,

relational identification, stress management, communication, and mutual support efforts necessary to successfully respond to negative life events such as onset or exacerbation of a CDC (e.g., Lyons & Meade, 1995; Hill, 1988).

Results of several investigations (e.g., Hill, 1988; Holman & Jacquart, 1988; Orthner, 1975; 1976) suggest that shared leisure experiences provide pleasurable interactions that improve relationship stability. These interactions can improve communication, problem-solving initiatives, and emotional and relational bonds between partners (e.g., Orthner & Mancini, 1990; 1991). Other investigations have emphasized the importance of shared leisure for improving relationship stability in families experiencing a CDC. For example, Mactavish and Schleien (1998) found that in families with a child with a developmental disability shared leisure was beneficial for (a) improving interpersonal connections, (b) developing social, activity, and communication skill, (c) setting foundations for the future, and (d) reprioritizing values and life goals. Similarly, Dupuis and Pedlar (1995) found that participating in shared leisure activities improved quality of interactions and enriched relationships in families that included an adult with dementia. Additionally, Voelkl (1998) found that mean levels of happiness were highest when seniors with dementia and their family caregivers engaged in shared leisure rather than self-care or other daily tasks. Collectively, these findings suggest that enjoyable interactions during shared leisure can help to strengthen relationships and provide a context where members are brought together in a way that increases relationship stability in the context of a CDC (Dupuis & Pedlar, 1995).

There is evidence that outcomes of shared leisure (e.g., communication, role continuity, relationship stability) are not associated with a return to pre-onset leisure lifestyle but with the ability to create new leisure experiences (Lyons, 1999). Relationship stability is affected by the

ability of members to alter relationship rules and roles in response to negative life events; therefore, there may be a connection between shared leisure, communication, role continuity, and relationship stability. Communication that is influenced by and results in new patterns of shared leisure may affect members' willingness and ability to modify and/or assume new relationship roles. Members may find that these relationship roles enhance their desire and ability to (a) accommodate changing needs and abilities in the context of a CDC, and (b) negotiate mutual intentions to offer and/or accept alternative forms of support. As a result of these role changes, patterns of mutually communal behavior may be maintained and perceptions of interpersonal loss may be reduced. The willingness to change in response to losses and limitations associated with onset or exacerbation of a CDC may therefore be reflective of the adaptability of the relationship. Couples' willingness to change may also be conducive to their ability to experience positive outcomes of shared leisure such as improved interactions and enriched relationships. In this way shared leisure may be one context that facilitates both short- and long-term relationship stability.

### Summary

Literature suggests that opportunities for couples to participate in shared leisure may promote relationship functioning (Holman & Epperson, 1984; Orthner & Mancini, 1990; 1991) and reduce perceptions of interpersonal loss in the context of a CDC (Williamson & Shaffer, 1996; 1998). In particular, leisure may be one context where couples can engage in activities, behaviors, and processes (e.g., Adams, 1993; Kleiber, 1999) that promote communication (e.g., Orthner, 1975), role continuity (e.g., Orthner, 1976; Lyons et al., 1995), and relationship stability (e.g., Hill, 1988; Holman & Jacquard, 1988). However, studies that have examined outcomes of shared leisure in the context of a CDC have only examined families that include a child with a

developmental disability (e.g., Mactavish & Schleien, 1998) or a senior with dementia or other type of cognitive impairment (e.g., Dupuis & Pedlar, 1995; Voelkl, 1998). Furthermore, it is unclear whether shared leisure is desired by and similarly perceived by both partners (e.g., Bedini & Guinan, 1996a; 1996b; Rogers, 1997). An exploratory, descriptive study that investigates these issues from the perspective of adults with a CDC and their partners may enhance theoretical understanding of these associations. Additionally, such an investigation may have implications for the delivery of therapeutic (TR) services to couples seeking assistance to participate in and benefit from shared leisure in the context of a CDC.

#### Implications for Therapeutic Recreation

Therapeutic recreation (TR) is concerned with direct delivery of treatment, education, and recreation participation services to people with CDCs (Peterson & Stumbo, 2003). According to Peterson and Stumbo (2003), the purpose of TR services is to improve client functioning in areas of general health, rehabilitation goals, and leisure functioning. These services can be offered in both institutional (e.g., Dupuis & Pedlar, 1995; Skalko, 1990) and community environments (e.g., Ashton-Shaeffer, Shelton, & Johnson, 1995; Dunn & Wilhite, 1997).

Since TR can address multiple issues related to leisure functioning in a variety of contexts, using a systemic approach for the delivery of TR services may be valuable for both adults with a CDC and their partners. Guerin and Dattilo (2001) suggested that a systemic approach to TR service delivery acknowledges the importance of relationships for leisure functioning and includes family members and significant others in treatment, education, and recreation participation programs. Using a systemic approach may be especially relevant in situations where adults with a CDC and their partners may not be aware of resources and

adaptive strategies that may assist their efforts to participate in shared leisure. Couples who have knowledge and skills helpful for participating in shared leisure may perceive less interpersonal loss, and may find that relationship functioning is protected despite losses and limitations associated with onset or exacerbation of a CDC.

### Approaches to TR Service Delivery

In recent years, several models of TR have been proposed (e.g., Dattilo, Kleiber, & Williams, 1998; Widmer & Ellis, 1998) or reconceptualized (e.g., Austin, 1998; Peterson & Stumbo, 2000) to assist in the provision of leisure services. Although these models acknowledge the importance of interpersonal interaction and provide guidance for acquisition or maintenance of knowledge and skills that promote social connections (e.g., leisure education, social skills development), the primary purpose of TR interventions is to maximize ability of people with CDCs to independently engage in leisure. Independent leisure functioning may be referred to as optimal leisure lifestyle (Peterson & Stumbo, 2003), self-actualization (Austin, 1998), or self-determination (Dattilo et al., 1998). However, it is increasingly recognized that *interdependent* leisure functioning is also important for normalization and inclusion (e.g., Bedini & Henderson, 1993/94; Schleien, Fahnestock, & Miller, 2001) and is more consistent with a systemic approach to TR service delivery.

Wilhite, Keller, and Caldwell (1999) proposed a model of TR service delivery that emphasized independent leisure functioning as not always possible or desirable; instead, the authors suggested that interdependent leisure functioning allows people to interact "cooperatively with others in a self-determined manner" (p. 104) to maximize goal attainment. A key aspect of interdependent leisure functioning is ability to maintain relationships with desired sources of support and companionship - especially with a partner. Lyons (1999) suggested that

need for membership in a collective becomes of primary importance during onset or exacerbation of a CDC because support and validation received from significant others reduces negative outcomes associated with functional losses and threats to personal identity. TR services can be developed based on a systems approach that "proposes that chronic illness and disability is an interpersonal issue rather than an individual issue and that the quality of relationships (one's interpersonal world) is a key factor in curbing and adapting to loss and change" (Lyons, 1999, p.22).

There is evidence that ability to participate in shared leisure may be especially important for promoting relationship functioning in the context of a CDC. For example, Mactavish and Schleien (1998) found that parents of children with developmental disabilities reported that shared leisure (a) provided fun shared activity, (b) improved family cohesion, (c) improved communication, (d) facilitated connection with other family members, (e) promoted social and activity skill development, (f) resulted in reprioritization of life goals, and (g) improved self-perceptions to set foundations for future functioning. Shared leisure may be equally salient in adult relationships. Voelkl (1998) found that seniors with dementia who resided in the community and their family caregivers reported greater levels of happiness when interacting during leisure than during other instrumental or activities of daily living. Similarly, Dupuis and Pedlar (1995) found that family caregivers of older adults residing in an institution who jointly engaged in a structured music program identified outcomes of participation as including enhanced (a) quality of visits, (b) social support, (c) ability to manage stress, and (d) relationships with family members.

Although these findings are not conclusive, they suggest that utilization of a systems approach for delivery of TR services may have merit. As suggested by Lyons et al. (1995), many

people seek and value opportunities to sustain patterns of shared leisure and interaction that are consistent with their lifestyle prior to onset or exacerbation of a CDC. Sullivan (1996) reported that there can also be a couple effect evident in the propensity of partners to enjoy leisure activities more when they are done together. However, Orthner (1976) cautioned that the potential of shared leisure activities to provide psychosocial benefits that promote relationship functioning is only maximized when participants initiate activities of mutual interest. Urey and Hengeller (1987) suggested that a strong emphasis should be placed on assisting couples to develop mutually enjoyable activities that can enhance relationship functioning. Consequently, TR specialists may consider couples to attend recreation participation opportunities so that both can engage in and benefit from activities, behaviors, and processes conducive to shared leisure. TR specialists may also wish to consider strategies for providing therapeutic services such as leisure education to couples to facilitate opportunities for both partners to acquire knowledge and skills helpful in their attempts to participate in shared leisure.

#### Approaches to Intervention Strategies

TR specialists can use several strategies when adopting a systems approach for provision of leisure services, and research suggests that these strategies may reduce perceptions of interpersonal loss that accompany disruptions in relationship functioning associated with onset or exacerbation of a CDC. Taylor, Sylvestre, and Botschner (1998) suggested that satisfying relationships provide members multiple ways of relating to each other and allow members to successfully engage in a variety of different social situations. When all members are supported within a range of activities and options for interpersonal interaction, and are encouraged to express different aspects of self within each, all can achieve a 'textured' life. To foster opportunities to create these textured lives, TR specialists can focus on developing skills for

maintaining and improving desired relationships, since it is difficult to create new social support systems among individuals who are socially marginalized or isolated as a result of a CDC (Taylor et al., 1998).

Leisure education is intended to improve functional capacities in the areas of leisure appreciation, self-awareness, self-determination, leisure decision-making, social interaction skills, leisure activity skills, and leisure resources (Dattilo, 1999). Leisure education can be especially helpful for promoting athletic involvement by enhancing knowledge and skills necessary to participate in adaptive sports and other physical activities (Coyle et al., 1993). Leisure education may also be helpful for developing social and assertiveness skills useful for (a) obtaining information about desired activities and accessible environments, (b) clarifying important aspects of relationships to create or sustain enjoyable leisure experiences with others, and (c) learning how to anticipate and effectively respond to the negative evaluations of others (Bedini & Henderson, 1993/94; Coyle et al., 1993; Sneegas, 1989). Consequently, TR specialists may use leisure education as a facilitation technique for engaging couples in processes that may be helpful for promoting shared leisure and interpersonal interaction in the context of a CDC.

There is some evidence that leisure education is an effective facilitation technique for people with CDCs residing in the community. For example, Ashton-Shaeffer, Shelton, and Johnson (1995) found that a home-school-community leisure education program (1x/wk, 12 wks) for an adolescent with mental retardation not only increased the adolescent's self-determination, but enhanced the family's (a) communication, (b) frequency and quality of leisure interactions, and (c) desire to participate in shared leisure. Similarly, Bollin, Voelkl, and Lapidos (1998) found that a home-based leisure education program (1x/wk x 6wks) for a man with dementia and his spousal caregiver enhanced their awareness of (a) modifications that facilitate shared leisure

activities, (b) leisure resources available in their home, (c) strategies to participate in mutually enjoyable activities, and (d) enjoyment they derived from their participation in shared leisure.

Though preliminary, these findings support the merit of using TR programs to assist couples experiencing a CDC in their efforts to participate in shared leisure. In particular, these findings suggest that TR may be especially helpful in providing opportunities for couples to minimize perceptions of interpersonal loss and promote relationship functioning despite losses and limitations associated with a CDC. However, ways in which TR can promote ability to participate in shared leisure are unclear since little is known of leisure-related needs and resources of adults with a CDC and their partners.

### Leisure Needs

Onset or exacerbation of a CDC can greatly affect opportunities for leisure participation regardless of age. Barriers to leisure frequently reported include (a) lack of information regarding physical activities, (b) perceived or actual lack of leisure activity skills, (c) lack of transportation, (d) lack of physical ability, (e) concern about bladder, bowel, and self-care needs, (f) safety concerns, (g) lack of physical accessibility, and (h) concerns about personal appearance in social activities (Caldwell & Weissinger, 1994; Coyle, Shank, Kinney, & Hutchins, 1993; Dattilo, Caldwell, Lee, & Kleiber, 1998). Barriers to leisure can contribute to leisure boredom and dissatisfaction for any person with a CDC (Coyle & Kinney, 1990). However, they may be especially detrimental for couples experiencing a CDC since their ability to derive psychosocial benefits helpful for relationship functioning may be severely limited by a limited repertoire of shared leisure activities.

Hill (1988) found that both passive (e.g., playing card games, watching television) and active (e.g., outdoor activities, active sports, travel) forms of shared leisure were strongly

associated with relationship stability among couples in the early stages of their relationship. However, many people with a CDC report only sporadic participation in active forms of physical (e.g., exercise, sports) or community recreation (e.g., attending plays, concerts); passive, home-based activities (e.g., reading, playing cards, watching television, listening to music) are their most common leisure activities (Coyle & Kinney, 1990). Furthermore, despite educational, legal, and political reform many adults with a CDC are unable to identify more than 3 or 4 accessible recreational, leisure, or cultural facilities in their community (Coyle & Kinney, 1990; Coyle et al., 1993). Consequently, onset or exacerbation of a CDC may greatly diminish the ability of couples to participate in active and/or community-based leisure activities that are most beneficial to relationship functioning.

In addition to architectural barriers, many people with a CDC experience societal barriers in the form of lack of acceptance (e.g., Devine & Dattilo, 2000; Vargo, 1983) by their peers and the community at large. Bedini (2000) interviewed adults with a CDC living in the community and found that negative self-evaluations and sensitivity to the negative evaluations of others (i.e., stigma) negatively affected their choices regarding community-based leisure activities. Sometimes the attitudes, stereotypes, and prejudices of people without CDCs is a deliberate deterrent that limits opportunities for people with a CDC to participate in usual life roles and behaviors (Henderson, Bedini, & Hecht, 1994). However, these opportunities can also become limited because of the general lack of awareness around the issue of disability itself (Bedini & Henderson, 1993/94; Vargo, 1983). Adults with a CDC and their partners may find that their ability to participate in leisure activities (individually and as a couple) are most affected by their own and peers' feelings of discomfort and reluctance to address non-normative changes associated with onset or exacerbation of a CDC (Randall, 1994a; 1994b).

One goal of TR services may be to increase relational competence around illness so that individuals with and without a CDC are better able to identify and express their interpersonal expectations (Bedini & Henderson, 1993/94; Lyons, 1999). Opportunities to increase relational competence may facilitate partners' efforts to interact with each other to promote relationship functioning, and may also improve their ability to interact with peers and members of the community as they attempt to participate in leisure activities (e.g., Sneegas, 1989). Leisure service professionals may be of assistance to adults with a CDC and their partners by providing educational opportunities that enhance their social and interpersonal skills and knowledge of adaptive strategies and resources helpful for participating in leisure activities.

### Leisure Resources

Several studies (e.g., Buettner & Langrish, 1999; Carter, Nezey, Wenzel, & Foret, 1999; Gignac et al., 2000) have investigated leisure-related adaptive strategies and resources available to, used by, or needed by adults with a CDC and their family caregivers. For example, Gignac et al. (2000) found that seniors with a CDC were less likely to use adaptive strategies and resources to continue or optimize involvement in valued activities (e.g., entertaining, travel, hobbies) than other activities of daily living (e.g., chores, shopping). Similarly, Buettner and Langrish (1999) found that spousal caregivers were aware of many strategies to help their partners with dementia continue to perform activities of daily living. Spousal caregivers were less aware of, but overwhelmingly interested in learning about, strategies to keep their partners busy or provide recreation activities for them. These studies imply that there are few leisure-related adaptive strategies available to, known by, or used by couples experiencing a CDC but that there may be a need for them.

TR has been successfully used to provide assistance to people struggling to sustain leisure-based interactions with partners and other family members who have a CDC (e.g., Carter et al., 1999; Weiss & Thurn, 1990). For example, Weiss and Thurn (1990) successfully trained family members to participate in a reminiscence program with their older relatives with dementia residing in an institution. Similarly, Carter et al. (1999) designed a leisure education program offered during family support group meetings for spousal caregivers of adults with dementia residing in the community. Carter and colleagues indicated that the most beneficial components of the program included leisure awareness, resource awareness, leisure skill development, and social skills training. These components included information relevant to spousal caregivers' attempts to incorporate leisure into both their daily routines and their partner's daily routines.

While these programs were modestly successful, they were specifically intended to provide services either *for* the caregiver (e.g., Carter et al., 1999) or *for* the adult with a CDC (e.g., Weiss & Thurn, 1990). The purpose of these programs was not to provide participants with knowledge, skills, and resources helpful for identifying and creating opportunities for *shared* leisure experiences that were desired and valued by both partners. Additionally, these programs were specifically interested in addressing leisure-related needs, challenges, and opportunities relevant to couples that included a senior with a cognitive impairment. Little is known of leisure-related needs, challenges, and opportunities in couples that include a partner with other types of CDCs such as arthritis, cancer, heart disease, or multiple sclerosis (Parker, 1993; Weiss & Thurn, 1990). Furthermore, little is known of the leisure-related needs, challenges, and opportunities of couples at early stages of their relationship. Consequently, the role that TR might play in the lives of adults with a CDC and their partners remains unclear.

Despite ambiguity regarding types of TR services that may be helpful for adults with a CDC and their partners, suggestions offered by service providers working with families that include adolescents with psychiatric disorders may be helpful. For example, DeSalvatore (1989) suggested that leisure-education programs focusing on members' knowledge, skills, and resources can be a valuable approach to service delivery. DeSalvatore suggested that it is important to integrate family members and significant others into the daily routine of the person with a CDC. Important components of a leisure education program using a systemic approach included participation by family members and significant others in treatment activities and therapeutic home visits.

Suggestions offered by Malkin, Phillips, and Chumbler (1991) for an interdisciplinary family leisure education program for adolescents in an inpatient substance abuse program might also be helpful. Leisure education sessions were based on dysfunctional aspects of codependent family systems, and emphasized communication styles, parenting styles, values clarification, and role-playing. Components of the program included (a) benefits and barriers to family leisure, (b) assessment of family leisure preferences, (c) trust-building and communication activities, (d) family leisure needs assessment, and (e) activity skill development. While the authors acknowledged that the program was designed to target needs of families with adolescents in treatment for substance abuse, they suggested that a systemic approach to TR interventions could promote relationship functioning regardless of clinical diagnosis.

### Summary

One purpose of TR may be to facilitate opportunities for couples to acquire knowledge and skills helpful to sustain leisure functioning (e.g., Bollin et al., 1998; Carter et al., 1999). Programs that include both adults with a CDC and their partners may assist both to become more

aware of their leisure-related needs. Such programs may also increase couples' awareness of resources and opportunities helpful in their attempts to participate in shared leisure (e.g., Carter et al., 1999; Weiss & Thurn, 1990). A continuation of patterns of shared leisure that are consistent with lifestyles prior to onset or exacerbation of a CDC may reduce perceptions of interpersonal loss by sustaining interactions during which members benefit from receiving valued forms of support (Williamson & Shaffer, 1996; 1998). These interactions may also contribute to communication, role continuity, and stability helpful for promoting positive relationship functioning in the context of a CDC (Dupuis & Pedlar, 1995; Hill, 1988; Mactavish & Schleien, 1998; Orthner & Mancini, 1990).

There is evidence that couples seek (Lyons et al., 1995) and value (Voelkl, 1998) opportunities to participate in shared leisure in the context of a CDC. There is also evidence that they are interested in learning about and acquiring knowledge, skills, and resources helpful for participating in shared leisure (e.g., Bollin et al., 1998; Carter et al., 1999; Dupuis & Pedlar, 1995; Weiss & Thurn, 1990). However, TR programs that have utilized a systemic approach have either addressed leisure-related needs in the context of a cognitive impairment (e.g., Bollin et al., 1998, Carter et al., 1999; Dupuis & Pedlar, 1995) or a psychiatric disorders (e.g., Ashton-Shaeffer et al., 1995; DeSalvatore, 1989; Malkin et al., 1991).

Clarification is needed regarding leisure-related resources for couples who experience losses and limitations associated with other types of CDCs such as arthritis, cancer, heart disease, and multiple sclerosis. Consequently, an exploratory study that includes perspectives of both adults with a CDC and their partners may be helpful. In particular, couples' recommendations regarding leisure service delivery may be valuable. TR specialists may benefit from this information in their efforts to design and implement leisure education and recreation

participation programs that address leisure-related needs, resources, and opportunities of adults with a CDC and their partners.

Therefore, the purpose of this study is to explore and describe associations between shared leisure, interpersonal loss, and relationship functioning from the perspective of adults with a CDC and their partners. Review of the literature led to the general questions such as: How do couples participate in shared leisure? What CDC-related changes do couples experience to their shared leisure? What resources (i.e., services and equipment) do couples use to participate in shared leisure? How is shared leisure associated with interpersonal loss and relationship functioning? What recommendations are offered by adults with a CDC and their partner for leisure service providers? These general questions prompted the following research objectives:

***Research Objective One:*** What is the nature of shared leisure for adults with a CDC and their partners?

***Research Objective Two:*** What factors shape the leisure patterns of adults with a CDC and their partners?

***Research Objective Three:*** What is the influence of shared leisure on relationship functioning among couples experiencing a CDC?

## CHAPTER 3

### RESEARCH METHODS

The purpose of this study is to explore and describe perceptions of (a) nature of shared leisure, (b) factors that shape leisure patterns, and (c) influence of shared leisure on relationship functioning from the perspective of adults with a CDC and their partners.

Since little is known about these issues, an exploratory study using a naturalistic perspective may be particularly helpful for fostering initial understanding. A naturalistic perspective assumes an ontological position of relativism that presumes that realities "exist in the form of multiple mental constructions that are socially and experientially based, local and specific, and dependent for their form and content on the persons who hold them" (Bullock, 1993, p. 28). Since perceptions, interpretations, and reactions to illness or disability are specific to the individual (e.g., Frank, 1995; Kleinman, 1988), a naturalistic perspective may be especially helpful for exploring relevance of shared leisure to interpersonal loss and relationship functioning among adults with CDCs and their partners. A naturalistic perspective may also be helpful in eliciting participants' perceptions of, and recommendations for, the design and delivery of leisure services for adults with a CDC and their partners.

Additionally, qualitative designs using a naturalistic perspective are frequently used to (a) clarify and understand phenomena and situations when it is difficult to identify pre-defined operative variables, (b) discover new or alternative approaches for examining frequently studied issues, (c) understand participants' perceptions of an experience, and (d) generate working

hypotheses that may be used to build theory and/or develop research questions that may later be tested empirically (Merriam, 1995).

### Research Method

The method of data collection to be used in this study is in-depth interviewing. Henderson (1991) suggested that in-depth interviewing is a useful method for exploring issues related to the meaning and relevance of leisure in people's lives. Use of this method to explore issues related to leisure in the context of illness or disability has also been supported (e.g., Bullock, 1988; Dattilo, McCormick, & Scott, 1991). In-depth interviewing has been successfully used to investigate leisure-related issues among adults with a CDC (e.g., Bedini, 2000; Charmaz, 1990) and their partners (e.g., Bedini & Guinan, 1996a; 1996b; Rogers, 1997; Weinblatt & Navon, 1993). In-depth interviewing has also been used by several researchers who specialize in the design, implementation, and delivery of TR services to individuals with CDCs and their family caregivers (e.g., Bedini & Phoenix, 1999; Bullock & Howe, 1991; Mactavish & Schleien, 1998).

Marshall and Rossman (1995) suggested that one of the strengths of in-depth interviews is that they can vary in terms of a priori structure and in the latitude the interviewee has in responding to questions. Although the process of interviewing can be highly systematic to promote consistency in the general topics addressed by participants, each participant's perspective on the phenomenon of interest can be respected and described as that individual views the issue(s) or association(s) being explored. Bryman (1988) specified the merits of in-depth interviewing as enhancing researchers' ability to (a) understand and present actions, events, values, and attitudes from the perspective and using the language of participants, (b) provide detailed descriptions of participants' social settings and environments, thereby facilitating

understanding of particular contexts and their influence on participants' process of interpretation, (c) understand events and behaviors being explored in their context and in relation to participants' environment, (d) examine longitudinal, processual development and unfolding of social life and how interlocking events may affect perceptions and behavior, (e) use sensitizing concepts rather than pre-ordained conceptual frameworks that provide a general backdrop and establish signposts to facilitate inquiry, but which do not necessitate establishment of absolute realities or creation of 'truths,' and (f) become aware of important issues not previously considered or discover the irrelevancy of issues and associations previously considered to be important.

Marshall and Rossman (1995) also suggested that use of naturalistic methods such as in-depth interviews can allow researchers to engage in direct contact with multiple members of a targeted group and elicit responses that can be immediately followed up and clarified. They suggested this might generate responses that are sufficiently unique, broad, and deep to facilitate researchers' attempts to gain insight and describe the meaning(s) people hold for their everyday lives.

#### Data Collection

The purpose of this study is to explore and describe perceptions of (a) nature of shared leisure, (b) factors that shape leisure patterns, and (c) influence of shared leisure on relationship functioning from the perspective of adults with a CDC and their partners. It has been suggested that when little is known about a phenomenon and the purpose is not specifically to generate theory, a useful strategy may be to conduct lengthy interviews with 15-20 people (e.g., Cresswell, 1998; Marshall & Rossman, 1985; Morse & Field, 1998). This may facilitate both general descriptions of the phenomena being investigated as well as development of preliminary

associations. These preliminary associations may be further investigated to develop theoretical models that are grounded in data from the field (Cresswell, 1998).

### Sample Selection

When little is known about a phenomenon and the purpose is not specifically to generate theory, a useful strategy may be to conduct lengthy interviews with 15-20 people (Creswell, 1998; Marshall & Rossman, 1985; Morse & Field, 1998). Gathering data from a sample of this size may facilitate both general descriptions of the phenomena being investigated as well as development of preliminary associations. These preliminary associations may be further investigated to develop theoretical models that are grounded in data from the field (Creswell, 1998). Therefore, in this study, eight dyads consisting of adults with a CDC and their partners were recruited for participation (N = 16). Participants responded to in-depth interviews lasting approximately 60-90 minutes. Although the sample was initially limited to young adults (i.e., aged 18-40 years) to enhance understanding of the influence of onset or exacerbation of a CDC among young couples, recruitment difficulties led the researcher to expand the age for eligibility. Upon revision, participants met the following criteria: (a) aged 18 to 60 years, (b) knew about one partner's CDC for a minimum of one year, and (c) not obviously impaired by cognitive deficits or diagnosed with a primary psychiatric disorder.

To find a convenience sample of participants who met established criteria and also represented couples experiencing several types CDCs, the researcher contacted representatives of Athens area research and support groups that were attended by adults with a CDC (see APPENDIX A). The researcher attended several support group meetings to introduce herself, describe the purpose of the research project, and solicit names and contact information of potential interviewees. One facilitator provided the researcher with a membership list and contact

information of a chronic fatigue support group. Four other facilitators were unwilling to provide membership lists but agreed to include the notice of participation (see APPENDIX B) in their newsletters. One facilitator was unwilling to provide a membership list but called several members of the support group to inform them of the study herself. Of the fifty adults with a CDC with whom the researcher had face-to-face or telephone contact who indicated they might be interested, only four adults with a CDC and their partner agreed to be interviewed. An additional three couples who were known to the researcher prior to beginning the study agreed to be interviewed for the study. One other couple who the researcher encountered as part of a graduate level class also agreed to be interviewed. In total, eight couples agreed to participate; couples were equally divided between those for whom onset of the CDC occurred prior to ( $n = 4$ ) or during ( $n = 4$ ) their relationship.

### Collection Procedures

Sixteen interviews were conducted between January and April 2002. Each interview was audiotaped and lasted approximately sixty minutes. Interviews were conducted in participants' homes ( $n = 5$ ), office ( $n = 2$ ), or mutually agreed location such as library or restaurant ( $n = 8$ ); due to travel restrictions and scheduling conflicts, one interview was conducted via telephone. Interviews were conducted using an interview guide (see APPENDIX C) designed to (a) address similar material across participants, and (b) observe nuances in individual experiences and perspectives. The researcher developed the initial interview guide with input from her doctoral advisor and Doctoral Advisory Committee. Semi-structured interviews provided participants with the flexibility to expand on unique ideas and experiences because they are not required to respond to an established order of questioning (Marshall & Rossman, 1995). Contact summary forms (see APPENDIX D) were used to document researcher thoughts and perceptions upon

completion of an interview, augment information obtained from interviews, and modify probes used throughout the interview process. Emerging themes and issues of importance not included in the original guide were added as probes (i.e., short supplementary questions designed to prompt additional commentary) throughout the process of data collection to reflect important constructs not initially considered by the research team (e.g., Glaser & Strauss, 1967; LeCompte & Preissle, 1993; Strauss & Corbin, 1998).

### Ethical Considerations

To ensure the ethical soundness of the study, a number of measures were used. Prior to collecting data, approval was obtained through the appropriate Institutional Review Board of Human Subjects at The University of Georgia. To ensure their willing participation, participants were required to sign consent forms (see APPENDIX E) that detail (a) the purpose of the study, (b) how the study will be conducted, (c) requirements of participation, and (d) voluntary and confidential nature of participation. To ensure that participants' right to privacy is maintained, all written documents completed by participants or the researcher were placed in a binder, coded, and stored in a locked filing cabinet in the researcher's home. All participants were identified by a pseudonym to conceal their true identity. All audiotaped interviews were stored in a locked cabinet in the researcher's home, and will be erased within two years to permit subsequent analysis and presentation of findings.

To ensure participant confidentiality the data management process suggested by Kirby and McKenna (1989) was employed. Four files were created to house information concerning (a) participants' true identities and contact information, as well as their pseudonyms, (b) audiotapes prior to transcription, (c) all original documents and transcriptions from which copies will be made, and (d) contact summary forms detailing questions, concerns, and

observations about interactions with participants and recommendations for subsequent interactions. These four files will be stored in a locked filing cabinet in the researcher's home.

### Data Analysis

The constant comparison method of data analysis developed by Glaser and Strauss (1967) was used to generate some initial categories and subcategories that represented phenomena described by participants. Constant comparison is an inductive procedure whereby particular incidents (e.g., words, phrases, quotes) from data sets are compared with other incidents in the same data set or another set. As incidents are identified as exhibiting similar properties, they may be grouped together as categories that can then be compared. Comparisons are constantly made within and between categories until conceptual links and associations can be proposed (Merriam, 1998; Strauss & Corbin, 1998).

Analysis was conducted through coding of transcribed interviews to identify categories and subcategories that may assist in developing a conceptual model. According to Merriam (1998), categories are conceptual elements (i.e., categories) that represent many individual examples of a phenomenon found in the data; that is, they are the answers to the research question(s). Categories are composed of subcategories (i.e., properties) that represent multiple perspectives or dimensions of experience concerning a phenomenon (Creswell, 1998). A conceptual model is a diagram depicting proposed interaction(s) or association(s) among the categories and subcategories. Conceptual models can be helpful for extending the level of data analysis and developing a theory that explains some aspect of a phenomenon and permits inferences to be made about similar phenomena under similar conditions (Merriam, 1998).

Coding is the process of identifying and naming categories and related subcategories according to the specific properties they exhibit (Glaser & Strauss, 1967). Coding is a valuable

analytic tool because it allows the researcher to (a) follow up on questions generated by data analysis, (b) separate data, (c) examine dimensions of data, (d) examine associations observed in data, and (e) achieve conceptual density (Strauss, 1987; Strauss & Corbin, 1998). The "coding paradigm" described by Strauss (1987, p. 27) can be helpful to discern (a) conditions, (b) interactions, (c) strategies and tactics, and (d) consequences of experience identified by participants. Use of this paradigm can assist researchers' to determine relevance of categories, subcategories, and interactions identified during the processes of open and focused coding.

Open Coding. Open coding is one analytic process designed to allow the researcher to discover categories in the data (Strauss & Corbin, 1998). According to Strauss and Corbin (1998), open coding is the process of opening up the text to expose thoughts, meanings, and ideas embedded in participants' remarks. During open coding, data are divided into discrete incidents, closely examined, and compared for similarities and differences. Events, happenings, objects, and actions or interactions found to be conceptually similar or related in meaning can then be grouped together and labeled in more abstract explanatory terms known as categories. Rather than attempting to provide answers or develop specific associations between categories, the purpose of open coding is to generate concepts and identify additional questions that may facilitate further inquiry (Strauss, 1987).

The purpose of focused coding is to (a) facilitate understanding of ways that categories relate to each other, and (b) develop subcategories illustrating specific properties of these categories (Merriam, 1998). Subcategories assist in the explanation of categories by answering questions (e.g., when, where, why, who, how) about phenomena described by participants and labeled by the researcher (Strauss & Corbin, 1998). Focused coding allows the researcher to utilize a limited set of codes across all data to examine and compare conditions, consequences,

and associations related to these specific sets of codes (Strauss & Corbin, 1998). Making comparisons across all data facilitates observation of associations between categories and subcategories, and can be helpful for the development of conceptual models.

For this study, the data set consisted of sixteen interview transcriptions; transcripts ranged from 22 to 45 pages in length. The researcher read each transcript twice during the process of open coding, during which the researcher underlined and highlighted words and phrases in the body of the text and marked in-vivo codes in the margins. As incidents were identified that seemed to correspond to research questions, the researcher wrote words and phrases on a separate sheet of paper that seemed to exemplify emerging categories.

Focused Coding. Techniques used during the process of open coding were replicated during focused coding. Using the keywords and phrases identified during open coding, specific codes were established as initial codes were revised to reflect similarities and differences observed in participants' responses. Specific incidents were bracketed and corresponding codes were written in the opposite margin to distinguish them for potential inclusion in a preliminary conceptual model. Each incident associated with a specific code was then compared and contrasted with all other incidents in that group; this process permitted similarities and differences to be observed and associated aspects of experience. Specifically, the researcher observed that each of the categories could be "dichotomized" into subcategories. The scope of analysis was narrowed further and a simple charting method was used to assist in identifying specific characteristics of each subcategory. Guidelines described by Merriam (1998) were used to evaluate categories and subcategories derived during focused coding. Merriam suggested that categories derived from the constant comparative method of analysis should be (a) reflective of the purpose of the research, (b) exhaustive, (c) mutually exclusive, (d) conceptually congruent,

and (e) sensitizing (i.e., fully descriptive of the meaning of the phenomenon observed in the data).

To further facilitate data analysis, the researcher re-formatted transcriptions to adhere to a 3 x 5 formula; transcripts were read through a third time, and important incidents, sentences, or paragraphs were identified, cut from the transcript page, and pasted onto index cards. Information stemming from interviews with partners with a CDC was pasted onto colored index cards while those stemming from partners without a CDC were pasted onto white index cards. Index cards from specific couples were then collated and inserted into index card binders. This process facilitated the researcher's attempts to continue the process of open and focused coding by temporarily removing potentially irrelevant content from the analytic process. As emerging categories and subcategories were re-confirmed using this process, the researcher developed outlines and participant quote files to illustrate the array of evidence to support emerging associations and arguments. However, during the writing process the researcher began to note that evidence used to support specific ideas could be used in conjunction with developing themes; as this occurred the researcher began to use a colored-tab system to identify the complex and sometimes overlapping nature of participants' comments.

Memoing. Memoing was used simultaneously with coding as a method of data analysis. Memos are a record of thoughts, musings, speculations, and hunches formed during the analytic process (Merriam, 1998). Theoretical memos were used to document, link, and compare emerging categories and subcategories generated during the processes of open and focused coding. Methodological memos were used to document questions, concerns, and observations regarding data collection and analytic procedures conducted throughout the study. Memos were

included as part of the re-formatted 3 x 5 transcriptions; blue ink was used to distinguish methodological issues from theoretical issues that were written in black ink.

### Rigor

To increase confidence in results of qualitative research, it is necessary to provide an accounting of the validity and reliability of procedures used during collection, analysis, and reporting of data (Merriam, 1998). Validity in naturalistic inquiry relates to the congruency of reported findings with the reality and meanings intended by participants, while reliability refers to the extent that research findings can be replicated or generalized beyond the experience of the study's participants (Guba, 1981; Strauss & Corbin, 1998). Merriam (1998) suggested that several strategies can greatly enhance validity and reliability throughout the process of data collection, analysis, and reporting. This study utilized Merriam's recommended strategies of (a) triangulation, (b) member checks, (c) peer examination, (d) audit trails, and (e) multi-site design

Triangulation is the strategy of using multiple (a) investigators, (b) sources of data, and (c) methods to confirm emerging findings (Merriam, 1998). Through triangulation, the researcher can promote greater internal validity and strengthen the accuracy of conclusions by reviewing data collected from different sources and determining whether similar results are observed (LeCompte & Preissle, 1993; Merriam, 1998). Triangulation is also helpful in reducing researcher biases and strengthening clarity, scope, and density of categories and associations developed from the data (Glaser & Strauss, 1967; Strauss & Corbin, 1998). In this study, triangulation was demonstrated by utilizing multiple sources of data and multiple analysts. Sources of data included (a) transcripts of interviews, (b) contact summary forms, and (c) theoretical and methodological memos.

Though the researcher was primarily responsible for data analysis, peer examination was provided by her doctoral advisor throughout the processes of coding, identifying categories, and presenting findings. Additional feedback was obtained from all other committee members, who reviewed initial reports of findings and offered feedback regarding codes, categories, and presentation of findings to arrive at pooled judgement (Merriam, 1998).

Conducting member checks involves taking data and tentative interpretations back to participants and asking them to confirm findings and associations described by the researcher (Merriam, 1998). In this study, member checks were conducted with four participants who declined to engage in a follow-up interview but agreed to review a preliminary draft of findings. Participants agreed with the researcher's identification and presentation of categories and subcategories. Several participants also suggested that they agreed with perceptions offered by other participants and wished they had included those comments within their interview as well.

The reliability of qualitative research is enhanced when findings are dependable and consistent (Guba, 1981). An audit trail is the systematic recording of all procedures used made during the processes of data collection, analysis, and reporting (Merriam, 1998) so that an outside source can verify and validate decisions made regarding identification of themes and categories and development of conceptual models. In-depth details of methods utilized during this study will be provided for the purpose of possible research replication. The audit trail will consist of (a) coded transcripts, (b) memos, (c) and contact summary sheets documenting emerging issues or probes and ways in which decisions were made throughout the research process.

One strategy to improve reliability of research findings is to use several cases or situations that maximize diversity in the phenomenon of interest (Merriam, 1998). This strategy

can also enhance generalizability of findings, since it may be possible for readers to apply results to a broad range of similar situations (Merriam, 1998). In this study, an attempt was made to recruit adults with a CDC and their partners from several educational, recreational, and support group environments. This strategy may facilitate recruitment of volunteers who represent some diversity with respect to (a) age, (b) type of CDC, (c) length of relationship, and (d) gender of the partner with a CDC. Reliability and generalizability of findings may be enhanced if findings are observed to be similar across multiple cases or situations.

#### Researcher Assumptions

There are several ways that my demographic characteristics, personal experiences and priorities, and background as a TR specialist may affect the assumptions I brought to this study.

As a result of my demographic characteristics I may have assumed that the experience of living with a CDC in the United States is similar to that of adults in other countries. As a Caucasian international student from Canada I may have assumed that the health, social, and leisure resources known by and available to these American participants were similar to those with which I am most familiar. However, since the majority of participants did not describe in detail their experience with existing health, leisure, and social service agencies it was relatively easy for me to attend carefully to the strategies and resources actually described by participants.

As a result of my changing status as a single to a married woman during the process of developing the study proposal, data collection and analysis, and eventual completion and defense of my dissertation, I may have listened to and reflected upon the stories and experiences related by my participants differently than another researcher. In particular, since I came to this study with a strong relationship focus in both my professional and private life, I may have been tempted to listen more empathetically and give greater attention to participants who identified

their relationships with a partner as being especially important. Since I understood this to be a potential area of bias for myself, I attempted to bracket my assumptions by (a) using in-vivo coding to use participants own thoughts and words that guided the development of categories, (b) including emerging thoughts and interpretations as theoretical memos, and (c) comparing the content of these theoretical memos with ideas and findings of previous studies to evaluate whether emerging findings seemed consistent with or complementary to existing literature.

As a result of my professional training and experience I assume that leisure is good and that (a) every person needs, wants, and deserves leisure, (b) most people with CDCs experience barriers to full and satisfying leisure, and (c) most people with CDCs experience more frequent, severe, or lasting barriers to satisfying leisure than their peers without CDCs (Peterson & Stumbo, 2003). Consequently, I believe that it is important to investigate ways that providing therapeutic and educational leisure services can enhance the leisure lifestyle of people with CDCs.

As a result of my professional training and experience I also assume that adults with CDCs and their partners want to participate in shared leisure but they are often not well informed about (a) alternative activities, (b) strategies and equipment available to modify or adapt activities, or (c) educational opportunities helpful for developing new leisure interests and acquiring new leisure and interpersonal skills. I have worked with or encountered numerous people who have indicated that their relationships have been negatively affected by their own or their partner's CDC. Descriptions of their lives have suggested to me that they experience substantial challenges in their ability to participate in shared leisure. Their dissatisfaction with their lack of shared leisure and frustration with their inability to obtain assistance may be one

factor that detracts from relationship functioning and contributes to their perceptions of interpersonal loss.

This study is based on assumptions that participants' responses to interview questions were truthful, and reflected an honest representation of their experiences of shared leisure in the context of a CDC. This study is also based on the assumption that I, as the person responsible for the analytic process and narrative report present findings in a thorough and accurate manner that is consistent with the honest representations provided by participants.

## CHAPTER 4

## FINDINGS

Table 1. Overview of Participant Dyads

<b>Post-Onset Couples</b>	<b>Pre-Onset Couples</b>
<p>Caroline is 25 years; Steve is 26 years            Caroline has: Fibromyalgia; known for 11 years            Relationship: 2 years            Employment: Both are Graduate students            Earned degree: Both have a Master's degree            Recruitment: known prior to study</p>	<p>Lisa is 52 years; Randall is 52 years            Lisa has: Chronic Fatigue Immune Dysfunction Syndrome; known for 15 years            Relationship: 36 years            Employment: Lisa is a retired school psychologist; Randall is a Full Professor            Earned degree: Lisa has a Master's degree; Randall has a Ph.D.            Recruitment: support group</p>
<p>Patty is 34 years; Lillian is 49 years            Patty has: Atrial Sceptal Defect and Cardiomyopathy; known for 12 years            Relationship: 2.5 years            Employment: Patty is a Graduate student; Lillian is an Associate Professor            Earned degree: Patty has a Master's degree; Lillian has a Ph.D.            Recruitment: known prior to study</p>	<p>Christine is 57 years; Jeff is 63 years            Christine has: Chronic Fatigue Immune Dysfunction Syndrome and Fibromyalgia; known for 3 years            Relationship: 33 years            Employment: Christine is a semi-retired historian; Jeff is an Associate Professor            Earned degree: Christine has a Master's degree; Jeff has a Ph.D.            Recruitment: support group</p>
<p>Kate is 32 years; Matthew is 35 years            Kate has: Degenerative Disk Disease; known for 13 years            Relationship: 3 years            Employment: Kate is a Graduate student; Matthew is a policeman            Earned degree: Both have a Bachelor's degree            Recruitment: met in a class during study</p>	<p>Sarah is 49 years; Bob is 56 years            Sarah has: Crohn's Disease; known for 2 years            Relationship: 4 years            Employment: Sarah is a retired bank executive; Bob is a semi-retired corporate executive            Earned degree: both have a Bachelor's degree            Recruitment: support group</p>
<p>Cynthia is 44 years; Walter is 47 years            Cynthia has: Multiple Sclerosis, known for 24 years            Relationship: 23 years            Employment: Cynthia is a retired multicultural counselor; Walter is a Full Professor            Earned degree: Cynthia has a Master's degree; Walter has a Ph.D.            Recruitment: known prior to study</p>	<p>Andrea is 47 years; Tim is 60 years            Andrea has: Chronic Fatigue Immune Dysfunction Syndrome; known for 3 years            Relationship: 17 years            Employment: Andrea is a writer; Tim is a Full Professor            Earned degree: Andrea has a Master's degree; Tim has a Ph.D.            Recruitment: support group</p>

### Participant Dyad Descriptions

The following are brief descriptions of the eight couples who agreed to be interviewed for this study. Demographic information such as age, occupation, type of and length of time since diagnosis, and duration of relationship is included to enhance readers' understanding of some factors that may be relevant to couples' opportunities for and participation in shared leisure.

#### Post-onset couples

Four Caucasian couples were interviewed who described their relationship as beginning post-onset of one partner's CDC. Diagnoses included fibromyalgia, atrial septal defect (ASD) and cardiomyopathy, multiple sclerosis (MS), and degenerative disk disease (DDD). Three of the four couples were comprised of at least one partner under the age of forty. In all cases the CDC had been diagnosed at least eleven years prior to the date of the interview.

Caroline and Steve. Caroline is a 25-year-old graduate student diagnosed with fibromyalgia in 1990. Her husband Steve, aged 26 years, is also a graduate student at the same university. They have known each other since 1995 and been married for a little over two years at the time of interview. Caroline and Steve both identified severe joint and muscle pain and chronic fatigue as the main manifestations of Caroline's CDC. Shared leisure activities include frequenting flea and farmer's markets, attending concerts and cultural events, socializing with friends, and reading to each other. Both recognize that the fluctuations in Caroline's CDC-related symptoms and mutual school-related obligations resulted in limited time and financial resources that negatively affected their joint participation in many activities. Additionally, both Caroline and Steve suggest that differences in the way they prioritize and attempt to incorporate leisure into their routine occasionally results in misunderstandings and stressful situations.

Patty and Lillian. Patty is a 34-year-old graduate student who has recently moved away from a neighboring state and from her partner (Lillian) of 2.5 years to attend graduate school. Lillian, aged 49 years, is an associate professor at the university where Patty had previously been employed. Patty's dual diagnoses of ASD and cardiomyopathy were identified in 1989 and 1995 respectively, but Patty has experienced several bouts of profound recovery and rapid deterioration since that time. At the time of the interview, Patty's health was improving after a recent period of six months during which she has been experiencing heart failure. Both Patty and Lillian identify common CDC-related symptoms as including cardiac arrhythmia, lack of oxygenation of the blood, edema, extreme shortness of breath, and chronic fatigue. Lillian also suggests that Patty can also become cognitively impaired with respect to decision-making skills and proactive healthy behavior (e.g., ensuring proper nutrition and sufficient rest). Both Patty and Lillian identify hiking, playing pool, watching movies, listening to music, and playing board games as activities they enjoy doing together. In addition to challenges posed by differences in age and the difficulty of sustaining a long-distance relationship, Patty and Lillian also suggest that fluctuations in Patty's health occasionally contribute to some frustration in leisure. In particular, Patty suggests that during periods of better health there is a mismatch between her preferences regarding the frequency and intensity of participation in physical activities and Lillian's preferences for participation in sedentary activities.

Kate and Matthew. Kate is a 32-year-old woman who has just begun a graduate program to become a social worker at the time of interview. Her husband Matthew, aged 35 years, is a policeman for a local metropolitan area but hopes to begin studying law at a state university. Kate and Matthew have known each other since 1990, began dating in 1994, and have been married for three years. Kate indicated that although she has been having back problems since

she was fourteen, she was diagnosed with DDD in 1988. In 1997, at age 27, Kate suffered additional physical trauma that nearly left her paralyzed; after a year of rehabilitation she regained muscle strength and mobility. Common manifestations of Kate's CDC include chronic lumbar pain, incapacitating spinal headaches, and fatigue resulting from lack of sleep due to inability to "get comfortable." Though both Kate and Matthew indicate a strong preference for sports and other physical activities (e.g., bowling, softball) they most often participate in sedentary activities such as watching TV and movies, shopping, eating out and socializing with friends. While Kate and Matthew have recently begun playing darts to expand their leisure repertoire, both describe some disappointment regarding restricted participation in physical activities imposed by Kate's CDC.

Cynthia and Walter. Cynthia is a 45-year-old woman who was diagnosed with MS in 1977, a year before meeting her husband Walter, aged 47 years; they have been married for 23 years at the time of interview. Cynthia worked as a multicultural counselor for several years before terminating formal employment due to the relapsing-remitting nature of her CDC; Walter is a professor and has recently been elected head of his department at a local university. Cynthia and Walter have one son, Chris, who is a high school senior at the time of the interview. Common manifestations of the CDC identified by both Cynthia and Walter include loss of balance and coordination, muscle fatigue, and short term memory loss/disorientation. Additionally, Cynthia explained that she experiences urinary incontinence and suffers frequent bladder infections. Furthermore, Cynthia described mood fluctuations and extreme anxiety as symptoms of the MS for which she is prescribed medication by a psychiatrist. Although both described home-based activities such as reading as their most regular form of shared leisure, both Cynthia and Walter indicate that they greatly enjoy their weekly outings to see movies and their

season subscription to the opera. Additionally, both explained at length the importance of travel in their relationship and the evolution of their travel experiences in response to Cynthia's changing CDC-related abilities and needs.

### Pre-onset couples

Four Caucasian couples whose relationships began prior to one partner's diagnosis of a CDC also agreed to be interviewed for this study. These participants were generally middle aged (i.e., 45-60 years) adults who had been married for at least four years. Diagnoses included fibromyalgia and/or chronic fatigue immune dysfunction syndrome (CFIDS), bipolar disorder, and Crohn's disease.

Lisa and Randall. Lisa and Randall, both aged 52 years, reported the longest relationship of all couples since Randall stated that "she was my girlfriend in first grade"; they have been married for 36 years and have two adult children. Randall is a professor and head of a research division at a local university; although Lisa had been employed as a school psychologist for many years she relinquished formal employment upon her diagnosis of CFIDS in 1986. Common manifestations of Lisa's CDC include post-exertional fatigue, muscle weakness, chronic tiredness, disrupted sleep patterns, and impaired cognition described as fibro-fog. Both Lisa and Randall describe perceptions of extreme loss at their inability to engage in many of the outdoor activities they enjoyed prior to the onset of Lisa's CDC (e.g., hiking, swimming, camping). However, they describe satisfaction with their current leisure lifestyle and suggest that their willingness to seek assistance and consider alternatives (e.g., sea kayaking, electric bicycles) allows them to focus on activities and experiences they can continue to share despite fluctuations in Lisa's CDC-related symptoms.

Christine and Jeff. Christine is a 57-year-old former historian who was diagnosed with a combination of CFIDS/fibromyalgia and bipolar disorder in 1998. She has been married for 33 years to Jeff, a 63-year-old history professor at a local university; they have three adult daughters who reside locally. The most common symptoms of Christine's CDCs include chronic fatigue, muscle pain and joint tenderness, and occasional cognitive impairment described as fibro-fog. Jeff also described that prior to the diagnosis and treatment of the bipolar disorder, Christine could become extremely anxious and have bursts of aggressive or violent behavior. Both Jeff and Christine describe enjoying the "quiet life" of reading and discussing books, newspapers, and magazines, taking walks, and socializing with friends. With their mutual interest in history, Christine and Jeff indicate that despite CDC-related limitations they continue to enjoy activities such as visiting old cemeteries, and investigating the historical background of subjects of mutual interest – including writing a sixteen-volume encyclopedia of historical participants with a CDC.

Sarah and Bob. Sarah is a 49-year-old woman who has recently retired from her position as an executive at a large southeastern bank in response to her diagnosis of Crohn's disease in 1999. Her husband Bob, age 56 years, is also in semi-retirement from his corporate job. Though Sarah and Bob have known each other for approximately thirteen years, they have only been married for four years; this is the second marriage for both, and each has an adult daughter from their previous relationship. The couple owns an expansive property in a rural southeastern town, and describes the time they spend maintaining the grounds and property as one form of shared leisure. Additionally, they describe taking walks on their property and fishing in their private lake as activities they greatly enjoy when Sarah is not experiencing a flare up. Crohn's is an autoimmune disorder that is identified as one of several inflammatory bowel diseases; common manifestations of Sarah's exacerbations include inability to digest certain foods, nausea and

upset stomach, disruptions in elimination, intestinal pain, and chronic fatigue and general flu-like symptoms that have a tendency to “rob you of your energy when you’re in either an acute or active phase.” Though the couple indicates that the recurring nature of Sarah’s CDC affects their participation in certain physical or social activities (especially involving food) during a flare-up, neither Sarah nor Bob perceives that the overall type or quality of shared leisure is greatly affected.

Andrea and Tim. Andrea is a 47-year-old writer has been married for 17 years to Tim, a 60-year-old physics professor at a local university. Andrea and Tim have a 16-year-old daughter and a 5-year-old son; Tim has two adult sons from a previous marriage. Although Andrea identifies her CDC as “Chronic Fatigue Immune Dysfunction Syndrome,” a diagnosis she received in 1998, Tim describes it as “chronic Epstein Barr, which was in my day called mono.” Manifestations of the CDC that were described by both Andrea and Tim include chronic fatigue, lack of energy, disruptions in sleep patterns, and cognitive impairments such as inability to read or concentrate. The couple describes themselves as family-focused people who enjoyed spending time with their children playing games and riding bikes. Together they enjoy taking walks, reading to each other, and cooking; recently Andrea has made the commitment to learn chess and the couple play fairly regularly. Despite enjoying some activities together, both Andrea and Tim describe feelings of loneliness and frustration at the other’s perceived lack of sensitivity to the type and severity of the CDC and associated changes. Specifically, Tim suggests that the illness is at least in part psychosomatic and that fluctuations in Andrea’s health and energy levels, most notably during participation in activities she considers enjoyable, are not consistent with a chronic disabling condition. In turn, Andrea indicates that she is acutely aware of Tim’s skepticism and that she feels lonely and frustrated because of his rigid attitude and unwillingness

to experiment with alternative or modified physical activities (e.g., electric bicycle) that would facilitate her participation and enhance the frequency and quality of certain types of shared leisure.

### Research Objectives

The initial purpose of this study was to address such questions as (a) how do couples participate in shared leisure? (b) do couples experience CDC-related changes to shared leisure? and (c) what resources are known to and used by couples to participate in shared leisure? However, analysis of the comments and observations of these sixteen participants suggests that findings may be better represented by using research objectives describing the (a) nature of shared leisure, (b) factors that shape participation in shared leisure, and (c) influence of shared leisure on relationship functioning among couples experiencing a CDC. The purpose of detailing relevant findings is to demonstrate both the variety of experiences described by participants, as well as similarities across participants with and without a CDC. With the exception of perceptions of the CDC, major categories are relevant across all participants. Although examples used to illustrate categories were not consistent across participants, this variation is included to offer insight regarding the breadth and dimensions of experience offered by participants. Therefore, introductory tables provide an overview of dimensions of experience used to illustrate main categories that emerged during data analysis. Table two is a summary of the nature of shared leisure in the context of a CDC, including changed leisure patterns and perceptions of shared leisure.

Table 2. Nature of Shared Leisure

**CHANGED LEISURE PATTERNS****Appraisal of Changes** (\*n = 8, \*\*np = 8)

- Few changes (n = 4, np = 4)
- Substantial changes (n = 4, np = 4)

**Challenges to Participation** (n = 8, np = 6)

- Having sufficient energy
  1. inability to counteract chronic fatigue (n = 3, np = 2)
  2. inability to combine events (n = 2, np = 3)
  3. inability to use strategies (n = 2, np = 2)
- Engaging in social activities
  1. difficulty fulfilling social obligations (n = 2, np = 2)
  2. difficulty planning social opportunities (n = 2, np = 2)
  3. difficulty attending social engagements (n = 2, np = 2)
  4. difficulty managing social reactions (n = 3, np = 3)
  5. difficulty reciprocating invitations (n = 2, np = 2)
- Maintaining travel
  1. difficulty sustaining desired frequency (n = 1, np = 1)
  2. difficulty sustaining spontaneity (n = 1, np = 1)
  3. difficulty accommodating ambiguity (n = 2, np = 2)
  4. difficulty changing travel patterns (n = 2, np = 2)
  5. difficulty accommodating increased expense (n = 2)

**PERCEPTIONS OF SHARED LEISURE****Positive Perceptions** (n = 7, np = 6)

- Take advantage of good health
  1. appreciate normal activity (n = 3, np = 2)
  2. reconnect to valued partner (n = 2, np = 2)
- Focus on interpersonal interactions
  1. emphasize interaction with partner (n = 3, np = 3)
  2. enjoy time with partner (n = 2, np = 4)
  3. improve quality of leisure with partner (n = 2, np = 2)
- Divert attention away from CDC
  1. minimize negative talk and complaining (n = 2, np = 2)
  2. interact positively and share humor (n = 3, np = 2)
  3. sustain desired routines (n = 2, np = 2)

**Negative Perceptions** (n = 8, np = 3)

- Experience frustration with participation
  1. encounter social isolation (n = 4, np = 2)
  2. substitute for preferred experience (n = 4, np = 2)
  3. contribute to physical discomfort (n = 4)
- Need to meet relationship expectations
  1. difficult to establish reciprocity (n = 3, np = 2)
  2. difficulty to make choices regarding personal preferences (n = 2, np = 3)
- Perceive a leisure mismatch with partner
  1. different definition of leisure (n = 1, np = 1)
  2. different activity preferences (n = 3, np = 3)
  3. different expectations regarding reciprocity (n = 2, np = 2)

\* n = partner with a CDC, \*\*np = partner without a CDC

## Nature of Shared Leisure

Participants described the nature of shared leisure in the context of a CDC as being an experience of change. Participants described change with respect to (a) leisure patterns, and (b) perceptions of shared leisure that evolved in association with onset or exacerbation of a CDC and related losses and limitations.

### Changed Leisure Patterns

Within this study, shared leisure is defined as activities, behaviors, and experiences that are engaged in simultaneously by adults with a CDC and their partners during periods of free time with the expectation of preferred experience for both (e.g., Kleiber, 1999). Participants described a variety of leisure activities they shared with their partners including reading, playing games (e.g., Scrabble, chess, pool, racquetball), hiking and going for walks, watching television, watching movies, dining out and/or socializing with friends, travel, and visiting cultural or historical venues (e.g., museums, antiques shops, flea markets, old cemeteries). Although all participants indicated that many aspects of their lives and interpersonal interactions had been altered in association with CDC-related losses and limitations, not everyone suggested that their overall leisure patterns had been greatly affected by onset or exacerbation of a CDC. Additionally, not all partners were in agreement regarding specific ways that their leisure. Nonetheless, partners were generally consistent in their **appraisal of changes to leisure participation.**

Few changes. Some participants suggested that the CDC was only a minor intruder in their shared leisure, and that cyclical exacerbations of CDC-related symptoms affected the intensity, rather than the content, of their activities. These participants suggested that they experienced few changes in their leisure patterns. For example, Sarah described how fluctuations

in her symptoms were more likely to limit her participation in activities that required physical exertion rather than preclude them altogether, and this contributed to perceptions of continuity.

I have been very fortunate in that there hasn't been a whole lot, I think, that has been completely, that we've had to cut out completely. There may be times when I'm more limited or I may postpone doing something, but I have been very fortunate in that the things that we do together...we do kind of a lot of just, kind of just really hanging out. Kind of just being, like renting movies or sitting on the front porch and talking, or on the back porch. And in the winter we can sit in front of the fire here and just talk for hours.

Sarah's husband Bob concurred with this assessment, and affirmed that CDC-related changes had not substantially altered most of their shared leisure.

What we do together before we knew and after we knew has not changed. That has not affected us. We enjoy anything to do with the outdoors. Yard work, gardening, recreational sports, swimming, she enjoys fishing as I do, and all those types of things. Reading, shopping...but nothing, that has not changed at all. Now of course, when she's not feeling well, I mean, we are probably not as intense in those particular areas as we would be but it does not stop us.

Participants that described few CDC-related changes in leisure patterns suggested that the nature of their pre- and post- leisure patterns was a factor that affected their appraisal of changes. For them, an ongoing preference for sedentary and intellectual activities (e.g., reading and listening to music) enhanced perceptions of continuity in spite of CDC-related losses and limitations. For example, since Jeff and Christine were both trained as historians, their ability to engage in preferred activities such as reading, discussion, and historical detective work was not completely affected by onset or cyclical changes of her CDC. Jeff articulated,

Actually much of what we did prior to the onset of the illness and much of what we do now is about the same. We like to explore the area around [name of town]. Just take drives of five to ten miles with no particular aims in mind, just go out to the surrounding counties and drive around and occasionally, we've done this more recently, is go to cemeteries. It's not morbid, I don't think it's morbid; I think it's more a historical interest. We just look for names and local history and things of that sort. And that we can do because it does not require a great deal of energy expenditure on her part. That can work into her energy reserves.

Christine affirmed this assessment of their shared leisure. She also indicated that while overall lifestyle changes were more pronounced for her, one factor that contributed to a sense of continuity was that Jeff's professional obligations as an academic, and their mutual interests in leisure, facilitated the quiet and sedentary lifestyle they both preferred. Christine suggested,

Since Jeff is, you know, scholarly and does a lot of reading and writing and that kind of thing then it doesn't affect us as much as I think it would some couples. Or we've been able to make the adjustment. And you do have to make the adjustment; otherwise you're very unhappy all the time.

Some participants suggested that they experienced slightly greater changes in their leisure patterns with their partner. One factor contributing to an appraisal of greater CDC-related change was the extent to which partners were obliged to participate in leisure without their partner, possibly contributing to perceptions of interpersonal loss. For example, Christine suggested,

So now, for example, he [Jeff] would ask me if I could do something. He wouldn't just automatically say, "Oh yeah, we'll do that." Or he wouldn't automatically assume that I might do it with him. He would do more things alone, perhaps, than he would have normally.

Among couples that participated in both active and sedentary or intellectual activities, onset or fluctuation of CDC-related symptoms often minimized ability to participate in physical activities such as bike riding, hiking, camping, and certain kinds of travel. Among partners without a CDC, these moderate changes were sometimes perceived negatively and associated with feelings of interpersonal loss. Interestingly, even these participants suggested that changes in their leisure lives were fairly minimal, perhaps because of their awareness that other couples experienced even more substantial and intrusive changes. For example, Tim observed,

So from my point of view we sometimes live parallel lives and they intersect and we'll do something together. But because that's a lot of the aspect, I would say, of who we are, then perhaps we are not as negatively affected by her chronic illness as some other couple who always did a lot of things together. I mean, if you've got somebody who had a whole relationship where they loved to go hiking and camping and so forth together, and all of a sudden that's taken away, and that was a big foundation of the relationship then that

would be a real negative impact on that relationship. So we haven't been hit that hard because we do have separate interests, and our main interests together are pretty family-oriented rather than activity-oriented.

One partner with a CDC suggested that although she and her husband also experienced moderate changes in their leisure patterns due to fluctuations in her CDC, she appraised these changes positively as an interpersonal gain. Cynthia described how, prior to meeting Walter and during their courtship, she was quite frenetic in her activities, such as traveling and studying abroad and becoming involved in several social and political organizations. Although the couple continued to travel and participate in many of these same activities early in their marriage, Cynthia suggested that eventually her previous interests and behaviors began to approximate her husband's more sedentary, home-based, and family-oriented leisure preferences – a lifestyle change that seems to have protected her health. Cynthia remarked,

He's just really, really predictable. And luckily that's worked out really well for me that he's a predictable person. He's a predictable person, he likes to be, that's the way he is and it's easier to live with, you know? You can kind of predict what you can and can't do, you know? My lifestyle was really more helter-skelter before I met him. Which has helped ground me in the way I needed to be grounded with my MS. Who would have known that would turn out to be what I really did need, you know, in many, many ways? His stability has, and his patience, have all contributed to my staying well. Absolutely. I mean, the fact that he's so stable and consistent is how I've been able to stay well. Honest. I have my medications and things like that, but you need that support from home, that the whole picture supports you getting better and staying well. Getting well and staying well, you know?

Substantial Changes. Not surprisingly, some couples did suggest that onset or exacerbation of CDC-related losses and limitations contributed to substantial changes in shared leisure with a partner, especially when a couple had previously participated regularly in sports and other physical activities. Participants suggested that it was the extensiveness and abruptness of CDC-related losses and limitations that affected their appraisal of substantial changes in their

leisure patterns. For example, Kate observed that her back injury had profound effects on shared leisure when she remarked,

Well, actually, we do have a pre-onset and post because he knew about my back but it didn't affect his life until 1997. So before 1997 we used to play sports, and be very active, and be able to go anywhere at the drop of a hat and not have to worry about what was going on with my back or how I was feeling. After '97, basically everything stopped. I mean, we really don't, we really don't do a lot in my opinion.

The abruptness and pervasiveness of leisure changes was perceived as especially negative when CDC-related losses and limitations also affected participants' ability to share leisure with their family, and often contributed to perceptions of frustration. Lisa described how onset of CFIDS dramatically altered shared leisure when she stated,

We were, um, most of our activities centered around active recreation. Activities, when the kids were growing up, we went camping a lot, we went hiking a lot, we did lots of hikes at one time. Several times we hiked to the top of a mountaintop and spent the night and camped and climbed back down. On weekends, if nothing else, we'd just take a five mile walk around or whatever. We swam a lot, for exercise or for fun. I don't know, it's been so long. We'd go [roller] skating with the kids, and bike riding....Well then there was a period of about four or five years when I couldn't do anything. I couldn't even walk to the mailbox, so we basically didn't do anything recreationally. We might go to a movie or that sort of thing, but since that initial four years of inactivity we had to...well, we went through a real hard time because we had lost what was so important to us. Like I said, in a way we couldn't do any of this any more. And we went through some really, really frustrating times.

Though partners without a CDC also described ways that shared leisure had been dramatically changed, some also suggested that they did not continue to view the changes quite as negatively as their partner. For example, Randall suggested that he viewed changes in shared leisure along a continuum, and that his and Lisa's current situation was substantially improved over even their recent past. Therefore, Randall described an appreciation of recent changes in Lisa's health that permitted greater opportunity for shared leisure. Randall observed,

In terms of the change part basically we went from being very active to doing virtually nothing. I mean, when I said she was in bed twenty hours a day something I'll always remember is that she couldn't walk to the mailbox for what seemed like years. So now, to

me, I think she thinks about how we used to be, you know, before she got ill. I mainly think about how we were in those worst years. And so we do so many more things than we'd do then, so in essence that's my baseline. She longs for the way it used to be. I don't think I even think in those terms anymore. So this is a way of life. It's a lot better than it was fifteen years ago and so to me this isn't so bad. You know, relative to what I've seen in her or to what I think it could be.

### Challenges to Participation

Although participants varied in their appraisal of the extent to which onset or exacerbation of a CDC changed their leisure patterns, many suggested that participation in core activities (i.e., those done regularly and with little advance planning or specialized equipment or environment required) posed sufficient challenges that most of their leisure followed patterns consistent with those of balance activities (i.e., those done less frequently and requiring planning and/or the use of special equipment or locations) among couples not experiencing a CDC. Participants suggested that challenges associated with participation in evening activities, social engagements, and travel required such extensive planning and investment that they often chose to forego these types of opportunities, thus contributing to their perceptions of changed leisure patterns.

Having sufficient energy. The extent to which participants were limited in their ability to engage in evening activities varied according to the type and severity of the CDC. Nonetheless partners with a CDC consistently suggested that an **inability to counteract chronic fatigue**, and cognitive impairments associated with fatigue, hindered their ability to participate in many dinner and post-dinner time activities. For some this was viewed as a great loss that substantially limited desired leisure opportunities. Christine illustrated this loss in her statement,

I mean, at this particular point in time I tend to live more like my mother, who's 84, and sometimes *she* does more than *I* do, you know. I'd say that in a week she definitely does more activities, I mean like going to concerts or that sort of thing, she definitely does more of that because I just don't go out in the evening.

Some participants with a CDC suggested that, although they could engage in some evening activities, this type of shared leisure was still limited by their **inability to combine events** in such a way that they would be out for more than a few hours at a time. For example, Andrea stated, “You know we can never do a movie and a dinner. Or we can never do a movie and a...we can sometimes do a movie and a coffee, but usually I’m so done in by a movie.”

Partners without a CDC also identified that evening activities were substantially curtailed. Although some differed in their assessment of the importance of that change, they nonetheless suggested that they perceived an **inability to use strategies** or modifications that could be implemented to alter that aspect of their leisure patterns. For example, Tim described how the inability to incorporate sufficient rest and healthful routines restricted ability to attend concerts. Tim observed,

We just don’t do it much anymore [evening activities]. I mean, I used to be able to buy tickets for the symphony for six weeks from now, and we would plan to drive to [nearby city], go to the symphony, and maybe meet some friends. We just don’t do that anymore. It’s not a question of what strategies do you have for making that work – it doesn’t work. So we just don’t do that anymore.

Jeff also iterated that it was difficult to plan on Christine having sufficient energy to incorporate evening activities as part of their leisure repertoire. He observed,

If we were going to plan an activity it would be midday, it wouldn’t be in the evening. We don’t go to concerts or anything. I’m not too keen on them; I don’t like driving at night. But that’s out because she just doesn’t have any energy at night. I mean to go to a concert at seven or eight in the evening would be just out of her energy possibilities.

Engaging in social activities. A challenge to participation in evening activities was factor that could affect participants’ opportunities for interaction with others, since many social engagements occur during the evening. Even when activities did not occur in the evening, some partners with a CDC suggested that they felt increasing social reluctance to initiate new relationships and develop friendships because they believed they would eventually experience

**difficulty fulfilling social obligations.** For example, Christine commented on her hesitation to initiate new friendships when she stated,

Sometimes you meet new people you're interested in and in the past I would have said, "Why don't we go and do so and so?" Now I wouldn't do that. I wouldn't do that because I foresee down the road I would get too involved and it might cause too much work or too much fatigue.

Several participants with a CDC acknowledged that one outcome of onset or exacerbation of a CDC was the combination of limited social contact (i.e., "small world") with an enhanced appreciation of opportunities to maintain relationships. Consequently, some partners without a CDC suggested that change in their leisure patterns was related to **difficulty planning social opportunities**. Nonetheless, some partners without a CDC attempted to minimize this challenge by assuming new roles and responsibilities to compensate for changes in their leisure patterns. For example, Randall suggested that he made a concerted effort to increase his role as social planner to provide more numerous opportunities for Lisa to maintain valued friendships when he stated,

But I think that the isolation, being ill and having restricted energy is a difficult thing. So in my best times I try to arrange or think about things socially we can do, you know, with other people around. It's probably not my natural inclination, though.

Regardless of partners' attempts at social planning, participants with a CDC suggested that they still experienced **difficulty attending social engagements** and certain types of social activities because of the limited planning or few strategies that could be used to anticipate or compensate for specific limitations associated with their CDC. For example, Sarah detailed the challenges of attending social events that included food:

So we probably limit some of the social eating out. We probably don't do that. We socialize and go out and do some things, but it's not a whole, whole lot because it's just way too easy to get yourself into a position of, you know, being faced with a meal and eating and then knowing while you're eating it, or part of it...well, what do you do when you sit down to dinner and not eat?

Similarly, Andrea described the embarrassment of experiencing impaired cognitive and social functioning at important social events. She described,

We were at a Christmas party once and I was supposed to read something, and I was pretty sick and I shouldn't have been there. And the standing up, and the noise – because of the cognitive problems – it just was like a nightmare. Socially, people don't understand that I can't socialize, so it gets embarrassing so I avoid those situations as much as I can.

Though partners may attempt to be mindful of each other's social needs and attempt to devise realistic activities and gatherings that accommodate the needs of the partner with a CDC, couples' shared leisure may also be changed by friends' lack of awareness of the scope, severity, or consequences of CDC-related losses and limitations. Partners with and without a CDC described the **difficulty managing other's reactions** in ways that did not alienate friends or put the partner with a CDC at greater risk. As stated by Matthew,

They are mindful of her limitations, but it doesn't affect...her family more, and my family more, knowing that she can't do some stuff. But our friends may or may not, you know, think about it as much....They know her back hurts, but they don't know exactly what can happen, or what might happen, or what's going on...But I don't think our friends understand the full scope of what can happen, you know. What I saw, and what can happen to her as far as paralyzation and so forth.

None of the participants with a CDC explicitly stated that they were evasive about the nature and severity of their CDC with friends. Several participants indicated that one aspect of managing other's reactions was developing strategies to educate family, friends, and acquaintances about the truth of CDC-related losses and limitations. Nonetheless, some participants also suggested that they did not invest much effort in, and often experienced difficulty as a result of, educating others because their efforts could contribute to social awkwardness. Kate observed,

Life is basically altered depending, on, you know, if my back hurts or if I have a headache. And it's hard to explain to people that they're spinal headaches, and it depends on the pressure of the spinal fluid in my back, and so basically I tell people I have migraines because it's easier and people understand that concept easier.

Similarly, Steve remarked on the challenges of managing the expectations and reactions of others, especially in situations where he usually participated in leisure independent of his partner. Steve expressed,

If I'm finding that I have to explain something to someone, to a group of people who I'd really like to do something with and who are looking for me to join them on something, it can be frustrating and awkward to explain, "Look, it just can't be done at the moment." She hides it so well that it can really be awkward to explain to a bunch of people who really have no concept of what's going on that, why can't I do something because Caroline's not feeling well? So give her a box of Kleenex? Well, it's not like that, you know what I mean?

Although the efforts of some partners with a CDC to downplay the seriousness of their CDC were meant to facilitate social interactions by minimizing complaints and negative talk, some partners without a CDC suggested this could sometimes result in social awkwardness because friends were less able to understand and respond appropriately to associated losses and limitations. Even in situations where friends claim that they are educated and respectful of the needs, losses, and limitations of the partner with a CDC, couples may question whether this is truly the case and whether attempts at social interaction gone awry will have long-lasting negative repercussions on valued relationships. For example, Randall described his ambivalence about traveling with long-standing friends and neighbors who appear to be enlightened regarding Lisa's CDC-related needs and limitations. But as Randall remarked,

All I can think about in doing things like this is the problems it's going to cause in terms of, you know, how late Lisa has to sleep. These people are very active people. You know, my inclination is just not to do this. I'd really just rather be with her, rather than trying to be with her while balancing her illness with two other people who verbally acknowledge, "Oh, we understand that things would be slower." They don't really understand it. They haven't been there. So for me it would be much easier not to, for just Lisa and I to go somewhere so she can be on the schedule that she needs to be on without trying to balance and trying to keep up this relationship with friends and making sure she's getting the rest she needs. But then on the other side she would probably rather be around additional people. So there's that kind of constant balancing act that, you know, my first inclination is to say no we'll just go do something ourselves but then beyond the fear of hurting one's friends maybe she really wants to go with them.

Although most participants described challenges associated with participating in social activities with friends, and balancing their own and their partner's needs to maintain relationships, Steve suggested that Caroline's CDC offered them a social advantage in that they could decline invitations which were not of interest with greater ease. Steve commented,

Actually in other situations it's quite a handy out. You know, I'm feeling pressured to do something that I'm not really enthused about...I can blame it on my wife and, because the circles don't inter-mingle, get away with it pretty well most times.

Although the ability to decline invitations might be viewed by some as a social advantage, many participants indicated that they welcomed most opportunities to gather with friends but felt at a disadvantage because they had **difficulty reciprocating invitations**. Inability or reluctance to host others as often as they were hosted was viewed by some as a factor contributing to a limited social circle. For example, Cynthia stated,

We don't have that many friends because I cannot reciprocate. I can't say, "Oh, come over and we'll do this." You know? I can't. So we just kind of, it worked out well that my husband is an intellectual and he just kind of does his thing with his books and his work, you know, because then I didn't have to be hopping and bopping and doing all kinds of things. I could have a slow life.

Christine also described the awkwardness of being unable to reciprocate invitations, especially with close friends and regular social contacts. Christine related,

I have a friend and she likes to cook and she wants to cook but I'll say let's go out. Because I don't want to get into...because cooking and having people over just takes too much energy. You know, I have to shop, I have to cook, I have to clean...you know, it takes so much energy. No, I would say I would try not to do entertaining that involves any cooking. Reciprocity yes, but...whereas before I would never have thought twice about that. I just wouldn't have. But it is, I know, it would be an effort....and I'll pay for it.

Partners without a CDC also identified that lack of reciprocity contributed to a limited social network. For example, Jeff acknowledged that it would be unrealistic and unfair to expect

Christine to take responsibility for hosting events in their home, but was also reluctant to assume this role himself. Jeff stated,

We never did entertain a great deal, but it's just too demanding and it takes too much out of her. And I would not put any pressure on her because I'm not particularly interested in having people over and things like that. So we don't really entertain; we did a little bit, previously. We have one couple that are very close friends but what's happened to them in the last year or so is that they tend to have us over or we eat out. But they haven't been to our house in about a year because Christine just hasn't been up to it. And I'm not going to be the host and cook. I do cook, I do most of the cooking, but I'm not going to cook for others.

Tim also described the challenges of reciprocating invitations, and suggested that spontaneity and simplicity were key to preserving social contacts of that sort. Tim remarked,

What we don't do – things keep coming to mind of what did we used to do that we don't do now – and one of the things that we used to do is entertain more than we do now. We very seldom entertain. We had a Christmas party last year. Both my sons, her stepsons, were in town and so we wanted to have a festive party for them, so you know, maybe once a year we'll have a party. But, you know, we don't very often have a dinner party per se. We will sometimes have friends and their kids that just come over impromptu for dinner of take-out pizza or something like that.

Maintaining travel. Travel was one activity that was described quite consistently among participants as an aspect of their leisure patterns that had changed substantially because of challenges in mobility and healthful routines. One challenge that was described by several participants was the **difficulty sustaining desired frequency** of travel. Interestingly, Randall suggested that Lisa's CDC was advantageous because it afforded them the opportunity to travel more than they might otherwise when he remarked that, "But no, if she wasn't sick we probably wouldn't be traveling as much because she would be working."

Despite Randall's observation, most participants suggested that their ability to travel had been substantially curtailed by onset or exacerbation of a CDC, as suggested by Christine who stated that, "Well, certainly at this time I would be traveling even more than I was even then because we have more freedom because our girls are grown up."

Jeff concurred with Christine's observation, and remarked,

A few years ago we went to Paris and did a few things. And we were thinking that in a few years after retirement we would do some more of that, but I don't think that's going to happen now. If her condition stays where it's at Christine is not going to be traveling – certainly not out of the country. It's somewhat disappointing, I guess, but we have these little trips.

Participants who persisted in traveling despite CDC-related losses and limitations often found it necessary to make very detailed plans to ensure that necessary equipment or resources could be brought with them or obtained upon arrival. **Difficulty sustaining spontaneity**, an often desired and frequently necessary aspect of travel, was consequently described as a challenge to participation, as suggested by Walter who stated,

It's just much easier to rent a car and throw all the stuff in the car and go somewhere. So that's one kind of adjustment. It means you can't do things in a kind of spontaneous way. You can't just say let's go ahead and do this. It also, of course, makes it much more difficult for her to travel on her own at all. So if we go somewhere...everywhere we go it has to be together, or she had to be with somebody who can help her. And so, needing assistance, in terms of getting places is a big issue.

Reduced mobility was an additional challenge to participation since participants experienced **difficulty accommodating ambiguity**. For example, Cynthia indicated that she often repeated aspects of previous travel excursions, reducing the novelty of experience, because misinformation or inexperience associated with an unfamiliar environment could result in disastrous consequences. She stated,

I can't always predict what the situation will be. So, like, if we've been somewhere that we think has good accommodations and things work out, we tend to then just stick with what we know. You know, we're not real explorers who check out something new or different, because we don't know if I can climb up there, you know, if I physically can get in or out.

Similarly, Matthew suggested that he and Kate were quite rigorous in implementing a carefully planned travel itinerary in their attempts to predict and accommodate Kate's inability to sit for extended periods of time. Matthew observed,

If we're driving down to Florida we try to stop at the same place because it's usually the same time. And we pretty much know how long we can go, and say we need gas or whatever, we try to build all that in together. Gas, food, walking around, because it usually works out to about the right time frame as far as she needs to walk around.

In addition to traveling less spontaneously and ambiguously, Cynthia and Walter described ways that changes in CDC-related losses and limitations were also associated with **difficulty changing travel patterns** in response to symptom and skill fluctuations over time.

Walter expressed,

We always enjoyed traveling, and that didn't present any problems. We didn't...maybe we might just have to make sure that she didn't get over fatigued, and that might be something. We didn't worry about making any special accommodations in terms of where we stayed, if we had to walk up stairs that was never a problem. So we could, I would say, during the earlier part of our relationship we could do pretty much anything we wanted...Now fatigue is less of a problem, which seems odd that I would say that, but it's simply because Cynthia can't walk as much. So when she could walk as much as anybody else, she would just get tired more quickly.

Kate also suggested that in addition to limiting travel in response to CDC-related needs and limitations, any traveling she did post-surgery differed in style than it had previously. For her, it was now necessary to factor in recovery time in response to prolonged fatigue and physical discomfort associated with travel. Kate stated,

You know, I try to, like if I know that I'm going on vacation or we're going to be out of town and I need to be up more, you know, we try to almost schedule an activity...like if we're there for a week, like if we come in on a Sunday we'll try to schedule something on a Tuesday, because that gives me a day to recover. And we won't really schedule any high-energy activity until Thursday because that gives me Wednesday to, you know, it really gives me a chance to rest and go, rest and go kind of thing.

Just as changes in Cynthia's physical abilities altered that couples' patterns of travel, so too was it associated with **difficulty accommodating increased expense**. Though the couple was adamant that travel was possible with the right attitude and appropriate equipment (e.g., walker, portable wheelchair), Cynthia also suggested that the greater financial and resource

investment required to sustain travel necessitated that this activity become a less regular component of their leisure patterns. According to Cynthia,

Getting on and off public transportation, we just don't go. We take taxis. We just take taxis. It's expensive, but you know that's the only way we cannot miss out. That's why we decided that we don't do things that often, because when we do it we know we have to spend money to do it appropriately. To do it and enjoy ourselves we're going to have to spend money, so we don't do it that often but we do it the way we can do it without a hassle.

Similarly, Kate described how the additional expense associated with managing her CDC-related pain and fatigue often restricted extended travel opportunities as part of a shared leisure patterns. She remarked,

Probably on an extended flight I would try to get – and it would be probably cost prohibitive – but definitely try to sit business or first-class because the seats are bigger and a lot of them recline farther. I mean, with flying, unfortunately, there's not a lot I can do.

### Perceptions of Shared Leisure

Regardless of the type of activity in which they engaged, participants suggested that the circumstances of their encounters in leisure could affect their appraisal of the experience. In many cases, participants' expectations for preferred experience were satisfied; consequently they described positive perceptions of shared leisure. When expectations of preferred experience were not satisfied, couples described negative perceptions of shared leisure.

### Positive perceptions of shared leisure

In many instances, shared free time activities were perceived positively and were described as enjoyable (i.e., preferred experiences) by both partners. Leisure activities shared with a partner were described as positive or enjoyable for several reasons. While some activities were enjoyable because they fostered feelings of excitement and freedom (e.g., travel) others were valued because they promoted sharing and conversation (e.g., attending a cultural event,

playing a game). Most often, however, shared leisure was described as enjoyable because participants could (a) take advantage of good health, (b) focus on interpersonal interactions, and (c) divert attention away from the CDC.

Take advantage of good health. Participants described a wide variety of activities that they considered shared leisure such as attending movies, plays, sporting, and cultural events, socializing with friends, going out for a restaurant meal, going for walks, bicycling, kayaking, gardening, cooking, and reading to each other. Regardless of activity, however, partners with a CDC indicated that opportunities to share leisure were enjoyable because it was a time when they could **take advantage of good health**. For example, Christine expressed the sentiment that,

Maybe in a sense you have a heightened enjoyment that, you know, because you come to cherish what you did do. It's just like if you decide to go out to eat with friends, you know, you really want to enjoy that time and remember that time because it might be the one thing that you went out and did all that week. Whereas when you're feeling well you can take a lot for granted.

Similarly, Sarah remarked that, "On my good days, you know, I really appreciate the good days and the time that we have together. And not knowing, that maybe tomorrow I won't feel so great."

Participants also suggested that shared activities, even those considered routine by others, could be considered important and meaningful due to the cyclical nature of the CDC's and the potential for relapse at any time. Consequently, most shared activities were perceived as valuable and enjoyable because participants learned to **appreciate normal activity** with a partner; what had previously been considered mundane became special or important in the context of a CDC. Christine observed,

So what you do, what other people take for granted, you know, say if we take the dog and walk on campus I'm probably going to remember that and enjoy that more because, you know, the next week I might not feel like doing that. You know, it's not like I can just say, "We'll come and do this again." We may not...for a while. So I enjoy that more.

Partners without a CDC also acknowledged the importance of shared leisure for participating and developing and enhanced appreciation for activities that might often be curtailed in the context of a CDC. Matthew remarked,

So I guess you enjoy the time together more, knowing that some, especially during the episode in '97 where she couldn't do anything. So our leisure time together was consisting of, you know, renting a movie and just basically laying there or sitting there, hoping she felt better or good enough to at least enjoy the movie or whatever we were doing. You know? There wasn't a lot. So I mean you take those leisure time activities, where other people would say "we watched a movie together, it was a good movie. So what?" You take them a little different, because it's time you spend where you're actually sharing something.

Other partners without a CDC also described the importance of valuing and taking advantage of good health to participate in leisure activities. Their perceptions of enjoyment were enhanced when they were aware that partners' CDC-related symptoms were less manifest and they could participate in activities of mutual choice and interest. Randall observed,

You know, the bottom line is if she's outside doing something, then ninety percent of the time it means she feels like doing that. So for me it's a very reinforcing or enjoyable time because in part she's out because she feels like being out, so she must be better. Or she feels better because she's out. So by definition for me that gives me something, it's a time to interact with her when she's at her best or close to it.

More important than participating in a specific activity, partners without a CDC appreciated shared leisure during times of favorable health because these experiences offered opportunities to **reconnect to a valued partner**. As stated by Matthew, "So I guess that's the big point, is you know, it's not what we're doing but the fact that we're doing it together, and you enjoy that time."

Bob also identified the importance of shared leisure for reconnecting to a valued partner when he remarked,

What I really miss is when she is feeling like that is the absence of her normal self. I miss that. I don't miss the fact that we are not able to participate in activities. I miss her. She has got just a wonderful personality when she's healthy, so when she's unwell I miss that.

Focus on interpersonal interactions. One change associated with onset or fluctuation of a CDC was the type, frequency, and intensity of participation in shared activities – especially those requiring more physical involvement such as sports or gardening. Nonetheless, participants suggested that, though changed in form and content, shared leisure was perceived positively because these activities and experiences encouraged them to **emphasize interactions with their partner**. For example, Christine articulated the importance of prioritizing relationships when she observed,

Well, it might not necessarily be a bad thing, you know? I think you have to, ah, I think that one thing is that your close relationships become much more important to you, and, ah, when you do go to do something you want to make it count.

Participants with a CDC also suggested that emphasizing interpersonal interaction during leisure was perceived as enjoyable because it reinforced their perception that it was important to **enjoy time with their partner**. For example, Sarah observed,

And I think it probably all boils down to the relationship that we have with each other. No matter what it is that we're doing, just that we want to be together and we realize how important it is and that we won't always be here.

Partners without a CDC also recognized ways that onset or fluctuation of a CDC changed their leisure lifestyles. They also suggested that perceptions of enjoyment were not diminished by changes in frequency and intensity of participation in specific activities. In fact, Randall suggested that in some ways perceptions of leisure were enhanced in the context of Lisa's CDC when he commented,

So I think we would be on the go more than we are, so some of the positive aspects of this is that it's slowed us both down. Her more than she would want to be, but it's slowed us both down. At least, for example, on a trip when her day is eleven to five or whatever it is, and that gives you some time to slow down and think about things. Assess, you know, your values in life and the things you value in your relationship.

Participants also suggested that when CDC-related limitations resulted in a greater focus on their interpersonal interactions rather than the activity per se, the **quality of shared leisure was improved**. For example, Matthew observed that increased insularity of some leisure activities enhanced his appraisal of the experience when he remarked,

It was...it was great. I mean, we probably spent more quality time in that situation (outdoor festival). Your...scope gets narrowed, right? It's more insular. Um...and you are by necessity more focused by what is around you and less distracted by all the goings on, so when your sphere is narrowed like that the two of you are the center of it. Then it's probably higher quality time than if we're both trying to take everything in. Then we become...probably more like two people, two separate entities in an environment than a couple taking in the environment.

Divert attention away from CDC. Many participants suggested that leisure was enjoyable when activities facilitated opportunities to share important experiences with a partner. Participants also perceived shared leisure positively when activities and experiences allowed them to divert attention away from the CDC and associated interruptions or alterations in their routines and interactions. Sharing time in leisure was especially important for partners with a CDC who recognized that much of their time and energy was devoted toward coping with the physical and cognitive effects of their CDC. Sarah observed,

I think it's too easy sometimes when you have a chronic illness to get too wrapped up in yourself and you focus on what's going on in your body. And I think it's good when you do things or have the grandchildren come over that it kind of diverts your attention and allows you to do something else.

Shared leisure was perceived quite positively because participation in activities of mutual interest and enjoyment prompted couples to **minimize negative talk and complaining** about the CDC. Participants suggested this type of conversation can easily become a dominant aspect of interpersonal interactions. Lisa commented,

I don't know how I would react if I were in his shoes, and I know a lot of people who have chronic illnesses who complain all the time. So I think just engaging in anything

that gets your mind off of it, and puts you in a different place, not only in space but mentally, it's not just good for the relationship it's necessary. It's survival.

The importance of conversation and minimizing negative talk and complaining was also identified by partners without a CDC, as evidenced by Bob who observed,

Well, I think it's...regardless of the condition that she has, from our marriage stand-point and everything, I think it has built a wonderful relationship that we do things together. That we don't go off on our own and I do my thing and she does her thing. And consequently it produces an awful lot of conversation and talking...And I think that builds a very good relationship, because there's nothing we won't talk about.

Some participants with a CDC also suggested that shared leisure was perceived positively not only when it minimized discussion of negative aspects of a CDC, but when it created opportunities to **interact positively and share humor**. Caroline suggested,

I think in our leisure it's important that I switch gears and I'm Steve's wife and that we kind of ...just that time together and enjoy each other. You know, a time when you just laugh and talk about stuff. These types of things are really important.

Similarly, Lisa observed that opportunities to share humor enhanced her relationship with Randall by contributing to the uniqueness of the relationship when she remarked,

Sometimes we'll get so tickled we can't stop, so really it's been a very positive kind of thing. Just...nothing specific, there's just instances where we'll start kidding one another. It wouldn't be funny to anyone else, but it's good for us.

Participants also suggested that shared leisure was perceived as positive and enjoyable when activities offered opportunities to **sustain desired routines**. For example, Cynthia and Walter attempted to maintain a weekly outing to the movies, a pattern they had created while dating, despite CDC-related losses and limitations. Other couples attempted to sustain desired routines because of CDC-related changes, as described by Sarah who noted that since she received her diagnosis,

We have a standing Thursday night date. It's just at a local café in (name of town), it's one of our social things, and we'll just have a glass or two of wine and sit across face-to-face and just talk for a couple of hours. We do that every Thursday.

Shared activities that allowed couples to sustain desired routines were perceived positively not only because they enhanced perceptions of normalcy, but because they helped protect against relationships becoming devalued or obscured in the process of coping with CDC-related changes and limitations. For these reasons, shared leisure was also important to partners without a CDC, as suggested by Tim when he remarked,

Well, it's...just doing it together. We'll often say to each other, "I really like cooking with you!" or something like that. You know, there's just a feeling of comradeship, it's just a feeling of doing something together and chatting while you're doing it and stuff like that.

#### Negative perceptions of shared leisure

Despite perceptions that shared leisure was positive and enjoyable, participants also suggested that expectations of preferred experience were not always satisfied. In some instances, the circumstances of their interactions in leisure were associated with a negative perception of that activity or experience. Shared leisure was perceived negatively when partners experienced (a) frustration with participation, and (b) needs to meet relationship expectations, and (c) perceptions of a leisure mismatch with a partner.

Frustration with participation. Many participants described situations or circumstances when shared leisure was perceived negatively because activities did not fully satisfy their expectations of preferred experience or enjoyment. While only a few participants suggested that some of their experiences could be extremely negative, it may be noteworthy that some partners with a CDC selected the word "chore" – the antithesis of preferred experience – to describe their attitude toward some shared activities and interpersonal interactions often considered leisure. Some partners with a CDC suggested that limitations on type and frequency of participation made it easy to **encounter social isolation**. These participants were highly aware that their CDC-related limitations often restricted partner's opportunities, and described shared leisure as a

“chore” when their participation was perceived as necessary to meet partner’s expectations for maintaining social ties with friends and family. For example, Christine suggested,

I identify with them [friends at support group] and I know several people whose marriages seem to have survived it [CDC] and what they do with their husbands, but it’s a common complaint of being, you know, of keeping up. And I guess leisure activities, if you look at them, that’s the enjoyable part of life so if you lose, if what’s enjoyable becomes a chore, that’s a big loss.

The appraisal of shared leisure as a chore that contributed to social isolation was also described by Caroline, who observed,

So usually it’s an issue in our marriage because I think we don’t have enough leisure time together and when we do have leisure time we often use it on these social activities which are fun, but we partly do them because you do need to have some social contact at some point and if we only see them [friends] every four months or something and they’ve invited us we’d better go and do this thing. So our leisure seems generally sort of a chore and a point of contention, I think, in our marriage.

Shared leisure activities were also perceived negatively among participants when the **need to substitute for preferred experiences** meant that they participated in activities or experiences that were less inherently interesting or enjoyable. In these circumstances, activities shared with a partner were chosen mainly to direct attention away from CDC-related symptoms (e.g., pain) when they experienced a fluctuation or worsening of their condition. This phenomenon was described by Caroline, who remarked,

When I’m not feeling well they tend to be mostly passive things...probably at the time I really don’t think of them as leisure activities because it’s just kind of like hanging out and I find that, generally I find leisure to be a chore.

Participants without a CDC also identified the need to substitute for preferred experiences to accommodate a partner’s needs and limitations. For example, Matthew suggested,

Even though I may not feel like doing it at the time I’ll do it. If she wants to go do something together, I’ll do it. Not that there’s anything that ever comes up, but there are times when I don’t feel like going to the mall, but she needs to go to get something and I’ll go. That’s just time together.

Additionally, partners with a CDC perceived shared leisure negatively and described these experiences as a chore when it was anticipated that participation would **create physical discomfort** or exacerbate CDC-related symptoms. For example, Christine described the potential risks of attending a movie when she described,

Well, say if you go to a movie and, you know, you get three quarters of the way through the movie and you can't move and you can't stretch out your legs in the theater. You're kind of boxed in. Well, when you get through the movie, no matter how enjoyable it is, what you're mostly going to think about is that you're very sore and very tired.

Attending a movie was also described as contributing to physical discomfort by a second participant with fibromyalgia. Caroline remarked,

I often think about how the activity is going to make me feel afterwards. For example, going to a movie. I'm not excited about going to the movie, I'm thinking about how uncomfortable the chair is going to be. I know that after that movie I'm not going to be able to walk. I'll be thinking about how in the movie theater it's going to be freezing, and I'm going to be sitting there and I'm going to be uncomfortable and I'm going to have to go to the bathroom and I'm not going to be able to because you can't go out of the movies. So...I'm all about that type of thing instead of "Yeah! I'm going to the movies."

Need to meet relationship expectations. Most participants did not specifically describe shared leisure as a chore. Nonetheless, many suggested shared leisure was perceived negatively when they participated in activities to satisfy the need to meet relationship expectations. Partners with a CDC were especially aware of ways that fluctuations in CDC-related symptoms affected their ability to keep commitments to their partner, family, and friends. Since it could be **difficult to establish reciprocity**, partners with a CDC sometimes pushed themselves to demonstrate they valued relationships with their partner, family, and friends. Sarah described challenges to reciprocity when she observed,

It's real hard, sometimes, I think sometimes there's a feeling of guilt. I think I put a lot of stress and pressure on myself. If someone, they may not understand why and may not realize what's going on in my personal life and, you know, I get concerned that people either think I'm not holding up my side of the bargain or think, you know, she committed to do this and now she's bailing out.

In addition to experiencing difficulty in establishing reciprocity with a broader social network, some partners with a CDC perceived leisure negatively when they felt pressured to satisfy their partner's expectations. For example, Andrea described her frustration with Tim when she remarked,

But for instance the other day when we went on the bike trail, I think if I could have had that motor on the way back I would have been a lot more comfortable. Because I know that if I expend that energy, and I get those toxins going in my cells, that then I'm going to have fallout sometimes in the next two days. And that makes me anxious. And it also makes me feel like I have to push to show that I'm *trying*.

In contrast, Lisa indicated that her husband was extremely accepting of the activity and social limitations imposed by her CDC. Nonetheless, she also felt compelled on occasion to push the limits of her physical abilities to attend social engagements or participate in activities she knew would be interesting or enjoyable for her husband. Though these experiences were not necessarily associated with preferred experience for her, Lisa felt it was important to challenge herself to meet relationship expectations and stated,

And on days that I feel like I can do that, knowing I may pay, I feel it would affect him if I couldn't. I wouldn't do it all the time or whatever, but it is necessary to do that for the relationship.

**Needing to overlook personal preferences** regarding type and intensity of activities could also contribute to negative perceptions of shared leisure. For example, Patty described how she greatly enjoyed kayaking and paddled whenever her health permitted. In contrast her partner, Lillian, preferred more sedentary activities. Since the couple lived in different states they alternated visiting each other; however, extensive driving was only possible for Patty when she was well – a time during which it was possible for her to kayak. To meet the relationship expectation of reciprocal visiting, Patty sometimes did not choose to participate in activities that

would satisfy her expectations for preferred experiences, and described her perception of a recent visit with her partner by stating,

Lillian wanted to come and visit or I'd said that I would go up there and see her, and when it actually came time to, like, go see her I was actually sort of bummed out because what I really wanted to do was go paddle my kayak.

Partners without a CDC also suggested that occasionally shared leisure did not satisfy their expectations of preferred experience, and suggested they too needed to overlook personal preferences – even in independent activities – to modify or accommodate a partner's CDC-related limitations and meet relationship expectations. For example, Steve remarked,

You know, on a nice Saturday or Sunday afternoon after Caroline's been working hard all week and has got the school stuff taken care of and she's actually feeling pretty good, on a Saturday, on a sunny Saturday afternoon is actually when I'd like, you know, it would be a great time to play a round of golf. So it's sort of a conflict every time that I want to do something really physically active...and that is by necessity separate from Caroline.

Perceive a leisure mismatch. Some participants suggested that shared leisure was occasionally viewed negatively when it contributed to relationship tension by revealing or strengthening perceptions of a leisure mismatch among partners. The foremost illustration of a leisure mismatch was described by Steve, who perceived that he and Caroline had developed a **different definition of leisure**. Steve stated,

Her definition of leisure probably isn't the same. She gets a lot of enjoyment out of her schoolwork, so there's probably a lot of stuff where I would say she's doing schoolwork where she might consider it more as a leisure activity.

Although having a different definition of leisure than a partner could mean finding enjoyment through work and other non-free time activities rather than traditional forms of leisure, it could also mean that partners had **different activity preferences** and enjoyed fairly distinct experiences. For example, Patty described her perceptions of a growing divide between

Lillian's and her own interests, especially in response to CDC-related losses and limitations.

Patty described a recent visit to Lillian by stating,

We went to the movies, we took naps, we sat on the couch and watched TV...which is something that I don't really do a lot. I'd rather read, or write, or play guitar or something like that...to be honest, and she and I haven't really talked about this, one of my frustrations is that I'd like to be more active, and when I'm able to do those things that I want to do [like kayaking and hiking].

Partners with and without a CDC suggested that shared leisure could be perceived negatively as couples moved toward living separate or parallel lives to satisfy individual activity preferences. Some participants suggested that they did, on occasion, use strategies to accommodate different interests and skill levels. However, participants who perceived shared leisure negatively with greater frequency indicated that they participated in preferred leisure activities independent of their partner because they did not share the same activity preferences.

For example, Tim observed,

You know, she's interested in a number of things that I'm not interested. She's very interested in spirituality, which doesn't interest me in the least. And she likes to knit and I don't knit. So from my point of view we sometimes live parallel lives and sometimes they'll intersect and we'll do something.

Similarly, Kate described a growing divide between her own and Matthew's current interests, especially in response to current CDC-related losses and limitations. This divide exacerbated negative perceptions of shared leisure. Kate observed,

I don't know, right now I think it's just boring, and in a rut. I'm afraid of trying a lot of sports anymore, because, you know, I'm not willing to not be able to walk again. And we've kind of come to an impasse where I don't like what he likes to do, and he doesn't like what I like to do. Because I don't get golf, you know? It's just not something I think I would find enjoyment in.

### Summary

Shared leisure was defined as those activities and interactions that occurred during free time with the expectation of preferred experience for both partners. Participants' descriptions of

CDC-related leisure changes varied according to their appraisal of changes to leisure participation. Some participants revealed that their leisure patterns had changed little in association with onset or exacerbation of a CDC. Others revealed that there were substantial changes to their leisure patterns, often in conjunction with physical and cognitive constraints such as fibro-fog and prolonged fatigue.

Participants also experienced many challenges to participation such as having sufficient energy to participate in evening and/or multiple activities such as combining dinner and a movie. Couples also had difficulty engaging in social activities as a result of difficulties associated with (a) planning for and making commitments to attend future social events, (b) reciprocating invitations, especially home-based events, and (c) managing the reaction of others and educating family and friends regarding the cyclical nature and severity of CDC-related symptoms. Finally, couples' opportunities for travel were sometimes challenged in association with difficulties accommodating (a) reduced spontaneity, (b) increased ambiguity, and (c) increased expense.

In association with changed leisure patterns and challenges to participation, participants described both positive and negative perceptions of shared leisure. Shared leisure was perceived positively when participants felt that activities and experiences offered opportunities to (a) take advantage of good health, (b) focus on interpersonal interactions, and (c) divert attention away from the CDC. In contrast, shared leisure was perceived negatively when participants felt that activities and experiences were associated with (a) frustration with participation, (b) need to meet relationship expectations, and (c) perceptions of leisure mismatch with a partner.

In association with changes in leisure patterns and varied perceptions of the nature of shared leisure in the context of a CDC, participants identified factors that shaped leisure patterns (see Table 3) including perceptions of the CDC and strategies to promote participation.

Table 3. Factors that Shape Leisure Patterns

**PERCEPTIONS OF THE CDC*****Perceptions of partner without a CDC*** (\*n = 4, \*\*np = 4)

Deny severity (n = 1, np = 1)

- unrealistic expectations

Accept severity but disagree on energy (n = 1, np = 1)

- inequitable expectations

***Perceptions of partner with a CDC***

Maximize severity (n = 1, np = 1)

- unrealistic expectations
- self-protection

Minimize severity (n = 1, np = 1)

- unrealistic expectations
- mental work
- different interpersonal standards

**STRATEGIES TO PROMOTE PARTICIPATION*****Activity-focused strategies*** (n = 8, np = 8)

- Create healthful routines

1. Minimize potential of hitting the wall (n = 4, np = 2)
2. Select among leisure activities (n = 2, np = 2)
3. Schedule leisure for peak times (n = 2, np = 2)
4. Establish mutual routines (n = 3, np = 2)
5. Pace & limit activities (n = 3, np = 3)
6. Create travel routines (n = 2, np = 2)
7. Anticipate & minimize travel challenges (n = 3, np = 3)

- Modify activities and expectations

1. Redefine the characteristics of leisure (n = 3, np = 4)
2. Consider alternatives (n = 4, np = 3)
3. Use adaptive aids (n = 4, np = 4)
4. Be separate but together (n = 4, np = 4)

***Relationship-focused strategies*** (n = 8, np = 8)

- Access leisure with partner

1. Overcome expectations of spontaneity (n = 2, np = 2)
2. Create opportunities for leisure (n = 3, np = 3)
3. Demonstrate respect for & responsiveness to a partner (n = 3, np = 3)

- Maintain open communication

1. Offer or accept reminders (n = 2, np = 2)
2. Become more assertive (n = 3, np = 3)
3. Take comments at face value (n = 2, np = 2)
4. Seek psychological counseling (n = 1, np = 2)

- Reconceptualize the role of leisure in the relationship

1. Focus on possibilities (n = 3, np = 3)
2. Minimize importance of CDC (n = 2, np = 3)
3. Reconsider leisure roles (n = 2, np = 2)
4. Support independent leisure (n = 4, np = 1)
5. Reciprocate support (n = 2, np = 2)

\* n = partner with a CDC, \*\*np = partner without a CDC

### Factors that Shape Leisure Patterns

Without exception, couples suggested that onset or exacerbation of CDC-related losses and limitations affected their participation in shared leisure. In addition to challenges to participation previously described, two additional factors that shaped leisure patterns were partner's (a) perceptions of the CDC, and (b) use of activity- and relationship-focused strategies to promote participation. Participants' perceptions and use of strategies also had implications for the affective quality of shared leisure and, consequently, on relationship functioning.

#### Perceptions of the CDC

Contrary to the literature describing associations between onset of CDC and relationship functioning (e.g., Brown & Geisy, 1986), most participants in this study who began their relationship post-onset of a CDC did not describe fewer CDC-related tensions than those for whom the CDC occurred during the course of the relationship. Research suggests that entering a relationship fully aware of CDC related losses and limitations usually promotes relationship functioning because partners do not have to negotiate sudden and unforeseen changes in their social, economic, and leisure lifestyles. However, the experiences of these participants suggests that it is not merely awareness, but also resolution of tensions associated with managing enduring and fluctuating CDC-related losses and limitations that may affect how shared leisure affects interpersonal interaction and relationship functioning.

Regardless of the type or severity of CDC, all participants were quick to acknowledge that, though they would prefer not to cope with CDC-related losses and limitations, they also would not alter their choice of partner or regret having entered or remained in the relationship. Nonetheless, some couples indicated that if partners differed in their perceptions and acceptance of CDC-related losses, limitations, and consequences – especially in shared leisure – tensions

could adversely affect desire for, and opportunity to, participate in shared leisure. Reduction of frequency or quality of interpersonal interaction associated with shared leisure could diminish relationship functioning. It may be important to note that many participants described ways that onset or exacerbation of a CDC contributed to conflict and tension in the relationship. However, despite the fact that onset or severe exacerbation of the CDC occurred during the course of the relationship for (a) Lisa and Randall, (b) Cynthia and Walter, (c) Christine and Jeff, and (d) Sarah and Bob, these did not appear to differ in their perceptions of the CDC. Although these couples also experienced challenges to participation previously described, they appeared to resolve CDC-related tensions that could negatively affect leisure patterns. In contrast, and despite the fact that relationships began post-onset of the CDC among three of four couples, some participants differed quite strongly in their perceptions of the CDC. Though one couple began their relationship post-onset of a CDC, they also described differing perceptions of the CDC that diminished relationship functioning. Therefore, the experiences of (a) Andrea and Tim, (b) Caroline and Steve, (c) Patty and Lillian, and (d) Kate and Matthew are included to provide evidence that differing perceptions of a CDC may be factor that contributes to tension that negatively affects leisure patterns and associated relationship functioning.

Perceptions of partner without a CDC. The most dramatic instance of how partners differed in their perceptions of the CDC was exemplified by Andrea and Tim, who independently acknowledged that Tim was often skeptical and would **deny** both the nature and **severity** of her CDC. Andrea suggested that in recent months her health had improved slightly and that she tried to participate in more activities with her husband and family as her energy permitted. Nonetheless, it appeared to Andrea that her husband was not accepting of the ongoing and cyclical nature of her CDC, and consequently held unrealistic expectations regarding both

the state of her health and her ability to participate in normal activities such as shared leisure.

Andrea stated,

I mean, he's always saying to others, "she's doing better, she's doing great." Well, I am doing better, but, you know, it's because of a very carefully...I run my life very carefully in order to do that. And there's not any extra to expend. So, you know, I don't know that he really accepts this as a chronic illness.

Andrea's perception was confirmed by Tim, who suggested that he was not only skeptical regarding the chronic nature of her condition but also of the diagnosis itself. Since Tim was disbelieving of the cyclical nature of the CDC, his perception was that there was little need to account for or accommodate fluctuations in Andrea's ability to participate in activities because of her health. Tim stated,

It's not whether I question whether she's sick or not, but I do question sometimes whether what she has is really what she thinks she has. You asked me at the beginning what does she have, and notice I did not say "chronic fatigue." I'll bet when you interviewed her she probably said "chronic fatigue immune deficiency syndrome and fibromyalgia." Right? When you ask me what she has, she's got "mono."...You know, in all candor, sometimes when I see her able to do things that she really wants to do, you know, you can't help but think – at least I can't help but think – well, is she really that sick or is it all in her head? You know, that is to say, I see her ski for two days and think, "well, come on! What is this chronic fatigue thing anyway?"

No other participants expressed disbelief regarding the veracity of their partner's CDC. Furthermore, none of the participants with a CDC doubted their diagnoses, or failed to recognize that symptoms and prognoses could fluctuate or be substantially worsened by both the cyclical nature of the CDC and self-induced behaviors. Nonetheless, several couples indicated that though they were in agreement regarding the nature of the CDC, they still differed in their perceptions of CDC-related losses and limitations. Differing perceptions could contribute to relationship tension when both partners were fully aware of and **accepted the severity** of bio-psycho-social limitations for the partner with the CDC, **but disagreed on energy** and partner's choices regarding ways that available energy should be spent. These disagreements could result

in partners feeling that there were inequitable expectations regarding how each should reconcile independent skills, interests, and abilities to maximize mutual benefit. For example, Caroline suggested that since she entered graduate school she had modified her priorities so that establishing her career became paramount. While both she and Steve agreed that this was a natural thing to do, it was also apparent that they experienced discord regarding how best to ensure that time spent together, especially in leisure, remained a priority. Caroline observed,

I don't know if he gets or understands why, for example, I will totally kill myself and have the same effect on my body for school but I don't necessarily do that for leisure or for fun...I know that he's said to me, "You know, why don't you save some of your good energy for me?" Good energy meaning energy when you're able to be productive or do something. Where I know that I end up spending all of my good energy looking after my responsibilities and not...and then by the end of the day or the end of the weekend all of that good energy is gone and I'm having to just recuperate.

Steve agreed that he and Caroline differed in their perceptions of the way that some of Caroline's energy and coping resources should be spent. Steve acknowledged that he derived less satisfaction from his professional endeavors than Caroline, and was therefore more interested in pursuing enjoyment through participation in more traditional forms of leisure – especially sports. In addition to joining a few sports leagues to establish some of his own leisure preferences into a mutual routine, Steve suggested that one of his strategies for trying to prioritize enjoyable time together was to schedule his own day to maximize the likelihood of sharing some of Caroline's good energy. Steve remarked,

I find I'm still able to work late at night, and Caroline is done with the day by then. She's sort of more of a morning person, and I sort of get this window of clarity, and it tends to be from whenever she goes to bed until I'm too tired to work anymore. I don't know if this is a chicken or egg scenario, which came first, whether she was a draw on my attention and so after she went to bed I was, you know, allowed to focus on schoolwork or if it has always just been a window of good work time for me. But I suppose that's one strategy. I will put stuff off and hang out with Caroline, make sure that she gets whatever she needs to get done, done. Tuck her in, then work for a few hours...So I guess that's sort of strategy that helps us to get our own things done and still have time to hang out.

Though Steve did not specifically indicate that he would prefer Caroline to arrange her activities and use coping strategies to schedule time and good energy for him, he did suggest that some tension arose from Caroline's expectations that Steve's schedule would always prioritize time with her. Steve perceived this tension as relating directly to his participation in athletic activities and ensuing social gatherings (i.e., having a beer after a game) that did not expressly include her. In his view, while Caroline was unrestricted in her ability to schedule time away from him to foster her academic and professional interests, he did not have the same authorship over his own time. Steve stated,

What is the frustration? Just in justifying those choices [time spent] to each other I guess. Because that would be my first choice all the time [share leisure with Caroline], but it's just frustrating to make sure that even if I have something regularly scheduled that it's not to supercede Caroline's 'good time'.

Though Caroline was aware that she devoted more time to her professional endeavors and was more likely to use her coping strategies to maximize her performance in this area, she was not unaware that there was an expectation that Steve should prioritize his schedule to coincide with times she was available for and interested in shared leisure. She suggested that part of this inequity stemmed from her perception that despite her efforts to anticipate and incorporate shared leisure with Steve, she was often unsuccessful in these initiatives. Caroline lamented,

Once in a while one of us needs a little support or whatever. But I really feel like in leisure we end up being in this vertical position [forefingers interlocked like a chain, one hand holding up the other] and that I'm the one on the bottom and he's like pulling me up and pulling me along – "Come on, let's have fun!" ...And I think that, although I can talk about it with Steve and he can do the stuff that I told you he does to help me, it really, I really feel a lot of pressure because I really feel that it boils down to me... And most if it is just that I don't think about it [leisure] or, um, sometimes I do plan for it and then I end up not feeling well anyway so I often feel like no matter what I do I'm not...you know, I just can't get it right with that.

Perceptions of partner with a CDC. While some couples were cognizant of and accepting of the CDC-related losses and limitations of one partner, other couples experienced relationship tensions because the partner with a CDC sometimes **maximized the severity** of CDC-related losses, limitations, and consequences more than the other. One factor contributing to partners' differing perceptions of the CDC was having a "hidden disability" whose symptoms and prognosis could be easily overlooked. For example, other than using painkillers to alleviate spinal headaches and orthopedic chairs with superior lumbar support, Kate did not use adaptive aids or specialized equipment. Though Kate's mobility was somewhat impaired (e.g., bending over, climbing steep stairs), she felt that Matthew had unrealistic expectations regarding her physical abilities. Kate remarked,

He's pretty understanding, but you know, there are just times, different thing [vacuuming, washing the bathtub, golf]...that he'll just take for granted that I can do it just because I'm walking. And that's difficult for me.

Matthew also recognized that he sometimes overlooked the severity of Kate's CDC and harbored unrealistic expectations regarding Kate's interest in, and capacity for, certain physical activities. Though he suggested that he tried to minimize Kate's involvement in physically demanding activities, he also recognized that he was not always successful. Matthew stated,

And you realize, her problem, it's not visible. It's not like missing an arm and a leg, or she's not in a wheelchair or something like that. It's not a visible disability. So I was in, I fell into the category of people that, if she's walking and up and around and can do something, she *must* be fine. Well, that wasn't the case at all, because she was dealing with so much pain. She just was able to deal with it. And you know, even now I catch myself – not as much, but I still catch myself – when she's having a bad day or having something like that....well, you know, I see her walking and all that and I think, "Okay, she's all better." And she's not. It's just that she's able to function. She may be, you know, up and down the stairs but she's not going to be carrying laundry up and down the stairs. You have to try a little bit more. So I try. I don't always succeed, but I try.

When a partner with a CDC had a heightened awareness of the negative consequences of a relapse, she was prone to reduce participation in potentially harmful activities. For example

Kate suggested that, since a traumatic back re-injury that nearly left her paralyzed, she engaged in self-protection and was reluctant to participate in any activities that might exacerbate her pain or further limit her mobility. Although Matthew was aware of her CDC prior to their marriage, it was only since she completed rehabilitation in recent months that she became aware of tensions associated with her changed attitude toward many activities, including shared leisure. For Kate and Matthew this was especially important because both partners had a strong interest in sports and other athletic activities, many of which were no longer possible for Kate, as indicated in her observation,

It affects him in ways that he doesn't even realize, you know? Because he doesn't, he came into my life later on and I had already been diagnosed, but I was definitely in denial of what I couldn't do. You know? So now it's like I'm in denial of things I *can* do, probably, where I'm just not willing to go there [risk paralysis] anymore.

Some partners with a CDC acknowledged that they sometimes had difficulty resolving current CDC-related losses and limitations with their former interests and abilities, and therefore had a tendency to be less concerned about potential relapse than their partners. For example, Patty suggested that as a former student athlete and someone who enjoyed vigorous and/or outdoor activities such as carpentry, hiking, and kayaking, she occasionally had difficulty resolving medical restrictions on physical activity with her optimal leisure lifestyle. She admitted that she sometimes **minimized the severity** of her CDC to avoid contemplating the potential likelihood and seriousness of relapses induced by participation in some preferred activities. Consequently, she sometimes engaged in social, athletic, or home maintenance activities beyond her physical limits. This behavior could contribute to tension in the relationship because her partner perceived greater seriousness of CDC-related losses and limitations and was proactive in reminding her of the consequences of her choices. Patty observed,

I'm just an active person, and I want to be that way still and I guess in my...in the back of my head I have this idea that this cardiomyopathy thing is going to go away or something. I don't know, I don't know what I think, but I think I don't tend to take it as seriously. So in some ways Lillian is a reality check to remind me that I do have a disability, there are some serious potential consequences when I do overdo [sports, lawn care], and that I do have physical limitations. So in one sense she's a reality check and that serves a good purpose, I guess. But in the other sense it messes with my little denial system and I don't like that.

Lillian also suggested that Patty sometimes minimized the severity of her CDC and had unrealistic expectations regarding participation in many activities, including shared leisure, because she underestimated the likelihood of negative consequences such as prolonged relapse or even death. Though Lillian felt that Patty was extremely clever and skilled at fostering proactive and responsible behaviors in others with CDCs, she “then sort of ignores things for herself.” From Lillian's perspective, ignoring things for herself could include behaviors such as failing to get adequate rest and nourishment, drinking caffeine when it was restricted as part of a cardiac rehabilitation program, or failing to question her cardiologist regarding activities that would most likely be contraindicated during times of poorer health. Accordingly, Lillian described that she often felt there was much mental work required to devise ways to reconcile Patty's desired “denial system” by refraining from overprotective behavior with her preference to protect Patty's health. Lillian offered,

That's why she got banned from kayaking, because of Bonny's [a friend] questions [that Lillian asked the cardiologist] that Patty was never going to ask. So for me it's hard to figure out when I need to intercede in her health care, and I know she's got a history of *not* paying attention when she doesn't feel well, for a lot of different reasons, and not wanting to pay attention to her health because it shouldn't be this way. It's not fair. And so, when do I intercede? When do I just let her have her own consequences? You've got to let them skin their knees, but I don't want them to have a myocardial infarction either! And figuring that out, that's the tough part about the partnership, I think. And then distinguishing that from just your everyday ‘can you just leave me alone to be who I am.’

Patty indicated that she was aware of Lillian's concerns, but suggested that her attempts to respect and acknowledge these by including Lillian in health care decisions could also have

negative effects on interpersonal interaction and relationship functioning by accentuating their different perceptions. Patty acknowledged,

She worries more about my disability, I think, than I do sometimes and, you know, whenever there's been a disagreement and we've talked to the cardiologist about it the cardiologist has agreed with Lillian. But it's still kind of frustrating and a source of tension.

Patty elaborated on her perspective by suggesting that there was also mental work for her as she strove to balance needs in the relationship by respecting Lillian's concerns without enabling what she perceived as Lillian's interference and overprotective behavior. Patty observed,

I think it kicks up that whole dynamic when she calls it caring for me and, you know, trying to help me take care of myself and I feel like it's overprotective and trying to control me. And so that is where it leads to some tension. And that will most likely, the area where that comes up most is in leisure.

Lillian also suggested that different perceptions regarding Patty's CDC was manifested as a struggle to balance each partner's needs. Lillian was a self-avowed "worrier" who acknowledged that she had a heightened awareness of the seriousness of CDC-related losses, limitations, and consequences. Lillian admitted that she could engage in interfering and overprotective behavior, but that part of the mental work she did was learning to refrain from enabling behavior that served to establish different standards of interpersonal behavior in response to Patty's CDC. Lillian expressed,

I'm not certain, but there are times when she gets really cranky and I don't want to say moody, it's more like just not receptive to suggestions and things like that, or not very flexible at all. And then later, you know, in the middle of the night she'll be, you know, not feeling well or needing to sit up to sleep because her chest is so heavy. Or it could just be that she's cranky. So that's the other thing that I try not to do is go "oh, you're not feeling well and then I'll be nicer to you", because sometimes she's just being a bitch! (laughter) And, you know, as do I but I don't have a disability to blame, so when I'm a bitch I'm just a bitch. (laughter)

### Strategies to Promote Participation

Variations existed in the extent to which couples differed in their perceptions of the CDC and experienced negative changes in their leisure patterns. Nonetheless, all participants described positive perceptions of shared leisure despite this, and other challenges to participation previously described. Consequently, participants reported using a variety of strategies to participate in activities and interactions that could satisfy the expectation of preferred experience for both partners. Broadly, these strategies may be described as activity-focused or relationship-focused in nature.

#### Activity-focused strategies

Activity-focused strategies were those that facilitated participation in all activities, including leisure. Couples devised strategies focused on minimizing the potential of “hitting the wall”; often participants worked to (a) create healthful routines, (b) modify activities and expectations, (c) access leisure with a partner, (d) maintain open communication, and (e) redefine leisure in the relationship.

Create healthful routines. Many participants with a CDC worked to create routines that promoted healthful behaviors (i.e., rest, nutrition, exercise, meditation) that would **minimize the potential of hitting the wall**. Preserving energy to participate in desired activities, including shared leisure, was paramount. For example, Andrea offered, “Well I am doing better but, you know, it’s because of a very carefully...I run my life carefully in order to do that. And there’s not any extra [energy] to expend.” Andrea elaborated regarding the time and attention required to restore and preserve health to participate in any activities. Andrea related,

I have to take a ton of supplements. So I have to get up an hour earlier for breakfast to take them. I have to get a certain amount of sleep every day, every night. When I get up in the morning I have to eat at certain times, and I take lots of supplements with my food, then I do yoga. I usually need time in the morning because I don’t wake up really easily.

And I have rituals and routines. I usually try to do meditation or journaling. These are some of the most important things that have helped me to get better. So I try to have that time, but you know, by that time it's getting late in the morning. Because I sleep. I usually don't get up until 7:30, which is pretty late. And then I get dressed, and it used to be that I wouldn't get dressed because just dressing took all my energy. Now it doesn't. I take injections, so I have to do my injections every morning. Then I try to take the dog for a little walk, not very far, just a little walk. And then I'm usually bushed! And then I come home, and I have my quiet morning to do anything I want that's productive. So I sit at my desk...in my office where I do any professional work. So I try to do that in the morning. Then my husband comes home for lunch, and we have lunch together. Then usually I have to have a nap, and I usually sleep at least an hour. It's vital! If I don't do that I can get very, very tired the rest of the day. And then I try to do a little more work before my son comes home. He's five, and he comes home around 2:30. And then, you know, it's family time and we do errands, cooking...I love that time and I try to be very present and rested for my children because they take a lot of energy and I want to be present with them. And my daughter comes home at about quarter to four, and they do homework and I try to be there to listen to their essays, or help do laundry and cook. Then my husband comes home and we always have a very nice dinner...And then my husband and son and I will read stories, and we'll put him to bed. And then I've got about another hour until – I usually go to bed at 9:00 – so we watch a little TV and I knit. And that's my day. Now I can't, there's no room to maneuver much on that schedule. And it's working, you know, but I have to have a lot of that quiet time in the morning. I have to have that nap in the afternoon. If I can do those things, then it's okay. I do still get a lot of frequent infections, and those can drag me down. I mean, there's still some days when I have to pretty much stay in bed.

Many partners with a CDC described the importance of preserving energy. Cynthia described the consequences of not preserving energy when she stated,

So much of the planning is a matter of conserving your energy, because you run out of energy. Fatigue is a big part of the whole thing. Conserving your energy and not finding yourself in a total catatonic, fatigued state.

Out of necessity and a desire to facilitate shared leisure experiences, partners without a CDC also contributed to their partner's efforts to minimize the potential of hitting the wall by assisting in the creation or maintenance of these healthful routines. For example, Steve detailed the importance of preparation and planning as part of a healthful routine when he explained, "And that preparation is just making sure that she's rested and does whatever exercise that she's, that she should be doing to maintain her feeling good."

Caroline confirmed Steve's perception of the importance of advance planning and preparation when she observed, "I think he's been doing more lately is he will tell me in advance, like, "On Sunday we are going to do this." And he reminds me about it each day so that I can prepare that I'm going to do that."

A further illustration of planning to promote healthful routines was offered by Matthew, who described the importance of considering environmental factors for Kate, whose headaches and backaches could be exacerbated by poor seating. Matthew explained,

Well I can go on further, now that I've remembered it, is anytime we go out, let's say to dinner, which we do a lot, she might have to, if we sit in the booth and she can't sit in the type of booth the restaurant has, and we try the table and she may or may not be able to sit in the chairs. We have to be mindful of that as soon as we get there, because that little half hour can ruin a whole night. Because if we sit there and she can't continue, if her back starts bothering her then that ruins, you know, movie plans or whatever we may have planned. So stuff like that, you know, I don't want to say normal, but people without disabilities don't think about, they just take for granted. And I used to, but now, you know, you become mindful of stuff like that.

In addition to ensuring ample sleep and rest, exercise, proper nutrition, medications, and other nutritional supplements, partners with a CDC suggested that they also learned to **select among leisure activities** in creating healthful routines. Choices were often made not only with preferred experience but also with duration in mind since it was difficult to sustain energy beyond three hours when activities required much physical exertion or social interaction. For example, Christine explained,

Which makes you carefully think about leisure time...how much you're going to have of it and what you're going to do when you're there. You know. I sort of pick out, pick and choose my leisure time and what it's going to be. I have a very good idea, for example, how long it will be. Three hours is a good time. It might go as long as four in some conditions, but three hours is usually a pretty good estimate.

In addition crafting a well-balanced lifestyle to conserve energy, many partners with a CDC acknowledged that their energy levels fluctuated dramatically during the day, and often chose to **schedule leisure activities for peak times**. In particular, activities or social

engagements occurring during the mid-morning to mid-afternoon hours (e.g., 10:00 a.m. to 2:00 p.m.) often accommodated needed rest periods in their daily routines. Christine offered, “Well, the first thing I will plan is sleep or rest. And to try to set the time, which most of the time when we do things, will be towards the middle of the day.”

Christine’s partner, Jeff, confirmed the importance of scheduling leisure for peak times, both out of personal preference and necessity. Jeff offered,

If we were going to do something, it would be midday, it wouldn’t be in the evening. We don’t go to concerts or anything. I’m not too keen on them; I don’t like driving at night. But that’s out because she just doesn’t have any energy at night. I mean to go to a concert at seven or eight in the evening would be just out of her energy possibilities.

Although partners with a CDC made efforts to incorporate leisure into daily routines, couples also work together to **establish mutual routines** that accommodated current energy levels or physical limitations. One example was offered by Cynthia, who explained, “I mean, we go [to the movies] every week if we can, and Walter has always sort of tried to make time on a Friday so we can go at the matinee time when there’s not as many people in the theater.”

Since it is not always possible to plan all shared leisure to occur during peak times, participants often learned to **pace and limit activities** to avoid creating unrealistic schedules and itineraries. This was especially relevant in circumstances where couples were away from their homes for extended periods of time, such as day trips or vacations. One example was offered by Lillian, who explained,

So some of the things we try to negotiate is, or...the ways we negotiate may be to say “Okay, let’s walk through this whole day. Okay. You’re going to leave the house at eight, and we want to do this and we want to do that.” And then I remind her, “And you know when you see people how excited you get and how it wears you out. And then we’re going to go do *this*. Do you think you’re going to be able to handle that?” And if she’s pretty flexible, I mean if she’s okay, we can walk through that.

A second example of pacing and limiting activities was explained by Walter, who described how travel and sightseeing had evolved in response to Cynthia's MS. Walter stated, "So fatigue was probably the primary symptom, and we would adjust to that by saying okay, we'll do that tomorrow. So we would kind of ration our activities, in a way, to deal with that."

In addition to pacing and limiting activities, participants often developed strategies to **create travel routines**. Partners with a CDC acknowledged this form of planning was especially important to their continued participation in activities such as sightseeing or visiting with distant family, since these activities are inherently disruptive to carefully planned healthful routines. Christine described the importance of creating home-like environments on the road when she explained,

And if we did travel, like the last time we went someplace we rented a condo and, ah, we always have since I've gotten sick, and that way I had a place to rest. I could cook if I wanted to, if I was too tired we could go out to eat, you know, you make plans like that. And when we went to do our sight- seeing we always did it in that window of opportunity that I had. And all of that he expected, that the schedule was the same. That the daily schedule was the same, so I think it's just become a way of life for the both of us.

Partners without a CDC also described the importance of establishing home-like routines to minimize travel challenges. Tim offered,

So certainly we make plans to go to the beach in the summer, and we've got a place that we usually go and it's a nice, big, room apartment. When she feels like doing something we'll do it, and when she doesn't she can sit on the beach or do something else.

With respect to car trips, participants described how they learned to **anticipate and minimize travel challenges** to minimize the likelihood of hitting the wall in transit. For example, Caroline explained the importance of breaking up a long car trip into manageable chunks when she offered,

But the only negative thought I think I did have was that we were in the car for quite a long time. But the way we coped with that was we actually ended up not driving the full way there or back, we ended up stopping at a hotel both ways. So that when I did come

back to school I wasn't sore or anything, like, there was no negative repercussion [pain or fatigue] of that.

Matthew also explained the importance of breaking up long car trips to minimize Kate's fatigue and discomfort. Matthew stated,

I mean, yes, we do [try to have a routine], if we're driving down to Florida we try to stop at the same place because it's usually the same time. And we pretty much know how long we can go, and say we need gas or whatever, we try to build all that in together. Gas, food, walking around, because it usually works out to about the right time frame as far as she needs to walk around.

Some participants with a CDC suggested that they were no longer willing to risk the hardships associated with travel, especially during overseas trips where plane travel could be restrictive. However, most participants agreed that travel was an activity they enjoyed and experimentation was helpful in efforts to anticipate and minimize challenges associated with prolonged flights. Although not all participants with a CDC experienced incontinence, Cynthia's experience is reflective of the type of planning required to sustain travel despite CDC-related symptoms and limitations. Cynthia explained,

And again, that's always the thing where I need to plan ahead in terms of where I am [on the plane] and where the bathroom is for me, in terms of any kind of incontinence, that I can get up. And if the stewardesses are moving food up and down the aisle, then I've got to plan ahead so I get up there and use the toilet before they get down the aisle with the car, you know, all that kind of stuff.

A second example of anticipating and minimizing challenges associated with foreign flights was offered by Randall, who explained the need to take into account Lisa's chronic fatigue. Randall remarked,

For example, we're going to a meeting in Australia this summer and checking airline schedules has shown that a thirty-hour flight is what we will need to do. So what we will probably do is take a flight to Hawaii and stay a couple of days to recoup and then go on, so, you know, I think it changes dramatically how we travel and probably what we do.

Modify activities and expectations. In addition to creating healthful routines, participants who intended to maintain domestic and foreign travel in their leisure repertoire also described how learning to **modify expectations**, especially with respect to sightseeing and accommodations, could greatly contribute to their continued participation in, and enjoyment of, those experiences. Randall offered,

We look for places when we go, for example, we might go to a hotel on the beach rather than actively sightseeing. We are both at an age where there are lots of people who go on tours, you know, where you get up and have your suitcase at the door at six-thirty in the morning. There will never be a time when she will do that. So I think it changes what you see and how you do it.

Walter also explained the importance of modifying expectations with respect to travel, and suggested that the quality of the experiences was not necessarily diminished by compromising on the way that experience was achieved. Walter stated,

And so, that's what I think I was trying to get at by saying the accommodation that you make to do this is not really huge. I mean, so what do you look for? Well, a hotel that's handicap accessible. A city that's reasonably easy to walk around. And possibly renting a car if you want to go any distance. Well, those aren't huge things to find out. It's not as if the world is shut off, just because one person can only walk short distances at a time.

Modifying attitudes and expectations concerning activities that were part of a shared history was an activity-focused strategy not restricted to travel. Willingness to re-evaluate and **redefine the characteristics of leisure** was also helpful in assisting couples create positive leisure experiences, especially during periods of relapse or exacerbation in CDC-related symptoms. Although Lisa and Randall had previously enjoyed active outdoor pursuits such as hiking and camping, Lisa explained that being outdoors was more important than the activity itself. As a result, Lisa described how the couple was able to modify both the activity and their expectations to participate in an enjoyable interaction. Lisa explained,

For instance, we might go on a trail that we once might have hiked on, and we'll just take a bottle of wine and cheese and sit there and talk and enjoy being in nature even though we're not necessarily walking around.

Redefining the characteristics of leisure was explained by several participants with and without a CDC. For example Kate and Matthew were limited in their ability to participate in sports and many other physically challenging activities. One valued characteristic of those activities was the physical challenge; however, competition and skill development were recognized as equally important. Kate explained,

And at least, it may not be a high-energy expenditure type of activity, but it's still doing something. And I haven't really perfected it, but it takes a skill, you know, and things like that. It's something that isn't really – unless I slip on a rug or something – there's minimal risk of me getting hurt. You know? And I played darts before when we lived in New York, and I think he – he definitely was in a league with his brother and things like that, so it's something that he likes too. You know? And I'm getting better, and there have been times that I've beat him, so that's always a plus. So that's why it gets frustrating for me that I can't do some of the things that definitely take skill and can show that, you know, either him or I or both together can accomplish a task that requires coordination and things like that.

Redefining the characteristics of leisure was not limited to outdoor or athletic activities. For example, Christine and Jeff, who both suggested that an important characteristic of leisure was that it be intellectually stimulating, learned to value other types of experiences. For example, Christine explained that while she did not watch much television prior to her CDC, she increasingly enjoyed some programs as a way to keep up with current events and sustain conversation with Jeff despite variations in her ability to read. Christine offered,

So what you try to do is you try to make that time profitable, you know, by reading, which even reading can be somewhat restricted because this condition affects your eyes and how much you see, and it changes constantly so your glasses don't always work for you. So I've found that so far television is the one thing that doesn't affect my vision too much the way reading print does. So it's something that I can do, and there is enough good television that you can find that you learn things or see things that it helps.

Jeff also acknowledged that he and Christine watched more television than they had in the past in response to CDC-related changes, and this was an acceptable change in their leisure patterns. Jeff also described how he also began to modify his expectations regarding the characteristics of leisure. Although most activities should be intellectually stimulating, Jeff increasingly appreciated ways that many other activities, including chores and household maintenance tasks, could be enjoyable and rewarding. For example, he eventually viewed cooking as a form of compensatory leisure that provided opportunities to complete discrete and immediately satisfying tasks that were quite different than tasks that comprised his professional role as an historian and college professor. Though Jeff did not describe himself as a good cook, and admitted that he would never host friends for a meal of his making, he nonetheless considered mealtimes with Christine as part of their shared leisure. Jeff stated,

I've learned to like to cook. It's simple, you know, it's really a pleasure because it's something unlike my work which you never, you never see the results because it's so vague and up in the sky. But to make a meal, you make it and it has a real beginning, middle, and end. And I like that because it's real.

Modifying expectations regarding the characteristics of leisure is an activity-focused strategy in that it enabled participants to continue participating in some preferred activities in a slightly different form. Participants' willingness to explore and **consider alternatives** – even those that were not initially of great interest to them – is also an activity-focused strategy that sustained or expanded their leisure repertoire. For example, Lisa explained how Randall's willingness to rethink characteristics of leisure allowed them to become more creative in responding to cyclical changes in her CDC. Lisa remarked,

Probably just...he helps come up with suggestions on days when I'm feeling really down. He tries hard to come up with something I might be interested in to keep my mind off of it, whether it's going to the movies, or we started going to baseball games. Not to see the (name of professional team) but to our, there's this team in (name of town) near our cabin in the mountains. He's always looking for things and sometimes he can be quite creative,

because when I'm really down and depressed and saying, "No, there's nothing I can do. Just forget it!" He'll say, "No, we can do this."

When participants were willing to consider alternatives that were not inherently of interest to them, they were often surprised by their enjoyment and rewarded by adding an additional activity to their leisure repertoire. For example, Andrea described how experimenting with board games increased the frequency of shared leisure with her husband. Andrea explained,

Again, you know, here I am and I don't have a lot of energy, you know, but we still like to play and still have fun. I actually started that [playing chess with husband]. I was never much of a game person, but he always was and always wanted me to play. And I finally figured out that would be a good way for us to do things together. Even though he always beats me, of course. But it was, it was fun! Even though it's not something, if I were well, would want to do. So that's kind of interesting.

Partners without a CDC also recognized the importance of considering alternatives not inherently of personal interest to expand a leisure repertoire. Randall offered,

But we go in spells, but I can remember thinking eight or ten years ago, that it was a waste. I don't know what I meant I should be doing, but to go to the movie every Friday night or something. And somehow...but that was something that she could go out, she could get some stimulation, and being out is pretty different from being home. And so now for some reason over a period of time I'm the one saying, "Hey! Do you want to go see this movie?" Do you want to do this?" So, and, my sense is that I enjoy it as much as she does. I didn't to begin with but I did it for her and then it became equally meaningful for me for whatever reason.

Considering alternatives was not solely related to experimenting with new activities but also included experimenting with new forms of participation to a previous activity. For example, Walter described the importance of accepting lesser seats to continue attending the opera. Walter remarked,

And the other setting that we've had to make an adjustment is that one of the things we've done since about the mid-nineties is go to the opera. And we used to have really nice seats that involved going up the stairs. Because the place is a box and it's really old-fashioned and doesn't have decent accommodation, at least for handicapped people. And so finally we took seats lower down. And again, that was, we'd had the seats every year and so we really regretted having to give up those seats and having to move downstairs.

But there again, it's just something you have to do if you want to keep on doing it. Things like that are actually the most difficult.

One activity-focused strategy described as important for expanding participants' leisure repertoire was to use **adaptive aids** and specialized equipment. In addition to items that facilitate mobility such as portable wheelchairs or walkers with a seat, partners with a CDC described sporting goods and devices that facilitated their participation in physical activities. For example, Lillian described how she and Patty now hiked with Aspirin, a cell-phone, and whistles in the event that Patty experienced chest pains. Other participants described these types of small and relatively inexpensive aids, but also suggested that they purchased expensive equipment to participate in shared leisure. Lisa offered, "We have a sit-on-top kayak. So as long as I don't have to use my leg muscles – and it's a tandem, so he can do most of the paddling so I don't get tired."

Lisa also described how the purchase of a moped and electric bicycle greatly expanded her leisure repertoire. Lisa explained,

A bike was not an option so we went to the Suzuki store and he [father] bought me a little moped. Well, that moped opened up a whole new world for me. Oh! I can get out of the house, I can ride down the street, I can see neighbors, I can ride farther out if I want to. Eventually we got Randall one as well, so that is an activity that we really enjoy together.

Lisa had already purchased an electric bicycle when the couple lived in Colorado, and this aid also greatly increased her leisure repertoire. Andrea expressed, "I want to get an electric motor [for my bike] that I can have an assist if I need it."

Cynthia and Walter also used adaptive aids to facilitate travel. Walter explained,

The first time we used it [portable wheelchair] it's such a sort of liberating feeling as well. You know, we can walk anywhere as long as it's not up the side of a mountain, or, you know, walking through Venice where you've got all these steps. You know, to go out in a city and just be able to walk. And Cynthia can sit and I can push her, I mean, that really makes a difference.

One adaptive aid that was not related to equipment per se was described by Matthew and Kate. Although the pair had not definitively decided to pursue golfing as an activity, they both acknowledged that seeking trained professional assistance might help them modify the activity to accommodate Kate's CDC.

I mean, we tried golfing but that's something that we really need to take time at. I mean, she can't just go out and play eighteen holes of golf. A: because she really doesn't know how, and B: if she goes out there and just starts swinging away it's not going to help. So we tried a little bit of that, and what we hope to do is get her lessons with a pro, or whoever knows what she's up against, and can adjust for it. And who may just say, "You're not going to golf. Don't even think about it."

Despite participants' attempts to modify activities and expectations, they also suggested that there were some activities that were so associated with preferred experience for both that they worked very insistently to accommodate the needs and abilities of both partners. For example, it recognized that due to physical limitations it was not always possible or preferable for each partner to engage in activities such as hiking with the same intensity and duration. To modify the activity and expectations couples sometimes needed to learn to **be separate but together**. The term "separate but together" was coined by Patty and Lillian to describe their strategy of hiking together for a period of time, hiking individually and at their own pace, and meeting at a pre-determined location and hour. As an activity-focused strategy, this approach permitted the couple to maintain hiking in their leisure repertoire while ensuring that the experience was positive and enjoyable for both. Patty explained,

So even though we did some of it [hiking] together and some of it apart it felt like sharing because when we got back to the car we would tell each other the adventures that we had on the individual part of the walk.

Lillian supported Patty's experience, and added,

But the separate thing, in some way's it's an added dimension that's really fun because I'm not feeling guilty that I'm holding her back. Because that's something that was horrible that I had before, I always felt guilty because I couldn't keep up with my ex. So

I'm not holding her back. She needs some time away from me because I talk a lot, and I know that, and I'm not good at being quiet.

Being separate together was also described by Kate and Matthew, who observed that they enjoyed many of the same types of sports and physical activities. Although Matthew recognized that it would be insensitive of him to ask Kate to attend a sporting event in which he was participating and she would like to but could not, Kate's support in the stands and vicarious enjoyment was perceived by both as being separate but together. Matthew remarked,

I guess just from the team aspect, like we just talked about, is her coming to see, and she would probably watch me golf...there was a time when I went to a golf tournament with a friend of mine, it was a police tournament, and she came along. She didn't come and watch us golf because of, for whatever reason, there was no way she was going to walk around like that. But she was there, and I knew she was there, and I knew when I was done golfing I could go back to the hotel and she would be at the pool or whatever and we would go out and eat. She was in the area.

#### Relationship-focused strategies

While the emphasis of activity-focused strategies was to facilitate couples' ability to engage in specific activities together, relationship-focused strategies were ongoing, mutual efforts to accommodate the cyclical nature of CDC-related limitations. Relationship-focused strategies were those that allowed couples to be responsive to both leisure and relationship changes without allowing the CDC to become the dominant focus in their lives. In devising relationship-focused strategies, couples learned ways to (a) access leisure with their partner, (b) maintain open communication, and (c) redefine leisure in the relationship.

Access leisure with their partner. Many participants indicated that one relationship focused strategy commonly used was to accept CDC-related fluctuations and limitations without bitterness. However, couples also suggested that it was important to recognize the cyclical nature of most CDCs in order to appreciate good days and **take advantage of leisure opportunities** during times of better health. For example, Sarah offered,

I think maybe that having an illness kind of reminds you to appreciate life. And I think to take it and not be angry about what the illness does to you, but to really focus on the good things that it can bring to your life. How it can enrich your relationships and make you pay attention to things that you might not do because you're too busy going through life.

Bob also expressed the importance of accessing leisure with a partner, and focusing on the quality of interactions with a partner. Bob explained,

It makes me, when she's feeling well then we do everything we can to enjoy the period in time when she is feeling well. It makes you appreciate, it makes me appreciate it that much more. You know, she's feeling good and we've got a month or whatever, so let's just really enjoy until the next flare-up occurs and then we'll deal with it, as we have before.

Participants suggested that an important aspect of accessing leisure with their partner was learning to recognize and be responsive to those good days; as Jeff suggested, to "strike when the iron is hot."

Steve also revealed the importance of spontaneity when he explained, "You have to be spontaneous because the good times are fleeting. When she's feeling good you want to take advantage of that."

Though a seemingly simple strategy, some participants suggested that it could be difficult to **overcome expectations of spontaneity** with respect to leisure activities. Caroline seemed to struggle particularly hard with the need to overcome this expectation; she offered,

It's not like I always expect something to be spontaneous or anything. But maybe I need to come to a kind of acceptance that nothing else in my life is spontaneous. I mean, I have to plan everything, so my leisure is not going to be. I mean, at least...at least not stuff with Steve.

Participating in activities with their partner often requires that couples **create opportunities for leisure** that coincide with cycles of optimal health or restedness. Christine explained how her routines had become Jeff's habits when she stated, "Well for example, if

someone would say, “Let’s go out for breakfast,” Jeff would say “Well, how about brunch”? Because that way my sleep time is more.”

Jeff also recognized that accessing leisure with Christine meant creating opportunities for leisure that coincided with her best times. Jeff explained,

Whenever the hour came during the day when she seems to feel okay, matinee, midday – it wouldn’t be in the evening. We don’t go to concerts or anything...because she just doesn’t have any energy at night. So she wanted to go [to the movies] and I went and we had a good time and that was new because we’d never gone to the movies together.

In general, relationship-focused strategies that encouraged partners without a CDC to **demonstrate respect for and respond to their partner** were described as most helpful for sustaining shared leisure because they were viewed as a natural contribution to the relationship. Caroline observed, “I guess really the way he sort of helps me is to help me with the rest of my life in hopes that I’ll be able to have leisure with him.”

Demonstrating respect also meant learning to become flexible in routines and expectations to avoid placing undue pressure on a partner to participate in specific activities. For example, Jeff described how it was important to respond Christine’s cyclical changes while on vacation. Jeff stated,

But there again, you have to sort of strike when the iron is hot, you know, talk about it and then say maybe this weekend and then if she’s up to it, you know, if she has sufficient strength to get in a car then off we go. But it’s no big plans. We’re not even talking about vacation this summer. I’d like to go to, you know, down to the beach in August after summer school, but we were thinking of that last summer but she just wasn’t up to it. Because it would be nice to take a week off, and we love to go to the beach and walk on the beach and, you know, eat seafood or something, but we may not do it. You know, that’s just sort of the way things are. You have to be flexible.

One way that partners without a CDC may have learned to become responsive to CDC-related losses and limitations was by observing their mate’s efforts to become more self-

accepting and respectful of their own limits. For example, Lisa described how a major attitude adjustment on her part enhanced interpersonal interaction with Randall. Lisa stated,

So I had to quit judging my former self with my present self. And that was really hard. You also have to learn not to judge your present self with others, because you can still think you don't get anything done...I had to start focusing on valuing more who I am as a person not what I do as a person, and focus more on just being. Somebody said we're human beings, not human doings. So I think by me letting go of focusing on and valuing all my accomplishments, I started focusing on, "Maybe I didn't do x, x, x," but maybe it's something like talking with my kids on the phone and helping them emotionally, or just being generally a nice person to be with. And valuing that has helped my attitude which in turn helps Randall.

Maintain open communication. In addition to strategies helpful for creating access to leisure with their partner, couples suggested that it was important to use strategies helpful in efforts to maintain open communication. One aspect of maintaining open communication was learning to **offer or accept reminders** regarding CDC- or leisure-related needs, abilities, and expectations to minimize the likelihood of hitting the wall as well as interpersonal misunderstandings and disappointments. For example, Andrea realized,

Well, I mean, he's got a lot of energy and he needs to be able to do those things, and I need to not try to keep up with him and not get my feelings hurt if I can't do them. And he recognizes now, he's gotten really good at recognizing that I need to rest. And so, you know...it's been good that he's been able to, at times, initiate saying, "I think you need to rest" or "I'll let you rest now and I'm going to go." But I think it's good that we don't feel we have to do things together, even when we're on a vacation together.

Similarly, Sarah described that Bob did not attempt to pressure her to participate in activities when she experienced a flare-up. In fact, Sarah suggested that Bob often discouraged her from pushing herself to attend social obligations to meet perceived relationship expectations. Sarah offered,

But he has been supportive and so understanding through all of this, you know, there've been times when we've literally had evening plans that we were really looking forward to that I just knew I couldn't go, and he has always been really great about saying, "Well, I'm disappointed but I think it's more important that you get your rest." Or whatever. And I'll say, "If you want to go, that's okay."

Although the process could be quite painful, partners with a CDC suggested that efforts to maintain open communication involved learning to **become more assertive** regarding current needs, expectations, and preferences to negotiate enjoyable leisure experiences. Patty revealed that she learned to protect personal time in order to enhance time with Lillian. Patty stated, “So I guess our system that works is that I’m more willing to say I need quiet time or alone time, and she’s more willing to, like, not take it personally.”

Andrea also acknowledged that while she and Tim had not resolved many CDC-related tensions, Tim had started to become more assertive in protecting Andrea’s health, especially when he perceived that she had unrealistic expectations or could potentially hit the wall. Andrea offered,

And he will say to me, you know, when we’re doing things he’ll say, “I see that you don’t look good, maybe you need to stop.” Like, you know about the kayaking, he said, “You might remember you have an illness, so I don’t think you can do kayaking.”

Partners without a CDC also described the importance of maintaining open communication in crafting a desired leisure lifestyle, and suggested that learning to **take comments at face value** was crucial to promoting relationship harmony, especially when CDC-related symptoms were exacerbated. For example, Lillian explained how she struggled to avoid becoming skeptical and overprotective in her interactions with Patty. Lillian explained,

So again the communication is like taking her at her word when I ask her to check, and she does a little inventory and says, ‘I’m feeling this, and this, and this, and my ankles aren’t swollen.’ Then I leave it alone, as opposed to my mother who would never leave me alone, so I just leave her alone and trust it. You know? And that’s hard for me to do, and it’s something that we’ve learned to do.

In some instances, maintaining open communication required that one or both partners **seek psychological counseling** to modify their own behaviors and or develop new patterns of conversation and interpersonal interaction. For example, Lillian explained that she sought

counseling from a social worker to manage the difficulties she had in her relationship with Patty. Lillian stated, “So how it affects me is I’m very frustrated, I’m in therapy for it, I’m trying to practice it out.”

Lisa and Randall explained that they mutually decided to seek assistance from a marriage counselor. Randall explained that they learned that healthy communication was important for dealing with CDC-related losses and limitations, but that communication should not center solely on that aspect of their lives. Randall expressed,

At one point we actually went to see a therapist. And I think we went three or four times to somebody we know, but what I took from it was that the whole focus of our marriage can’t be on her illness. She probably heard things like that I should be more emotionally responsive (laughter), and to me that’s the critical part. That you have to have time where you don’t talk or think about the illness all the time. And that’s what leisure activities give you, I think.

Redefine leisure in the relationship. Regardless of whether psychological counseling was sought, participants suggested that an important relationship-focused strategy was working to redefine leisure in the relationship. One way of redefining leisure in the context of CDC-related changes was to **focus on possibilities** rather than ways that losses and limitations affected leisure patterns. Lisa supported Randall’s comments regarding the importance of communication, and added that therapy had helped shift attention away from dwelling solely on the negative. Lisa stated, “So it was at that point [relationship crisis] that we started seeing a therapist to help us deal with changing our lives, changing our attitudes, focusing on what we *can* do and not what we *can’t* do type of thing.”

Partners without a CDC also recognized the importance of focusing on activities and experiences that remained or could become part of a leisure lifestyle. Matthew suggested,

Yeah, that [golf] would be great! Because that would be something else that we can do together. But you don’t, I don’t ever dwell on the fact that I *can’t* do something with her, I

always turn it around and say, “Well, I *can* do this with her.” And that’s how I think about it.

Randall also suggested that it was important not to dwell on losses and limitations associated with a CDC, and not to compare actual leisure patterns with idealized leisure patterns.

Randall observed,

It has affected what we do together, but sometimes I think about what we would do differently now if she wasn’t sick. I mean, the easiest thing would be to say we’d go hiking more or something, but how often do you *really* go hiking, you know?

Redefining the role of leisure in the relationship to emphasize possibilities often required partners to **minimize the importance of the CDC** in the relationship. Some partners with a CDC attempted to find benefits associated with onset or exacerbation with a CDC. For example, Sarah explained, “But learning how to not let it get me really crazy and really depressed about it. That’s when I’ll say “Okay, that’s an opportunity to read.” And there’s probably a reason why my body is slowing down now.”

Partners with and without a CDC both acknowledged the importance of minimizing the importance of the CDC by recognizing benefits to their, and other, relationships. For example, Christine reflected,

In some ways you, you get some payment back in time that you didn’t have before, you know. And you...the assumptions you make about your relationships and what you’re going to do in time you set aside it...demonstrates the importance of those things. I think you’re much more clear about the importance of your family ties, the importance of your marriage, the importance of your friends than you were before.

Similarly, Randall suggested that onset or exacerbation could have benefits to the relationship. He stated,

So I think we would be on the go even more than we are, so some of the positive aspects of this is that it’s slowed us both down. Her more than she’d want to be, but it’s slowed us both down...and that gives you time to think about things. Assess, you know, your values in life and the things you value in your relationship.

Minimizing the importance of the CDC in the relationship also involved minimizing the importance of frustrations associated with changed leisure patterns. For the partner without a CDC, minimizing frustrations often involved considering what leisure experiences would be like without the other or if the couple chose to eliminate that activity. For example, Walter described his experience of travel with Cynthia. Walter stated,

It certainly makes it more challenging. And obviously, I would say I would prefer it if those obstacles weren't there. But it's, the way I look at it, it's...you know, there are various circumstances that cause you to make adjustments. I've traveled with a small child, and I know there that there are logistical problems that you face....And Cynthia's handicap is just a different kind of issue...And if there are things that I want to do with Cynthia, then we'll find a way to do them. And mostly it works pretty well. Yeah, it can be annoying and frustrating, but if it's something you enjoy doing then it's still better than not doing it.

Similarly, Lillian described how she learned to minimize frustrations associated with Patty's cardiomyopathy relative to some of her past relationships. Lillian explained,

And you know, I didn't expect anything to work because I just figured that it was going to get in the way. And they're not. It's so secondary to who we are. I mean, it's who she is, it's part of that. But there's so much more value in the depth and richness of our interaction, that it doesn't matter that sometimes we have to say that we can't go hiking because she's not feeling well, or that she needs to take a nap so we have to skip the movie. We've had to do that before. It's a little disappointing, but I'd much rather have that than be with somebody who's controlling, or who doesn't do stuff with me.

Minimizing the importance of the CDC in their leisure lifestyle was one aspect of redefining leisure in the relationship. Additionally, some partners also suggested that they learned to **reconceptualize roles** as contributors or participants in shared leisure. For example, Randall explained that he increasingly assumed the role of social and leisure planner in the relationship. Randall revealed,

So you know, I think that's just one example of how we really have to plan for things far more than other people. Everything has to be, you know, planned and thought down to the last detail. Which I happen to be great at, it's what I do in life. I'm a planner, so we make a great pair.

Cynthia also described how she reconceptualized her role as a participant in leisure with Walter. Cynthia explained that she learned that it was important for her to become a self-advocate to ensure that desired leisure options remained available to them. Cynthia stated,

And you know, going out to the movies and things like that, I am a really committed handicapped person. And I have no problem going and using the facilities that I need to use, and I show my handicap sticker and I say, "Please, I need to get to the front of the line."

A further example of how partners reconceptualized leisure roles was in relation to their willingness to participate vicariously and become sideline supporters. Matthew and Steve both suggested that they would enjoy the presence of their wives at various sporting events in which they competed. Although Caroline did not pursue this avenue of participation with Steve, Kate revealed that she did not mind vicarious participation because she acknowledged that this was a valuable role she could play for Matthew. Kate explained,

I know that I end up, not necessarily hindering but, you know, he likes spending time with me. And I know that because physically I can't do a lot of things that, you know, in the beginning we had talked about when we first got together. I would rather, you know, get the enjoyment of seeing him have fun. Vicariously through him, kind of thing. And I do feel like he...I feel he feels that he shouldn't do things because I can't participate with him.

Redefining leisure in the relationship and assuming new leisure roles sometimes meant learning how to respond to a partner's needs and preferences. For example, Andrea began to play board games with Tim to modify and expand their leisure repertoire. Andrea stated,

Well, I mean, I just realized that you can play chess sitting down and it's something he's loved to do. And he loves playing poker and things like that. And I always used to think they were boring, and would much prefer to do something else. And now that I'm sort of stuck, I've realized this can be a really fun way to interact. It is. It was really fun, and it was good.

Redefining leisure in the relationship could also mean learning to **support independent leisure**. For partners with a CDC, often this meant encouraging the other to participate in sports and other physical activities in which they could not participate, often by becoming a spectator

rather than player. For example, Kate explained how she encouraged Matthew to pursue his interest in hockey; she stated,

And his friend is in a league, so I've been trying to get him in that. And if he does that, you know, that I'll definitely go watch him do because I like hockey. So I don't have a problem with that, but other than that...and this bowling thing has really just started within the last month. So his friends asked him, and I was like, "Go do it!" You know? Because he's always talking about how he wants to do different things, so I was like, "I don't have a problem." And I think that actually made it easier for him to do, because I told him I'd go with him.

Similarly, Andrea explained the importance of supporting independent leisure for Tim. She offered,

I think one of the strengths of our relationship is that we're both pretty independent, and we've allowed each other to be pretty independent. I don't know that we really talked about it. At first it was just necessity. Like why would he pace in a room in a hotel [while Andrea napped] if there was a beach, or a bike, when he wouldn't have to? I mean, it doesn't make sense, you know? So I told Tim to go ahead and continue his bike ride [on a recent vacation] while I napped, because for him it was just a warm up and for me it was all I could manage.

While participants with a CDC described the importance of supporting independent leisure for a partner to recognize their leisure needs and preferences, they also suggested that it was important for them to pursue individual activities and experiences. Maintaining friendships was important for relationship functioning, as explained by Lisa who stated,

Every day I struggle with keeping a good attitude. And I feel like you need a really good balance with keeping ties with people in your former life and also it's really important to keep ties with people who are struggling with a chronic illness as well. I need a fix of both, and if I didn't have support from people who are struggling like I am I would have a much harder time. I know there are others who are dealing with the same issues and I talk to these people when I'm down.

Although CDC-related limitations often resulted in a smaller social world for partners with a CDC, participants suggested that an additional benefit of utilizing supports fostered opportunities to develop friendships separate from a partner. These friendships facilitated

participants' efforts to reduce discussion and complaining about CDC-related losses and limitations with their partner. Christine observed,

So I think one of the problems with a chronic condition is you tend to withdraw and that is true in conversation, you know? And you don't always want to talk about, the things that I talk about over and over with my friends and in the chronic fatigue support group is, basically, the same complaints. And those are that you have a small world, that you don't know what to talk about, that you're, you know, not as interesting as you once were. And you know, you just say that over and over. You don't say that over and over to a spouse because it gets boring. It *is* boring. So that makes a really neat divide which is very handy, because I get that out and I don't have to say that to Jeff. I don't have to complain as much.

Partners without a CDC supported the value of this relationship-focused strategy. They suggested that willingness to support independent leisure and enjoy some activities separately or vicariously facilitated efforts to **reciprocate support** because they valued opportunities to demonstrate understanding and responsiveness to the other's leisure needs, interests, and preferences. Matthew offered,

It just, I mean, it helps...I guess it helps me in dealing with her, because she is saying, "Hey! If you want to go do that, go do it. I can't, but go ahead." That helps me, I don't say tolerate, but some of the stuff she wants to do I will do it. Even though I may not feel like doing it at the time, I'll do it knowing that, "Hey! She doesn't care what I do by myself." If she wants to do something together, I'll go do it.

An important aspect of reciprocating support was explained by Lillian, who suggested that developing strategies to respect each other's needs and preferences minimized changes in leisure patterns as well as perceptions of interpersonal loss from feelings of rejection. Lillian remarked,

So we've negotiated our differences, and I actually enjoy the time alone...I guess it's, there's trust that I'm not being rejected, and there's trust that she will come back [from independent hike] and we'll have fun on that last part [hiking together] because we'll share all our experiences and our adventures.

### Summary

Previous research suggests that couples who begin their relationship post-onset of a CDC such as spinal cord injury report better marital functioning and relationship satisfaction than

peers whose relationship began pre-onset. Researchers posited that post-onset couples adjust better because they are fully aware of and willing to accommodate physical, economic, and social losses and limitations associated with one partner's CDC. Unlike couples who negotiate CDCs where post-rehabilitation needs are well understood and skill levels are reasonably stable for extended periods of time, participants in this study revealed that tension and relationship dissatisfaction could exist among post-onset couples if they differed in their perceptions of the CDC. Four couples exemplified that when one or both partners had a tendency to (a) deny, (b) maximize, or (c) minimize the severity of the CDC and associated losses and limitations, they had to engage in substantially more mental work to overcome unrealistic expectations and different interpersonal standards. Differing perceptions of the CDC appeared to be one factor that shaped leisure patterns among some participants in this study.

Irrespective of participants' perceptions of the CDC, partners with and without a CDC described strategies to overcome challenges and promote participation in shared leisure. Activity-focused strategies promoted participants' ability to engage in multiple aspects of normal daily life, including leisure. Activity-focused strategies included creating healthful routines and modifying activities and expectations to accommodate leisure needs, interests, and skills of both partners. Relationship-focused strategies facilitated participants' attempts to accept and accommodate one partner's CDC with the aim of minimizing the importance of losses and limitations. Relationship-focused strategies included accessing leisure with a partner, maintaining open communication, and reconceptualizing the role of leisure in the relationship. These strategies appeared to shape couples' leisure patterns and may also have influenced perceptions of relationship functioning (see Table 4).

Table 4. Influence of Shared Leisure on Relationship Functioning

<p><b>DIMINISHED RELATIONSHIP FUNCTIONING</b></p> <p><i>Exacerbated CDC-related symptoms</i> (*n = 4, **np = 4)</p> <ul style="list-style-type: none"> <li>• Increased health-related costs (n = 2, np = 2)</li> <li>• Resulted in hitting the wall (n = 3, np = 2)</li> <li>• Created restrictions in other aspects of life (n = 2, np = 2)</li> </ul> <p><i>Highlighted CDC-related changes</i> (n = 6, np = 4)</p> <ul style="list-style-type: none"> <li>• Identified inequitable leisure lifestyle (n = 3, np = 3)</li> <li>• Contributed to feelings of guilt (n = 2)</li> <li>• Contributed to frustration (n = 4, np = 2)</li> <li>• Contributed to perceptions of obligation (n = 2, np = 1)</li> </ul> <p><i>Diminished connection with partner</i> (n = 4, np = 2)</p> <ul style="list-style-type: none"> <li>• Reduced time spent together (n = 4, np = 2)</li> <li>• Contributed to perceptions of interpersonal loss (n = 4, np = 2)</li> </ul> <p><b>ENHANCED RELATIONSHIP FUNCTIONING</b></p> <p><i>Enhanced connection with partner</i> (n = 4, np = 6)</p> <ul style="list-style-type: none"> <li>• Contributed to understanding of limits (n = 2, np = 2)</li> <li>• Contributed to demonstrations of support (n = 2, np = 4)</li> <li>• Reduced perceptions of interpersonal loss (n = 3, np = 4)</li> </ul> <p><i>Enhanced conversation &amp; dialogue</i> (n = 5, np = 5)</p> <ul style="list-style-type: none"> <li>• Improved humor (n = 2)</li> <li>• Exposed to a variety of interpersonal interactions (n = 3, np = 3)</li> <li>• Strengthened relational bonds (n = 3, np = 4)</li> </ul> <p><i>Instilled sense of relationship continuity</i> (n = 5, np = 4)</p> <ul style="list-style-type: none"> <li>• Provided reminders to appreciate partner (n = 2, np = 2)</li> <li>• Rediscovered &amp; reinforced roles (n = 2, np = 2)</li> <li>• Contributed to shared history (n = 3, np = 2)</li> <li>• Contributed to perceptions of normalcy (n = 2, np = 2)</li> </ul> <p><i>Expanded the relationship</i> (n = 4, np = 3)</p> <ul style="list-style-type: none"> <li>• Provided opportunity to explore new interests (n = 3, np = 2)</li> <li>• Provided opportunity to modify mutual expectations and goals (n = 3, np = 2)</li> </ul>
---

\* n = partner with a CDC, \*\*np = partner without a CDC

### Influence of Shared Leisure on Relationship Functioning

Just as encounters during shared leisure could satisfy expectations for preferred experience and be perceived positively or negatively, participants' reflections regarding consequences or outcomes of these encounters were described positively or negatively. Although some outcomes of shared leisure were identified as occurring immediately during or after participation (e.g., conversation or improved humor), others were identified as occurring gradually and contributing to sustained changes in relationship functioning or interpersonal

interaction (e.g., instilled sense of relationship continuity, highlighting CDC-related changes). Therefore, changes in leisure patterns and outcomes of shared leisure may be described as contributing to participants' perceptions regarding diminished or enhanced relationship functioning.

### Diminished Relationship Functioning

While numerous positive outcomes of shared leisure were identified, participants also suggested that changes in the type, frequency, or intensity of participation could contribute to negative outcomes. Shared leisure was described as contributing to diminished relationship functioning when activities and experiences (a) exacerbated CDC-related symptoms and routines, (b) highlighted CDC-related changes, and (c) diminished connections with a partner.

Exacerbated CDC-related symptoms. Partners with a CDC frequently suggested that they were acutely aware of ways that their participation in daily activities, including leisure, could exacerbate CDC-related symptoms such as reduced mental clarity, fatigue, or pain. Caroline and Christine previously described the experience of going to a movie as one that could exacerbate symptoms. As a result, Christine suggested that for many partners with a CDC, eventually all activities are viewed in relation to the potential for **increased health-related costs**. Christine stated, "The question is always how much it will cost you. So you view the world, even leisure or enjoyable things, you view that in terms of cost."

Costs of shared leisure were usually associated with the physical repercussions that could have effects for days or even weeks later if participation **resulted in "hitting the wall."** "Hitting the wall," a term coined by Christine, described the often prolonged relapse or exacerbation that could result by pushing oneself to complete or engage in tasks and activities beyond one's usual limits. Christine remarked,

I didn't realize it but I was really doing things and feeling pretty good, so, ah, and so that's why you want to be careful not to deliberately hit the wall. Because there's two ways of hitting the wall. One is a physical cycle that is not seemingly under your control but just happens, and one, is, ah, when you really go all out and do a lot of things and cause it yourself.

Hitting the wall was also described by Sarah, who explained how pushing through certain activities to meet desired or perceived relationship needs could result in prolonged exacerbation or relapse. Sarah expressed,

Well, over the holidays, that's the best example I can think of right now, is I'll say in my mind that I want to do these certain things, and I did a good bit of sewing over the holidays and wanted to do some things with Bob. And there were some days that I thought, "I'm so tired and I just need to back off." Then I think, "Well, I've only got a certain number of days left." So I'll push and I managed to push the whole way through the holidays on some things, but then it comes back and I pay for it later.

Often relapses or exacerbations **created restrictions to other aspects of life**. Greater need for sleep and rest, and further challenges to physical mobility could reduce participants' desire for and ability to engage in shared leisure and social opportunities. When this occurred, the frequency and quality of interpersonal interaction with a partner was greatly diminished because the focus of living was exclusively on the CDC. Christine observed,

Because there have been times when I've really done nothing but stay in bed. That's all I've done, so then I'm not having any activities...you're aware of it [CDC] all the time, but it depends on how much your life shrinks, you know. And when it's shrunken down to being on the sofa all day and in the bedroom at nights then it's a very small world, and you're just miserable all the time.

That participation in shared leisure created restriction in other areas of life did not go unnoticed by partners without a CDC, many of whom recognized that their partners evaluated and made choices in anticipation of potential costs. Tim stated,

She very seldom feels up to a bike ride. I mean, lots of times she says that she feels like a bike ride, that we like to do on a weekend or something like that. Often it's not that she can't do it but she's afraid if she does it she'll feel crummy for a couple of days afterwards. If she pushes herself too hard, then she usually has to pay. I can only think of one time in the last two years that she suggested going for a bike ride.

Similarly, Randall acknowledged that hitting the wall could exacerbate Lisa's symptoms for lengthy periods of time, and had mixed feelings about her desire to participate in leisure in this way. Randall stated,

I don't know how it affects but I do know that she makes conscious decisions about "I'm going to do this but I know it may cost me. I may be in bed for three days if I do this." You know, like go somewhere and stay out too late or whatever. I would prefer that she not do that; to me the costs never outweigh the benefits.

Highlighted CDC-related leisure changes. Shared leisure could diminish relationship functioning by exacerbating CDC-related symptoms and routines that reduced time and energy. The process of evaluating and making choices regarding their involvement in various activities often highlighted CDC-related leisure changes. Some participants suggested that shared leisure also diminished relationship functioning when they **identified inequity in their leisure lifestyle**. For example, Patty suggested that one source of recurring tension in the relationship related to relative differences in the desire and ability to enjoy food, especially snacks. Patty revealed,

The only other thing I know that sometimes is an issue in the relationship and is tangentially related to my disability is one of the things that she really likes to do for leisure I've mentioned is to go out to eat or go get ice cream or...you know, it's centered around food. And I, before my heart stuff, I was running seventy or eighty miles a week and I could eat whatever I wanted to....And I noticed around Christmas when I was home, I didn't want to go to a lot of movies [one of Lillian's preferred activities] because that would be a lot of popcorn. You know, I'm not self-disciplined enough to let her get popcorn and me not eat it. So my way of doing that is I don't, if we don't go to the movies then that's just not an issue.

Partners without a CDC also identified inequities as an outcome that diminished relationship functioning. For example, Steve described that he often struggled to pursue his own interests despite the fact that this could conflict with the expectation that he should be available for shared leisure with Caroline at any time. Steve suggested,

Well, it's sort of a pain because if I want to be involved in one of those sort of more physical activities I feel like I've always got to check out that it's all right that I spend

time in that circle. Because if I'm over there, almost assuredly Caroline isn't a part of that so it's time that's away from Caroline. So I have to be careful about managing that. And I guess there's some things that I probably don't do as often as I would like because it's time away from Caroline that she doesn't seem interested in...pursuing as an avenue for making her own network.

Participants generally acknowledged that they tried to anticipate or be responsive to each other's leisure needs and preferences. However, partners with a CDC acknowledged that sometimes they became acutely aware that their leisure lifestyle was inequitable to or restrictive for their partner and this understanding **contributed to feelings of guilt**. Sometimes when leisure opportunities presented themselves these participants felt compelled to push beyond their physical limits to accommodate the needs, preferences, and relationship expectations of their partner. Feeling guilty also diminished relationship functioning, as described by Caroline who explained,

And sometimes I *force* myself to go do these things, and other times when I just say "no" I feel guilty so, I just feel so guilty because it makes me feel like: one, I'm not actually getting to do what I would really like to do which is to have fun with Steve, and second I'm sure that...from Steve's perspective having someone always say that to you it kind of makes..I mean, I think it must make him feel that he is not a priority or that...you know, we'll end up doing the social thing on a Friday night well then on Saturday when it becomes time for [flea or grocery] market I've already used up my energy doing that social thing.

Feeling guilty was also described by Lisa, who suggested that while she was aware of Randall's preference that she not push herself when she was not well, she also perceived that she had let him down. Lisa revealed,

And then getting into these leisure activities, where I don't talk – even if, now, I'm not saying I'm a martyr because I'm not – but if we're out and I'm not feeling well I won't say anything. It's hard on him! I don't know how I would react if I were in his shoes, and I know a lot of people who have chronic illnesses who complain all the time.

Participants also suggested that the mental work required to understand and be responsive challenged relationship functioning by contributing to feelings of **frustration** when shared

leisure highlighted ways that they were unable to overcome or compensate for CDC-related changes. For example, Caroline lamented that while she valued leisure with Matthew, she had tremendous difficulty incorporating those activities and experiences as part of her regular routine. Caroline revealed,

I know that he wishes that I would save some of that for him. And I think it hurts his feelings sometimes that I don't and that's when I feel guilty, again, because I don't...I think well why didn't I save that good energy for him?

Similarly, partners without a CDC also experienced frustration that diminished relationship functioning, especially when they had difficulty managing current CDC-related limitations and expectations in light of previous relationship challenges. Lillian commented,

What I'm trying to get at is that if there's like a sudden change of demeanor while were in an event or an activity, I have to really work though [issues from a previous relationship]. At the same time I don't want to over dote. So, you know, what's it like for me? I guess I do a lot of mental work on it.

Some participants suggested that relationship functioning could be diminished when differing perceptions of CDC-related losses and limitations that affected shared leisure contributed to feelings of **obligation**. Adults with a CDC suggested because they were acutely aware of their partner's expectations regarding shared leisure, they could become overly critical of themselves and less responsive to their partner. Caroline explained,

And I think that he's, I mean, generally he's very understanding and he...um, I don't know that I could ever really say that he makes me feel guilty, really, because I don't think he ever does or tries to. I think it's just my own guilt that I feel and, you know, if someone says a little thing or a little joke about it, it's very easy to put the blame on them that they're making you feel guilty when it's really yourself...your own issues or your own self.

Kate also described perceptions of obligation to Matthew, and felt that she was falling short of her ideal. Kate stated,

And I kind of feel, like, if I was the dutiful wife I would try it, but you know, he knows that I'm kind of scared. And I don't want to pay a fortune to take golf lessons from some

specialist, you know, who's going to say maybe you can do it but maybe you can't, kind of thing.

Diminished connection with a partner. Some participants suggested that lack of acceptance of CDC-related losses and limitations or resistance to alternative leisure activities substantially **reduced time** spent with a partner and this contributed to feelings of loneliness, thereby diminishing relationship functioning.

Well, it's not a case of resentment, I guess it's a case of loneliness. A feeling of loneliness. You know, you'd like to have...if you're reading a book you'd like to giggle and share a passage that's funny to you or something like that. You know, my five-year-old is in bed, and my daughter is often up the street at her friend's house. Andrea is usually in bed by nine o'clock, so I'm left to fend for myself.

Participants who felt that their partners were not fully accepting of the CDC and therefore supportive of the use of modifications or adaptive aids also described loneliness. This lack of support not only reduced the time spent together but also reduced opportunities to shared moments of fun and enjoyment together. Andrea stated, "It's painful. I feel very lonely. I feel that it's just indicative of his not totally accepting this situation we have. It's painful."

Kate further articulated loneliness that comes from spending less time with a partner when she stated, "It's been a very limiting factor in our life. And it doesn't...it's taken a lot of the fun out of the relationship."

Lack of acceptance of CDC-related losses and limitations and associated changes in shared leisure not only diminished connections with a partner but also **contributed to perceptions of interpersonal loss**. Though participants did not expressly use the words "communal relationship," to indicate that they had expectations of reciprocal support, it was evident that some partners were disappointed that they did not receive expected support from a partner as they would have done if places had been reversed. For example, Andrea expressed,

And you know, just a lot of things that are the markers that make you feel like a productive, generative adult in terms of work and love relationships, in terms of participation in social things, I had to let all of those go. So therefore where do you get your sense of who you are? You know. So part of my sense of who I am came from my ability to fight the illness, to advocate for myself, join support groups. And I think there's a part of my husband that hasn't really accepted this disease, either. I mean, he never wants to talk about it, or really learn. I do all my own research, and I do my own decision-making. And it's been an extremely painful part of it that he wouldn't kind of come along with me. And I've just sort of accepted that.

Interpersonal loss was also described in relation to shared leisure. In particular, partners without a CDC suggested that when they perceived inequity in the way their partners participated in activities. Some experienced suspicion and resentment and felt that they were not being treated as a valued partner. Tim offered,

So I guess the one thing I would say, the one negative thing I would say about her being able to draw on her resources to be able to do things is that sometimes it makes me resentful and suspicious. Okay? I'll think, "Wow! Isn't that curious that she can find the energy to go shopping all afternoon with my daughter? Or isn't that curious that she can find the energy to go off on some workshop about spirituality or something like that, but then she can't find the energy to go off on a half hour bike ride with me?"

Lillian also explained that relationship functioning could be diminished and perceptions of interpersonal loss exacerbated when partners were unable to establish limits and boundaries on the type and frequency of support expected by each other in shared leisure and other interactions. Lillian explained,

I don't ever want to do for her, but I do need to – and that's where the interceding issue comes in – but I want to try to empower her. So if I can get her to be alert, but then sometimes she just doesn't even want to hear it. So sometimes am I crossing the line, or is she not coming to the line?

### Enhanced Relationship Functioning

Although participants suggested that shared leisure could contribute to perceptions of diminished relationship functioning, they described many more ways that shared leisure contributed positively to the frequency and quality of their interpersonal interactions. Shared

leisure was described as contributing to enhanced relationship functioning when activities and experiences (a) enhanced connection with a partner, (b) enhanced conversation and dialogue, (c) instilled a sense of relationship continuity, and (d) expanded the relationship.

Enhanced connection with a partner. Many adults with a CDC and their partners suggested that an important aspect of resolving CDC-related tensions was encouraging the other to sustain friendships and activities independent of the other. Nonetheless, use of activity and relationship focused strategies to participate in shared leisure had positive effects on relationship functioning by fostering conversations and interactions that greatly enhanced connection with a partner. Bob stated,

Well, I think it's...regardless of the condition that she has, from our marriage stand-point and everything, I think it has built a wonderful relationship that we do things together. That we don't go off on our own and I do my thing and she does her thing. And consequently it produces an awful lot of conversation and talking. We talk constantly, all the time about everything. Every evening, during the day, and certainly on the weekends we are always conversing and talking. And I think that builds a very good relationship, because there's nothing we won't talk about.

Although conversation was important for contributing to perceptions of enhanced relationship functioning, some partners without a CDC suggested that shared leisure also contributed to enhanced connection by facilitating their **understanding of limits** and acceptance of CDC-induced lifestyle changes. Bob explained,

If we understand each other, whether it be by cooking or planting herbs, along those lines, then I have a better understanding of her. Because I know, when she is not feeling bad, I know how she operates. And then I can detect, I can just tell instantly if she's beginning to have a problem. And again I think it gets back to the overall closeness these outside activities bring about. We understand each other so well and I understand her so well. I know when she's not feeling good.

Walter also explained how shared leisure enhanced relationship functioning by enhancing his understanding of Cynthia's limits. Walter offered,

I think...you know, when we, say, travel...it certainly makes me more aware of what Cynthia's needs are, and so she probably needs my assistance more than she normally would. And so, I guess, in a sense, doing that reminds me, at least, of what she's confronting. That Cynthia has to live with this disease all the time, and sometimes, you know, I can sort of forget about it, although I don't *really*.

Even among couples that had not yet fully resolved CDC-related tensions in the relationship, partners suggested that shared leisure enhanced connections with a partner because these experiences provided opportunities to **demonstrate support** for a partner irrespective of ongoing differences in perception. This was especially true when partners without a CDC made efforts to understand the others limits. Andrea offered,

I think that especially playing the games and getting out to a movie once in a while, those things have really kind of brought us back together, and kept the focus of the....just about the illness all the time. But I also think that his growing understanding and acknowledgement of my limitations has made it safe for me to do things with him. Where I don't have to go through explaining myself, or asking for special help.

Tim concurred with Andrea's assessment of the importance of demonstrating support, and suggested that this enhanced relationship functioning by contributing to the perception that they were a team. Tim explained,

And I would say that the more often that we are able to find things which we can do together, even if it's just standing side by side cooking together, those kinds of things, I think, let us both know that although we have some serious disagreements about the nature and treatment of the illness we still love each other, and we still do things together, and we still think of ourselves as a team. So those leisure activities are very important in that they let us know that although we disagree about something, or are hurt about something, or whatever the problem, that we still have a marriage and it's the two of us. Relationship functioning was enhanced when partners created opportunities to engage in

interpersonal interactions that fostered trust and mutual respect. Consequently, shared leisure had positive effects on relationship functioning when activities and experiences **reduced interpersonal loss** among partners. Demonstrations of understanding and encouragement from partners without a CDC often increased participants with a CDC's desire to ensure that reciprocity was established in their patterns of support. Andrea remarked,

I think maybe it [support and understanding of CDC-related losses and limitations] makes me more willing to do things. Because then I know that he...I won't have to go through explaining my illness, disappointing him, and all those things if I know that he'll meet me halfway. You know. So it makes me want to do the same.

Partners without a CDC also suggested that perceptions of interpersonal loss were lessened through ongoing participation in shared leisure; conversations and interactions that fostered mutual understanding and empathy were vital in establishing reciprocity in demonstrations of support. Bob explained,

Not that she and I have any great utopian marriage or anything. We have a wonderful marriage, and I think to do that you have to be able to understand and feel the other person's feelings. If you don't it gets one-sided and then problems occur in the marriage and everything else. I mean, I think because of that we, you know, just feel that we do it and we want to do it. It's not that we say, "Oh gosh, she's sick again and now I've got to go and do..." You know, it's none of that! I want to help and she does too.

Enhanced conversation and dialogue. Many participants suggested that shared leisure contributed to relationship functioning when activities and experiences enhanced conversation and dialogue with their partner. Caroline observed,

I think in a relationship leisure is important for one reason because I think your conversations are different. You're not talking about...I mean, although you can still have a nice conversation with someone on a daily basis, when you're actually put in some sort of a leisure experience I think you forget about the world you're in...and you have better conversations or more in-depth conversations or more date-like conversations that you had when you first met and you were trying to learn about each other. Christine also acknowledged the importance of conversation when she stated, "That's

probably one way that we've escaped and gotten off easily because we've done projects together and are interested in the same things so we do have things to talk about."

Ability to enjoy laughter and "in-jokes" frequently associated with conversations and dialogue generated in leisure contributed to participants' **improved humor**. Lisa observed,

“Some of the best humor comes when you’re out doing something together. It can also occur when you’re being quiet and just sitting around or whatever, but yeah, engaging in activities has really improved our ability to find more humor in these situations.”

Participants also suggested that ability to create and sustain meaningful conversations in leisure had positive outcomes for the relationship in that couples had greater opportunity to be **exposed to a variety of interpersonal interactions**. Lisa explained,

Mostly, just finding these things we can do has brought more togetherness in the relationship. It’s [shared leisure] given us more variety. It has increased the amount of time that we sit and communicate because, you know, you just kind of talk more when you’re out doing something than when you’re just sitting.

Partners without a CDC concurred regarding the importance of conversation for enhancing relationship functioning. Bob explained,

Oh, I think that’s probably the reason that we are able to converse so much, because we spend that time together. Because of the commonality of interests and everything that we have, we have so much to talk about.

Shared leisure was also described as contributing to positive relationship outcomes because participating in activities and experiences of mutual interest and enjoyment **enhanced relational bonds**. Patty stated,

We also tend to talk a lot, and sometimes it’s surface stuff about, you know, what’s happening at work or you know, with me here in school, or with just different people in our lives. But sometimes we get into, like, more deep level conversations about, you know, how our relationship is doing or, um, where we see our lives going as individuals and as a couple and what we might envision for the future. And so it ties, it just binds us closer, you know, it just creates more of a...it sort of webs us together. And it’s very positive, and it’s very enriching, and it makes us feel close.

Enhanced connection with a partner through leisure experiences that reinforced bonds was described as enhancing relationship functioning. Additionally, when partners sustained participation in activities of mutual interest and enjoyment they sustained desired patterns of

interpersonal interaction that also strengthened relational bonds by devoting time specifically to each other. Walter explained,

And I think that the activity is nice, but the second thing is that I think in a sense that you're carving out some time for your relationship. That you're creating a space in which the two of you are doing something. It's building, I think, a more solid relationship and establishing a foundation of memories and shared interests that I think will make the relationship more likely to flourish. And so you do it, in a sense, because you say that this relationship is important, that you want to do things with this person at this particular point because it's important that you have some time together to do that.

Cynthia concurred with Walter's assessment, and added,

It's very much similar in the things that we like and don't like, and it just reinforces our bond, and how much we are alike, and that we are one in many, many ways. And that's, I think, the activity of going to the movies has always just reinforced our bond.

Instilled sense of relationship continuity. Participants suggested that shared leisure also enhanced relationship functioning by instilling a sense of relationship continuity. Despite numerous CDC-related losses, limitations, and relationship changes, shared leisure was one context that allowed participants to perceive that many former aspects of their relationship remained intact. One aspect of relationship continuity was associated with participants' ability to sustain activities that **provided reminders to appreciate their partner**. For example, Walter described the importance of travel with Cynthia when he explained,

And she's capable of getting things done [during travel] that I couldn't do, that she has a way of talking to people, of dealing with them, of getting to know people, that I think is certainly one of the things that attracted me to her when we first met. That she had the kind of personality that I really liked, and one that was quite different from mine, and still is.

Similarly, Caroline described the importance of shared leisure to provide reminders about valued aspects of a partner. Caroline stated,

You can still be having an enjoyable life together just going through the motions of daily life and, I think leisure provides us with sort of a reconnection like "Oh yeah! This is why we got married!" or "I remember you!" or just getting into the place where you remember that the reason you're together is not because of all this stuff that's around you

and what you're doing in your life. It's just about you...it's just about Steve and I, and that's it. And I think leisure helps us get into that space and connect again.

Shared leisure also created contexts that allowed couples to engage in interpersonal interactions during which they **rediscovered or reinforced roles** each assumed in the relationship. Andrea offered, "And I think the basic thing is it [shared leisure] strengthens our friendship and being together. And not being in a parenting role, or the role of a sick person, or role of a caretaker. I think that those are positive things."

Lillian further exemplified the importance of reinforcing roles through shared leisure when she explained,

It's relaxing. It's a low maintenance friend type of thing. I mean, even though we're partners, this is like the best buddy type of stuff. And I've always said that I wanted to be involved and have a long-term relationship with my best friend – not meaning that if I had a best friend I'd want to be with her, but I wanted my partner to be my best friend. And we are.

In addition to providing participants opportunities to rediscover or reinforce roles, shared leisure **contributed to shared history** and relationship cohesiveness by demonstrating that not all desired routines or activities were altered by CDC-related losses and limitations. For example, Cynthia described the importance of maintaining a weekly outing to the movies. Cynthia stated,

It's part of something we've always shared and we like the same stuff, you know? Every week we get the paper and look through what movies are showing, and we both come down to the exact same thing we want to see. We know what we like.

Maintaining activities that promote conversation and intellectual development were also important and preserved a sense of continuity. Christine observed,

We both have history degrees so we have a lot in common in terms of what we're interested in so that the history provides a lot of our leisure time. I mean, it is a form of leisure for us, discussions and reading and writing. So that's been fortunate because it's something that I can continue to do.

Partners without a CDC also valued the importance of having a shared history and relationship continuity. Jeff explained,

We always enjoyed quiet type things. We enjoyed, you know on vacation, we enjoyed going to the beach and walking along the beach. Or sitting and watching the beach. Sort of sitting and watching the grass grow, so to speak, and that's our idea of fun. You know, a very quiet type of thing. And you can do that whether you're sick as well as you can do when you're healthy. There's no transition from one to the other, they're the same thing basically.

Shared leisure also instilled a sense of continuity and enhanced relationship functioning because activities and experiences **contributed to a sense of normalcy** (i.e., that couples' emulated the lives of peers without CDCs). Though participants worked to accommodate CDC-related losses and limitations, it was also important that not all aspects of their lives become completely overshadowed by the CDC. Christine explained,

You know, I don't have much of a life. And, ah, you know you can sort of begin to believe there's a life lived in television or something like that, but if you can say "Jeff and I watched a movie on so and so" then somehow that seems, you know, more normal.

This sentiment was also described by some partners without a CDC, who suggested that one aspect of a reconfigured relationship was increased capacity to participate in work and other professional activities, since partners' needs for sleep and rest dramatically altered daily routines. For these participants, shared leisure contributed to a sense of normalcy by ensuring that they continued to engage in activities and sustain interpersonal interactions with a valued partner. Randall explained, "What it [shared leisure] does is forces me to put work down and focus on *her*."

Expanded the relationship. Although continued participation in activities of historical interest and preferred experience was described as important for creating relationship continuity, couples also indicated that relationship growth required exposure to alternative and varied activities and experiences. A positive outcome of shared leisure was that it **provided**

**opportunities to explore new interests** that could contribute to the health and longevity of the relationship. Sarah remarked,

So I think it makes it stronger. I mean, I just truly believe that in any relationship you need to continue to explore new interests. So...and tend to the relationship as if it were, well it is, I mean, it's a living, changing entity or being. Because we create, between the two of us, there's an entity we create. And I think that as you explore things and find things that you enjoy doing together that it feeds that relationship part between us.

Exploring new interests also provide partners with opportunities to interact in ways that promoted learning, trust, and respect. Bob explained,

You know, like things in the kitchen probably, we learn from each other and we, I guess, we enjoy learning from each other and still continuing to discover things about each other that we haven't learned yet. I think it just, you know, the respect, I think it grows. I think the mutual support of each other whether it's, you know, the spices you use or, you know, that it turns out great. Or, you know, the base that you put on. The mutual respect, and just enjoying each other and the time that we have together.

Relationship functioning was enhanced through shared leisure experiences that allowed participants to demonstrate reciprocal support that reduced perceptions of interpersonal loss.

Some participants suggested that experiences that solidified reciprocal trust, respect, and support allowed them to change the nature of their interactions and also expanded the relationship. Lisa observed,

So I think we both started to focus on what we had to offer to one another, and most of it was the beginning of a new relationship. It was the beginning of focusing on how we were being considerate and helpful to one another.

Shared leisure also enhanced relationship functioning when partners perceived the

**opportunity to modify mutual expectations and goals** despite CDC-related losses and limitations. Sarah explained,

We are all faced with a myriad of things in our lives, and I think no matter what it is, I think your attitude towards it and what you do with it, and from this there is growth, I think, for me. I think we have grown as a couple because we've had to...we've had to maybe make adjustments and rethink things, but we've used that. I think it's made us stronger and to grow together and make the best out of it and find the good in it. And yes it's helped me redefine things and to look at things differently.

Participants without a CDC also recognized the value of shared leisure to provide opportunities to modify mutual expectations and to establish modest goals that promoted behaviors that enhanced relationship functioning. Jeff revealed,

And as a family I think we've achieved quite a bit under very difficult circumstances. And still are doing that because there are times when I get depressed over her condition, but I'm not at the point where I'm paralyzed or anything. I feel there are depressing moments because we're in a difficult situation. I can't do a lot of things I want to, and we were never able to get the money together that would enable me to do the research I wanted to do and, you know, I couldn't travel and all these things happened. But we just narrowed, narrowed our horizon. We got into a much smaller world which most people would find appallingly small, but in that little world we function.

Overall, though, the preponderance of experience describing the importance of shared leisure for contributing to enhanced relationship functioning despite CDC-related changes can perhaps be best described by Lisa, who observed,

I think it's been crucial in keeping us together as a couple and as close. And the fact of being creative in coming up with different sorts of activities, it really has kept the marriage fresh. I know that it's not as important to everyone as it was to us, because different people focus on different things. But for us it's been, I think it's what has gotten us through a lot of days when other things might not have. You know, what more can I say? It's been a lifesaver.

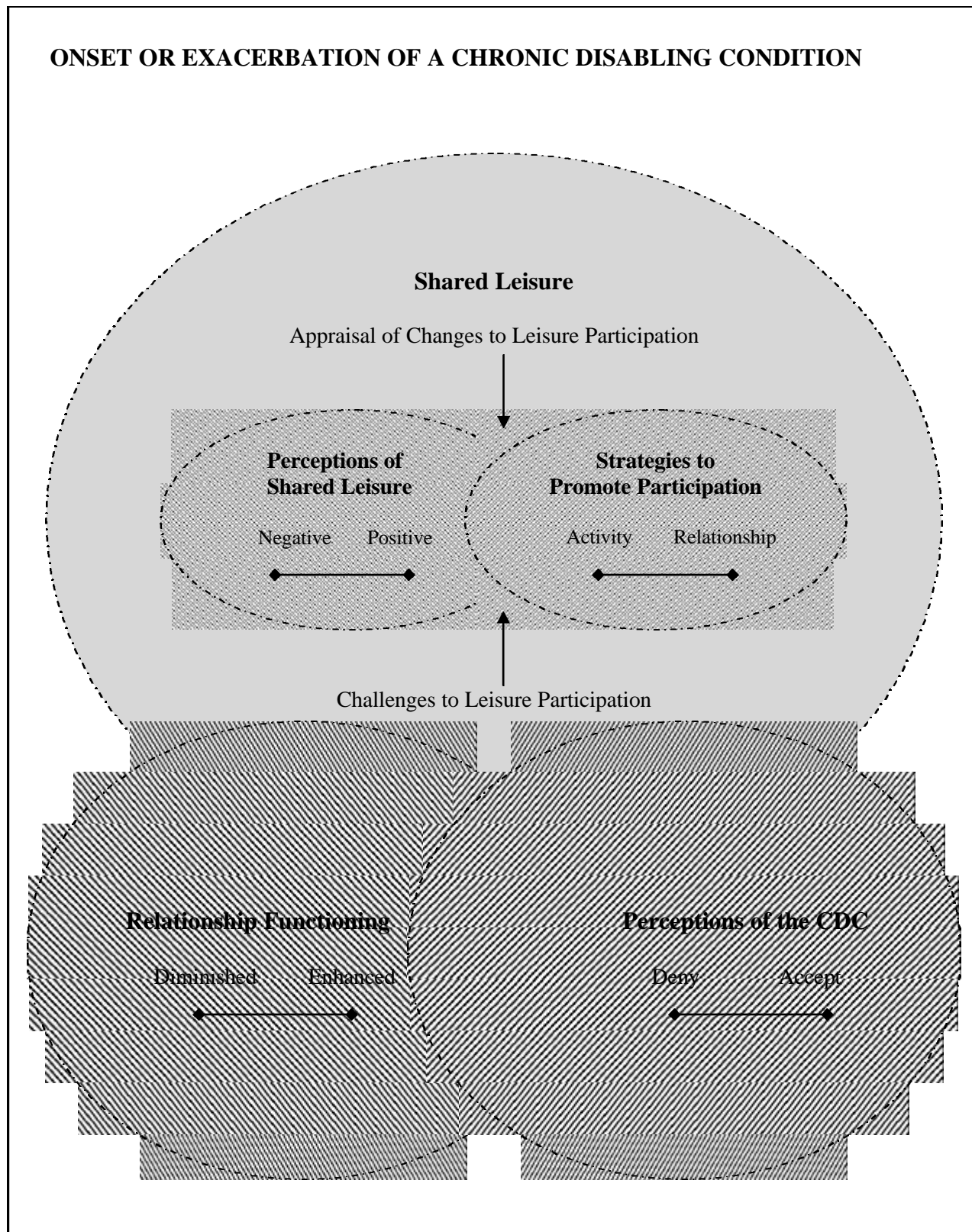
### Summary

Within this study, shared leisure is defined as activities and experiences that occur during free time with the expectation of preferred experience for both the adult with a CDC and their partner (Kleiber, 1999). Relationship functioning refers to patterns of interpersonal interaction that promote communication, role continuity, and stability desired by adults with a CDC and their partners (e.g., Orthner, 1975; Mactavish & Schleien, 1998). Interpersonal loss is defined as negative evaluations of changes in the ability of one person to provide supports (e.g., emotional, financial, instrumental) that were characteristic of a relationship prior to onset or fluctuation of a CDC (Williamson & Shaffer, 1996). Generally, participants who suggested that shared leisure

diminished relationship functioning acknowledged that one or more partners had difficulty fully resolving themselves to the CDC and associated losses and limitations in independent or shared lifestyle. Similarly, participants who suggested that shared leisure could be positively associated with relationship functioning and reduce interpersonal loss acknowledged that, while neither partner had lost hope for a future remedy and full recovery, the couple had moved closer to resolving tensions associated with the CDC and associated losses and limitations.

Shared leisure diminished relationship functioning in the context of a CDC when activities and experiences (a) exacerbated CDC-related symptoms and routines, (b) highlighted CDC-related changes, and (c) diminished connections with a partner. Conversely, shared leisure enhanced relationship functioning when activities and experiences (a) enhanced connections with a partner, (b) enhanced conversation and dialogue, (c) instilled a sense of relationship continuity, and (d) expanded the relationship. Perceptions of interpersonal loss were heightened when shared leisure exacerbated CDC-related symptoms, highlighted CDC-related changes, and diminished connections with a partner. Conversely, perceptions of interpersonal loss were reduced when shared leisure offered participants opportunities to understand limits and demonstrate support, become exposed to a variety of interpersonal interactions, and experience normalcy, and explore new interests or develop new and mutual goals. Figure one is a conceptual model representing associations among shared leisure, relationship functioning, and perceptions of the CDC as described by couples participating in this study.

Figure 1. Shared leisure and relationship functioning among couples experiencing a CDC



### Summary of Figure One

A visual representation of three main constructs that address the major categories and subcategories identified in the study may be helpful when interpreting the data. Numerous factors may influence any of these constructs independent of the other and irrespective of a CDC. Nonetheless, within this study, onset or exacerbation of a CDC is the context in which partners experience reciprocal and reinforcing associations among (a) shared leisure, (b) relationship functioning, and (c) perceptions of the CDC.

Within this study, shared leisure (upper large circle) is defined as activities and interactions that couples participate in during free time with the expectation of preferred experience for both partners. Onset or exacerbation of a CDC (labeled at top of figure) may influence shared leisure in that partners may appraise changes to the nature, frequency, and intensity of their leisure participation (depicted above inner circles in shared leisure circle) when they experience challenges to participation (depicted below inner circles in shared leisure circle) such as having sufficient energy, engaging in social activities, and maintaining travel. As partners become aware of challenges to participation (depicted below smaller circle inside shared leisure circle) that change their leisure participation, their perceptions of shared leisure may be affected. At times partners may perceive leisure negatively when they experience frustration with participation, needs to meet relationship expectations, and perceive a leisure mismatch with a partner. Partners with a CDC may be more likely to perceive leisure negatively when activities and interactions contribute to physical discomfort, social isolation, or need to substitute for preferred experiences. These sources of frustration with participation may contribute to difficulties establishing reciprocity with a partner without a CDC when activity preferences differ. However, partners may also perceive leisure positively when activities and interactions

provide opportunities to take advantage of good health, focus on interpersonal interactions, and divert attention away from the CDC. Partners with a CDC may especially appreciate normal activity while partners without a CDC may especially enjoy spending time together in ways that are not centered on the CDC.

Although partners with and without a CDC may perceive shared leisure both positively and negatively depending on the context or consequences, numerous strategies are employed to participate in shared leisure (small circle to the right inside shared leisure circle). Activity focused strategies include creating healthful routines and modifying activities and expectations regarding the frequency, intensity, and form of participation. Relationship focused strategies include learning how to access leisure with a partner, maintain open communication, and reconceptualize the role of leisure. Type of challenge and appraisal of changes to leisure participation may influence partners' choices regarding activity and relationship focused strategies to facilitate participation. Additionally, there may be an association between partners' use of strategies to promote participation and perceptions of shared leisure. Successfully using a combination of activity and relationship focused strategies in response to the type and severity of challenge may contribute to positive perceptions of shared leisure. Partners who frequently perceive shared leisure positively may be more inclined to continue using current, additional, or alternative strategies to facilitate more opportunities for enjoyable activities, experiences, and interactions. Alternatively, when individuals use a combination of strategies unsuccessfully, or rely mainly on one type of strategy, they may diminish their partners' ability to respond to the type and severity of challenge and may subsequently contribute to negative perceptions of shared leisure. Partners who perceive shared leisure negatively may be less inclined to continue using

current, additional, or alternative strategies to facilitate more opportunities for activities and interactions that they do not find enjoyable.

Relationship functioning (large circle at bottom left of figure) was described as the extent to which participants perceived that quality of their interactions was diminished or enhanced. An association between shared leisure and relationship functioning may also be relevant for couples experiencing a CDC (shaded overlapping area between shared leisure and relationship functioning). Partners who successfully use strategies to promote leisure participation, and frequently perceived those activities and interactions positively, seem more likely to describe enhanced relationship functioning despite CDC-related losses and limitations. Partners who describe enhanced interpersonal connections, conversation and dialogue, and relationship continuity as well as expansion of the relationship as outcomes of shared leisure may persevere in using strategies that promote interactions contributing to healthy relationship functioning. In contrast, partners who are less successful in using strategies to promote leisure participation, and frequently perceived those activities and interactions negatively, seem more likely to describe diminished relationship functioning in association with CDC-related losses and limitations. Partners who describe exacerbated symptoms, increased awareness of CDC-related changes, and diminished interpersonal connections as outcomes of shared leisure may become less likely to use existing strategies or consider alternative strategies that may promote interactions contributing to healthy relationship functioning.

Perceptions of the CDC (large circle at bottom right of figure) are the extent to which partners differed in their appraisal of the illness identity and associated losses and limitations. There may also be an association between shared leisure and partners' perceptions of the CDC (shaded overlapping area between shared leisure and perceptions of the CDC). Partners who

agree on a diagnosis and do not differ substantially in their perceptions of the CDC appear to be more consistent in their appraisal of challenges and changes to leisure participation. These partners appear more successful in using strategies to promote participation that contribute to positive perceptions of shared leisure. Partners who are successful in creating enjoyable experiences and interactions in shared leisure may be more likely to sustain similar perceptions of the CDC. These partners may also remain consistent in their appraisal of challenges and changes to leisure participation as well as their identification of strategies that promote participation. In contrast, partners who disagree on a diagnosis or who differ substantially in their perceptions of the CDC seem less consistent in their appraisal of challenges and changes to leisure participation. These partners seem less successful in using strategies to promote participation and perceive negative aspects of shared leisure more frequently. Partners who are less successful in creating enjoyable experiences and interactions in shared leisure may be less likely to reconcile differing perceptions of the CDC, and differences may become greater over time. Consequently, these partners may be less able to develop consistency in their appraisal of challenges and changes to leisure participation and strategies that promote such participation.

There may also be associations among shared leisure, partners' perceptions of the CDC, and relationship functioning (as depicted in the center of the figure). Partners' appraisal of relationship functioning may be one factor that influences whether, and how greatly, partners differ in their perceptions of the CDC. However, the extent to which partners differ in their perceptions of the CDC may also influence their perceptions of relationship functioning (shaded overlapping area between perceptions of the CDC and relationship functioning), especially when they perceive inequitable or unrealistic expectations for participation in leisure activities. Different interpersonal standards regarding leisure participation may require that partners engage

in mental work that diminishes the quality of activities and interactions and contributes to negative perceptions of shared leisure. Partners who frequently perceive shared leisure negatively may be less inclined to use strategies to promote participation in activities and interactions that do not satisfy their expectations for preferred experience. Partners who engage less frequently and less successfully in shared leisure may also find they have a heightened awareness of their differing perceptions of the CDC and diminished relationship functioning during those activities. These partners may become less inclined to pursue opportunities for shared leisure when they do not satisfy expectations for preferred experience. Consequently, they may be less likely to create opportunities to derive benefits from enjoyable interactions in shared leisure that may promote healthy relationship functioning. In contrast, partners who do not differ greatly in their perceptions of the CDC may not perceive different interpersonal standards regarding leisure participation. These partners may not have to regularly engage in mental work that diminishes the quality of activities and interactions, and may be more likely to perceive shared leisure positively. Partners who frequently perceive shared leisure positively may be more inclined to use strategies to promote participation in activities and interactions because their expectations for preferred experience are often satisfied. Partners who engage more frequently and successfully in shared leisure may find they have a heightened awareness of the consistency in their perceptions of the CDC and enhanced relationship functioning during those activities. These partners may eventually become more inclined to pursue opportunities for shared leisure, thereby deriving potential benefits from shared leisure that may contribute to healthy relationship functioning despite losses and limitations experienced in the context of a CDC.

## CHAPTER 5

### DISCUSSION

An attempt was made to recruit a variety of couples that would represent a diversity of CDCs, ethnicities, and socio-demographic variables that may influence the experience of shared leisure. Despite these efforts, participants in this study reflect what may be considered a specific, if not elite, sample of the population: (a) all couples were Caucasian, (b) all partners with a CDC were female, (c) with the exception of one partner who was employed as a law enforcement officer but who intended to enroll in law school in the autumn of that year all participants had earned, or were in the process of earning, at least a Master's degree, and (d) six of sixteen participants worked counseling-based professions. While the purpose of exploratory research using a qualitative research design is not to extrapolate data from a representative sample to make broad generalizations to the larger population, the fairly homogenous qualities of this sample would appear to make any findings quite limited for either theoretical or practical application. Although the small and non-representative sample of this study is undoubtedly one of its limitations it may also be a factor that informs the findings of this study. Findings may benefit because this sample more accurately contextualizes the social reality and reflects the experience of shared leisure among couples experiencing CDCs that are (a) more commonly experienced by women, (b) less visible, and (c) more susceptible to cyclical symptom change than other types of physical disabilities. Consequently, perspectives and experiences described in this study may be increase understanding of the relevance of (a) sample characteristics of

educated women with a CDC, (b) perceptions of the CDC, (c) perceptions of shared leisure and interpersonal loss, (d) influence of leisure patterns on relationship functioning, (e) implications for therapeutic recreation, and (f) limitations and areas for future research.

#### Sample Characteristics: Educated Women with a CDC

Much of the research exploring associations among CDC-related variables and relationship functioning has focused primarily on CDCs that most often affect men, such as spinal cord injury (e.g., Brown & Geisy, 1986; Crewe, Athelstan, & Krumberger, 1979). Researchers and health professionals increasingly recognize, however, that men and women differ in terms of type and prevalence of CDCs. Currently, men outnumber women 4 to 1 in CDCs resulting from trauma such as acquired brain and spinal cord injury and amputation (Nosek & Hughes, 2003). There is no doubt that these CDCs are associated with dramatic physical, economic, and social changes for both adults with a CDC and their partners. However, couples are often assisted in their efforts to manage losses and limitations since functional levels often remain stable for extended periods post-rehabilitation and health professionals are well aware of equipment and resources helpful for community reintegration (Brown & Geisy, 1986).

In contrast, women are substantially more likely to experience losses and limitations associated with CDCs that are not well understood in terms of diagnosis, treatment, or prognosis. Compared to men, women are three times more likely to have rheumatoid arthritis, four times more likely to have multiple sclerosis, five times more likely to have back disorders not resulting from trauma (e.g., spinal cord injury), and nine times more likely to have autoimmune diseases such as lupus, fibromyalgia, chronic fatigue immune dysfunction syndrome (CFIDS), or gastrointestinal problems such as irritable bowel syndrome, colitis, and Crohn's disease (Nosek & Hughes, 2003). Although not intentionally recruited in this way, the women in this study typify

this profile of well-educated, upwardly mobile, career-oriented individuals for whom onset and fluctuation of CDC-related losses and limitations may result in sudden and pervasive changes in many aspects of relationship functioning, including shared leisure, providing increased understanding of these types of CDCs.

Furthermore, the majority of women who receive actual or suspected diagnoses of autoimmune diseases such as lupus, fibromyalgia, or CFIDS are 25-35 years of age, Caucasian, and middle to upper-middle class. For couples experiencing these types of CDCs, diagnostic and treatment difficulties are further challenged by a pervasive attitude among health professionals that many CDC-related problems are psycho-somatic in origin or symptomatic of stress and/or depression from overload of personal, professional, and social roles and responsibilities (Kralik, 2002). Difficulty obtaining an accurate diagnosis and prognosis was detailed by several participants, especially Susan, Lisa, and Christine, who described the situation as one in which she was always an active and energetic person and that “one day it was like the switch just went off.” Consequently, couples may experience greater difficulty coping with a CDC to the extent that health care professionals are more inclined to dismiss, or less able to provide intervention and assistance for the physical, social, and economic changes associated with the types of CDCs most commonly experienced by women.

Participants in this study also typify patterns of behavior with respect to utilization of support groups. The initial intent of the participant recruitment process was to enlist the cooperation of both men and women experiencing a variety of CDCs. Two couples known by the researcher agreed to be interviewed, and in both cases the partner with a CDC was female. As a product of enrolling in a university course about issues related to work and disability, the researcher met and was granted two additional interviews with couples in which the female

partner had a CDC. Although the researcher attended several support groups for adults experiencing a CDC (e.g., chronic illness, arthritis, acquired brain injury, cancer, fibromyalgia/chronic fatigue, Crohn's and colitis) it was apparent that the majority of participants who attended and/or received literature from these organizations were both female and Caucasian. Of the 50 contacts made in person or via telephone, four couples agreed to participate and in all cases the female partner was diagnosed with the CDC. Although two additional referrals were made to the interviewer concerning men experiencing a spinal cord injury and type II diabetes, neither was associated with any support group and both declined to participate. The process and result of participant recruitment was consistent with evidence that although adults with a CDC and their partners may join support groups to learn more about a diagnosis and share concerns and compare physical and emotional progress with others, the majority of adults (67% for women, 87% for men) do not join support groups (Krizek, Robers, Ragan, Ferrara, & Lord, 1999). Participants in support groups are primarily Caucasian women whose social and professional obligations permit sufficient flexibility to attend meetings that often occur during regular business hours (Cox, 1999; Krizek et al., 1999). All of the four women recruited through support groups were, in fact, unemployed at the time of the interview and did not have plans to resume regular jobs any time in the near future.

It may be important to note that no participants in this study expressed regrets about beginning or continuing a relationship with their partner despite CDC-related relationship changes. Research suggests that in many situations a male partner's CDC is more negatively associated with variables associated with relationship functioning and relationship satisfaction than a female partner's CDC. For example, Hafstrom and Schram (1984) found that wives, rather than husbands, of a spouse with a CDC were less satisfied with the amount of personal attention

received from their partner, the amount of time spent together, partner's personality, and their partner as an overall companion. Additionally, wives indicated less satisfaction than husbands with changed roles as partner, parent, income earner, caregiver, and financial decision-maker. In contrast, a wife's CDC did not appear to make a difference in husband's time involvement in understanding her problems and feelings, in providing attention, in carrying out roles as husband and father, in helping around the house, or in her involvement in financial decision-making. As a result, Hafstrom and Schram (1984) suggested that traditional roles of wife, mother, and homemaker might facilitate compatibility with the experience of disability in the sense that disruption or loss of these roles is less detrimental to partners' perceptions of relationship satisfaction and functioning. Despite the findings of Hafstrom and Schram, recent studies demonstrate that women's patterns of employment increasingly resemble those of men (Mattingly & Bianchi, 2003) and that a female partner's inability to maintain employment because of a CDC might profoundly affect the couple's socioeconomic status (Goodwin, 2000). To the extent that financial strain is an additional burden in the context of a CDC, relationship functioning may be negatively affected by couples' inability to find mutual time, acquire adaptive aids, or experiment with alternative activities that may be helpful for sustaining shared leisure.

Couples' efforts to sustain shared leisure in the context of a CDC may be hampered by economic constraints, a barrier to leisure that is reported by both men and women (Shaw, 1994). However, Henderson (1996) argued that women, especially women in non-dominant groups (e.g., little education, low socioeconomic status, having a CDC) or women who exist on the margins of society may experience financial constraints more acutely. Work, especially paid

work, is positively associated with sense of entitlement to leisure (Henderson & Bialeschki, 1991).

Furthermore, the ethic of care linked to women's role as the primary caregiver and/or primary person responsible for ensuring the quality of leisure experiences for others has been linked to the lack of sense of entitlement to leisure (Mattingly & Bianchi, 2003; Shaw, 1994). Since none of the women in this study were employed full-time, it might seem that a natural outcome of onset or exacerbation of a CDC might be a reduced sense of entitlement to leisure. The women might feel that they should not pursue many independent leisure activities, or restrict involvement to shared leisure to satisfy the needs of their partner. Although the women in this study described specific constraints to leisure and to participation in shared leisure, none of them suggested that they did not feel entitled to leisure. Interestingly, some women such as Lisa, Susan, and Cynthia suggested that onset or exacerbation of their CDC encouraged them to clarify their values and re-evaluate priorities such that they now felt more entitled to leisure despite changes in current roles and ongoing constraints to leisure.

All women in this study described the magnification of leisure constraints associated with their CDC. Consistent with findings of Henderson et al. (1995) and Samdahl and Jekubovich (1997), participants in this study described constraints associated with CDC onset or exacerbation. Energy deficiencies were associated with elaborate strategies to pace themselves and perform expected social roles, including leisure. Time shrinkage was associated with additional health maintenance routines and an inability to perform many daily tasks with great speed. Restriction of opportunities and choices was associated with increased planning and problem-solving to accommodate physical and cognitive limitations on a given day. Restriction of opportunities was sometimes associated with the difficulty friends and, more importantly,

partners had believing and understanding the cyclical nature of these participants' CDC. Increased dependency on the assistance of a partner to participate in some activities, and enhanced concern for physical and psychological safety, were associated with the potential for exacerbating CDC-related losses and limitations and creating additional restrictions on valued activities. Ethic of care was associated with heightened awareness of responsibility for addressing a partner's social and leisure needs, as well as perceptions regarding mismatched leisure needs and preferences with a partner, and lack of reciprocity with a partner in leisure.

Despite these types of CDC-related structural, interpersonal, and intra-personal constraints, all of the women participated in some type of shared leisure, and in many cases an existing repertoire of shared leisure activities was expanded in ways that contributed to, or resulted in, perceptions of hope, novelty, and relationship growth. Participants' experiences support Henderson's (1994a; 1994b) argument that any understanding of leisure is highly dependent on the social context in which individuals experience leisure. For example, variables such as age, income, and family structure are described as constraints that negatively affect women's opportunities for, and experience of, leisure. However, Henderson (1996) suggested that these variables may also be mediating factors that alter or alleviate constraints for women depending on the context and type of constraint. The women in this study may have found these variables to promote, rather than diminish, opportunities for shared leisure.

With respect to education, since all of the women had earned, or were in the process of earning, at least a Master's degree some may have been especially aware of available resources and opportunities helpful to participate in shared leisure. For example, as a former school psychologist, Lisa was aware of and selected a "good" marriage therapist to assist during a time of particular stress in the relationship. Participants who were not aware of available resources

and opportunities prior to onset or exacerbation of their CDC may have had skills that facilitated their efforts to acquire knowledge and gain access to resources. For example, Andrea admitted that it was she who had done much of the research about her CDC and became aware of traditional and alternative approaches to treatment that improved her overall health and increased her ability to participate more fully in daily activities, including shared leisure.

With respect to income, none of the women lived in a situation where both she and her partner were unemployed and lacked funds for health care, necessities of living, and discretionary spending. Although none were especially affluent, all participants described participating in activities that required funds (e.g., eating out, movies) and several described purchasing equipment (e.g., dart board, electric bicycle) or modifying travel (e.g., longer layovers, renting condominiums) to facilitate participation in shared leisure. For these women, opportunities for shared leisure may have been increased through their own, or their partner's, steady employment and income.

With respect to family structure, since all of the women had partners with whom they described having fairly positive relationships, they were able to create stable routines and living arrangements that promoted good health and minimized the likelihood of hitting the wall. When any of the women experienced an exacerbation or relapse, they could count on their partner to assume social, familial, and household roles and responsibilities while they recuperated. The ability to create a lifestyle and rely on a partner to “get well and stay well” may have been especially helpful for these women to protect their health and create routines that increased the type and frequency of opportunities for shared leisure. Additionally, only one woman in this study had children who were under the age of eighteen and lived at home. It is well understood that children contribute to constraints to adults' leisure in terms of time, attention, planning and

effort, and financial resources. Since women are frequently the primary caregiver, having children in the home may constrain leisure more profoundly for women than for men (e.g., Shaw, 1994;1995). Furthermore, evidence suggests that leisure activities that include partners and their children are often intended to be purposeful and instrumental for establishing family cohesiveness, instilling family values, and providing opportunities for children to acquire leisure and life skills (e.g., Shaw & Dawson, 2001; Zabriskie & McCormick, 2003). When children are included shared leisure appears to become more child-focused rather than adult-focused and may provide partners with fewer opportunities to engage in activities and interactions that satisfy their needs for conversation, humor, and exploration of new interests that enhance relationship functioning. Thus it would appear that in the context of a CDC, variables commonly perceived as constraints to leisure (e.g., income, inflexible employment obligations, availability of leisure partner, limited or extended social network) actually enhance, rather than diminish, women's opportunities for shared leisure. Additionally, participants in this study may have found that variables such as their own and partner's education, flexibility of partner's work schedule, and steady source of income facilitated their acquisition of knowledge, skills, and resources helpful for using activity- and relationship-focused strategies that were conducive to shared leisure.

Furthermore, Henderson, Hodges, and Kivel (2002) suggested that leisure opportunities and constraints may change over the life span in relation to age and affiliation with traditional gender roles. Although this study did not specifically examine issues related to age and gender roles, it may be that these variables are also relevant to discussions of CDCs. Five of the eight women with a CDC were (a) in their early forties to mid-fifties, (b) semi-employed or retired, and (c) transitioning into new, and less time consuming, familial roles. The other three women with a CDC were (a) in their mid-twenties and thirties, (b) enrolled in graduate school, and

(c) transitioning into new employment roles such as educator or social worker. Henderson (1996) suggested that the more roles undertaken by a woman, the less likely she is to have personal leisure. These findings support that view, and may also reveal that opportunities for shared leisure area also diminished, especially in the context of a CDC. Not surprisingly, the three younger participants experienced greater constraints to, or felt the most conflicted about, shared leisure; these women described issues such as intense focus on career development and the perceived need to save good energy for career-related tasks as factors that reduced time available for shared leisure. It may be important to note that Patty was in a long-distance relationship with her partner Lillian; in addition to intense focus on graduate school and career obligations, this couple had to negotiate additional constraints relating to increased time, planning, and reciprocity in travelling to maintain the relationship.

Additionally, these women alluded to accomplishment of household tasks (e.g., cleaning the bathroom, vacuuming, refurbishing a closet) as an occasional source of conflict with a partner. Unlike Patty and Lillian who did not reside in the same home and did not have to negotiate division of labor according to gender, other young women suggested that negotiation of household tasks further reduced available time for shared leisure. Furthermore, these interactions sometimes became a context in which expectations regarding gender and CDC-related roles and responsibilities would be confronted and contribute to perceptions of relationship equity. For example, Kate's frustration with Matthew's ongoing resistance to fully assuming responsibility for vacuuming resulted in her (a) regularly performing that task despite it's likely detriment to her CDC rather than insisting that Matthew do it or allowing it to remain uncompleted, and (b) becoming increasingly resentful of that inequity and reluctance to reciprocate support in ways that were meaningful to Matthew (e.g., golf). Kate explained that she was unwilling to allow that

and other chores to remain undone, that she felt increasingly hostile because of Mathew's cavalier attitude to her CDC, and that it diminished her desire to negotiate other aspects of their relationship including shared leisure. Thus, younger women who perceive and desire current gender-role expectations regarding career, home, and leisure equity may find that, in the context of a CDC, they may prioritize economic and household tasks. If partners do not share these assumptions of equity, the frequency and quality of shared leisure may be diminished as women with a CDC feel compelled to attend to their priorities and less willing to respond to a partner's preferences, especially with respect to shared leisure.

In contrast, the older participants often suggested that though they valued past roles such as parent, wage earner, family social coordinator, they could embrace a slower life. While they were aware that, relative to peers without a CDC, they did not accomplish as many household or employment tasks, or assume as many traditional social roles such as volunteer, they suggested that despite occasional feelings of guilt or disappointment they did not dwell on these discrepancies. Furthermore, these women were less sensitive to inequities in expected gender- and CDC-related roles and responsibilities with respect to accomplishment of career and household tasks. Although several of these women remarked that they would prefer to work at least part-time to contribute to family income, they did not feel pressured to assume any roles or responsibilities that could negatively affect their health. Additionally, these women acknowledged that frequently, and for extensive periods of time, their partners assumed substantial, if not total, responsibility for completing household tasks. They overlooked personal preferences regarding the process by which tasks were accomplished or level of tidiness or clutter, and valued this as a contribution that protected good health and enhanced opportunities to interact in meaningful activities. Rather than perceiving their CDC solely as an impediment to

their career, household, and social aspirations, these women suggested that they perceived many of those roles and activities as less valuable than their relationships with friends and family, especially with their partner. These women became quite stringent in their priorities and devised strategies to preserve energy for participation in shared leisure rather than the fulfillment of expected social roles such as wage earner, volunteer, or facilitator of family leisure.

Minimization (through choice or circumstance) of some expected social roles in the context of a CDC appeared to reduce some constraints to leisure commonly described by women. Thus, it may be that in the context of a CDC, age may be associated with willingness to surrender expected roles to preserve energy and protect health for prioritized activities such as sustaining valued relationships and participating in leisure with a partner.

#### Perceptions of the CDC

Women's perceptions of and reactions to expected social roles may be one factor that affects shared leisure in the context of a CDC. Another factor that may also have implications for relationship functioning may be partners' perceptions of the CDC itself. Hafstrom and Schram (1984) suggested that it is the perception, rather than the reality, of a CDC that may affect variables associated with relationship satisfaction, and this may also be relevant with respect to shared leisure.

Studies (e.g., Brown & Geisy, 1986; Crewe et al., 1979) that have examined relationship functioning in the context of a CDC have argued that timing is an important variable affecting relationship satisfaction and strong predictor of relationship dissolution. Among adults aged 18 to 65 years, partners in relationships that begin post-onset of a CDC report significantly less conflict, emotional distress, and relationship dissatisfaction than those whose relationship began prior to onset of a CDC (e.g., DeVivo & Fine, 1985; Simmons & Ball, 1984). Although age and

life experience undoubtedly affect partners' ability to contend with unexpected disruptions associated with CDC-related losses and limitations, Gordon & Feldman (1998) suggested that relationships beginning post-onset of a CDC may also fare better because partners are aware of and better able to embrace the CDC as part of their lives because they are aware of the breadth and scope of losses and limitations prior to deciding to pursue or commit to the person with a CDC. However, among the eight couples who participated in this study four experienced numerous challenges to positive relationship functioning and interpersonal interaction, including shared leisure. Three of the four couples were, in fact, "young couples" (young in age and longevity of relationship), providing additional support that effective problem-solving and negotiation skills are coping resources that couples acquire over time and experience (e.g., Randall, 1994a; 1994b; Gordon & Feldman, 1998). Interestingly and contrary to previous research (e.g., Brown & Guisy, 1986; DeVivo & Fine, 1985) these three young couples also began their relationship post-onset of one partner's CDC and, presumably, were aware of CDC-related needs, losses, and limitations prior to committing to an enduring an exclusive partnership.

It may be important that previous studies have predominantly examined effects of a CDC on relationship functioning among adults experiencing a spinal cord injury (SCI), a visible, diagnosable, and reasonably well understood physical disability among health professionals and the general population. While the effects of SCI are enduring and often result in numerous losses and limitations for both the adult with a CDC and a partner, it is important to note that while modest physical and cognitive changes may occur as part of ongoing rehabilitation, an adult with SCI will eventually plateau to a stable level of functioning that can be accommodated with little variation for extensive periods of time (Stumbo & Bloom, 1990). Consequently, it is not unreasonable to infer that couples who begin a relationship post-onset of a visible, diagnosable,

and stable physical disability will experience less interpersonal distress because they are, or can become, well-informed and appropriately responsive to CDC-related needs, losses, and limitations. In contrast to previous studies, these couples experienced a range of CDCs that were not always visible, easily diagnosable, or well understood by either health professionals or the general public. Furthermore, the CDCs represented in this study are highly unpredictable in terms of the source, frequency, duration, and severity of numerous physical and cognitive symptoms such as fatigue, dizziness, headache, muscle weakness, pain, and information/sensory processing. Rather than reaching, and expecting to achieve, a prolonged plateau of physical and cognitive functioning, these participants admitted that many facets of their lives were affected by the erratic and often uncontrollable cyclical nature of their CDC and potential for prolonged if not permanent exacerbation.

However, several couples embraced and accommodated the challenges and inconveniences of the erratic nature of their CDC less successfully than others despite the fact that many of them began their relationship post-onset. Goodwin (2000) suggested that symptom change associated with cyclical CDCs generates new information that requires adaptation and change to the relationship, but movement away from stability is known to be highly disruptive. Goodwin suggested that symptom change prompts energy change that may affect conflict and adjustment; relationship satisfaction is enhanced when both partners feel supported in the context of these changes. Consequently, it may be that timing is an important factor affecting relationship stability and perceptions of satisfaction, especially among couples experiencing a CDC such as SCI. However, it may be that in the context of less stable CDCs it may be equally important for partners to offer and receive support that is conducive to energy changes that minimize conflict and stress. Since partners' willingness to engage in supportive behaviors may

be affected by their illness beliefs, perceptions of the CDC may be an equally important factor affecting relationship satisfaction.

According to Heijmans, DeRidder, and Bensing (1999), perceptions of a CDC include the components of illness identity (i.e., symptoms), time line or expected progression, cause, control/cure, and consequence. Components of CDC perception that are most strongly associated with measures of psychological and interpersonal distress are (a) consequence, indicating that the CDC is perceived as having serious and detrimental effects on most aspects of bio-psycho-social functioning and daily lives, and (b) control/cure, indicating that the CDC is perceived as uncontrollable and unresponsive to efforts at resistance or change (Murphy, Dickens, Creed, & Bernstein, 1999). However, when partners differ in their appraisal of these components, the couple is more likely to experience conflict and diminished relationship functioning than if they agree on the nature, severity, and prognosis of the CDC and work collaboratively to cope with its detrimental effects (Helder, et al., 2002). Although this study did not specifically probe issues related to perceptions of the CDC, it was apparent that some partners differed substantially in their perceptions of the CDC. These differences in perceptions of the CDC contributed to conflict in shared leisure that subsequently diminished relationship functioning.

Illness identity may be one component that affects partners' appraisal of the other components and overall perception of the CDC. Helder et al. (2002) examined couples' perceptions of Huntington's Disease, and found that partners were in agreement regarding (a) long duration of the disease, (b) negative consequences on their daily lives, and (c) little hope of cure or control of the disease, because the genetic factors and numerous and tangible symptoms contributed to a strong illness identity. A similar study was conducted by Heijmans, De Ridder, and Bensing (1999) in which the CDC perceptions of couples experiencing Addison's Disease

(AD) and Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) were compared. Heijmans et al. (1999) found that all partners of the adult with a CDC exaggerated the illness in the sense that they were more pessimistic about the future course of the CDC and about possible cure/control, but that couples with CFIDS were more likely to differ in their perceptions of illness identity as well as cure/control. Heijmans et al. suggested that an important factor affecting perceptions of illness identity is that some CDCs, such as AD, are genetic and diagnosable while others such as CFIDS have no known cause and no standardized method of determination. In fact, the idiopathic nature of CFIDS has resulted in decades-long debates about whether the etiology of the CDC is organic or psychological (Moss-Morris, Petrie, & Weinman, 1996). Among participants in this study, it was evident that some partners differed in their illness perceptions and in their tendency to deny, minimize, or maximize the severity of the CDC especially in shared leisure.

Among participants in this study, only one couple readily admitted that they differed outright in their assessment of the illness identity; Andrea perceived, and Tim concurred, that he questioned both the diagnosis of CFIDS and, if this was in fact the correct diagnosis, whether its etiology was organic or psychological. Not surprisingly, this couple diverged greatly in their overall perception of the CDC and described conflicts that negatively affected shared leisure and diminished relationship functioning. For example, Tim's reluctance to modify activities or utilize adaptive equipment to facilitate participation in physical activities in acknowledgement of Andrea's limitations contributed to her feelings of frustration and resentment. In turn, Andrea's attempts to participate in physical activities (e.g., biking, skiing) without the use of aids to "show that I'm trying" contributed to the constant struggle for recognition of her symptoms as constituting a real medical problem (Heijmans et al., 1999). Her efforts also contributed to Tim's

skepticism regarding the nature and severity of her CDC. Both partners described feeling lonely, frequently mismatched in leisure, and in many respects living parallel lives. This couple offered the most support to the findings of Heijmans et al. (1999) that less marital satisfaction is associated with a higher degree of dissimilarity in perceptions of the CDC and failure to recognize and acknowledge its consequences in all aspects of daily living.

Several other couples differed in their perceptions of the CDC, especially with respect to their tendency to maximize or minimize symptoms. Shared leisure was one context in which couples' differences appeared to negatively affect relationship functioning. For example, Lillian's tendency to maximize the severity of Patty's symptoms potential for a myocardial infarction caused her to feel the need to curb Patty's enthusiasm for participating in physically strenuous activities (Heijmans et al., 1999). In turn, Patty's minimization of her symptoms and tendency to downplay the risks of participation in response to the inequity in her desire and ability to participate (Henderson, Bedini, & Hecht, 1994) caused her to perceive Lillian's actions as controlling and overprotective. In contrast, Kate's fear of paralysis led her to maximize the severity of her symptoms and engage in self-protective behaviors and to perceive the downside of participating and looking "healthy" as contributing to Matthew's unwillingness to respect the limits of her ability. In turn, Matthew's tendency to minimize Kate's symptoms led him to increase his efforts to motivate Kate to become more active (Heijmans et al., 1999), such as persisting in his requests that Kate learn how to play golf.

Couples who differed greatly in their perceptions of the CDC struggled to reciprocate support with a partner, and described detrimental effects of shared leisure on relationship functioning. These couples spent less time with each other and described feeling lonely and frustrated. When they did participate in shared leisure, they sometimes did so because of

perceived obligation, and struggled mentally to sustain the energy needed to understand and accommodate cyclical changes as well as engage in less satisfying interpersonal interactions. In contrast, couples such as Cynthia and Walter, or Lisa and Randall, whose perceptions of the CDC did not significantly diverge regarding symptoms, course, consequence, or cure/control were better able to resolve CDC-related tensions. These couples were better able to use adaptive aids, change the emphasis of leisure participation, and sustain shared interests. For these couples, shared leisure became a context in which they could redefine the relationship, modify aspirations, and reciprocate support with a partner in ways that promoted more satisfying interpersonal interactions and enhanced relationship functioning. Consequently, it may be that diverging perceptions of a CDC also affects couples' ability to engage in, and perceptions of, shared leisure. Couples' perceptions of shared leisure may, in turn, affect perceptions of interpersonal loss and associated aspects of relationship functioning such as communication, stability, and role continuity.

#### Perceptions of Shared Leisure, Interpersonal Loss, and Relationship Functioning

Couples who diverge greatly in their perceptions of the CDC may be described as being at differing points on the illness trajectory where lack of agreement regarding the nature, severity, and duration of the CDC may negatively affect partners' ability to cooperate and effectively respond to evolving needs, losses, and limitations (Goodwin, 2000). In contrast, couples whose perceptions of the CDC do not substantially differ may be better able to incorporate episodes of uncertainty, exacerbation, and stability as part of their lifestyle. Couples whose perceptions of the CDC do not substantially differ may also be better able to effectively respond to various states of transition associated with evolving needs, losses, and limitations and make changes so that the CDC can have a place in their lives (Kralik, 2002). One area in which

couples differed in their ability to respond to and embrace the CDC was shared leisure. While all participants described positive and negative perceptions and outcomes of shared leisure on interpersonal interaction and relationship functioning, there do appear to be differences in the affective quality of couples' experience that affected perceptions of interpersonal loss.

Studies (e.g., Holman & Jacquart, 1988; Orthner, 1975; 1976; Orthner & Mancini, 1990;1991) examining shared leisure among couples have argued that quantity of time spent together, especially in highly interactive pursuits, is associated with measures of relationship functioning such as communication, stability, and role continuity. Recently, it has been suggested that it is not time, but the nature of those interactions and the affective quality of couples' time together as reflected in their expressions of affection and negativity that is important for relationship functioning (Berg, Trost, Schneider, & Allison, 2001; Crawford, Houts, Huston, & George, 2002). Although leisure is generally assumed to be positive (Henderson, 1996), participants in this study perceived it as both negative and positive and suggested that the affective quality of time spent together was an important factor in their appraisal of the experience and outcomes of shared leisure and perceptions of interpersonal loss.

Flora and Segrin (1998) suggested that joint activity acts as a potential context for interaction in which the quality of time and execution of rewarding behaviors can enhance or detract from relationship functioning. Among these participants, shared leisure was perceived negatively when a partner experienced constraints to participation and the outcome of that activity included exacerbation of CDC-related symptoms and restriction of daily activities, including leisure. Perhaps more importantly, shared leisure was perceived negatively when challenges to participation stemmed from the need to meet relationship expectations and the outcome of that activity highlighted CDC-related changes. When combined with additional

CDC-related tensions such as differing perceptions of the CDC, it is not surprising that partners may resist alternatives, rebuff suggestions, elect to “wear a good face” and participate despite a lack of interest or potential risk, and struggle to understand and respond appropriately to conflict stemming from interpersonal interaction in shared leisure. The positive emotions associated with these interactions likely diminished as partners experienced feelings of frustration or guilt with inequities in leisure lifestyle, difficulty in establishing reciprocity, and the need for them to overlook personal preferences for the sake of a partner.

When positive emotions associated with shared leisure are diminished because partners perceive the experience and outcomes of that interaction negatively, relationship functioning may be compromised. Each partner’s leisure satisfaction affects his or her relationship satisfaction, which directly influences a partner’s relationship satisfaction (Berg et al., 2001). Partners who had not resolved CDC-related tensions suggested that the mental work required to engage in shared leisure and other interpersonal interactions contributed to frustration with participation, perceptions of obligation, and guilt for unsuccessfully reciprocating support with a partner through shared leisure. They also described diminished connection with a partner and feelings of loss, as evidenced by perceptions of inequity in participation, feelings of loneliness, and spending less time together in shared leisure. These findings provide additional support that negative evaluations of changes in the ability of one person to provide supports (e.g., emotional, financial, instrumental) to another person contribute to perceptions of interpersonal loss. These findings may also provide evidence that positive affective interaction, frequently experienced through shared leisure, is an expected and desired form of support that can also influence perceptions of interpersonal loss in the context of a CDC.

Although the experience and outcomes of shared leisure were perceived negatively and in some circumstances appeared to contribute to perceptions of interpersonal loss, participants' positive appraisal of the experience and outcomes of shared leisure may contribute more substantially to an understanding of how the affective quality of shared leisure is associated with perceptions of interpersonal loss and relationship functioning. Seigenthaler and O'Dell (2001) suggested that couples who share common views about leisure experience greater relationship satisfaction and longevity; sharing a common view about leisure may be especially relevant in the context of a CDC. Partners were consistent in their explanation of why they perceived shared leisure as a positive experience. Taking advantage of good health, diverting attention away from the CDC, and focusing on interpersonal interactions reflect a view of leisure that emphasizes social and interactional qualities (Shaw & Dawson, 2001) that may be especially important for relationship functioning.

Emphasizing the social and interactional qualities of shared leisure may influence partners' positive appraisals of the outcomes of shared leisure; these positive appraisals provide additional support that shared leisure can enhance aspects of relationship functioning such as communication, role continuity, and stability. Consistent with findings of Lyons (1999) and Dupuis and Pedlar (1995), participants described shared leisure as providing contexts and experiences in which partners could minimize negative talk and complaining, share humor, increase the variety of interpersonal interactions, and strengthen relational bonds through empathy and improved understanding. Partners' ability to offer and receive suggestions and take comments at face value reflect the behaviors associated with positive communication, such as reflective listening and providing supportive comments (Olson et al., 1989). Opportunities for more frequent and varied conversation and dialogue also enhanced perceptions of connection

with a partner. Shared leisure often provided opportunities for interaction in which partners could acquire knowledge of the CDC, learn or rediscover valued attributes, and reciprocate support and understanding.

Shared leisure also contributed to relationship stability in that opportunities and interactions instilled partners with a sense of continuity. Consistent with the findings of Helgeson (1993), participants described numerous changes in relationship roles and responsibilities in association with CDC-related losses and limitations. However, participants also provided support for Kleiber's (1999) assertion that in the face of negative life events leisure can be used as one context in which to reconnect with significant others in familiar and/or mutually agreed activities. For example, maintaining a weekly date night at a local restaurant created a sense of shared history for Sarah and Bob, while continuing a honeymoon tradition of yearly foreign travel provided reminders to appreciate valued aspects of a partner for Cynthia and Walter. The memories of shared activities and of having good times together is an important part of building a sense of cohesiveness (Shaw & Dawson, 2001) and preserving a sense of connection with one's past self and life (Hutchinson, Loy, Kleiber, & Dattilo, 2003). Furthermore, these findings provide additional support that leisure creates a context in which partners may rediscover or reinforce roles important to their self-identity (Samdahl, 1992). Additionally, shared leisure creates a context in which to demonstrate abilities and express important self-attributes (Hutchinson et al., 2003) that allow both partners to be perceived as valuable, interesting, and desirable individuals possessing important skills and gifts to contribute to the relationship (Lyons, 1999).

These findings also provide additional support that outcomes of shared leisure are not solely associated with maintenance or return to a prior leisure lifestyle, but with the ability to

create new leisure experiences (Lyons, 1999) and reconfigure the relationship to reflect CDC-related changes. Participants provided additional support that shared leisure contributed to a desirable sense of normalcy in that they resumed previous or engaged in new activities and experiences similar to those of peers without CDCs (e.g., Hutchinson et al., 2003). A desirable sense of normalcy was also associated with companionship that generated positive feelings and a sense of common identity that subsequently enhanced relationship satisfaction (Crawford et al., 2002). Not only did participants value opportunities for normalcy, they also desired opportunities to experience “ordinariness” (Kralik, 2002 p. 151). Ordinariness requires active transition in which participants not only embrace the CDC and make changes so that it has a place in their lives, but also perceive themselves as making progress in their lives regarding social and interpersonal issues that have little to do with the CDC. Normalcy entails establishing equilibrium and lifestyles comparable to those of peers without a CDC, while ordinariness entails forward movement. Participants suggested shared leisure was an important context in which to move forward and make progress by exploring new interests and reconfiguring the relationship as they “coped with the flow of everyday relating” (Baxter & Dindis, 1990, p.123).

Exploring new interests was important for reconfiguring the relationship because when partners focus primarily on the CDC, they tend to lose their sense of self (Tuck & Wallace, 2000). Perceptions of the self include those beliefs, values, and expectations that provide insight into what one would like to achieve and what one is capable of doing (Henderson et al., 1994). For example, Andrea suggested that her prolonged inability to work, complete household tasks, actively participate in childrearing activities, and sustain a social life eroded her sense of self because “when all the markers of a generative person are gone, where do you get your sense of who you are?” Shared leisure is a context in which all participants described making progress, or

experiencing “self-expansion” and developing a sense of potential efficacy (Reissman, Aron, & Bergen, 1993). As participants explored new interests through shared leisure they reported that their self-perceptions in leisure evolved. Christine’s willingness to become a “television watcher” facilitated efforts to continue learning and discussing topics of interest with Jeff despite her increasing inability to read. Kate’s rethinking of what it meant to be physically active and competitive facilitated efforts to participate in sports-like activities by including darts as an acceptable alternative to volleyball or softball. Jeff’s evolving perception of himself as a cook allowed him to experience enjoyment from experimenting with various recipes and preserved Christine’s energy to participate in valued activities such as dinner conversation or a post-dinner walk.

Irrespective of how couples explored new interests to reconfigure the relationship, relationship functioning was enhanced through partner’s enhanced mutual understanding and ability to modify mutual expectations and goals. Positive emotions that were experienced during shared leisure confirmed a feeling of reciprocity that minimized partners’ perceptions of interpersonal loss and enhanced their relationship satisfaction. Findings provide additional evidence that relationship continuity associated with shared leisure is not dependent on the type of activity or intensity of engagement, but rather that partners participate in activities that have personal meaning and situate them in their past, present, and future lives (Hutchinson et al., 2003). Additionally, these findings support the argument by Samdahl and Jekubovich (1997) that an understanding of the value of leisure in people’s lives may be enhanced by moving away from a focus on leisure activities towards a deeper respect for the significance of relationships. Although shared leisure is not a panacea for all relationship problems, it may be that those activities and experiences may be particularly helpful for facilitating relationship functioning by

promoting communication, role continuity, and stability. Consequently, it may be important to examine factors that influence couples' leisure patterns and, in particular, understand the relevance of core and balance activities (e.g., Kelly, 1996; Zabriskie, 2001; Zabriskie & McCormick, 2001; 2003) in the context of a CDC.

#### Influence of Leisure Patterns on Relationship Functioning

According to Zabriskie and McCormick (2001) it is important to recognize leisure involvement as a valuable component of family life and relationship satisfaction. Participants in this study also described shared leisure as an important component of their lives, and described a wide variety of activities in which they participated. The most frequently identified activities included outdoor recreation such as hiking, bicycling and kayaking, conversation, reading, watching movies/television, cooking, eating out, socializing with friends, attending special events (e.g., concerts, sports), gardening, and travel. These activities represent an array that is consistent with Zabriskie's (2001) assertion that it is important to have both core and balance activities to promote healthy relationship functioning.

Core leisure activities are done on a regular and consistent basis, may be spontaneous, and do not require substantial inputs of time or money (e.g., watching television and videos, playing board games, playing in the yard, gardening (Zabriskie & McCormick, 2003). Core activities address needs for familiarity and stability by regularly providing predictable experiences that foster personal relatedness and feelings of closeness (Zabriskie, 2001). In contrast, balance activities tend to be less ordinary and include elements of unpredictability or novelty which require participants to negotiate and adapt to new input and experiences that stand apart from everyday life (Zabriskie, 2001). Balance activities include vacations, outdoor recreation, and special or sporting events (Zabriskie & McCormick, 2003). Although both core

and balance leisure patterns are significantly related to relationship cohesion, balance activities appear to have a greater influence on relationships at the lower or higher end of the relationship functioning spectrum (Zabriskie & McCormick, 2003). Within the context of couples experiencing a CDC, this may mean that participation in balance activities may be especially important for promoting adaptability while core activities may be important for developing perceptions of family cohesion.

Despite the array of activities in which couples participated, they also described numerous challenges to participation associated with having sufficient energy, engaging in social activities, and maintaining traveling activities. Having insufficient energy meant that a partner with a CDC had little ability to counteract chronic fatigue during afternoon and evening hours, was less able to combine events such as dinner and a movie, and was less able to use helpful strategies and routines to minimize the risk of “hitting the wall.” Social activities became problematic when a partner with a CDC had difficulty fulfilling social obligations, planning social opportunities, reciprocating invitations, and attending social engagements. Travel became problematic when a partner with a CDC was less able to accommodate ambiguity and the need for spontaneity, and required increased planning and expense to modify travel patterns to accommodate physical limitations.

In accordance with these challenges to participation, couples identified numerous ways in which their leisure patterns had changed in response to onset or exacerbation of a CDC. Some couples, such as Christine and Jeff, indicated that while the frequency and intensity of participation was reduced, they experienced few changes to their preferred activities of walking, reading, and conversation. Others, such as Lisa and Randall, indicated that the frequency, intensity, and type of activities changed because they could no longer participate in many of the

physically exerting activities that they had engaged in prior to onset of CDC. Others such as Cynthia and Walter, indicated that while the type of activities had not changed much, they found it increasingly necessary to modify their participation and utilize adaptive aids. All couples engaged in actions to promote participation, such as modifying their strategies, minimizing the magnitude of the CDC, anticipating CDC-related needs, and developing an appreciation of home-based leisure.

Examination of these couples' leisure patterns suggests that they had difficulty in pursuing both core and balance activities that were suggested by Zabriskie and McCormick (1991; 1993) as being helpful for the cohesion and adaptability that promotes healthy relationship functioning. It may be that in the context of a CDC, the frequency, intensity, effort, and planning required for participation closely resembles that of balance activities regardless of the actual activity. For example, the need to preserve energy to go on a daily walk, play a board game, or stay awake to watch an evening television program may alter the nature of that activity so that it becomes extremely arousing, interesting, and novel. Cooking dinner with or for a partner may require sufficient planning to rest and minimize unpredictability that the activity becomes exciting and infused with positive meaning. In fact, participants suggested that one positive outcome of onset or exacerbation of a CDC was that they learned not to take shared leisure for granted.

Balance activities may inform partners regarding each other's values and expectations about life (Zabriskie & McCormick, 2003). Balance activities promote feelings of novelty or arousal that facilitate risk-taking in conversation (Aron, Aron, Heyman, Norman, & McKenna, 2000) that may also enhance partners' mutual understanding and expand the relationship. In contrast, core activities may be associated with feelings of boredom that comes from expressive

predictability (Baxter & Dindis, 1990) associated with participating in merely pleasant, rather than exciting activities (Reisman et al., 1993). Nonetheless, findings suggest that core shared leisure patterns may be more important than balance types of activities for promoting healthy family functioning, especially regarding perceptions of family cohesion (Zabriskie & McCormick, 2001). Consequently, it may be important to consider factors that affect couples' patterns of core and balance activities when developing leisure programming or therapeutic interventions.

### Implications for Therapeutic Recreation

Couples' leisure activity patterns and perceptions of the experience and outcomes of shared leisure were influenced by the strategies they used to negotiate constraints to participate in those activities and interactions. Findings provide additional support that couples experiencing a CDC desire and work to sustain shared leisure despite CDC-related losses and limitations (Lyons et al., 1995; Lyons, 1999). Participants described using a variety of activity-focused and relationship-focused strategies to sustain or modify existing activities and develop new interests and leisure patterns. Activity-focused strategies, such as creating healthful routines and modifying leisure activities and expectations regarding the nature of leisure, facilitated efforts to participate in a variety of valued activities, including shared leisure. Relationship-focused strategies, such as accessing leisure with a partner, maintaining open communication, and redefining leisure in the relationship, facilitated efforts to develop new patterns of interpersonal interaction. Most couples identified, negotiated, and included these strategies without benefit of professional assistance and, in some cases, relative ease. Nonetheless, the experiences and observations of these participants offer several important implications for therapeutic recreation. Leisure education, which is intended to improve functional capacities in the areas of leisure

appreciation, self-awareness, self-determination, leisure decision-making, social skills interaction, leisure activity skills, and leisure resources (Dattilo, 1999), may be helpful. Findings support arguments offered by Guerin & Dattilo (2001; 2003) that using a systems approach to provide leisure education services to both adults with a CDC and their partner may be helpful in assisting them to acquire knowledge, skills, and resources that facilitate shared leisure in the context of a CDC.

Evidence suggests that adults with a CDC who believe they have some control over the CDC report using more positive coping responses such as active coping, planning, and reinterpreting the situation and less behavioral disengagement (Moss-Morris, Petrie, & Weinman, 1996). Therefore, an important first step in the delivery of therapeutic recreation services may be to assist couples to view shared leisure as a resource for emotion and problem-focused coping following onset or exacerbation of a CDC (Kleiber, Hutchinson, & Williams, 2002). The focus of some interventions could be to encourage couples to use behavioral strategies such as seeking emotional support. For example, leisure education techniques (e.g., social skills development, assertiveness training, role playing) may have assisted these participants in learning how to (a) offer and accept reminders regarding limits to participation, (b) take comments at face value, and (c) demonstrate respect for and responsiveness. Acquiring skills helpful for seeking emotional support may also help adults with a CDC manage social reactions and reduce frustration and awkwardness with respect to inequities in their ability to attend social engagements or reciprocate invitations. These types of interventions may promote greater participation in and enhance satisfaction with shared leisure if couples are provided opportunities to learn skills helpful to negotiating CDC-related change and associated conflict (Crawford et al., 2002).

Findings provide additional support that preserving energy is an important focus of couples' lives, and that the person with a CDC eventually comes to understand, through trial and error, how much energy is available on a given day and will work to preserve that energy for participation in valued activities (Goodwin, 2000). Problem-focused coping strategies, such as learning to preserve energy, may also be enhanced by leisure education techniques that promote partners' self-determination in leisure. For example, couples' perception of choice and control and ability to accommodate constraints (Henderson et al., 1994) may have been enhanced through problem-solving and role-playing techniques that assisted their efforts to (a) prioritize and select most valued leisure activities, (b) establish mutual routines that allowed the partner with a CDC to schedule leisure for peak times and pace and limit activities to minimize the potential of hitting the wall, and (c) anticipate and minimize travel challenges by creating travel routines and budgeting for increased travel expenses.

Evidence also suggests that returning to past activities, or engaging in new activities that provide a sense of connection with valued self-perceptions despite changes in functional abilities and relationship roles is important for minimizing losses associated with onset or exacerbation of a CDC (Hutchinson et al., 2003). Couples may benefit from opportunities to increase their level of engagement as they work to redefine leisure in the relationship in ways that promote connections with the past and offer possibilities for the future. Examples of engagement may include seeking out information, using role models, and proactively modifying activities. Since leisure engagement is influenced by level of awareness, leisure education interventions that promote development of activity skills and identification of resources may enhance couples' ability to modify leisure activities and expectations. Leisure education may have assisted couples in this study to (a) become more aware of adaptive devices, such as electric bicycles, (b) access

trained professional assistance, such as a golf expert, (c) consider alternative activities, such as tandem kayaking rather than hiking, or (d) modify expectations, such as limiting travel to environments that facilitate the use of a portable wheelchair.

Evidence further suggests that values clarification may be helpful for assisting couples experiencing a CDC redefine leisure in the relationship and focus on the affective quality of the experience rather than specific activities (Henderson et al; 1994). Consistent with findings presented by Samdahl and Jekubovich (1997), participants suggested that the significance of sharing meaningful activities and experiences with a valued partner became more important than the activity itself. Techniques that promote decision-making and self-awareness may have assisted couples in their efforts to compromise on activities (e.g., playing chess), choose alternatives (e.g., playing darts), or reconceptualize their leisure roles (e.g., social planner). Findings also support ideas proposed by Juniu (2000) that time spent experiencing leisure is valuable time spent understanding one's inner-self and identifying priorities in one's social and family life. Accordingly, values clarification may also have been helpful in assisting couples focus on possibilities and minimize the importance of personal losses. An important component of this may be assisting partners to appreciate "simple pleasures" (Neill, 2002) that are derived from the quality of experience rather than the nature of the activity itself (e.g., picnicking rather than hiking on a trail). Values clarification may assist couples in recognizing and valuing the affective quality of their interactions so that they become more comfortable as "human beings, not human doings" (Lisa, CFIDS).

Although the purpose of this study was to examine shared leisure in the context of a CDC, one possible implication for TR is that it may be important to support the need for independent leisure. Consistent with findings of Bedini and Guinan (1996a; 1996b) and Rogers

(1997), partners without a CDC desired and were appreciative of opportunities to participate in leisure activities independent of their partner. Independent leisure was recognized by both partners as valuable because it accommodated the leisure needs, abilities, and preferences of the partner whose leisure options were not constrained by physical or cognitive losses and limitations rather than providing opportunities for respite from caregiving responsibilities. Findings support evidence that participation in shared leisure, or commitment to the same activities, was not essential to relationship satisfaction if partners' perceived that they were supported in their recreational choices (Baldwin, Ellis, & Baldwin, 1999). Findings also support evidence that a dialectical appreciation of the need for both togetherness and autonomy is potentially constructive to relationship functioning (Baxter & Dindis, 1990). Consequently, techniques that enhanced leisure appreciation and self-awareness may have assisted couples in their efforts to develop patterns of interdependence that supported independent leisure (e.g., bowling, biking, soccer). These techniques may also have assisted couples to participate in leisure that was "separate but together" (Lillian & Patty, ASD/cardiomyopathy) such as hiking different distances along the same path with a predetermined rendezvous, or attending and vicariously enjoying a partner's hockey game.

A final implication for therapeutic recreation may be with respect to the use of adaptive devices and modification strategies. Consistent with findings of Gignac et al. (2000) couples indicated that, other than assistance from therapists, they did not seek or receive assistance regarding adaptive devices or modification strategies that may have been helpful in promoting shared leisure. It is increasingly recognized among health and social service providers that using an ecological approach employing home-based educational and preventive techniques can be helpful for maintaining quality of life (Gitlin, Levine, & Geiger, 1993). However, it is frequently

occupational therapists that are charged with facilitating community-based leisure programs and assisting adults to acquire leisure competencies as a result of reimbursement policies (Schwietzer, Mann, Nochajski, & Tomita, 1999; Tatham & McCree, 1992). Participants in this study did not receive, nor did they report seeking, assistance from leisure service providers working in hospital, day treatment, or parks and recreation environments. Rather, they independently attempted to acquire knowledge or access equipment via the Internet, talking with colleagues at support groups, and by trial and error. Therefore, it may be important for TR service providers to increase their efforts to understand and respond to the needs of couples with a CDC who reside at home.

One way to address the needs of couples with a CDC who reside at home may be for Therapeutic recreation specialists to conduct needs assessments and develop purchasable workbooks or web-based resources that respond to couples' needs for information and skill development. A compilation of values clarification and leisure awareness activities may be used to assist couples with identifying valued aspects of shared leisure or modifying attitudes and expectations, and provide examples of alternatives or modification strategies to sustain desired participation. Alternatively, a list of manufacturers that provide specialized or adaptive devices could help couples identify contacts that could provide assistance. Similarly, a list of therapeutic recreation specialists who are available for private consultation may be helpful for couples who require additional assistance to negotiate CDC-related losses and limitations and sustain desired patterns of shared leisure.

A second way to address the needs of couples with a CDC who reside at home may be for therapeutic recreation specialists who work in community-based environments (e.g., inclusion specialists in parks and recreation organizations) to consider the specific symptoms and

unique lifestyles experienced by adults with a variety of CDCs (e.g., CFIDS, fibromyalgia, or MS). For example, therapeutic recreation specialists may find that varying the timing of their programs during the day to correspond with participants' peak times (e.g., 10:00 – 4:00) or peak seasons (e.g., early fall through late spring) may facilitate couples' attempts to participate in shared leisure while still promoting healthful routines. Additionally, therapeutic recreation specialists may find that programs that offer couples experiencing a CDC an opportunity to learn more about and experiment with various types of adaptive aids or equipment (e.g., motorized bicycles, tandem kayaks) may facilitate efforts to adjust to the losses and limitations of one partner. Furthermore, therapeutic recreation specialists may find that leisure education programs developed in collaboration with family counselors and support group facilitators can provide couples with opportunities to develop or enhance communication, problem-solving and other behaviors that promote shared leisure and healthy relationship functioning in the context of a CDC

Thus, these findings support implications for TR suggested by Zabriskie and McCormick (2001), who recommended that practitioners provide opportunities to acquire knowledge, skills, and resources helpful for participating in common home-based shared leisure activities on a regular basis and identify the diversity of resources available. Therapeutic recreation specialists may provide these same opportunities to assist couples' in their efforts to participate in other types of activities (e.g., travel, outdoor recreational pursuits, and sports). Providing these opportunities may assist couples in sustaining previous patterns of shared leisure and develop new patterns that promote stable interactions that foster positive communication, and role continuity promoting healthy relationship functioning despite losses and limitations associated with a CDC.

## Limitations

This study has limitations associated with both its design and the researcher's unique perspectives on the issues that were explored. However, when these limitations and perspectives are made explicit in naturalistic inquiry there is enhanced confidence in the (a) validity and reliability of data collection and analysis procedures and decisions, and (b) dependability of reported findings (Creswell, 1998). In addition, identification of research strategies that can be explored may be helpful for establishing an agenda for future research

There are several limitations associated with this study. One limitation relates to the choice of interview questions. Interview questions were developed to explore, with some consistency across participants, perceptions of shared leisure and its influence on interpersonal loss and relationship functioning from the perspective of both adults with a CDC and their partner. Although questions were developed to obtain specific types of information rather than specific responses per se, they may nonetheless have influenced the content of participants' responses since they were aware that they were being researched. Future investigations may benefit from more extensive pilot testing of the interview questions so that more feedback may be obtained. This feedback can be used to modify questions to minimize the extent to which questions are perceived as leading.

A second limitation relates to the format of interviews. Although participants were interviewed separately, some were interviewed in their home when their partner was also at home. It is possible that their responses were influenced by the presence of their domestic partner. Additionally, some participants were interviewed in a public venue (e.g., restaurant, cafeteria). It is possible that their responses were influenced by the presence of others or by their level of comfort in that surrounding. Future investigations may benefit from interviewing all

participants in their home at a time when their partner is not on the premises to establish consistency across all participants and enhance maximum comfort and familiarity.

A third limitation is the possible influence of health fluctuations affecting participants' responses. It is possible that the prevalence and severity of symptoms for the adult with a CDC or their partner at the time of interview affected both the content and the quality of their responses. Future investigations would benefit from using a longitudinal approach by conducting multiple interviews with each participant over a pre-determined period of time (e.g., one year) to better understand the fluctuating nature of the CDC as a factor that may influence shared leisure and relationship functioning.

A fourth limitation is the low response rate obtained in this study. Of the fifty individuals directly contacted by the researcher, only sixteen agreed to participate in the study. Reasons presented by adults with a CDC when they declined to participate included (a) the presence of chronic pain, (b) limited energy, and (c) an unwillingness to commit to an interview on a potentially "good day." Some adults with a CDC agreed to participate in the study but their partners declined, indicating that they were also unwilling to commit limited time and energy to an interview. Future investigations may benefit from obtaining a less selective sample, perhaps by obtaining the support and cooperation of potential gatekeepers. Gatekeepers who may work in hospitals or houses of worship may be able to serve as trusted intermediaries for researchers and potential participants, thereby securing a larger and more representative sample.

A fifth limitation is that sampling procedures restricted the pool of potential participants to individuals who were known to the researcher or who were utilizing community support services for adults with a CDC in the southeastern region of the United States. In addition, the sampling procedures resulted in a non-representative sampling of adults with a CDC in that

(a) all partners with a CDC were female, (b) all participants were Caucasian, (c) all participants had earned, or were in the process of earning, at least a Master's degree, and (d) none of the CDCs represented in this study were of a stable, predictable nature. One area deserving additional inquiry is the relevance of these findings to couples who represent a more diverse representation regarding (a) gender of partner with a CDC, (b) type of CDC, (c) same-sex partners, (d) race, (e) education, and (f) socio-economic status. Although the purpose of naturalistic inquiry is not to generalize from the sample to a larger population, it may be that findings from this study are too unique given the non-random nature of this sample.

A sixth limitation related to sampling bias is that none of the couples that were included in the study had young children; only one of eight couples had children aged five and fourteen residing at home. Not only may partners differ in their desire for, and opportunity to, participate in shared leisure independent of their children, but the frequency and quality of their interpersonal interactions during family leisure may also be affected. Future investigations may benefit from examining shared leisure and relationship functioning in the context of a CDC as it relates to a family including children.

A seventh limitation also related to sampling bias is that participants did not represent couples across the continuum of lifespan development. No couples aged 65 and older were recruited for or included in the study. Existing research demonstrates the need for and value of independent leisure among spousal caregivers, and strategies for spousal caregivers to facilitate shared leisure with a partner. Future investigations may benefit from examining the nature of shared leisure, factors that shape leisure patterns, and influences of shared leisure on relationship functioning among elderly couples.

An eighth limitation is the low number of member checks conducted to confirm participants' agreement with presentation and interpretation of findings. Of the sixteen participants in the study, only two couples agreed and actually reviewed preliminary findings and provided feedback. One other couple agreed to a member check but did not provide feedback despite reminders. Two couples moved residence and did not provide a forwarding address. Three couples declined to perform a member check because of time and health constraints. Future investigations may benefit from obtaining feedback from all participants, perhaps by requesting agreement to a member check as an additional requirement for inclusion in the study.

Another limitation of the study was that participants could only share perspectives and experiences that were within their realm of consciousness. Consequently, this study was limited by participants' awareness of their lives and the extent to which they accurately reflected via language and conversation their views regarding the issues being examined. Some participants known to the researcher were familiar with concepts and terminology relevant to the study of leisure and may have been better able to articulate their thoughts and experiences regarding the relevance of shared leisure in the context of a CDC. Future investigations may benefit from including fewer participants who may be familiar with leisure scholarship. Future investigations may also benefit from including artifacts (e.g., photographs, home videos, journal entries) relevant to participants' lives to supplement or complement data obtained from in-depth interviews.

#### Areas for Future Research

It is not clear whether leisure is a buffer that enhances, or it is a point of contention that diminishes relationship functioning in the context of a CDC. Additionally, it is not clear whether couples would specifically identify shared leisure as a variable that influences relationship

functioning in the context of a CDC. Furthermore, it is not clear whether associations between leisure and relationship functioning described by participants in this study are different than those described by partners not experiencing a CDC. It may be that many categories and dimensions of experience described by participants are descriptive of perceptions, challenges, and outcomes of shared leisure in the context of any type of enduring, committed, romantic relationship. In addition, it may be that some strategies used by couples to participate in shared leisure are similar irrespective of a CDC. Despite this ambiguity, as well as the aforementioned limitations, findings presented in this study may offer insight regarding areas for future research. Future research may be conducted in association with (a) theory building, and (b) alternative theoretical frameworks.

### Theory Building

Findings from this study may be used as a foundation upon which to engage in theory building that enhances understanding of associations between shared leisure and relationship functioning among couples experiencing a CDC. Future research may replicate and extend findings by using a more ethnically and socio-economically diverse and representative sample that includes adults with both stable and fluctuating CDCs, couples that have children of various ages, elderly adults, and more same sex partners. Additionally, inclusion of couples not experiencing a CDC may permit comparison across groups that enhance understanding of the role of a CDC as a variable that may influence leisure and relationship functioning. This information may help to clarify whether findings presented in this study are broadly representative across other groups not included in this study.

This study offered evidence that partners describe a variety of concepts associated with the nature of shared leisure, factors that shape leisure patterns, and the influence of shared leisure

on relationship functioning. Future research may replicate and extend findings by using additional and/or multiple methods of data collection to further replicate and extend findings. For example, using a phenomenological approach may allow for replication of findings without the use of a semi-structured, and potentially leading, interview guide. Similarly, concept mapping is a phenomenological approach that allows participants to rank self-generated themes in ways that permit both visual representation in the form of a map and simple statistical analysis with corresponding survey data. Use of additional qualitative methods may enhance understanding of the scope and breadth of findings that emerged in this study. These methods may help to understand perceptions of a more diverse and representative sample relative to the salience of certain dimensions of experience or the identification of additional dimensions. For example, one category that deserves additional investigation is partners' perception of the CDC, since findings emerged from the comments and experiences of only eight participants.

Once the scope and breadth of categories and subcategories are better understood through investigations via qualitative methods, findings could be used to inform investigations employing quantitative methods. For example, based on further understanding of the categories and subcategories a survey could be designed to obtain data from large samples of participants; these findings may be supplemented with additional interview data. This information may be helpful to further enhance the validity and generalizability of findings and help health and leisure service providers develop programs and interventions useful to couples experiencing a CDC.

This study offered evidence that examining shared leisure in the context of a CDC is relevant because it expands theoretical understanding of a special or unique context in which leisure participation may both positively and negatively influence relationship functioning. This study also provided evidence that partners use a variety of strategies to participate in shared

leisure. Future research might attempt to gain greater insight into personal and relationship factors that influence couples' willingness and ability to use these strategies to negotiate CDC-related conflicts. These conflicts may affect perceptions of interpersonal loss and relationship functioning. This information may be helpful for practitioners to understand issues and variables that affect perceptions of shared leisure and associated perceptions of relationship functioning. In particular, it may be helpful to better understand factors that influence patterns of communication, coping, problem-solving, negotiation, and other forms of interpersonal interaction that may affect couples' desire for, and ability to, participate in shared leisure.

This study provided additional evidence that returning to normalcy is perceived positively among adults experiencing a CDC and their partners. However, participants in this study offered several examples of normalcy that suggest that "normal" activities and interactions (e.g., going for a walk, having dinner with friends) may be perceived as "special" because of the number and severity of challenges to participation. Future research may be helpful to better understand how adults with a CDC and their partners define normalcy and whether differences in their perceptions may affect perceptions of shared leisure and other variables that may influence relationship functioning. This information may be helpful for therapeutic recreation specialists, counselors, and support group leaders as they develop and facilitate interventions designed to encourage couples to negotiate and embrace mutual definitions of normalcy that contribute to healthy relationship functioning.

This study provided additional evidence that couples desire, seek, and create opportunities for shared leisure in the context of a CDC. However, findings demonstrate that couples reported an alteration in the type, frequency, and intensity of participation in many preferred activities. Although participants, especially partners without a CDC, suggested that

modifying activities and expectations was preferable to foregoing shared leisure altogether; it is not clear whether changes in the intensity of shared leisure affected perceptions of enjoyment. It may be helpful for future research to attempt to clarify whether partners experiencing a CDC actually desire current patterns of shared leisure, or whether it is perceived positively because there are few, if any, perceived alternatives. This information may be helpful for therapeutic recreation specialists who are designing interventions that may facilitate couples' efforts to reconceptualize leisure or support some independent leisure opportunities to maximize partners' enjoyment given existing interests and abilities.

This study provided additional evidence that support groups might be a resource that is under-utilized by couples experiencing a CDC. Therefore, a second area of inquiry may be to examine in greater depth how couples' use of support groups and other forms of support and information (e.g., chat rooms, on-line catalogues, CDC web sites) contribute to couples' desire for and knowledge of leisure alternatives, adaptive aids, or modification strategies. This information may be helpful for Therapeutic recreation specialists when they offer assistance to couples that include a partner with a CDC residing at home.

This study also provided evidence that couples enjoy travel but experience a variety of challenges in association with CDC-related losses and limitations. Therefore, a third area of inquiry may be to examine resources, modifications, and strategies helpful for couples' efforts to preserve travel as part of their leisure repertoire. Though significant majorities of people with CDCs want to travel more frequently, there is a lack of accurate information by providers of tourism experiences (Darcy & Durawalla, 1999). This information may be helpful for Therapeutic recreation specialists when they offer assistance to couples who intend to sustain or initiate travel, especially independent travel, as part of their leisure repertoire.

### Alternative Theoretical Frameworks

During the process of data analysis emerging categories appeared to support a theoretical framework described by Adams (1993) regarding the structure and purpose of shared leisure for the development and maintenance of relationships. Adams suggested that participation in shared activities provides a structure (e.g., game, hobby) and/or an environment (e.g., home, park) in which people can interact. Shared leisure also provides a context in which people can engage in the behavioral, cognitive, and affective processes that influence their relationship. According to Adams (1993), behavioral processes are those actions that people do with and for others during the shared activity, such as self-disclosure, resource exchange, displays of affection, or conflict resolution. Cognitive processes are the internal thoughts that members have about themselves, other members, and relationships, such as evaluations of attractiveness, character, or similarity to self. Affective processes are the emotional reactions to members, including empathy, indifference, joy, anger, jealousy, or loyalty. This analytic approach seemed consistent with stories and experiences described by participants, and helpful in classifying challenges to, and strategies for, participation as primarily activity-focused or relationship focused. However, future research may benefit from using alternative theoretical frameworks such as (a) coping theory (e.g., Folkman & Lazarus, 1980), (b) conflict resolution (e.g., Schneewind & Gerhard, 2002), (c) selective optimization (e.g., Baltes & Baltes, 1990), and (d) constraint negotiation (e.g., Jackson, 2000) to guide data analysis and the development of emerging themes.

Coping is defined by Folkman and Lazarus (1980) as the cognitive and behavioral efforts to “master, tolerate, or reduce external and internal demands and conflicts” (p. 223). Folkman and Lazarus argue that coping efforts may be dichotomized as efforts to (a) manage or alter the person-environment relationship from which the stress arises (i.e., problem-focused coping), or

(b) regulate stressful or negative emotions (i.e., emotion-focused coping). Additionally, Stetz, Lewis, and Primomo (1986) proposed that family coping strategies in the context of a CDC might differ from an individual response model. Stetz et al. found that families having a mother with a CDC used a variety of composite coping strategies that were more complex than the dichotomous classification of problem- and emotion-focused coping. Future research may use both individual response and family approaches to coping to better understand associations between shared leisure and relationship functioning in the context of a CDC. This information may enhance theoretical understanding of the complexities of coping and problem solving among couples as contrasted with an individual's coping behavior, and provide greater insight regarding the importance of leisure participation as a context or strategy that influences coping. This information may also enhance the ability of therapeutic recreation specialists, counselors, and support group leaders to develop programs and interventions that facilitate couples' efforts to develop and use individual and mutual coping strategies. These strategies could be developed so that healthy relationship functioning was promoted within the context of a CDC.

A second theoretical framework that may be helpful is conflict resolution (e.g., Schneewind & Gerhard, 2002). Conflict resolution is related to couples' use of constructive (e.g., talking, working it out) or destructive (e.g., insistence, talking endlessly without coming to a solution) communication behaviors to resolve differences and respond to challenges. Schneewind and Gerhard suggested that couple conflict resolution style is one variable that affects relationship satisfaction. Future research may use conflict resolution as a framework to enhance understanding of associations among shared leisure and conflict resolution. In addition, this research may examine ways that leisure participation may contribute to constructive or destructive communication behaviors that influence relationship functioning. Evidence suggests

that group discussion regarding conflict resolution is more beneficial for relationship satisfaction and sexual and intellectual intimacy than simply receiving information or having unstructured group interventions (Worthington, Buston, & Hammonds, 1989). Therefore, research findings using conflict resolution as a theoretical framework may enhance the ability of therapeutic recreation specialists, counselors, and support group leaders to develop specific and highly structured programs and interventions. These programs and interventions can be designed to facilitate couples' discussion of conflict resolution styles, leisure participation, and associated relationship functioning in the context of a CDC.

Selective optimization is a third theoretical framework that may be used to enhance understanding of associations among shared leisure and relationship functioning in the context of a CDC. Baltes and Baltes (1990) suggested that life-management strategies of selection, optimization, and compensation are relevant to adults who encounter a variety of losses and limitations inherent in the aging process. These life management strategies may also be relevant to couples experiencing a CDC, since onset or exacerbation of symptoms may also require that partners engage in loss-based (a) selection (e.g., focusing on most important goals, adaptation of new standards, (b) optimization (e.g., acquiring new skills/resources, resource allocation, modeling successful others, and (c) compensation (e.g., use of external aids/assistance, use of therapeutic intervention, acquiring new skills/resources). Future research may use selective optimization as a theoretical framework to enhance understanding of the importance of shared leisure in couples' lives and ways in which couples enact decision-making and implementation processes in association with their perspectives on leisure participation. This information may assist therapeutic recreation specialists in developing leisure education and functional interventions that promote couples' awareness of and ability to access and use adaptive aids,

resources, and alternative activities (if shared leisure is a valued and desired component of their lifestyle.)

An additional theoretical framework that may be used is leisure constraints (e.g. Jackson, 2000; Samdahl & Jekubovich, 1997). Leisure constraints are factors that are assumed and/or perceived to limit the formation of leisure preferences, prohibit leisure participation, and/or limit ability to experience enjoyment in leisure. Leisure constraints have been explored in the context of a CDC (e.g., Henderson et al., 1993). However, Jackson (2000) suggested that a general critique of research on constraints is that emphasis is frequently on structural, rather than intrapersonal or interpersonal factors that may influence real and perceived opportunities for satisfying leisure. Future research may benefit from using leisure constraints as a theoretical framework with which to enhance understanding of the variety and interplay of constraints that influence opportunities for, and satisfaction with, shared leisure for adults with a CDC and their partners. Additionally, future research may enhance understanding of relationship- and activity-focused strategies that couples use to adapt to CDC-related losses and limitations and, subsequently, negotiate leisure constraints. This information may assist therapeutic recreation specialists in providing a variety of educational and functional interventions designed to assist couples acquire knowledge and skills that are helpful as they attempt to navigate cyclical CDC-related changes. These interventions can be developed to create or sustain desired patterns of shared leisure that promote healthy relationship functioning despite losses and limitations.

Examination of these issues may expand theoretical concepts and empirical evidence relevant to scholars and health care providers, especially therapeutic recreation specialists. This enhanced knowledge may improve practitioners' ability to promote relationship functioning by addressing the educational, social, and leisure needs of couples experiencing a CDC.

## REFERENCES

- Adams, R. G. (1993). Activity as structure and process. In J. Kelly (Ed). *Activity and aging* (pp. 73-85). Belmont, CA: Sage Publishing, Inc.
- Andrich, R., & Serenella, B. (2002). Being informed, demanding and responsible consumers of assistive technology: an educational issue. *Disability and Rehabilitation, 24*, 152-159.
- Aron, A., Aron, E. N., Heyman, R. E., Norman, C. C., & McKenna, C. (2000). Couples' shared participation in novel and arousing activities and experienced relationship quality. *Journal of Personality and Social Psychology, 78*, 273-284.
- Aron, A., Aron, E. N., Tudor, M., & Nelson, G. (1991). Close relationships as including other in self. *Journal of Personality and Social Psychology, 60*, 241-253.
- Aronson, K. J. (1997). Quality of life among persons with multiple sclerosis and their caregivers. *Neurology, 48*, 74-80.
- Ashton-Shaeffer, C., Shelton, M., & Johnson, D. E. (1995). The social caterpillar and the wallflower: Two case studies of adolescents with disabilities in transition. *Therapeutic Recreation Journal, 29*, 324-336.
- Austin, D. (1998). The Health Promotion/Health Protection Model. *Therapeutic Recreation Journal, 32*, 109-117.
- Baldwin, J. H., Ellis, G. D., & Baldwin, B. M. (1999). Marital satisfaction: An examination of its relationship to spouse support and congruence of commitment among runners. *Leisure Sciences, 21*, 117-131.

- Baltes, P. B., & Baltes, M. M. (1990). Psychological perspectives on successful aging: The model of selective optimization with compensation. In P. B. Baltes & M.M. Baltes (Eds.), *Successful aging: Perspectives from the behavioral sciences* (pp. 1-34). New York: Cambridge University Press.
- Baxter, L.A., & Dindia, K. (1990). Marital partners' perceptions of marital maintenance strategies. *Journal of Social and Personal Relationships*, 7, 187-208.
- Bedini, L. A. (2000). "Just sit down so we can talk": Perceived stigma and community recreation pursuits of people with disabilities. *Therapeutic Recreation Journal*, 34, 55-68.
- Bedini, L. A., & Guinan, D. M. (1996a). The leisure of caregivers of older adults: Implications for CTRS's in non-traditional settings. *Therapeutic Recreation Journal*, 30, 274-288.
- Bedini, L. A., & Guinan, D. M. (1996b). "If I could just be selfish...": Caregivers' perceptions of their entitlement to leisure. *Leisure Sciences*, 18, 227-239.
- Bedini, L. A., & Phoenix, T. L. (1999). Addressing leisure barriers for caregivers of older adults: A model leisure wellness program. *Therapeutic Recreation Journal*, 33, 222-240.
- Berg, E. C., Trost, M., Schneder, I. E., & Allison, M. T. (2001). Dyadic exploration of the relationship of leisure satisfaction, leisure time, and gender to relationship satisfaction. *Leisure Sciences*, 23, 35-46.
- Bollin, S., Voelkl, J. E., & Lapidos, C. (1998). The at-home independence program: A recreation program implemented by a volunteer. *Therapeutic Recreation Journal*, 32, 54-61.
- Bullock, C. C. (1988). Qualitative research in therapeutic recreation. *Therapeutic Recreation Journal*, 17, 36-43.

- Bullock, C. C. (1993). Ways of knowing: the naturalistic and positivistic perspectives on research. In M. J. Malkin & C. Z. Howe (Eds.). *Research in therapeutic recreation: Concepts and methods* (pp. 25-42). State College, PA: Venture.
- Bullock, C. C., & Howe, C. Z. (1991). A model therapeutic recreation program for the reintegration of persons with disabilities into the community. *Therapeutic Recreation Journal, 25*, 7-17.
- Bryman, A. (1988). The nature of qualitative research. In A. Bryman (Ed.). *Quantity and quality of social research* (pp. 45-71). London, GB: Unwin Hyman.
- Buettner, L. L., & Langrish, S. (1999). Rural vs. urban caregivers of older adults with probable Alzheimer's disease: Perceptions regarding daily living and recreation needs. *Activities, Adaptation, and Aging, 24*, 51-65.
- Carter, M. J., Nezey, I. O., Wenzel, K., & Foret, C. (1999). Leisure education with caregiver support groups. *Activities, Adaptation, and Aging, 24*, 67-81.
- Charmaz, K. (1990). Discovering chronic illness: Using grounded theory. *Social Science and Medicine, 30*, 1161-1172.
- Chick, G. (1998). Leisure and culture: Issues for an anthropology of leisure. *Leisure Sciences, 20*, 111-133.
- Clark, M. S., & Mills, J. (1979). Interpersonal attraction in exchange and communal relationships. *Journal of Personality and Social Psychology, 37*, 12-24.
- Clark, M. S., & Mills, J. (1993). The difference between communal and exchange relationships: What it is and is not. *Personality and Social Psychology Bulletin, 19*(6), 684-691.
- Crawford, D. W., Houts, R. M., Huston, T. L., & George, L. J. (2002). Compatibility, leisure, and satisfaction in marital relationships. *Journal of Marriage and Family, 64*, 433-449.

- Cresswell, J. W. (1994). *Research design: qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.
- Cresswell, J. W. (1998). *Qualitative inquiry and research design*. Thousand Oaks, CA: Sage.
- Csikszentmihalyi, M. & Kleiber, D. A. (1991). Leisure and self-actualization. In B. L. Driver, Perry J. Brown, & George, L. Peterson (Eds). *Benefits of leisure* (pp. 91-102). Philadelphia, PA: Venture Publishing, Inc.
- Cutrona, C. E. (1996). *Social support in couples*. Thousand Oaks, CA: Sage Publications, Inc.
- Darcy, S., & Daruwalla, P. S. (1999). The trouble with travel: People with disabilities and tourism. *Social Alternatives*, 18, 41-47.
- Dattilo, J. (1999). *Leisure education program planning: A systematic approach*. State College, PA: Venture.
- Dattilo, J., Kleiber, D., & Williams, R. (1998). Self-determination and enjoyment enhancement: A psychologically-based service delivery model for therapeutic recreation. *Therapeutic Recreation Journal*, 32, 258-271.
- Dattilo, J., McCormick, B., & Scott, D. (1991). Answering questions about therapeutic recreation part II: Choosing research methods. *Annual in Therapeutic Recreation*, 2, 85-95.
- DeSalvatore, H. G. (1989). Therapeutic recreators as family therapists: Working with families on a children's psychiatric unit. *Therapeutic Recreation Journal*, 23, 23-29.
- Dunn, N. J., & Wilhite, B. (1997). The effects of a leisure education program on leisure participation and psycho-social wellbeing of two older women who are home-centered. *Therapeutic Recreation Journal*, 31, 53-71.
- Dupuis, S. L., & Pedlar, A. (1995). Family leisure programs in institutional care settings: Buffering the stress of caregivers. *Therapeutic Recreation Journal*, 29, 184-205.

- Dupuis, S. L., & Smale, B. J. A. (2000). Bittersweet journeys: Meanings of leisure in the institution-based caregiving contest. *Journal of Leisure Research, 32*, 303-340.
- Flora, J., & Segrin, C. (1998). Joint leisure time in friend and romantic relationships: The role of activity type, social skills and positivity. *Journal of Social and Personal Relationships, 15*, 711-718.
- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine, 45*, 1207-1221.
- Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior, 21*, 219-239.
- Folkman, S., Moskowitz, J. T., Ozer, E. M., & Park, C. L. (1997). Positive meaningful events and coping in the context of HIV/AIDS. In B. H. Gottlieb (Ed.), *Coping with chronic stress* (pp. 293-314). New York: Plenum Press.
- Frank, A. W. (1995). *The wounded storyteller*. Chicago, IL: The University of Chicago Press.
- Gignac, M. A. M., Cott, C., & Badley, E. M. (2000). Adaptation to chronic illness and disability and its relationship to perceptions of independence and dependence. *Journal of Gerontology, 55B*, P362-P372.
- Gitlin, L. N., Levine, R., & Geiger, C. (1993). Adaptive device use by older adults with mixed disabilities. *Archives of Physical Medicine and Rehabilitation, 74*, 149-153.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. Hawthorne, NY: Aldine de Gruyter.
- Goodwin, S. S. (2000). Couples' perceptions of wives' CFS symptoms, symptom change, and impact on the marital relationship. *Issues in Mental Health Nursing, 21*, 347-363.

- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology, 29*, 75-91.
- Guerin, N., & Dattilo, J. (2001). Family leisure in the context of a chronic disabling condition. *Annual in Therapeutic Recreation, X*, 73-82.
- Guerin, N., & Dattilo, J. (2003). Shared leisure among couples experiencing a CDC. *Abstracts from the Leisure Research Symposium*. Arlington, VA: National Recreation and Park Association.
- Gulick, E. E. (1995). Coping among spouses or significant others of persons with multiple sclerosis. *Nursing Research, 44*, 220-225.
- Hafstrom, J. L., & Schram, V. R. (1984). Chronic illness in couples: Selected characteristics, including wife's satisfaction with and perception of marital relationships. *Family Relations, 33*, 195-203.
- Heijmans, M., De Ridder, D., & Bensing, J. (1999). Dissimilarity in patients' and spouses' representations of chronic illness: Exploration of relations to patient adaptation. *Psychology and Health, 14*, 451-467.
- Helder, D. I., Kaptein, A., A., Van Kempen, G. M. J., Weinman, J., Van Houwelingen, J. C., & Roos, R. A. C. (2002). Living with Huntington's Disease: Illness perceptions, coping mechanisms, and spouses' quality of life. *International Journal of Behavioral Medicine, 9*, 37-53.
- Helgeson, V. S. (1993). The onset of chronic illness: Its effect on the patient-spouse relationship. *Journal of Social and Clinical Psychology, 12*, 406-428.
- Henderson, K.A. (1991). *Dimensions of choice: A qualitative approach to recreation, parks, and leisure research*. State College, PA: Venture.

- Henderson, K. A. (1994a). Broadening an understanding of women, gender, and leisure. *Journal of Leisure Research, 26*, 1-7.
- Henderson, K. A. (1994b). Perspectives on analyzing gender, women, and leisure. *Journal of Leisure Research, 26*, 119-137.
- Henderson, K. A. (1996). One size doesn't fit all: The meanings of women's leisure. *Journal of Leisure Research, 28*, 139-155.
- Henderson, K. A., Bedini, L. A., & Hecht, L. (1994). "Not just a wheelchair, not just a woman": Self-identity and leisure. *Therapeutic Recreation Journal, 28*, 73-85.
- Henderson, K. A., Bedini, L. A., Hecht, L., & Schuler, R. (1995). Women with physical disabilities and the negotiation of leisure constraints. *Leisure Studies, 14*, 17-31.
- Henderson, K. A., Hodges, S., & Kivel, B. D. (2002). Context and dialogue in research on women and leisure. *Journal of Leisure Research, 34*, 253-271.
- Hill, M. S. (1988). Marital stability and spouses shared time. *Journal of Family Issues, 9*, 427-451.
- Holman, T. B., & Jacquart, M. (1988). Leisure-activity patterns and marital satisfaction: A further test. *Journal of Marriage and the Family, 50*, 69-77.
- Hutchinson, S. L., Loy, D. P., Kleiber, D. A., & Dattilo, J. (2003). Leisure as a coping resource: Variations in coping with traumatic injury and illness. *Leisure Sciences, 25*, 143-161.
- Jackson, E. L. (2000). Will research on leisure constraints still be relevant in the twenty-first century? *Journal of Leisure Research, 32*, 62-68.
- Juniu, S. (2000). Downshifting: Regaining the essence of leisure. *Journal of Leisure Research, 32*, 69-73.
- Kelly, J. R. (1996). *Leisure* (3<sup>rd</sup> ed.). Needham Heights, MA: Allyn & Bacon.

- Kennedy, J., & Walls, C. (1997). *A national profile of intra-household ADL/IADL assistants: Population estimates from the 1992-1993 Surveys of Income and Program Participation*. Department of Community Health, University of Illinois at Urbana-Champaign.
- Kirby, S., & McKenna, K. (1989). *Experience research and social change: Methods from the Margins*. Toronto, Ont: Garamond Press.
- Kleiber, D. A. (1999). *Leisure experience and human development: A dialectical interpretation*. New York: Basic Books.
- Kleiber, D. A., Brock, S. C., Lee, Y., Dattilo, J., & Caldwell, L. (1995). The relevance of leisure in an illness experience: Realities of spinal cord injury. *Journal of Leisure Research*, 27, 283-299.
- Kleiber, D. A., Hutchinson, L. L., & Williams, R. (2002). Leisure as a resource in transcending negative life events: Self-protection, self-restoration, and personal transformation. *Leisure Sciences*, 24, 219-235.
- Klein, D. M., & White, J. M. (1996). *Family theories: An introduction*. Thousand Oaks, CA: Sage Publications, Inc.
- Kleinman, A. (1988). *The illness narratives*. New York: BasicBooks.
- Knight, R. G., Devereux, R. C., & Godfrey, H. P. D. (1997). Psychosocial consequences of caring for a spouse with multiple sclerosis. *Journal of Clinical and Experimental Neuropsychology*, 19, 7-19.
- Kralik, D. (2002). The quest for ordinariness: Transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, 39, 146-155.
- Larson, R. W., & Richards, M. H. (1994). *Divergent realities*. New York: BasicBooks.

- LeCompte, M. D., & Preissle, J. (1993). *Ethnography and qualitative design in educational research* (2<sup>nd</sup> ed.). San Diego, CA: Academic Press, Inc.
- Lyons, R. F. (1999). Personal relationships, illness, and disability. *Journal of Leisurability*, 26, 22-32.
- Lyons, R. F., & Meade, D. (1995). Painting a new face on relationships: Relationship remodeling in response to chronic illness. In S. Duck & J. T. Wood (Eds.), *Confronting relationship challenges* (pp. 181-210). Thousand Oaks, CA: SAGE Publications, Inc.
- Lyons, R. F., Sullivan, M. J. L., Ritvo, P. G., & Coyne, J. C. (1995). *Relationships in chronic illness and disability*. Thousand Oaks, CA: Sage Publications, Inc.
- Mactavish, J. B., & Schleien, S. J. (1998). Playing together growing together: Parents' perspectives on the benefits of family recreation in families that include children with a developmental disability. *Therapeutic Recreation Journal*, 32, 207-230.
- Mactavish, J. B., & Schleien, S. J. (2000). Exploring family recreation activities in families that include children with developmental disabilities. *Therapeutic Recreation Journal*, 34, 132-153.
- Malkin, M. J., Phillips, R. W., & Chumbler, J. A. (1991). The family lab: An interdisciplinary family leisure education program. *Annual in Therapeutic Recreation*, 2, 25-34.
- Marshall, C., & Rossman, G. B. (1995). *Designing qualitative research* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage.
- Mattingly, M. J., & Bianchi, S. M. (2003). Gender differences in the quantity and quality of free time. *Social Forces*, 81, 999-1031.
- Merriam, S. B. (1998). *Qualitative research and case study applications in education*. San Francisco, CA: Jossey-Bass Publishers.

- Moss-Morris, R., Petrie, K. J., & Wienman, J. (1996). Functioning in chronic fatigue syndrome: Do illness perceptions play a regulatory role? *British Journal of Health Psychology, 1*, 15-25.
- Murphy, H., Dickens, C., Creed, F., & Bernstein, R. (1999). Depression, illness, perception and coping in rheumatoid arthritis. *Journal of Psychosomatic Research, 46*, 155-164.
- National Center for Disease Control and Prevention. (2003). *Chronic diseases and conditions*. [on-line]. Available at: [www.cdc.gov/nchs.hus.htm](http://www.cdc.gov/nchs.hus.htm)
- Neill, J. (2002). Transcendence and transformation in the life patterns of women living with rheumatoid arthritis. *Advanced Nursing Science, 24*, 27-47.
- Nieboer, A. P., Schulz, R., Matthews, K. A., Scheier, M. F., Ormel, J., & Lindenberg, S. M. (1998). Spousal caregivers' activity restriction and depression: A model for changes over time. *Social Science and Medicine, 47*, 1361-1371.
- Nosek, M. A., & Hughes, R. B. (2003). Psychosocial issues of women with disabilities: The continuing gender debate. *Rehabilitation Counseling Bulletin, 46*, 224-233.
- Olson, D. H., McCubbin, H. I., Barnes, H. L., Muxen, M. J., Larsen, A. S., & Wilson, M. A. (1989). *Families: What makes them work*. Newbury Park, CA: Sage Publications, Inc.
- Orthner, D. K. (1975). Leisure activity patterns and marital satisfaction over the marital career. *Journal of Marriage and the Family, 37*, 91-102.
- Orthner, D. K. (1976). Patterns of leisure and marital interaction. *Journal of Leisure Research, 8*, 98-111.
- Orthner, D. K., & Mancini, J. A. (1990). Leisure impacts on family interaction and cohesion. *Journal of Leisure Research, 22*, 125-137.
- Perry, S. (1994). *Living with Multiple Sclerosis*. Newcastle, GB: Athenaeum Press Ltd.

- Peterson, C. A., & Stumbo, N. J. (2003). *Therapeutic recreation program design* (4<sup>th</sup> ed.). Needham Heights, MA: Allyn & Bacon.
- Reissman, C., Aron, A., & Bergen, M. R. (1993). Shared activities and marital satisfaction: Causal direction and self-expression versus boredom. *Journal of Social and Personal Relationships, 10*, 243-254.
- Rogers, N. B. (1997). Centrality of the caregiving role and integration of leisure in everyday life: A naturalistic study of older wife caregivers. *Therapeutic Recreation Journal, 31*, 230-243.
- Randall, J. S. (1994). *Families, illness, and disability: An integrative treatment model*. New York: Basic Books.
- Sausser, C. E. (1997). *Leisure in the lives of people with HIV: Implications for Therapeutic Recreation Services*. Unpublished master's thesis. University of Georgia, Athens, Georgia.
- Samdahl, D. M. (1992). Leisure in our lives: Exploring the common leisure occasion. *Journal of Leisure Research, 24*, 19-31.
- Samdahl, D. M. (1991). Issues in the measurement of leisure: A comparison of theoretical and connotative meanings. *Leisure Sciences, 13*, 33-49.
- Samdahl, D. M. (1988). A symbolic interactionist model of leisure: Theory and empirical support. *Leisure Sciences, 10*, 27-39.
- Samdahl, D. M., & Jekubovich, N. J. (1997). A critique of leisure constraints: Comparative analyses and understandings. *Journal of Leisure Research, 29*, 430-452.
- Sato, A., Ricks, K., & Watkins, S. (1996). Needs of caregivers of clients with multiple sclerosis. *Journal of Community Health Nursing, 13*, 31-42.

- Schleien, S. J., Fahnestock, M. K., & Miller, K. D. (2001). Severe multiple disabilities. In D. R. Austin & M. E. Crawford (Eds.). *Therapeutic recreation: An introduction* (pp. 157-189). Needham Heights, MA: Allyn & Bacon.
- Schneewind, K. A., & Gerhard, A. K. (2002). Relationship personality, conflict resolution, and marital satisfaction in the first 5 years of marriage. *Family Relations, 51*, 63-71.
- Shaw, S. M. (1985). The meaning of leisure in everyday life. *Leisure Sciences, 7*, 1-24.
- Shaw, S. M. (1994). Gender, leisure, and constraint: Towards a framework for the analysis of women's leisure. *Journal of Leisure Research, 26*, 8-22.
- Shaw, S. M. (1997). Controversies and contradictions in family leisure: An analysis of conflicting paradigms. *Journal of Leisure Research, 29*, 98-112.
- Shaw, S. M., & Dawson, D. (2001). Purposive leisure: Examining parental discourses on family activities. *Leisure Sciences, 23*, 217-231.
- Schweitzer, J. A., Mann, W. C., Nochajski, S., & Tomita, M. (1999). Patterns of engagement in leisure activity by older adults using assistive devices. *Technology and Disability, 11*, 103-117.
- Siegenthaler, K. L., & O'Dell, I. (2000). Leisure attitude, leisure satisfaction, and perceived freedom in leisure within family dyads. *Leisure Sciences, 22*, 281-296.
- Skalko, T. K. (1990). Discretionary time use and the chronically mentally ill. *Annual in Therapeutic Recreation, 1*, 9-14.
- Strauss, A. L. (1987). *Qualitative analysis for social scientists*. Cambridge, NY: Cambridge University Press.
- Strauss, A. L., & Corbin, J. (1998). *Basics of qualitative research* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications.

- Tatham, M. G., & McCree, S. (1992). Leisure facilitator: The role of the Occupational Therapist in senior housing. *Journal of Housing for the Elderly, 10*, 125-139.
- Taylor, A. R., Sylvestre, J. C., & Botschner, J. V. (1998). Social support is something you do, not something you provide: Implications for linking formal and informal support. *Journal of Leisurability, 25*, 3-13.
- Tuck, I., & Wallace, D. (2000). Chronic fatigue syndrome: A woman's dilemma. *Health Care for Women International, 21*, 457-466.
- Urey, J. R., & Henggeler, S. W. (1987). Marital adjustment following spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 68*, 69-74.
- Voelkl, J. E. (1998). The shared activities of older adults with dementia and their caregivers. *Therapeutic Recreation Journal, 32*, 231-239.
- Weinblatt, N., & Navon, L. (1993). Flight from leisure: A neglected phenomenon in leisure studies. *Leisure Sciences, 17*, 309-325.
- Weiss, C. R., & Thurn, J. M. (1990). Perceived effects of a training program to enhance family members' ability to facilitate reminiscing with older disoriented residents. *Therapeutic Recreation Journal, 24*, 18-31.
- Widmer, M. A., & Ellis, G. D. (1998). The Aristotolian good life model: Integration of values into therapeutic recreation service delivery. *Therapeutic Recreation Journal, 32*, 290-302.
- Wilhite, B., Keller, M. J., & Caldwell, L. (1999). Optimizing lifelong health and well-being: A health enhancing model of therapeutic recreation. *Therapeutic Recreation Journal, 33*, 98-108.

- Williamson, G. M., & Shaffer, D. R. (1996). Interpersonal loss in the context of family caregiving: Implications of communal relationships theory. *Journal of Personal and Interpersonal Loss, 1*, 249-274.
- Williamson, G. M., & Shaffer, D. R. (1998). Implications of communal relationships theory for understanding loss among family caregivers. In J. H. Harvey (Ed.), *Perspectives on loss: A sourcebook* (pp. 173-187). Philadelphia: Taylor & Francis.
- Williamson, G. M., Shaffer, D. R., & Schulz, R. (1998). Activity restriction and prior relationship history as contributors to mental health outcomes among middle-aged and older spousal caregivers. *Health Psychology, 17*, 152-162.
- Worthington, E. L., Buston, B. G., & Hammonds, T. M. (1989). A component analysis of marriage enrichment: Information and treatment modality. *Journal of Counseling and Development, 67*, 555-560.
- Yaffe, R. M. (1996). *Leisure and adjustment to date rape*. Unpublished doctoral dissertation. University of Georgia, Athens, Georgia, USA.
- Zabriskie, R. B. (2001). Family recreation: How can we make a difference? *Parks and Recreation, 36* (10), 44-46.
- Zabriskie, R. B., & McCormick, B. P. (2001). The influences of family leisure patterns on perceptions of family functioning. *Family Relations, 50*, 281-289.
- Zabriskie, R. B., & McCormick, B. P. (2003). Parent and child perspectives of family leisure involvement and satisfaction with family life. *Journal of Leisure Research, 35*, 163-189.

APPENDIX A  
PARTICIPANT RECRUITMENT SITES

### Local Support Groups

1. Arthritis Awareness Support Group
2. Chronic Illness Support Group
3. Diabetic Support Group
4. Facing Cancer with Love and Laughter Support Group
5. Lupus Support Group
6. Multiple Sclerosis Support Group
7. Ovarian Cancer Support Group
8. The Breathe Club

APPENDIX B

NOTICE OF PARTICIPATION IN A RESEARCH STUDY

**VOLUNTEERS NEEDED:****TO PARTICIPATE IN A STUDY EXPLORING LEISURE EXPERIENCES IN THE  
CONTEXT OF A CHRONIC ILLNESS OR DISABILITY****Purpose:**

I am seeking adults with a chronic disabling condition and their partners who are willing to be interviewed about their leisure-related experiences, opportunities, and needs.

**Who is eligible?**

Couples who:

- Are both 18-40 years of age
- Are both willing to be interviewed
- Were partners prior to onset of one partner's chronic illness or disability
- Have known about one partner's chronic disabling condition for at least 1 year

**Benefits of Participation:**

- Help human service providers gain insight into leisure-related experiences, opportunities, and needs of couples experiencing a chronic disabling condition
- Help professionals provide beneficial services to couples needing assistance and support services

**What is involved:**

- One interview, lasting approximately one hour

**If interested, please contact:**

Nathalie Guerin

Work telephone number: (706) 542-431

Monday - Friday 8 a.m. to 5 p.m.

- or -

home telephone number: (706) 354-8153

anytime, leave a message on answering machine

- or -

e-mail at: [nguerin@coe.uga.edu](mailto:nguerin@coe.uga.edu)

\*\*The study will be conducted by Nathalie Guerin, a doctoral student at the University of Georgia in the Department of Recreation and Leisure Studies, under the supervision of Dr. John Dattilo. Participation in this study is strictly confidential and entirely voluntary.

APPENDIX C

INTERVIEW GUIDE FOR ADULTS WITH A CDC AND THEIR PARTNERS

After initial introductions, the researcher read through the consent form with the participant and addressed any questions or concerns the participant may have had. The participant was informed of the audio taping procedure. The participant signed two copies of the consent form: one for the participant and one for the researcher. The participant was reminded that he or she could request a break at any time during the interview, and that the expected length of the interview was approximately one hour.

A brief period of introduction and casual questioning preceded the formal interview questions to build rapport between the researcher and the participant. Informal questions included information relating to background information and lead into the research questions developed for this study. The purpose of the interview guide was not to ask each participant questions in exactly the same order, but to remind the researcher of the research questions so that each participant was asked the same questions. Therefore, the wording of questions and the order in which they were asked varied for each interview to respond appropriately and effectively to the remarks of participants and elicit the most useful and comprehensive information from them.

### **Background information:**

*I'd like to ask you a few questions so I can learn a little bit about you and (name of partner).*

1. What is your name?
2. What is your age?
3. What is the name of your (partner)?
4. How long have you known (partner)?
5. How long have you lived with (partner)?
6. What is your chronic disabling condition?
7. How did you discover your chronic disabling condition?
8. How long have you known about your chronic disabling condition?

### **Research questions:**

*Now I'd like to ask you a few questions about the things you do in your free time for fun and enjoyment, especially those activities and experiences you share with your partner.*

1. What are some of the leisure activities you do with (name of partner) when you (or partner) are feeling well?
2. What are some of the leisure activities you do with (name of partner) when you (or partner) are **not** feeling well?
3. What are your thoughts about doing any of these leisure activities with (name of partner)?
4. How do you think participating in these leisure activities may affect your relationship with (name of partner)?

5. What do you think may affect your participation in these leisure activities with (name of partner)?

6. What have you found that helps you when you participate in leisure activities with (name of partner)?

Probes:

- You mentioned \_\_\_\_\_. Can you tell me more about that?
- What was that like for you?

APPENDIX D  
CONTACT SUMMARY FORM

**Contact Summary Form**

1. The main issues or themes in this contact:

2. Summary of information obtained from this contact:

3. Ideas that seemed salient, interesting, illuminating, or important in this contact:

4. New (or remaining) questions to ask during the next interview:

5. Concerns about this or future contacts:

APPENDIX E  
CONSENT FORM

### Consent Form to Participate in a Research Study

I am voluntarily participating in the study conducted by Nathalie Guerin, a doctoral student in the Department of Recreation and Leisure Studies at the University of Georgia, under the supervision of Dr. John Dattilo, Professor. I have discussed any concerns that I may have about my involvement in this study with Ms. Guerin. If I have questions or concerns about my participation in this study, I may contact Ms. Guerin at any time at her home (706-369-0228) or at her office (706-542-4311). I may also contact John Dattilo (706-542-5064).

I understand that I am being asked to participate in one face-to-face in-depth interview about the association between shared leisure experiences and my relationship with my partner. I will be asked questions about my leisure-related needs and resources in association with my or my partner's chronic disabling condition. The interview will last about one hour and will be tape recorded using a cassette audio recorder. I understand that I may ask for my partner to be present during this interview. In addition, I may have an opportunity to participate in additional interviews individually or with my partner.

I understand that my participation in this study is confidential. My name will never be used in association with this project and that transcripts will not be identified by my name. Audiotapes and transcripts of my interviews will be stored in a locked filing cabinet in Ms. Guerin's home. Audiotapes and transcripts of my interviews will be kept for five years to facilitate ongoing analysis, at which time they will be erased and physically destroyed by Ms. Guerin.

I understand that my participation is entirely voluntary and that I may refuse to answer any questions or discontinue at any time. In the event that I become fatigued or emotionally distressed, the interview will be stopped until I am ready to continue. I will be given the option to reschedule or discontinue the interview. If I choose to discontinue the results of my participation, to the extent they can be identified as mine, can be returned to me, removed from the research records, or destroyed.

I understand that this research may have no immediate practical benefit to me. However, the benefits I may expect from it are a chance to reflect on leisure experiences shared with my partner and our relationship, leisure experiences, opportunities, and needs of myself and my partner, and a better understanding of myself. Findings from this study may also benefit leisure service professionals who work with people with chronic disabling conditions and their partners.

\*\*\*\*\*

I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

Research at The University of Georgia with involves human participants is overseen by the Institutional Review Board. Questions or problems regarding your rights as a participant should be addressed to Dr. Christina Joseph; Institutional Review Board; Office of V.P. for Research; The University of Georgia; 606A Graduate Studies Research Center; Athens, Georgia, 30602-7411; Telephone (706) 542-6514; email address IRB@uga.edu.